

Uncovering sedentary behaviour: a comprehensive exploration of patterns and health effects among older adults with an intellectual disability



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A thesis submitted to the University of Dublin, Trinity College,
for the Degree of Doctor of Philosophy

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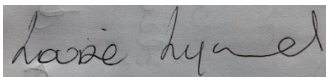
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January 2024

DECLARATION

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SUMMARY

Methods

This thesis explores the sedentary behaviour (SB) levels of adults with an intellectual disability using diverse self-report methods and an objective measurement tool, to ultimately determine the effects of this SB on their physical health. The study was conducted as part of the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging (IDS-TILDA), a longitudinal study running in Ireland for over thirteen years which gathers health and lifestyle information every three years from a group of randomly selected Irish adults over 40 years of age, of all levels of intellectual disability, across all living circumstances to improve their health outcomes as they age. The IDS-TILDA study runs in parallel with the general population TILDA study so results may be directly compared. There were three main sources of data for this study, the Computer Assisted Personal Interview (CAPI), Pre-interview Questionnaire (PIQ) and the Health Fair. The CAPI was the primary source of self-reported information. It was a face-to-face personal interview between participants and/or a proxy and a trained researcher. Information on social, environmental, health, functional limitations and areas including physical activity (PA) and TV habits were collected. The PIQ was sent to participants to complete a week before the CAPI interview and consisted of questions on demographic, chronic health, medication and PA. Objective assessment of activity was also part of the data contributing to this study. As part of the objective health measurement of IDS-TILDA a device called an activPAL was fitted to gather sedentary and activity information on those participants who consented.

Initially, a systematic review was executed to determine the prevalence of SB in the adult intellectual disability population and a literature review explored the effects of SB on health. The Systems of Sedentary Behaviour (SOS) framework was used to structure and frame results. Risk factors for SB were determined from the literature and examined. Objective measures of SB were investigated using several activPAL variables including total sedentary time, time spent lying down and time in various bouts of SB. In addition, inactivity was evaluated using steps, METs and Physical

Activity level (PAL). The Barthel Index (BI) was used to examine the functional status of participants. Individual health conditions, the number of health conditions and a comorbidity index, Cumulative Index Rating Scale (CIRS-G) were used to assess participant's health status. Comprehensive bivariate and multivariate investigations were completed on all data using regression models and decision trees. Data imputation was completed to improve the reliability of results.

Major findings

High levels of SB are present in the intellectual disability population. The systematic review determined prevalence of SB was over 60% which compared to 67% observed in this study. Mostly people purported to watch between 1-3 hours of TV a day but overall using TV as a proxy for SB may not be the best choice especially for those with a more severe/profound level of intellectual disability. Novel risk factors for SB in the intellectual disability population were found including those who had difficulty walking 100 yards and those who got up later in the morning. People who were more active, as measured by activPAL, performed more sit-to-stand transitions and had more functional independence, while those who were less active had more cardiac health conditions. Participants who had elevated sedentary time observed associations with more endocrine conditions. More time spent in extended periods of SB saw a decrease in functional capacity and an increase in comorbidities present, particularly upper GI conditions. Conversely more time spent in shorter periods of SB was related to an increase in functional independence and the presence of decreased comorbidities, specifically a reduction in respiratory conditions, which is one of the leading causes of death in this population. Psychiatric conditions, which were the most common comorbidity observed in this study, were associated with more sedentary periods of up to two hours.

DEDICATION

I would like to dedicate this thesis to my wonderful family, Colin, my rock and Aisling, Nikki and Jack, my fabulous children, for your enduring support on this PhD journey. Those morning coffees, treats, walks and late-night mint teas were a lifesaver. Thanks for the laughs, listening, proof-reading, being interested and just for bearing with me. I am so proud of you all and love you more than words can express.

ACKNOWLEDGEMENT

Firstly I would like to sincerely thank my incredible supervision team, Professor Eilish Burke, Professor Mary McCallion and Professor Philip McCallion for their encouragement, guidance, patience and time over the past four years. I am so privileged to have had such an esteemed team to support me and will keep their counsel with me moving forward.

I loved all the time I spent with the study participants and would like to thank them and their families and carers as well as all the service providers for being part of this study, without whom any of this would have been possible.

I am honoured to be part of the wonderful IDS-TILDA team including Gavin Dann, who were always there to help if needed. Thank you to the statistics team Aviejay Paul, Pavithra and Dr Triona Ryan for your data and insights. Fidelma and Judy, my fellow-PhD students, I've really appreciated the chats and I look forward to continuing our journey working together.

To my running buddies Clodagh and Paula who have kept me going, thanks for being such great friends.

I am blessed to have the most amazing extended family, including the best mother-in-law Mary and father-in-law John who have been nothing but supportive and always available to help. Thank you so much. Auntie Elizabeth and Auntie Noirin you have always been there for us and I will be forever grateful to you. Gillian, my gorgeous, talented sister I've missed our chats and time together but appreciate your support from across the Irish sea.

PUBLICATIONS PRIZES & CONFERENCE PRESENTATIONS

Publications

Lynch, L., McCarron, M., McCallion, P. and Burke, E., 2020. Sedentary behaviour levels in adults with an intellectual disability: a systematic review protocol. *HRB Open Research*, 3.

Lynch, L., McCarron, M., McCallion, P. and Burke, E., 2021. Sedentary behaviour levels in adults with an intellectual disability: a systematic review and meta-analysis. *HRB Open Research*, 4.

Lynch, L., McCarron, M., Eustace-Cook, J., Burke, É. and McCallion, P., 2022. Physical health effects of sedentary behaviour on adults with an intellectual disability: a scoping review. *Journal of Intellectual Disabilities*, p.17446295221107281.

Prizes

May 2021; 'Sedentary behaviour levels of adults with an intellectual disability'. Awarded second prize in the Faculty of Health Sciences Research blitz.

Oral Presentations

Lynch, L., McCarron, M., McCallion, P. and Burke, E. (2021), '*Sedentary behaviour levels in adults with an intellectual disability: a systematic review*', TheConf2021, School of Nursing and Midwifery, Trinity College Dublin.

McDermott, S., O'Donovan, MA., McCarron, M., McCallion, P., **Lynch**, L., Burke, E., (2021), '*Training Older Adults with intellectual disabilities (ID) as Physical Activity*

leaders 2020 (PPALS2)’, TheConf2021, School of Nursing and Midwifery, Trinity College Dublin.

Lynch, L., McCarron, M., McCallion, P. and Burke, E., (2021), ‘Examining the sedentary behaviour levels among older adults with intellectual disability’, IASSIDD Europe 2021 Congress.

Lynch, L., McCarron, M., McCallion, P. and Burke, E., (2022), ‘Examining the sedentary behaviour levels in adults with an intellectual disability’, School of Nursing and Midwifery day for Duquesne University, USA, Trinity College Dublin.

Lynch, L., McCarron, M., McCallion, P. and Burke, E., (2023) ‘A longitudinal exploration of self-reported TV behaviours as a surrogate for sedentary behaviour in older adults with an intellectual disability’. TheConf2023, School of Nursing and Midwifery.

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Chapter 1

1.1 Introduction

This chapter introduces the reader to the thesis. The structure of the thesis is presented and the importance of understanding sedentary behaviour (SB) in people with an intellectual disability is contextualised. While it is known that SB is detrimental to health and highly prevalent in people with an intellectual disability, it is an aspect of life that has not been given a lot of attention and there is insufficient evidence to define exactly how much of it will have a negative impact on health (WHO, 2020; Lynch *et al*, 2021). This study will provide evidence to support the need for the reduction of SB in people with an intellectual disability. Descriptions and comparisons between diverse self-report measures and objective measures were completed to assess concurrent validity and increase confidence in results. Key definitions are described. The background and study rationale are outlined. Lastly the thesis research question, aims and objectives are detailed and mapped to the relevant thesis chapter.

1.2 Chapter layout and contents

Chapter 1: Title: *Introduction*. This chapter introduces the reader to the overall thesis, its layout, and contextualises the topic and provides the reader with the definitions of terms used throughout the thesis. The concept of movement and fundamental movement skills are explained and how they could relate to physical activity (PA) and SB. The research question, aims and objectives are laid forth and mapped to the appropriate chapters.

Chapter 2: Title: *Sedentary behaviour levels in adults with an intellectual disability: a systematic review and meta-analysis*. This chapter describes the systematic review and meta-analysis that was executed to determine the state of the science of SB in the intellectual disability population.

Chapter 3: Title: *Physical health effects of sedentary behaviour on adults with an intellectual disability: a scoping review*. This chapter describes the scoping literature review which was designed to establish the effects of SB on the physical health of adults with an intellectual disability.

Chapter 4: Title: *Research design and methods*. This chapter explains the methodology used in this study including the research design, all data sources and any ethical considerations required. The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing [IDS-TILDA] study is explored in detail.

Chapter 5: Title: *An investigation into the risk factors for increased TV viewing in the intellectual disability population*. This chapter details the investigation into risk factors for increased TV viewing and the identification of a framework to structure results. These risk factors are mapped onto variables from the IDS-TILDA study and framed using the Systems of Sedentary Behaviour (SOS) framework.

Chapter 6: Title: *A longitudinal exploration of self-reported TV behaviours as a surrogate for SB in older adults with an intellectual disability from the IDS-TILDA study*. TV viewing was used as a proxy for SB. This chapter presents a detailed analysis of the risk factors for increased TV viewing and summarises the results.

Chapter 7: Title: *To measure the relationship between objectively measured SB and age, sex, level of intellectual disability, living circumstances, comorbidities and functional capabilities*. This chapter examines the relationship between the objectively measured SB and the standard covariates, as well as with health as measured by an established comorbidity index, individual health conditions and functional capabilities using the standardised Barthel Index.

Chapter 8: Title: *Systematic review and meta-analysis to determine the prevalence of sedentary behaviour in the intellectual disability population: revisited and updated*. This chapter details the impact of the objectively measured SB results from this study on the original systematic review and meta-analysis results.

Chapter 9: Title: *Un-sedentary for health*. This chapter presents and discusses the overall findings of the thesis. It includes recommendations for clinical practice and future research.

1.3 Definition of Terms

- Physical activity

Physical activity is any bodily movement which uses skeletal muscles and results in energy expenditure (WHO, 2019). Physical activity is characterised by frequency, type, level and duration of activities (WHO, 2019). The WHO PA recommendations for adults are shown in table 1.1.

Table 1. 1: WHO physical activity recommendations for adults

Activity Type & intensity	Time (mins)	Frequency
Moderate intensity aerobic activity e.g. Walking fast, doubles tennis, cycling	150-300	Per week
OR		
Vigorous intensity aerobic activity e.g. Running, skipping, singles tennis	75-150	Per week
AND		
Muscle strengthening activities		2 x per week
AND		
Functional balance & strength training		3 x per week

Physical activity is classified into intensity level by the level of energy expenditure required to perform the activity. As this energy requirement increases due to more intensive activity levels and with more demands placed on the body, an incremental metabolic response results. A metabolic equivalent (MET) is the resting metabolic rate and all activities can be classified as multiples of this basic metabolic rate. Figure 1.1 shows a graphical representation of this activity range with the equivalent metabolic responses shown underneath, including VO_2 (oxygen consumption) requirements, where VO_2 is the maximum amount of oxygen that one inhales when exercising at a maximum intensity. Hence low MET expenditure corresponds to low oxygen requirements. Sedentary behaviour has a low energy expenditure of approximately 1 MET using less than 20% VO_2 max, while at the other end of the spectrum the MET expenditure for vigorous activity is in excess of 6 METs with a VO_2 max in excess of 60%.

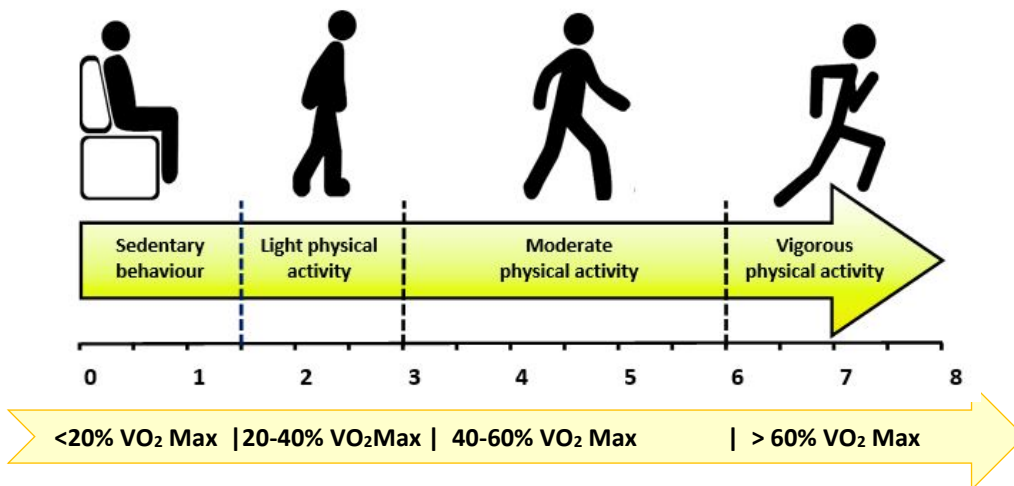


Figure 1. 1: Activity continuum with MET equivalent (Adapted from Schneider *et al*, 2018)

- Physical inactivity

Physical inactivity is the term to describe those who do not meet the minimum recommended levels of PA as specified by the WHO in table 1.1.

- Metabolic equivalent

A metabolic equivalent (MET), known as the resting metabolic rate, is an objective measurement (OM) scale used to classify activity types and levels. A MET is the amount of oxygen (O_2) burned at rest and is the equivalent of 3.5ml O_2 per kg bodyweight per minute (Jette *et al*, 1990) or 1kilocalorie per kg of bodyweight per hour (Newton *et al*, 2013). Ainsworth and colleagues proposed METs as the basis for calculating PA intensities (Ainsworth *et al*, 2011). The three MET intensities of interest are mild (3.3METs), moderate (4METs) and vigorous (8METs) so that calculations may be made in line with the World Health Organisation (WHO) recommendations (WHO, 2020). Thus the equivalent adult weekly MET recommendations would be 600 to 1,200 METS per week for moderate or vigorous activity (WHO, 2020).

- Sedentary behaviour

Sedentary comes from the Latin word *sedere* which means to sit and can describe a wide range of distinct activities which require low levels of energy expenditure in any setting (Thorp *et al*, 2011). The first real attempt to officially define the term 'sedentary' to avoid confusion by standardising the terms referring to sedentary or inactive behaviours used in journals, was made in 2012 by the Sedentary Behaviour Research Network (Tremblay, 2012). The proposed definition of SB was finetuned to 'any waking behaviour characterized by an

energy expenditure of ≤ 1.5 METs while in a sitting, lying or reclining posture' for example watching television or working on a computer (Tremblay *et al*, 2017, pp1-17). However for the purposes of this thesis this definition was expanded to 'Low physical activity as identified by metabolic equivalent (MET) or step levels or as measured by the Rapid Assessment of Physical activity questionnaire (RAPA) or the International Physical Activity questionnaire (IPAQ) or sitting, lying or reclining for more than 3 hours per day'. Hence SB constitutes too much sitting or stationary activity as opposed to physical inactivity which is insufficient exercise or physical movement for health. People may be sedentary but also active if they meet the minimum activity recommendations.

- Exercise

Exercise is a subset of physical activity which is structured, repetitive and planned with an overall goal of improving physical fitness for all types of muscle contraction (Caspersen *et al*, 1985; Winter and Fowler, 2009).

- Cadence

Cadence is walking speed. It represents the number of steps per minute and hence the intensity. A cadence of greater than 100 represents moderate intensity and greater than 130 represents vigorous intensity in adults up to 60-years (Tudor-Locke *et al*, 2020).

- Intellectual Disability

Intellectual disability begins before adulthood and is characterised by having a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence and mental capacity) which results in a reduced ability to cope independently (impaired social functioning) and has a lifelong effect on development (AAIDD, 2020). According to the American Association of Intellectual and Developmental Disabilities, an intelligence quotient (IQ) of less than 75 is indicative of limitations in intellectual functioning (AAIDD, 2020).

1.4 Study Background

While there is strong evidence to suggest that physical inactivity is harmful to health, the same cannot be said for SB (WHO, 2020). Sedentary behaviour has been linked to increased cardio-metabolic risks, obesity, earlier mortality, physical multimorbidity and cancer risk in

the general population (Shields and Tremblay, 2008; Schmid *et al*, 2015; Patterson *et al*, 2018; Kandola *et al*, 2020). Similar research on the health effects of SB for people with an intellectual disability is sparse (Lynch *et al*, 2022). Given the twenty-year shorter lifespan of adults with an intellectual disability compared to their peers in the general population, combined with their elevated ill-health issues, it is critical that research on their sedentary behaviours is completed and understood (Krahn and Fox, 2014; McCarron *et al*, 2015).

To fully understand SB it is important to appreciate the concept and physiology of movement. Physiology is the term to describe how organisms or body parts function. It is the science behind how the body works from a cellular level to the function of all bodily systems, to maintain balance in health and disease (Carroll *et al*, 2013). The physiology of movement is a complex phenomenon, and a number of areas need to be explored to understand the science of movement and SB, and how it relates to people with an intellectual disability.

1.4.1 Movement

According to Goodway and colleagues (2019), movement occurs when any body part makes an observable change in position. Movement, whether voluntary or involuntary, is essential for everyday life and comes from muscle contraction. Muscle contraction is under the complete control of motor neurons in the Central Nervous System (CNS) and conscious thought from the motor cortex, which is the area of the brain that controls voluntary movement and generates signals to direct body movements (Yip and Lui, 2020). When motor neurons are active, there will be movement. Neurons send commands through the generation of electrical signals to and from the muscular system. Muscles consist of hundreds of fibres which are innervated by these neurons and the consequent electrical signals from the CNS to cause movement. A signal from the CNS is the only way for a muscle to contract which indicates that movement is under voluntary control. The basic unit of muscle contraction is the motor unit which consists of motor neurons and muscle fibres, all fundamental to movement (Cunningham and Mayson-Bates, 2021).

1.4.2 Fundamental movement skills

A motor skill is a movement of any body part which is learned and goal oriented (Goodway *et al*, 2019). Similarly, fundamental movement skills (FMS) are the basic movements required to perform everyday tasks. They do not develop naturally and need to be learned

or practiced (Barnett *et al*, 2016). These are typically divided into three broad areas: locomotor (movement) skills like walking and running, body control (stability) skills like standing on one leg or twisting, and object control (manipulative) skills like catching and kicking (HSE, 2021). Fundamental movement skills are deemed as the foundation to future movement and PA capabilities (Stodden *et al*, 2008; Clark and Metcalfe, 2002). While these types of movements are developed and refined in childhood, they may change across the lifespan depending on the individual, environment and the movement-task requirements (Goodway *et al*, 2019). Evidence suggests that enhanced motor skills are positively related to development outcomes, however any delays in motor skill development in children could be precursors to developmental, cognitive or social deficits as they age (Focaroli *et al*, 2016; Libertus and Hauf, 2017). Children with below-average motor skills were less likely to meet PA recommendations (De Meester *et al*, 2018). A 20-year longitudinal study found that adult PA levels were directly related to the proficiency of motor skills as young children and that adults with better self-perceived motor skills spent less time sedentary (Lloyd *et al*, 2014). In fact, perceived motor competence was directly related to actual motor competence (Wang *et al*, 2013). Yu and colleagues (2021) discovered an inverse relationship between FMS patterns and SB in children while others have shown that although FMS are related to PA levels in children and adolescents, an inconclusive relationship exists with SB (Lubans *et al*, 2010; Yu *et al*, 2021). Hence FMS could be a correlate of PA and SB. Given the importance of reducing SB and increasing PA for health, a focus on FMS should be fundamental in life (WHO, 2020). An adequate level of FMS can be trained and nurtured and can predict the engagement of children in PA through their lifespan (Clark, 2007). A dynamic relationship exists between PA and FMS, where FMS skills which require continuous training, can evolve, and change over the lifespan depending on an individual's environment as well as their perceived competence and physical health status (Robinson *et al*, 2015; Hulteen *et al*, 2018). Therefore the contribution of FMS to PA engagement is critical to engagement in activity and for people with an intellectual disability where motor impairment is highly prevalent, this may lead to consequent challenges in PA participation and be a prelude to increased SB.

- Fundamental movement skills and people with intellectual disability

To date the majority of studies on FMS have focussed on the general population, particularly on children (Lubans *et al*, 2010; Wick *et al*, 2017; Dobell *et al*, 2020). Similarly, studies undertaken on FMS in the intellectual disability population have focussed predominately on

children (Maïano *et al*, 2019; Regaieg *et al*, 2021; Sutherland *et al*, 2021). Motor skill development delays have been observed in children with an intellectual disability before two-years of age (Lee *et al*, 2020). Limitations in perceptual organisational skills, which is the ability to make sense of what is seen, in children with an intellectual disability, as well as being related to their level of intellectual disability could also be the reason for impaired motor skill development (Blasi *et al*, 2007). Similarly, it is reported that children and adolescents with an intellectual disability had deficits in FMS and performed significantly lower in locomotor and object control skills than children without an intellectual disability (Staples and Reid, 2010; Westendorp *et al*, 2011; Maïano *et al*, 2019). It appears that motor skills deteriorated as intellectual disability level increased along with the level of participation in PA, including steps per day, and were all correlated with motor skill proficiency (Westendorp *et al*, 2011; Wouters *et al*, 2019; Sutherland *et al*, 2021). Difficulties in normal motor skills like running and walking have been conveyed as one of the causes of inactivity in the intellectual disability population (Scifo *et al*, 2019). Aetiology also plays a part in motor function, with people with Down syndrome (DS) presenting with more motor skill issues compared to those with other aetiologies but some studies have shown that motor deficiencies were also pervasive in adults with Autism Spectrum Disorder (ASD) (Latash *et al*, 2002; Fournier *et al*, 2010).

People with an intellectual disability appear to have basic postural balance challenges which has been linked with reduced motor capacity (Cabeza-Ruiz *et al*, 2011; Bahiraei and Daneshmandi, 2022). In a study by Sanchez-Lastra and colleagues (2022) issues with balance and motor competence impeded participant's ability to participate in functional movement screening tests and contributed to lower resulting scores. This reduction in FMS capabilities is a concern given that the observed link between FMS and PA levels could contribute to less participation in PA and increased levels of SB (Farmer *et al*, 2017). However, FMS skills can be trained and learned and consequently improved, leading to more enjoyment and long-term participation in PA (Focaroli *et al*, 2009; Loprinzi *et al*, 2015; Capio *et al*, 2018). Activity intervention programs which ranged from eight to 24- weeks for people with an intellectual disability including DS and autism, have demonstrated that motor skill, physical fitness, balance and flexibility improvements ensued (McKeen, 2013; Silva *et al*, 2017; Bahiraei and Daneshmandi, 2022; Cai and Baek, 2022). Hence basic FMS, which appear to be important for PA participation, can be improved with practice. The aging process may also impact FMS and should be considered.

Ageing has been shown to affect motor skills in the general population and should be considered when discussing FMS (Serrien *et al*, 2000). The fact that people with an intellectual disability age prematurely compared to the general population, may contribute to an accelerated deterioration of motor skills (Janicki *et al*, 1999). Gait, which is the pattern of an individual's walking, is a strong indicator of health status and is an important element of locomotor skills linking balance and co-ordination (Studenski *et al*, 2011; Whittle, 2014). In the general population slower gait speeds were linked to an increased risk of falls, frailty and other adverse health problems in older adults, as well as increased sedentary time (Van Kan *et al*, 2009; Fini *et al*, 2021). Gait characteristics of adults with intellectual disability were comparable to those in the general population who were twenty years older and their gait competency was positively associated with PA level (Oppewal *et al*, 2018). Of concern is that reduced physical fitness was indicative of a diminished capacity to perform basic instrumental activities of daily living (IADL), where IADL is the ability to provide oneself with the basic care required to live more independently like cooking, shopping, etc, in a group of older adults with intellectual disability (Lawton and Brody, 1969; Oppewal *et al*, 2015). People with an intellectual disability have different needs to those in the general population, which are evident from childhood, and solutions to reduce SB should be tailored to these needs (Foley and McCubbin, 2009). Given the proposed relationship with FMS proficiency and PA level and SB, it is critical that sufficient time and training be given to people with an intellectual disability to improve their FMS skills. Functional motor skills can be improved by practice. In fact, motor skills training reduced SB in youths with DS (Agiovlasitis *et al*, 2020). Ultimately, to be more physically active and less sedentary, adults with intellectual disability require more support, suitable facilities and motivational support but this support should commence in childhood where habits can be more easily established (Heller *et al*, 2011).

1.4.3 Physical activity and physical fitness

It is said that 'practice makes perfect' and the more someone executes and performs a task the more proficient they will become at this task. This is also true for PA where improvements in physical fitness are observed with higher activity levels and the more frequent activity is, the more habitual it becomes (Koplan *et al*, 1989; Wood and Neal, 2007). However, adults with an intellectual disability perform at a much lower level in PA assessments than adults in the general population and younger adults with an intellectual disability operate at a level equivalent to those at least 20-years older (Hilgenkamp *et al*,

2012). An example of this is identified in McCarron et al (2013) where moderate PA levels in the adult intellectual disability community were 10% lower than adults in the general population (24% versus 34%). The implication of this is the potential consequences for long term independence, health and overall capabilities, especially since physical fitness is related to more positive health outcomes and predictive of long-term daily functioning and IADL abilities, independent of intellectual disability level (Oppewal *et al*, 2014; 2015). However fitness levels can decrease with age and lead to increased health problems, mobility issues and a reduced ability to live independently (Oppewal *et al*, 2015; Oppewal & Hilgenkamp, 2019). The issue of lower activity levels may well commence in childhood as evidenced by children with an intellectual disability who were found to be significantly less active than children in the general population and continue through the life course ultimately affecting the daily functional movements and actions required (Hinckson and Curtis, 2013). Therefore, people with an intellectual disability may have inherent challenges laid down from an early age which may affect their FMS proficiency and physical fitness and contribute to increased SB. There needs to be a focus on these functional skills to improve activity levels and reduce SB. Physiological differences such as FMS, enhanced by a deficit of lifelong practice, a lack of occupational pursuits and habits of inactivity could be a contributor to elevated SB and reduced PA.

1.4.4 Study rationale

In the general population, the WHO (2020) purports that one quarter of all adults are insufficiently active. This figure reduces further when those with intellectual disability are considered. For example, approximately 9% of adults with an intellectual disability achieved minimum activity recommendations with most spending approximately 60% of their waking-time in sedentary pursuits (Dairo *et al*, 2016; Lynch *et al*, 2021). This lack of activity and increased SB is a lethal combination because even if minimum moderate or vigorous physical activity (MVPA) levels are met, SB is still a significant health risk factor especially for cardiovascular disease (Rezende et al, 2014; Yerramalla *et al*, 2021). Those who had high sitting levels and consequently high sedentary time could be classified as active as much as inactive, depending on whether they meet the minimum requirements for PA (Rosenberg *et al*, 2008). However for individuals with an intellectual disability, new literature proposes that light intensity activity may be as beneficial as MVPA and warrants further investigation (Hsu *et al*, 2021).

A general population longitudinal study showed a linear relationship between SB and all-cause mortality in a group of older women and increased levels of SB have been associated with a plethora of physical health conditions like type-2 diabetes, obesity, metabolic risk factors and cancer (Edwardson *et al*, 2012; Seguin *et al*, 2014; Henson *et al*, 2016; Lynch *et al*, 2018). In fact, Jefferis *et al* (2019) report that every 30-minute increase in sedentary time per day resulted in a 15% higher mortality risk in a group of older men after 5-years follow-up. However, SB-induced cancer mortality risk may be alleviated by introducing any type of movement (Gilchrist *et al*, 2020). Those with an intellectual disability (excluding DS) had almost 3.5-times higher chance of having obesity or diabetes than their general population peers (Flygare-Wallén *et al*, 2018;). However these bad health effects are not a foregone conclusion. Breaking up sedentary time with any type of activity has shown improvements in postprandial insulin and glucose levels while extended sitting time increased the risk for abnormal glucose metabolism (Dunstan *et al*, 2004; 2012). Similarly Henson and colleagues found that breaking up sitting periods with either standing or walking breaks of 5-minutes duration every 30-minutes, had a positive postprandial metabolic effect, which continued for 24 hours (Henson *et al*, 2016). Accelerometer-measured sedentary time found that independent of MVPA or time spent sedentary, breaks in sitting time of predominately low intensity and less than 5-minutes long, were beneficially associated with reducing cardiovascular disease (CVD) risk factors like waist circumference, triglycerides and BMI in healthy adults (Healy *et al*, 2008). Generally it is proposed that SB contributes negatively to overall health, an area already compromised for so many people with intellectual disability (Kandola *et al*, 2020; Cao *et al*, 2022).

Sedentary behaviour occurs in multiple domains and has many different areas of influence which may change across the lifespan (Santos *et al*, 2018). In the general population, non-occupational SB increases with age and is exasperated with retirement (Leskinen *et al*, 2018). The ageing process naturally lends itself to decreased muscle mass which may be enhanced by SB and counteracted by movement (Miszory *et al*, 2022). In the intellectual disability population this sedentary age-gradient has not been observed although individuals are said to be more sedentary overall, however there is little investigation on SB within the field (Oppewal *et al*, 2018). People with an intellectual disability are living longer but inequality in mortality rates persist and they have approximately a 20-year shorter lifespan than adults in the general population (O’Leary *et al*, 2018). Better physical fitness has been

identified as a significant predictor of longevity in older adults with intellectual disability as well as an indicator of better quality of life (Oppewal *et al*, 2019; Cuesta Vargas *et al*, 2022). Living longer and better-quality lives should be the goal and reducing SB could help with both.

1.4.5 Physical effects of sedentary behaviour

In the general population inferior performance in sit-to-stands, grip strength and low gait speed has been associated with increased risks of premature all-cause mortality, with grip strength having a more significant relationship with cardiovascular mortality than blood pressure (Leong *et al*, 2015; Veronese *et al*, 2018; Medina-Mirapeix *et al*, 2022) . However the behaviour of the general population may not be directly translatable to adults with an intellectual disability who often experience chronic diseases and disabilities at a younger age and are less physically active overall (Cooper *et al*, 2010; Hermans & Evenhuis, 2014). The physical effects of SB for those with an intellectual disability requires further investigation.

1.5 Aims, research question and objectives

1.5.1 Aims

To explore and establish the sedentary behaviour level (sitting, lying or reclining) of a cohort of Irish older adults with an intellectual disability in two ways.

- to determine SB using TV as a surrogate
- to objectively measure SB using an activPAL, an OM tool,

and to determine how this behaviour affects their physical health.

1.5.2 Research question

What is the prevalence of sedentary behaviours in adults with an intellectual disability and how does this affect their physical health?

1.5.3 Study research objectives

The study aim will be achieved through the following objectives. Table 1.2 shows the relevant chapter for each objective.

- Determine the state of the science of SB in the adult intellectual disability population and if this SB has any health effects.

- A systematic review and meta-analysis will be completed to determine the prevalence of SB
 - A literature review will be used to examine any health effects of SB
- Examine the self-reported SB (or inactivity if SB unavailable) of older adults with intellectual disability longitudinally over 10 years.
 - The self-reported SB will be examined longitudinally using the TV question from IDS-TILDA Wave 1 to 3.
- Measure the relationship between measured SB & age, sex, level of intellectual disability, living circumstances, comorbidities and functional capabilities.
 - Relationships with the Wave 4 objectively measured SB will be compared to the standard covariates.
 - Relationships with the Wave 4 objectively measured SB will be compared to health status using different health indicators including standardised indexes; the Cumulative Illness Rating Score comorbidity index and the Barthel Index.
- Compare Wave 4 objectively measured SB to systematic review and meta-analysis determined self-reported and measured SB.
 - This study's results will be pooled with the original systematic review meta-analysis and results compared.

Table 1. 2: Study objectives mapped to the relevant thesis chapters

Objective 1: Determine the prevalence and health effects of sedentary behaviour (SB) in adults with an intellectual disability	• A systematic review and meta-analysis will determine the prevalence of SB in adults with an intellectual disability: Chapter 2 • A literature review will establish the health effects of SB in adults with an intellectual disability: Chapter 3
Objective 2: Examine the self-reported SB of adults with an intellectual disability longitudinally over 10 years	• An investigation into the risk factors for increased TV viewing in the intellectual disability population: Chapter 5. • A longitudinal exploration of self-reported TV behaviours as a surrogate for sedentary behaviour in older adults with an intellectual disability from the IDS-TILDA study: Chapter 6.
Objective 3: Measure the relationship between measured SB & age, sex, level of ID, living circumstances, comorbidities and functional capabilities.	• To measure the relationship between objectively measured sedentary behaviour and age, sex, level of intellectual disability, living circumstances, comorbidities and functional capabilities: Chapter 7.
Objective 4: To compare the Wave 4 objectively measured SB to the systematic review determined SB	• Where available, the results from this study are integrated into the original systematic review and meta-analysis determined results to determine if there was an impact on overall results: Chapter 8.

1.6 Conclusion

This introductory chapter has provided the reader with an overview of each chapter's content. Background and study rationale are stipulated. The study's research question, aims and objectives are explained. This study is critical to improve the health and wellbeing of adults with an intellectual disability who have low employment rates and high levels of free time which needs to be spent in more active pursuits. However, activity levels may be hampered by historical FMS issues which may be improved by increasing PA, for example by simply replacing tabletop activities with more active pursuits. Viable, sustainable activity options need to be provided and facilitated to minimise SB. The benefits of activity levels are well-researched and activity recommendations are evidence based but SB and its health effects are currently less-well understood, with insufficient evidence to quantify the levels of SB that would be detrimental to health. This study will help bridge this gap.

Chapter 2

Systematic review and meta-analysis to determine the prevalence of sedentary behaviour in the intellectual disability population.

Chapter summary

This chapter describes the process undertaken to conduct the systematic review and meta-analysis to investigate the prevalence of sedentary behaviour (SB) in the adult intellectual disability population. The Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P) checklist was used as a guide for the reporting and development of the systematic review protocol and the systematic review. The search strategy was framed using the Population Intervention Comparison Outcomes (PICO) process and executed in four databases and grey literature using two broad concepts. A total of 48 articles went forward for full review by two independent reviewers and 25 articles passed the stringent quality assessment to be included in the review. The results show that studies were not consistent in their measurement or assessment of SBs. The total range for steps per day was almost 24,500 while the average steps per day was 6,500. Adults with an intellectual disability spent over 60% of available time in SBs.

Publications

Lynch, L., McCarron, M., McCallion, P. and Burke, E., 2020. *Sedentary behaviour levels in adults with an intellectual disability: a systematic review protocol.* *HRB Open Research*, 3. Accepted August 2020. Available at doi: 10.12688/hrbopenres.13123.2.

Lynch, L., McCarron, M., McCallion, P. and Burke, E., 2021. *Sedentary behaviour levels in adults with an intellectual disability: a systematic review and meta-analysis.* *HRB Open Research*, 4, p.69. Accepted June 2021. Available at doi: 10.12688/hrbopenres.13326.3.

The student was responsible for article conceptualisation, investigation, analysis, methodology, draft preparation and final review and editing.

2.1 Introduction

Approximately 1% of the global population and 1.4% of the Irish population, have an intellectual disability (Maulik *et al.*, 2011; Census, 2016). This means that in Ireland over 70,000 people have impaired social functioning and intelligence which originated before adulthood (Census, 2016). There is a need to prevent age-related diseases and facilitate healthy aging because people, including those with an intellectual disability are living longer than they have in previous decades (McCarron *et al.*, 2015). Physical activity is a known contributor to living a longer, healthier life with evidence showing increased PA contributes to frailty reduction in older adults through improvements in gait speed, balance and daily activities (Chou, Hwang and Wu, 2012; WHO, 2020). Furthermore, there is consistent evidence that PA improves health-related quality of life scores (Bize *et al.*, 2007). Despite this, over 27% of the world's adult population and two thirds of the Irish population are insufficiently active, with Ireland's older adult population having one of the lowest activity levels in Europe (Bartlo & Klein, 2011; Løyen *et al.*, 2016; Healthy Ireland Survey, 2017; Guthold *et al.*, 2018). Inactivity and lower levels of activity contribute to all-cause mortality and have been associated with poorer health outcomes and higher rates of multi-morbidity (Tyrer *et al.*, 2019; WHO, 2020b). Unfortunately compared to their non-disabled peers, older adults with intellectual disability appear to have even higher rates of obesity, inactivity and multi-morbidity and experience a higher incidence of health disparity and consequent negative health experience (McCarron *et al.*, 2013; Krahn & Fox, 2014; Gawlik *et al.*, 2018; Tyrer *et al.*, 2019). Obesity is a key contributor to negative health outcomes and levels of up to 71% have been observed in adults with intellectual disability (Ranjan *et al.*, 2018). In fact, the evidence shows that adults with intellectual disability appear to be more susceptible to adverse age-related health problems (Graham & Reid, 2000). The likelihood for adults with intellectual disability aging with poorer health is greater due to the elevated levels of ill-health and inactivity observed in this population and highlighted by the fact that their lifespans are almost 20 years shorter than their peers in the general population (Krahn *et al.*, 2006; Krahn & Fox, 2014; McCarron *et al.*, 2015). Modifiable health conditions like Type 2 diabetes and cardiovascular disease and consequent metabolic syndrome are common in the intellectual disability population and multimorbidity is extensive (de Winter *et al.*, 2009; McCarron *et al.*, 2013; Chalk *et al.*, 2016; Bryant *et al.*, 2017). These increased health problems lead to additional

healthcare requirements and elevated healthcare costs. In fact, in the USA, healthcare costs for those with intellectual disability, at over \$51 billion, was over three times that of the general population (Honeycutt *et al.*, 2003; Catlin and Cowan, 2015). While it should be possible to improve this health outlook through increasing activity levels and lifestyle improvements, the self-management of health for those with intellectual disabilities is more complex and poses challenges (O’Leary *et al.*, 2018; Burke *et al.*, 2017). According to Burke and colleagues (2017), older adults with intellectual disability are less physically active than the general population and these lower activity levels could be a contributor to their observed poorer health status. In fact, several studies from Ireland to the US and Australia, observed that the number of people with intellectual disability who did not attain the minimum recommended activity guidelines ranged from 66% to 77% and as people aged these activity levels declined even further (Phillips & Holland, 2011; Barnes *et al.*, 2013; Koritsas & Iacono, 2016; Burke *et al.*, 2017). While inactivity is a global problem, new research has highlighted that independently SB is increasingly important as a contributor to ill-health (Bull *et al.*, 2020).

2.1.1 Sedentary behaviour

Physical inactivity, which is too little exercise or physical movement and not attaining the minimum recommended activity levels, and SB which constitutes too much sitting or stationary activity, are different and should be addressed separately. Recommendations for different PA intensities and types are long established for all populations and age groups but corresponding recommendations for SB are not (Bull *et al.*, 2020). To provide clarity in the literature a definition for SB has been proposed as a standard:

‘Any waking behaviour characterized by an energy expenditure of ≤ 1.5 METs while in a sitting, lying or reclining posture’,

for example, reading, watching television or working on a computer (Tremblay *et al.*, 2017).

A scoping review revealed that many publications confused physical inactivity and SB and used the terms interchangeably. Hence a much broader definition of SB, to also include physical inactivity, was required for this systematic review to ensure that all relevant publications were captured and thus support the thorough identification of the prevalence of SB among this population. As seen earlier, for the purposes of this thesis the definition of SB is:

‘Low physical activity as identified by metabolic equivalent (MET) or step levels or as measured by the Rapid Assessment of Physical activity questionnaire (RAPA) or the International Physical Activity questionnaire (IPAQ) or sitting, lying or reclining for more than 3 hours per day’,

where a MET is the resting metabolic rate and is an OM scale used to classify activity intensity and types. The overall trend for SB appears to be increasing but the types of SBs observed are changing, with rising computer and mobile phone use for both adults and children, while TV viewing remains stable at a prominent level (Yang *et al*, 2019). For example, it was found that women who watched over ½ hour of TV on a handheld device were at an increased risk of higher BMI (Falbe *et al*, 2017). A US-based cross-sectional study proposed that over 25% of US adults spent greater than 8 hours sedentary per day (Ussery *et al*, 2018).

Overall SB and its physical health effects are poorly understood. There is strong evidence to suggest that SB could be detrimental to health with studies in the general population showing dose-response relationships to cardiovascular disease, type 2 diabetes, obesity, all-cause mortality, metabolic syndrome and increased cancer risks but it is unclear exactly how much SB can lead to health issues (Patel *et al*, 2010; Tremblay *et al*, 2011; de Rezende *et al*, 2014; Thorp *et al*, 2011; Patterson *et al*, 2018). Replacing SB with PA of any type or intensity for any duration can provide health benefits, with additional health improvements observed if more than 5 hours a week of moderately intense activity is performed (Piercy *et al*, 2018). Furthermore, replacing sedentary time with the equivalent activity time reduces mortality by 14% to 50%, with a larger effect seen when more intensive activities are performed (Schmid *et al*, 2016). If only the minimum recommended activity levels are achieved, health problems like increased risk of heart disease, diabetes, and stroke due to excessive SB can occur, but these may be mitigated in individuals who are highly active i.e., perform about 60-75 minutes per day of moderate intensity activity (Patel *et al*, 2010; Ekelund *et al*, 2016). If prolonged periods of SB are broken up with activity of any type or intensity the detrimental effect of SB may be alleviated and a protective effect ensues (Healy *et al*, 2008). More breaks in sedentary time were found to be related to improved physical function and consequent improved performance of activities of daily living in older adults (Sardinha *et al*, 2015). Emerging evidence supports the adoption of a holistic public health approach which targets the concurrent reduction of sedentary levels and the growth of activity levels (van der Ploeg and Hillsdon, 2017; Ekelund *et al*, 2016).

Research in SB is novel and focused primarily on the general population. This systematic review was required to understand the condition of SB in the adult intellectual disability population. The aim of this systematic review was to understand the prevalence of SB in adults with an intellectual disability. The primary outcome of this investigation into SB determined the prevalence of SB levels in adults with an intellectual disability.

2.2 Methods

This systematic literature review was designed to understand the prevalence of SB in the adult intellectual disability population. PRISMA-P, for the robust reporting and development of systematic review protocols was used as the guide for the writing of the protocol and systematic review (Shamseer *et al.*, 2015). See Appendix 2.1.

The PICO framework, which is applied to develop searches for quantitative studies was used to define the research question as follows (Schardt *et al.*, 2007):

- P [Population or problem]: Adults aged 18+ with an Intellectual Disability
- I [Intervention or exposure]: Sedentary behaviour level (in line with the definition of SB defined for this review)
- C [Comparison]: Individuals with all levels of intellectual disability living in residential, institutional or hospital settings, community group homes, with family or independently
- O [Outcome]: Prevalence of SB

The research question to be addressed is:

‘What are the sedentary behaviour levels of Adults with an Intellectual Disability?’

2.2.1 Eligibility criteria

The criteria for study inclusion in the review are as follows:

- Population: adults aged 18+ with an Intellectual Disability

- Language: English
- Study type: All types of studies including primary studies, peer reviewed, grey literature
- Study design: Randomised controlled trials, cohort, cross-sectional
- Content: Must reference SBs of adults with intellectual disability to be eligible for inclusion
- Timeframe: no restriction on timeframes up to March 2020.

The criteria for exclusion in the review are as follows:

- Population: Children with or without an intellectual disability and Adults without intellectual disability
- Language: Articles that are not available in English
- Study design: Any type of reviews
- Conference proceedings and published conference abstracts only

2.2.2 Information sources

The following four databases were used to perform the search:

- Medline
- Embase
- PsycINFO
- CINAHL

In addition, the following sources were explored for grey literature sources:

- The CORDIS library
- Grey Literature Database from the Canadian Evaluation Society
- The U.S. Department of Housing and Urban Development (HUD) User database

- National Technical Information Service (NTIS)
- Open Grey
- Social Care Online
- Social Science Research Network (SSRN) eLibrary
- RIAN
- Google Scholar
- ProQuest (Dissertations and Theses)

2.2.3 Search strategy

The search strategy was refined into two concepts following the application of PICO. Concept one is 'Sedentary behaviour or inactivity' and Concept two is 'Intellectual Disability'. Each of the two concepts were

searched using MESH terms and keywords and then combined using OR. Then the total results of each concept were combined using AND, see figure 2.1.

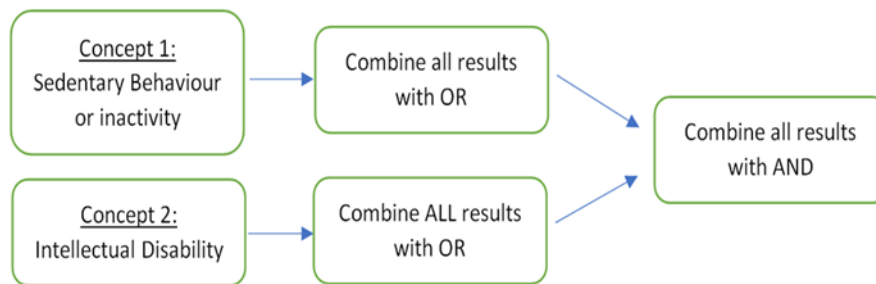


Figure 2. 1: Search strategy.

This search was repeated for each of the four databases. The resulting article list was the complete combined database search results. This list was screened for inclusion. An example of the search string used for the Medline database is shown in table 2.1.

Table 2. 1: Medline search string.

Concept	Index	Keywords
Concept Sedentary behaviour physical inactivity	1: (MH "Sedentary & Behavior")	sedentary lifestyle* OR sedentary behavior* OR sedentary behaviour* OR physical* inactiv* OR inactive lifestyle
Concept Intellectual disability learning disability	2: (MH "Intellectual or Disability+") OR (MH "Learning Disabilities+")	((intellectual AND disabilit* OR 'mental retardation'/exp OR 'mental retardation' OR (mental AND ('retardation'/exp OR retardation)) OR 'learning'/exp OR learning) AND disabilit* OR developmental) AND disabilit* OR 'learning disabilities'/exp OR 'learning disabilities' OR (('learning'/exp OR learning) AND disabilities)

2.2.4 Screening process

All articles identified from the four databases, as well as all grey literature sources, were combined and duplicates removed. Endnote software was used to store all the identified articles which were stored in folders named after the search process used. Using the inclusion criteria as detailed above, all articles were initially screened by title and then by abstract by the two assessors [LL and EB]. The remaining 48 full text articles were retrieved and read thoroughly. Those that did not meet the inclusion criteria were omitted. The PRISMA search flowchart which details the search process is shown in figure 2.2. An excel spreadsheet served as the data extraction tool to summarise the remaining articles. Article details were captured under 22 category headings, see table 2.2. Exclusion criteria eliminated 20 articles.

Table 2. 2: Categories captured from articles for data synthesis

Author, title, year
- study focus
- study type
- Intervention type
- country
- duration
- dates
- numbers
Participants
- number
- mean age
- sex (%)
- level of intellectual disability
- living circumstances
- employment type
Assessment
- type
- intervention
- Assessment type
- measurement device
- outcome/data
- Statistical results
Summary
Comment

2.2.5 Quality assessment and risk of bias

The remaining 28 articles were quality assessed separately by two assessors using two validated quality assessment tools from the National Institute of Health (NIH) (National Institute Health, 2020). There are diverse types of study quality assessment tools for the different study types,

the first for observational cohort and cross-sectional studies and the second for randomised controlled trials (RCTs). See appendix 2.2 and 2.3. A third person was available as an adjudicator for any discrepancies. For Controlled Intervention Studies and Observational Cohort and Cross-sectional studies, 14 criteria were used to evaluate the study quality, while for Case-Control studies 12 criteria were used. Eleven criteria were used to determine the study quality of RCTs. This means that a maximum quality score of 11, 12 or 14 could be achieved depending on the study type. This quality score was used to determine if the study should be included in the review. Quality scores were divided into 3 main categories: Good, Fair or Poor. For details see table 2.3.

- Quality scoring

Scores were attributed to distinct parts of the study design for example type of study, design and blinding, where a 'yes' answer gives a score of '1', a 'no' answer a score of '0' and could potentially highlight an issue with the article.

Table 2. 3: Quality assessment Scoring System

Quality Rating	Observational Cohort & Cross-Sectional Studies	Case Control Studies	RCTs	Action
Good	9–12	10–14	7–11	Data extraction
Fair	6–8	7–9	4–6	2 reviewers to discuss. Adjudicate with 3rd reviewer if required.
Poor	<=5	<=6	<=4	2 reviewers to discuss. Reject
Other	CD, NR, NA*			

The final number of articles that progressed for a full quality assessment was 28. Using the NIH's quality assessment tools to assess the internal validity of each article and any sources of potential bias only articles rated in the fair to good range by the two assessors [LL and EB] were included (National Institute Health, 2020). Two assessors [LL, EB] reviewed and quality assessed each of the final articles. There were no big discrepancies in quality assessment results so the third adjudicator [MMcC] was not required. Appropriate quality scores for

inclusion in this systematic review were achieved by 25 articles. These 25 articles are summarised in table 2.4. The reasons for study exclusion are shown in figure 2.2.

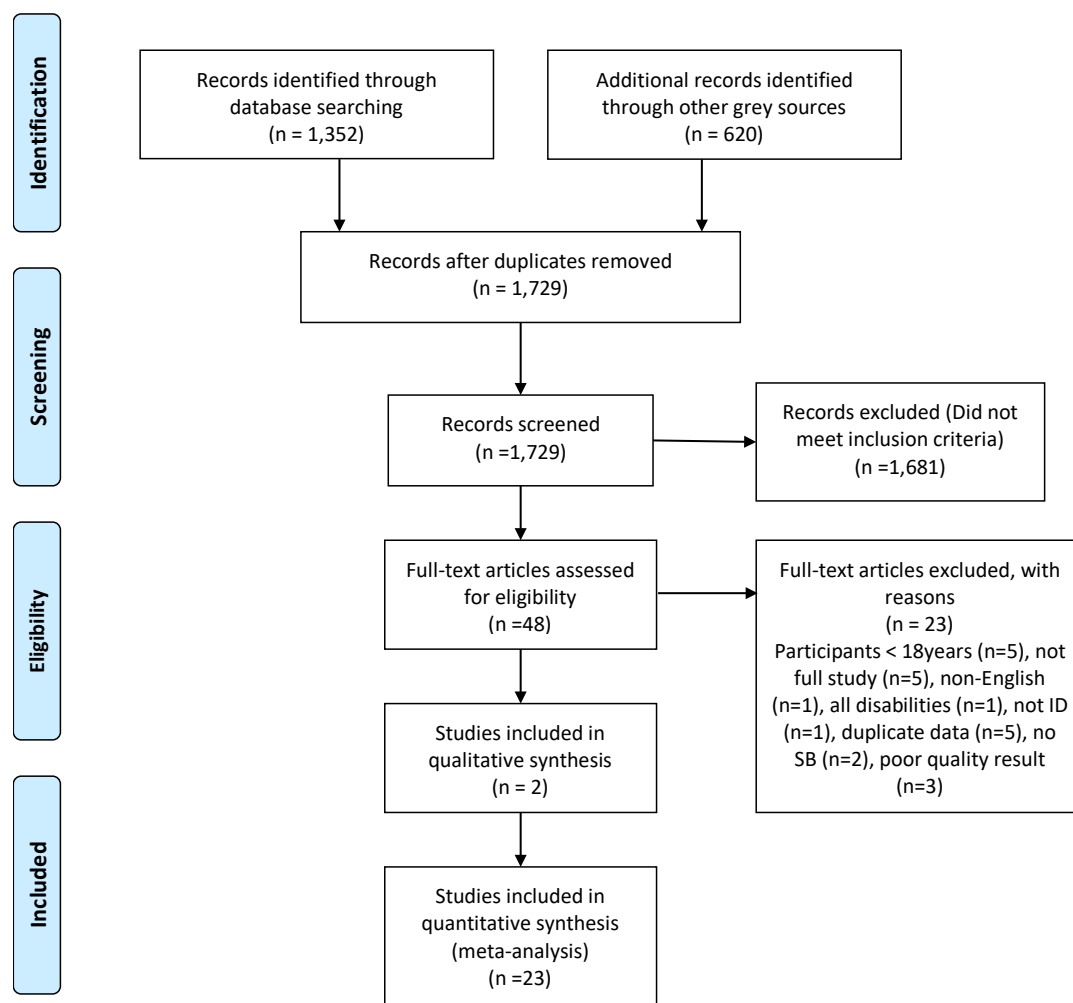


Figure 2. 2: PRISMA search flow diagram

Table 2. 4: Final articles used

No	Article	No of Parts.	Study Focus	Assessment type	Measurement device	Sedentary or (in)activity	Country	Age	Sex	Level of intellectual disability
1	Temple and Walkley, 2003.	37	Concurrence of accelerometer readings of PA and proxy generated estimates of PA via diary recordings	Staff completed Bouchard 3day activity record (which has 9-point scale) and accelerometer worn for the 3 days of this diary completion	Caltrac accelerometer	PA	Australia	N/A	18 women, 19 men	Mild to Mod
2	Temple, 2007.	37	Examine relationships between doing PA/sedentary behaviour & factors consistent with behavioural choice theory enjoyment, preference and barriers	Pedometer	Yamax Digi walker SW-700	PA	USA	18-52 yrs.	18 men, 19 women	Not specified
3	Peterson <i>et al</i> , 2008.	131	Aim to objectively monitor steps accrued by sample of 131 adults with ID and describe patterns across day and week	Steps via pedometer	Omron pedometer HJ-700IT, worn for 7 days	PA	US (IOWA)	Mean age of 37.2 yrs (18 -60 yrs)	51.9% female	73 mild, 41 mod, 17 unknown, 28 DS
4	Finlayson <i>et al</i> , 2011.	62. 41 worn activity monitors for at least 5 days	Aim of study is to measure the levels and patterns of activity of adults with ID to inform design of studies aimed at increasing activity and health in this population	Self-report and activity monitor	ActivPAL. Interview before and after 7-day period	Both	UK, Scotland	Mean age 37.1 (Range 18-66)	27 males, 35 females	Mild to mod
5	Matthews <i>et al</i> , 2011.	45	To assess level of agreement between accelerometer and proxy-respondent questionnaire (IPAQ short version). Obese focus	IPAQ and accelerometer. Wore device for 7 consecutive days. Kept diary of non-wear times	Actigraph GT1M	Both	Scotland, UK	Mean age = 48.3 years (23-72)	17 male, 28 female	30 mild/mod 15 severe

6	Hilgenkamp <i>et al</i> , 2012.	257 (out of group of 1050)	Measure the physical activity levels of older (50+) adults with ID	Pedometer. Caregiver was instructed to record the no of steps, distance and activity in minutes in a diary every evening. Worn for 14 days	NL-1000 pedometer. Said to take reliable measurements at walking speed of ≥ 3.2 km/hr	PA	Holland	50+ years. 50-59: 146 60-69:83, 70-79:25, 80-89:3	133 men, 124 females	Borderline-11, mild-88, mod-143, severe-10, prof-0, unknown -5
7	Bergström <i>et al</i> , 2013.	130	To improve diet and PA by a 3-way complex approach using Social Cognitive Theory, targeting caregivers and residences	Average No of steps per day (3 valid days min). Results of 500 steps per day or less were discounted as being inaccurate. Steps taken each day were recorded each evening.	Keep walking LS2000	PA (by pedometry)	Sweden	20-66 years	74 women, 56 men	Mild & mod
8	Dixon-Ibarra <i>et al</i> , 2013.	109	To examine the physical activity patterns of older adults with ID compared with younger adults with ID and older adults without ID	Pedometers and accelerometers	GT1M actigraph accelerometer and Omron HJ 720ITC Pedometer	Both. Sed classed as when accelerometer registers <100 counts/min	USA	Mean age adults w/ID= 32.34 mean age older adults w/ID= 57.87	48 = male, 36 = female.	Mild to mod ID. 20 had Down Syndrome
9	McKeon <i>et al</i> , 2013.	17	Pilot study to test 2 instruments used to measure PA of men with ID prior to use in larger study	IPAQ & Sensewear armband	Sensewear armband worn for 7 days all the time except when washing or swimming	PA	Ireland	Mean age 42 years. 19-39yrs = 5; 40-59yrs= 12	17 men	6 mild, 2 mod, 9 severe & profound
10	FitzGerald and Hahn, 2014.	17	Determine if self-report health status influences physical activity	PAM for objective measurement of activity. Reported by interview the exercise and activity inventory reporting of activities, types and frequency per week	Personal activity monitor (PAM)	PA but did capture hours SB/day	USA (LA)	18 to 59yrs. Mean age men= 33.9yrs Mean age women= 35.7 yrs	10 male, 7 female	Not specified

11	Johnson <i>et al</i> , 2014.	37	To examine evidence of convergent and discriminant validity for self-report with assistance from secondary source as a measure of PA in adults with ID	NHANES III PA survey and Actiwatch accelerometer and Omron HJ-112 pedometer	NHANES III PA survey and Actiwatch accelerometer and Omron HJ-112 pedometer	PA	US	19-74 years	21 females, 16 males	Not specified. 11 had DS
12	Hsieh <i>et al</i> , 2015.	4282	Examine (1) the impact of three adulthood stages— younger (20–39 years), middle (40–59 years), and older (60 years and older) on BMI & PA, (2) the relationship between social-environmental context (i.e., residence type, everyday choices, and community participation) and BMI and PA	Question on a questionnaire	None. Single question on a questionnaire	Inactivity	USA	20+ yrs	56.6% male, 43.4% female	42% mild, 30.1% mod, 15% severe, 12.8% profound
13	Melville <i>et al</i> , 2015	102	Examine effectiveness of walking intervention to reduce SB and increase PA.	Accelerometer	Actigraph GT3X. Min data were 3 days from 7, with minimum 6 hours data on it	PA	Scotland	Mean age in walk well group= 44.9yrs (SD 13.5). In control = 47.7yrs (SD 12.3)	45 females, 57 male	58 mild, 35 moderate, 8 severe

14	Carlson, 2016.	17	To examine if there is a relationship between PA and physical functioning in adults with DS	PA levels assessed by wear of accelerometer for 7 days. Compared to the results of physical functioning tests. Sedentary behaviour classified as any movement <100 hz. Daily sedentary value determined by subtracting the sleep time of each participant. Time spent watching TV (called media time) was recorded with the health history questionnaire.	Triaxial accelerometer (GT3X+, Actigraph, Pensacola, FL)	Both	USA	Mean age 33 years +/-15yrs	8 women, 9 men	Down syndrome
15	Hsieh <i>et al</i> , 2017	1618	Investigated the prevalence of reported low levels of PA and hours spent watching TV	Mixed methods, Mail and online survey for data collection	Survey	SB (TV viewing)	US	Mean age 37.67 yrs (18 to 86 yrs)	893 men, 725 women	52.4% mild/mod, 12.4% borderline 8.2% severe or profound
16	Oviedo <i>et al</i> , 2017.	84	Sedentary behaviour and physical activity	Accelerometer data over 4 days/week with min of 10hr/day wear	Actigraph GT3X		Spain Catalonia	44 +/-12 years	49 male, 35 female	30 mild, 34 mod, 28 severe
17	Chow <i>et al</i> , 2018.	67	Describes the habitual daily physical activity (PA) and the health-related physical fitness (PF) of adults with mild and moderate ID. Secondary focus is determine health-related PF components explain the variance in PA levels and SB	Device worn all waking hours except for bathing and bedtime. Wore for at least 5 consecutive weekdays. Not worn on weekends. Used Freedson to categorise activity types, MVPA>1951 counts/min, Sedentary <100 counts/min and light intensity was classed as in between	WGT3X-BT Activity Monitor; Actigraph LLC	PA	Hong Kong	Mean 41.7 yrs. 18-64 yrs	71 males, 43 females	Mild & mod ID

18	Melville <i>et al</i> , 2018.	725	SB prevalence and correlates	Demographic and health data collected during a structured interview and physical examination. Screen time is measure of SB	Question ' on average how many hours do you spend watching TV, DVDs, videos or on a PC? Response used 9point scale: none, 1-3hrs/ month, 1 hr/ week,2-4hrs/ week, 5-6hrs/ week, 1hr/day, 2-3hrs/ day, 4-5hrs/ day or 6+hrs/ day	SB (screen time)	Scotland, UK	Mean age = 43.6 yrs (18-90 yrs)	55% men (399), 45% women (326)	258 mild, 192 mod, 130 severe, 145 profound
19	Moss and Czyz, 2018.	58	Determine level of agreement between objectively measured Actiheart and IPAQ	Actiheart monitors for 7 days, only removing for bathing. Caregivers completed IPAQ-S	Actiheart activity monitor. Measures and calculates activity energy expenditure based on accelerometry and heart rate measurements	Both	South Africa (NW province)	39.6 years +/-9.1	28 female & 28 male	Mod to mild
20	Woods <i>et al</i> , 2018.	19	Determine associations between body composition, diet, PA and timed walk for adults with PWS	Accelerometer worn for up to 7 days. Goal was min of 4 days.	ActivPAL accelerometer.	PA	USA Oklahoma	18-62 years	11 male, 8 female	Not specified
21	Harris <i>et al</i> , 2019.	143	Investigate the patterns of objectively measured sedentary behaviour in adults with ID	Sedentary behaviour variables output from accelerometer	Actigraph GT3X + accelerometer	SB	Scotland	54 < 45yrs, 86 > 45yrs	69 male, 74 female	69 mild, 51 moderate, 18 severe, 4 profound
22	Oviedo <i>et al</i> , 2019.	97. 37 from active group, 29 non-active, 31 no ID	Objective investigation of PA levels and sedentary behaviour in groups of adults with ID and without	Accelerometer. Needed to be worn for >10hrs/day for 4 days/week	Actigraph GT3X	Both	Spain	43+/-12 years (20-60 years)	51 male, 41 female	18 mild to 48 mod

23	Tyrer <i>et al</i> , 2019	920	Determine prevalence of multimorbidity in adults with ID and identify risk factors	Cross-sectional analysis	Data analysis	Both	UK	Mean age 42.9 yrs (18-74yrs)	530 male, 390 female	259 mild, 243 mod, 310 severe/profound
24	Bellicha <i>et al</i> , 2020.	10	To objectively quantify spontaneous PA in adult patients with Prader-Willi syndrome	Habitual PA. wear an accelerometer for 7 consecutive days during waking hours but not water-based activity (3 valid days min with wear time of 8 hours per day). Freedson cut-offs used for sedentary behaviour	Tri-axial GT3x Actigraph accelerometer	PA	France	18-60 years	10 females	Not specified
25	Ghosh, 2020.	52	To examine levels and patterns of SB in adults with ID	Accelerometer data. Attached to waist during waking hours. Valid accelerometer data were ≥ 10 hours/day for 4 days including at least 3 weekdays & 1 weekend day	WGT3X-BT accelerometer (ActiGraph, Pensacola, FL) and data obtained using ActiLife 6 Software v.6.13.4.	SB. SB time as time spent below a threshold of < 100 cpm	US	20-79 years. Median 48	25 men, 27 women	4 men & 6 women had DS, 1 cerebral palsy. 5.8% severe ID. Rest mild to mod

2.2.6 Data items

The PICO framework was used to define what data and variables would be sought from articles as follows:

- P: Adults with an Intellectual Disability
 - Age, sex, living circumstance, country, number in study, level of intellectual disability
- I: Sedentary behaviour
 - Level, types of behaviour, quantify change
- C: Level of SB or physical inactivity
 - Level, intensity, types of activity/SB, type of employment
- O: Prevalence of SB

2.2.7 Data Synthesis

Article data were grouped according to the SB assessment category used in each article. Four methods for quantifying SB were identified in the 25 articles that passed the quality assessment. These four methods were:

1. Number of steps per day
2. Amount of screen time per day
3. Time in SB per day
4. Different methods

The data were scrutinised to establish the breakdown of SB time, steps and screen time by various categories i.e., level of intellectual disability, sex, age and residence type. However, this type of analysis was not always possible as few studies analysed results by residence type, sex or intellectual disability level and age ranges were not consistent across studies.

RevMan Review Manager Version 5.4.1 was used to synthesize results in a graphical format (The Cochrane Collaboration, 2020). This graphical illustration of a meta-analysis is called a Forest Plot, where individual study's results are represented by a box and lines which denote the 95% confidence interval (CI). The size of the study box represents the study weighting, which is the influence a study has on the overall meta-analysis. The variance between individual studies is represented by the heterogeneity value, I^2 , of the forest plot (Israel and Richter, 2011). A higher I^2 value means a greater difference is observed between studies which is not due to chance and a meta-analysis may be inappropriate, as studies may not have similar populations (Higgins *et al.*, 2003), see table 2.5.

Table 2. 5: Forest plot heterogeneity values

I^2 value	Level of heterogeneity
>75%	High
>50%	Moderate
25%	Low

To account for inter-study differences such as the use of different measurement devices, a random effects model was used in the Forest plots. The mean difference and standard error for each study were used to determine a pooled mean prevalence for SB. In addition, a cumulative mean-of-means was calculated to determine the pooled prevalence of SB. Pair-wise comparisons were calculated where data were available using means and standard deviations. Scales were adjusted on the Forest plots so results may be seen more clearly.

2.3 Results

2.3.1 Measurement devices

A selection of devices were used across studies to gauge SB levels. While the prominent devices for measurement were accelerometers, which were used in 14 studies, 4 used pedometers, 1 used a personal activity monitor, 1 used a survey as well as pedometers and accelerometers, 3 used a questionnaire or survey, 3 used IPAQ and accelerometers and 2 studies used self-report and accelerometers.

2.3.2 Steps per day

Steps as a measure of PA or SB were used in 11 studies, which involved 985 participants. The OM of steps per day in these 11 studies was obtained using accelerometers and pedometers as shown in table 2.6, which also shows the mean and range of steps per day, the number of participants in each study and the variety of measurement devices used.

Table 2. 6: Studies that used steps to determine SB/PA

Article no	Article name	Measurement device	No of participants	Steps/day Mean(SD)	Step Range [Low-high]
1	Temple & Walkley, 2003	Caltrac acc.	37	8100 (3735.4)	1,658 - 19,303
2	Peterson <i>et al.</i> , 2008	Pedometer [Omron HJ-700IT]	131	6,506 (3296)	1,703 - 24,369
3	Finlayson <i>et al.</i> , 2011	ActivPAL acc., Self-report	62	8509 (4384)	380 - 21,139
4	Hilgenkamp <i>et al.</i> , 2012	Pedometer [NL1000]	257	6601 (3610)	NA
5	Bergström <i>et al.</i> , 2013 Bergström <i>et al.</i> , 2013	Pedometer [LS2000]	130	8,042 [Int]* 6,296 [Ctrl]*	(5,524) NA (4167)
6	Dixon-Ibarra <i>et al.</i> , 2013	Actigraph acc. pedometer [Omron HJ720ITC]	109	Done by age	NA
7	Mckee <i>et al.</i> , 2013	Sensewear acc., IPAQ	17	5,308 (5,502)	44 - 21,219
8	Johnson <i>et al.</i> , 2014	Actiwatch acc., pedometer Omron [HJ112], survey [NHANES III]	37	6,625.4 (3,303.72)	NA
9	Melville <i>et al.</i> , 2015	Actigraph GT3X acc.	102	4,780 (2432)	NA
10	Oviedo <i>et al.</i> , 2017	Actigraph GT3X acc.	84	6,192 (2814)	NA
11	Woods <i>et al.</i> , 2018	ActivPAL acc.	19	7,631.7 (1171)	NA

*=Pre-intervention, NA=Not available, Acc=accelerometer

The average steps per day ranged from 4,780 to 8,509 but the range for all 11 studies was very wide at 44 to 24,369 steps per day. Melville and colleagues in a Scottish-based RCT to investigate the effect of a walking intervention on sedentary levels of a group of 102 participants with varying intellectual disability levels and from diverse residential settings, found the participants were sedentary for 65.5% of the day at baseline and the average difference in step counts after the intervention was 69.5 steps per day (Melville *et al.*, 2015). Reduced levels of PA could be significantly predicted by female sex, mobility

impairments, a more severe intellectual disability and being older (Hilgenkamp *et al.*, 2012).

- Steps per day and age

Several studies proposed that age could be a contributing factor to the number of steps taken per day. One of these studies which compared the SBs of younger (aged 18-49years) and older adults (aged 50+ years) found that step levels decreased with age and that 40% of the younger adults and over 50% of the older adults took less than 5,000 steps per day (Dixon-Ibarra *et al.*, 2013). However, the authors felt the younger adults may have had more wear time. Similarly, Hilgenkamp and colleagues (2012) in the Dutch Healthy Aging and Intellectual Disability (HA-ID) study, which investigated 257 adults aged over 50 with all levels of intellectual disability who wore a pedometer for 14 days, showed that age and the number of steps a day were inversely related and 39% had less than 5,000 steps per day, see table 2.7.

Table 2. 7: Steps per day and age categories (Hilgenkamp *et al.*, 2012)

Age group (years)	No in group	No of steps per day	% of group
50-59	146	> 10,000	17.8%
		> 7,500	41.1%
60-69	83	>10,000	18.1%
		>7,500	34.9%
70-79	25	> 10,000	8%
		> 7,500	16%
80-89	3	>7,500	0%

Woods *et al.* (2018) which examined the behaviour of 19 participants aged 18 to 62 years with Prader-Willi Syndrome, found that even though the 18–30 years and 40+ age group had similar steps and the 30–40 years had less steps, timed walking test results were inversely proportional to age. A US-based study with 131 able-bodied community living adults with intellectual disability showed that intellectual disability and age were strong contributing factors in the numbers of steps taken per day with over 39% of the participants classed as sedentary due to achieving less than 5000 steps per day (Peterson *et al.*, 2008). Conversely, 84 adults with varying levels of intellectual disability who participated in a Spanish study, observed no age dependency on SB levels (Oviedo *et al.*,

2017). Consequently, the relationship between age and step count per day is unconvincing. Table 2.8 shows a summary of studies with age-related steps per day.

Table 2. 8: Steps per day by age group.

Article no	Article Name	Age (years)	Steps per Day Mean (SD)
1	Dixon-Ibarra <i>et al.</i> , 2013	18–49	6831 ($\pm$ 3221)
	Dixon-Ibarra <i>et al.</i> , 2013	50+	4596 (3052)
2	Hilgenkamp <i>et al.</i> , 2012	50–59	7038 (3565)
	Hilgenkamp <i>et al.</i> , 2012	60–69	6578 (3699)
	Hilgenkamp <i>et al.</i> , 2012	70–79	4616 (2818)
	Hilgenkamp <i>et al.</i> , 2012	80–89	2511 (1336)
3	Woods <i>et al.</i> , 2018	18–30	8243.19 (2237.1)
	Woods <i>et al.</i> , 2018	30–40	5411.51 (1379.84)
	Woods <i>et al.</i> , 2018	40+	8379.74 (1660.86)

- Steps per day and sex

The effect of sex on steps taken per day was investigated by four studies and some found a relationship between sex and steps per day. A 2011 Scottish study with sixty-two community-based adults with mild to moderate intellectual disability found that women were much more likely to be sedentary (Finlayson *et al.*, 2011). Conversely, Johnson and colleagues found the step count measured over two weeks was similar for both sexes, in a study which investigated PA levels of thirty-seven community-based ambulatory adults with intellectual disability (Johnson *et al.*, 2014). Likewise, a study which had nineteen participants with Prader-Willi Syndrome discovered that the mean steps per day was equitable for males and females (Woods *et al.*, 2018). Contrastingly, the Dutch HA-ID study, discovered that men took more steps than women; 21.8% of male participants and only 11.3% of females had $\geq$ 10,000 steps/day, while 42.9% men and 29% women had $\geq$ 7500 steps/day (Hilgenkamp *et al.*, 2012). Thus, the effect of sex on steps per day is questionable. Table 2.9 shows the mean steps per day by sex.

Table 2. 9: Mean Steps per day by sex.

Article no	Article Name	Female Mean (SD)	Steps/day Male Mean (SD)
1	Finlayson <i>et al.</i> , 2011	6481 (2998)	11,101 (+/-4575)
2	Hilgenkamp <i>et al.</i> , 2012	5966 (2937)	7193 (4063)
3	Johnson <i>et al.</i> , 2014	6809.63 (3056.2)	6406.72 (3693.61)
4	Woods <i>et al.</i> , 2018	7894.3 (2021.1)	7325.4 (1173.6)

The forest plot shown in figure 2.3 shows the sex pairwise comparison. This plot shows that females take more steps per day than males, which is contrary to some study results (Westrop *et al.*, 2019). The mean difference seen is 1,089.2 steps per day at 95% CI [-69.72, 287.57]. However, the high heterogeneity value ($I^2 = 79\%$) indicates that it may not be appropriate to pool article results due to differences between studies (Higgins *et al.*, 2003). Furthermore, because the diamond shape touches the line of no effect (Y axis) the overall effect is not significant.

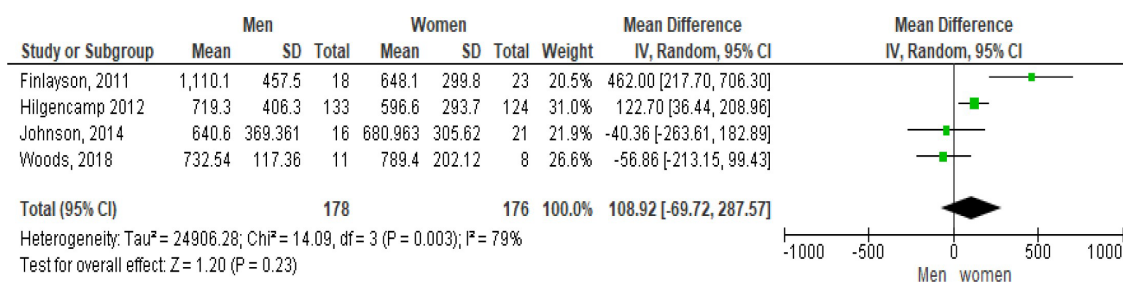


Figure 2. 3: Pairwise comparison of steps per day by sex (divided by 10)

- Steps per day and day of week

The influence of weekday versus weekend on the daily step count was investigated by some studies. Dixon-Ibarra *et al.* (2013) showed that all the adult participants with intellectual disability took significantly less steps from weekdays to weekends. On weekends, adults (18-49years) with intellectual disability had an average of 4,530 (SD±2337) steps per day compared to older adults (50+) with intellectual disability who had 3,504 (SD±2239) (Dixon-Ibarra *et al.*, 2013). Finlayson and colleagues (2011) concurred when their study found the 62 participants were more active on weekdays than weekends. Equally, a Spanish study found the average step levels were higher on weekdays with 6,523

(SD±2807) steps per day compared to 5,378 (SD±3686) steps per day at the weekend (Oviedo *et al.*, 2017). Peterson *et al.* (2008) found that weekday steps per day ranged from 1,796 to 21,744 while weekend steps per day ranged from 1,189 to 30,931. Overall, there does appear to be a weekday versus weekend influence on step levels.

- Summary steps per day

A forest plot was created using each study's individual mean and standard error which was used to calculate a pooled mean of steps per day. The pooled study mean for the 11 studies was 6,715 steps per day, at 95% confidence interval (CI) [6,086, 7,344] (See figure 2.4). However, the high variability between studies as indicated by an I^2 heterogeneity value of 88% may signify that it is inappropriate to combine studies due to potential variability in studies (Higgins *et al.*, 2003). A collective mean-of-means was also calculated for the 11 studies. This calculated pooled mean result for the 985 study participants was 6,555 steps per day, which was a difference of only an average of 160 steps per day between the two calculations.

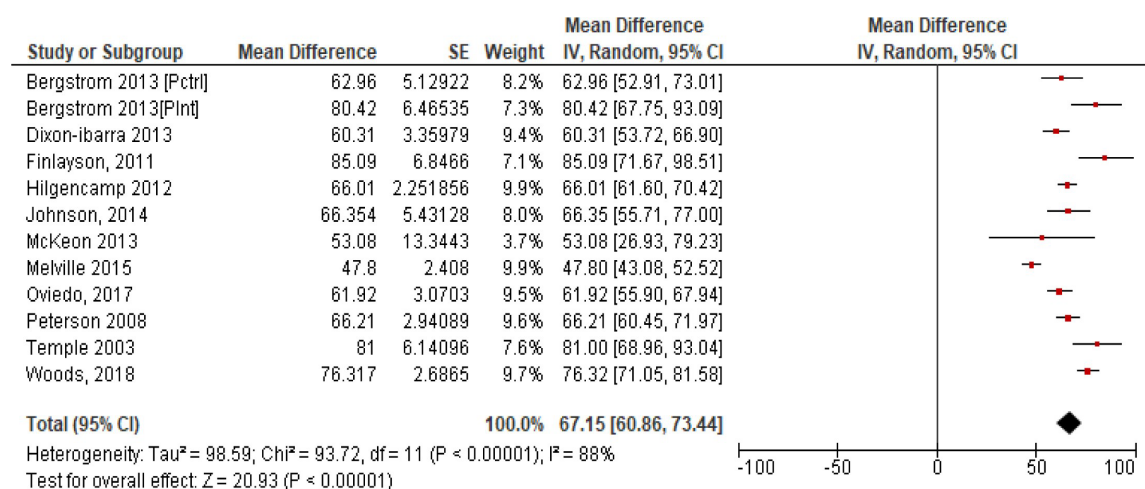


Figure 2. 4: Study steps per day means with SE (Divided by 100)

2.3.3 Screen time

Screen time which included using a computer, watching DVDs, playing video games and watching TV was used as a subjective measure of SB. Only three articles used TV time alone as a means of evaluating SB while two articles quantified SB by the total time spent looking at a screen. In a cross-sectional study of 725 people with an intellectual disability, a proxy-based measure of subjective screen times showed that 50.9% of participants spent four or more hours per day watching TV (Melville *et al.*, 2018). This study which categorised screen

time into low (<4 hours) and high (>4 hours) levels, showed that increased screen time was associated with having mobility issues, more severe levels of intellectual disability, being male, obesity, hearing issues and epilepsy (Melville *et al.*, 2018). A mixed methods study, with 1,618 participants with an intellectual disability, which used an online and mail survey to gather data, indicated that over 60% of participants watched three or more hours of TV per day and 40% watched four or more hours per day (Hsieh *et al.*, 2017). In addition, this study found that increased TV viewing time was associated with being male, living in family homes or independently and having a mild or moderate intellectual disability while no age-effect was observed (Hsieh *et al.*, 2017). The Carlson study which had 17 participants with DS found that the average TV viewing time was approximately four hours (Carlson, 2016). A meta-analysis was not possible with all three studies as the Melville study did not give raw screen time values. Figure 2.5 illustrates the forest plot for screen time for the remaining two studies. While the low heterogeneity value of the forest plot, at $I^2=0\%$, indicates that the two studies are comparable, the heavier weighting of the Hsieh study due to the larger sample size may skew results. The forest plot shows the mean screen time per day is 3.42 hours at 95% CI [3.32, 3.53].

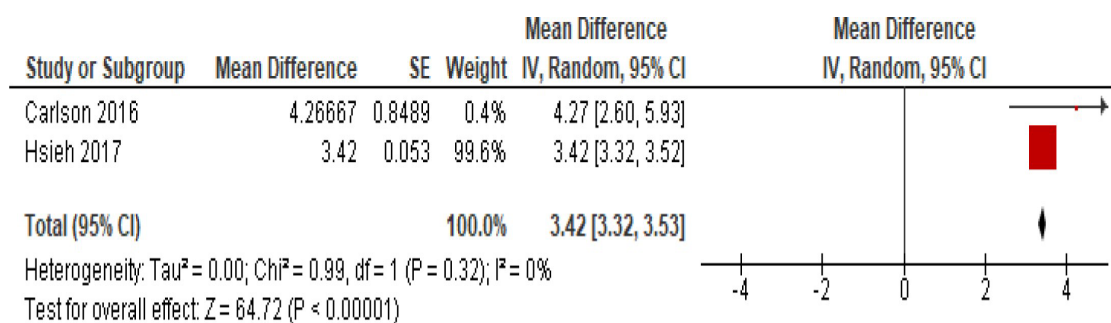


Figure 2. 5: Screen time.

2.3.4 Assessing sedentary behaviour by time

The third method used in studies for assessing SB was time in hours or minutes per day. A total of 13 studies which included 713 participants used time as the measurement tool for SB. These studies and the mean sedentary time per day are shown in table 2.10. Accelerometers, pedometers and personal activity monitors were used to gather OM as shown in table 2.10. In this meta-analysis the mean sedentary time per day ranged from 8.1 to 23.2 hours per day but another study observed sedentary time in the range of four to twenty-four hours a day (McKeon *et al.*, 2013). According to Fitzgerald and Hahn (2014), time spent in SB was inversely related to self-rated health as well as PA minutes in a group of 17 adults with an intellectual disability. A Spanish study which compared the SB and activity levels of 66 active and non-active adults with an intellectual disability to 31 adults without an intellectual disability, found that even if the minimum PA guidelines were met, SB was widespread and consecutive sedentary time was higher in the intellectual disability participants (Oviedo *et al.*, 2019). In fact, bouts of sedentary time ranged from one to thirty minutes in a US study which had 52 participants of all intellectual disability levels (Ghosh, 2020). Similarly, a study with 143 adults with intellectual disability showed that although sedentary time was high at an average of 8 hours (73%) per day, this sedentary time was predominately accumulated in small blocks (mean bout time was 19.8-22.3 minutes per day) and a median of 7 breaks per day were taken (95% CI, 4-11) where the median break duration was over 43 minutes (Harris *et al.*, 2019). An Australian study which used a Bouchard 9-point scale to classify activity according to energy expenditure and classifies levels 1 and 2 as sedentary due to being in a reclining or sitting posture, discovered that the 37 participants with mild to moderate intellectual disability were sedentary for an average of 83.7% a day (Bouchard *et al.*, 1983; Temple & Walkley, 2003). Disproportionate daily SB of 79.4% was also observed in a Spanish study with 84 adults of varying levels of intellectual disability who attended a day center (Oviedo *et al.*, 2017). Similarly, a study focused on 90 group-home dwelling adults with mild or moderate intellectual disability found that an average of 67.3% a day was spent sedentary (Chow *et al.*, 2018).

Table 2. 10: Studies that used time to assess sedentary behaviour.

No	Article name	Measurement device	No of participants	SB per day (Hours)
1	Temple & Walkley, 2003	Accelerometer [Caltrac]	37	20.105 (4.73)
2	Finlayson <i>et al.</i> , 2011	Accelerometer [ActivPAL], Self-report	62	18.71 (1.88)
3	Dixon-Ibarra <i>et al.</i> , 2013	Accelerometer [Actigraph GT1M], pedometer [Omron HJ720ITC]	109	NA
	Dixon-Ibarra <i>et al.</i> , 2013 [18–49Yrs]	Actigraph GT1M & Omron HJ720ITC	40	6.75 (1.94)
	Dixon-Ibarra <i>et al.</i> , 2013 [50+Yrs]	Actigraph GT1M & Omron HJ720ITC	28	7.35 (1.77)
4	McKeon <i>et al.</i> , 2013	Accelerometer [Sensewear armband], IPAQ	17	15 (6)
5	Fitz Gerald & Hahn, 2014	Personal activity monitor, interview	17	NA
	Fitz Gerald & Hahn, 2014 [Males]	Personal activity monitor, interview	12	22.9 (0.47)
	Fitz Gerald & Hahn, 2014 [Females]	Personal activity monitor, interview	10	23.2 (0.19)
6	Carlson, 2016	Accelerometer [Actigraph GT3X]	17	7.28 (1.33)
7	Matthews <i>et al.</i> , 2016	Accelerometer [Actigraph GT1M]	45	10.17 (2.06)
8	Oviedo <i>et al.</i> , 2017	Accelerometer [Actigraph GT3X]	84	10.22 (1.34)
9	Chow <i>et al.</i> , 2018	Accelerometer [Actigraph WGT3X-BT]	90	8.25 (1.45)
10	Harris <i>et al.</i> , 2019	Accelerometer [Actigraph GT3X]	143	8.1 (2.1)
11	Oviedo <i>et al.</i> , 2019	Accelerometer [Actigraph GT3X]	66	NA
	Oviedo <i>et al.</i> , 2019 [Active group]	Accelerometer [Actigraph GT3X]	37	10.25 (1.78)
	Oviedo <i>et al.</i> , 2019 [Nonactive group]	Accelerometer [Actigraph GT3X]	29	10.25 (1.34)
12	Bellicha <i>et al.</i> , 2020	Accelerometer [Actigraph GT3X]	10	8.712 (0.363)
13	Ghosh, 2020	Accelerometer [Actigraph WGT3X-BT]	52	8.6

Only 23% of the studies investigated the influence of a weekday versus a weekend on SB levels and the results were inconclusive. Table 2.11 shows these three studies. However, Harris and colleagues (2019) did observe significant differences in break time between weekend and weekday minutes, with weekend breaks being significantly shorter 62.6 (SD±55.7) minutes compared to 79.8 (SD±151.6) minutes on a weekday, but the number of breaks was similar.

Table 2. 11: Weekend versus weekday sedentary behaviour

No	Article name	SB Weekday (Hours)	SB Weekend (Hours)
1	Oviedo <i>et al.</i> , 2017	10.4 (1.39)	9.73 (1.7)
2	Finlayson <i>et al.</i> , 2011	18.49	19.28
3	Harris <i>et al.</i> , 2019	8.2	8

- Sedentary time and sex

The effect of sex on SB was investigated by six studies. The paired comparison of mean sedentary minutes per day by sex is shown on the forest plot, see figure 2.6.

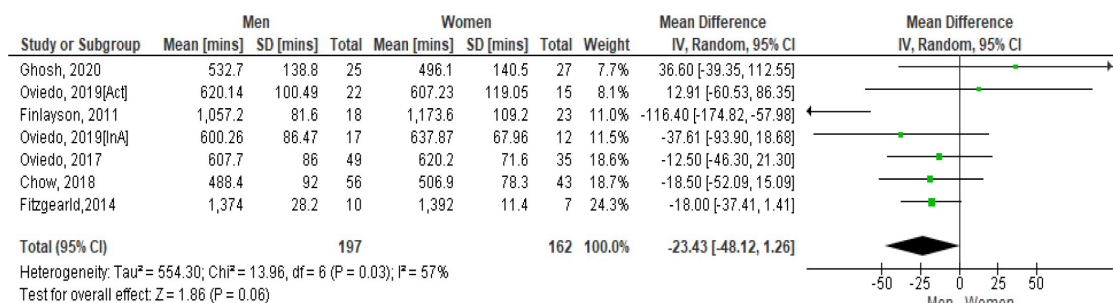


Figure 2. 6: Mean sedentary minutes by sex (divided by 10)

Oviedo and colleagues (2019) divided both male and female participants into active (act) and inactive (InA) categories and these are represented separately on the forest plot. Finlayson and colleagues (2011) compared the SB time of 62 community living people with mild and moderate intellectual disability on weekdays and weekends and found that men were sedentary for 17.62 hours per day on a weekend and 17.24 on a weekday while women engaged in SB for 19.56 hours on a weekend day and 19.46 on a weekday. Overall, the forest plot indicates that men have less sedentary minutes per day than women with a mean difference of -234.3 minutes [95% CI, -48.12, 1.26]. However moderate heterogeneity, as demonstrated by an I^2 of 57%, is present so it may not be appropriate to combine results (Higgins *et al.*, 2003). However, the Finlayson study appears to be an outlier and if this is excluded from the analysis the heterogeneity falls to zero indicating that studies have high similarity and may be combined, see figure 2.7 (Higgins *et al.*, 2003). Even with this exclusion, men still have less sedentary minutes per day compared to women, with a mean difference of -153.7 [95% CI, -293.9, -1.36]. This result is significant

as both lower and upper points of the horizontal plane of the diamond lie to the left of the axis.

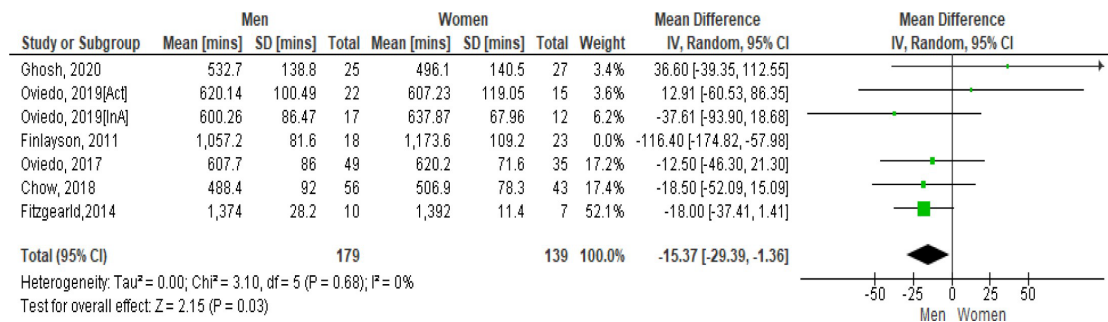


Figure 2. 7: Mean sedentary mins by sex (excluding Finlayson) (divided by 10)

- Sedentary behaviour time summary

All study times were converted to minutes for analysis purposes. A forest plot was completed with the mean sedentary time in minutes, see figure 2.8. The Fitzgerald study was excluded as only sex-based summaries were available (Fitzgerald & Hahn, 2014). The high heterogeneity value ($I^2=99\%$) indicates that it may not be appropriate to combine studies as prominent levels of variation may be present (Higgins *et al.*, 2003). The forest plot mean sedentary time across the 12 studies was 599.9 minutes per day (95% CI [520.3, 679.5]) or 9.99 hours per day. This compares to a calculated pooled mean for sedentary time for all studies of 606.3 minutes or 10.1 hours per day, a mean difference of 6.4 minutes. Overall, the observed sedentary time in the studies ranged from 437 minutes (7.28 hours) to 1206.3 minutes (20.1 hours) per day which equated to 72% to 83.77% of waking time in SB (Temple & Walkley, 2003; Bellicha *et al.*, 2020).

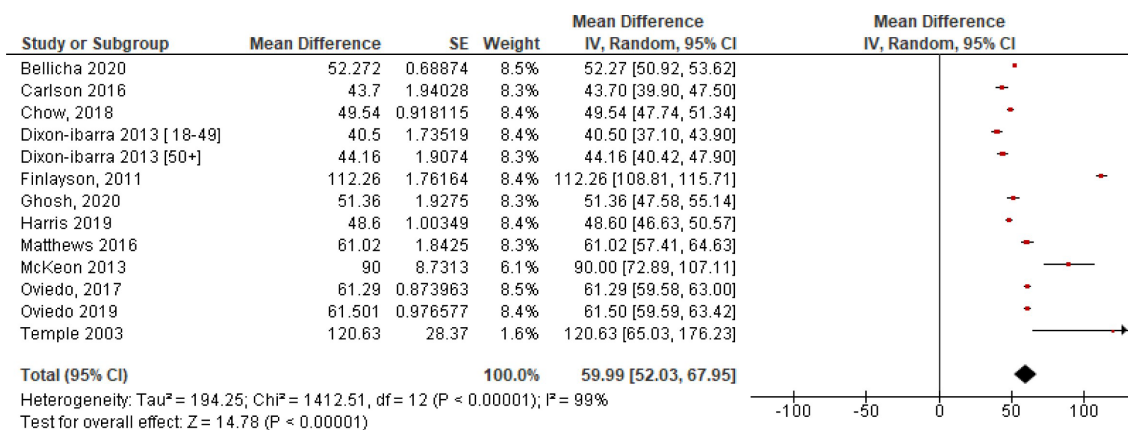


Figure 2. 8: Mean time sedentary with SE (*minutes divided by 10*)

2.3.5 Different methods

Two studies could not be included in the meta-analysis as different methods were used to quantify SB. Tyrer and colleagues (2019) used the amount of time spent sitting as a representation measure of SB. This was ascertained by a single question and found that almost 50% of the 920 participants sat for 'all or most of the time' (Tyrer *et al.*, 2019). In the second study, a pre-calibrated Actiheart accelerometer was used to determine activity energy expenditure and the Physical Activity Level (PAL), which is the ratio of total energy expenditure to resting energy expenditure, was reported, where PAL levels of less than 1.4 were associated with SB (United Nations Food and Agriculture Organisation, (2001). The PAL of 1.39 (SD±0.15) observed in this study was symptomatic of a sedentary regime (Moss *et al.*, 2018).

2.4 Discussion

Sedentariness has only recently been recognised as an independent risk factor which is detrimental to health with no definitive recommendations on safe quantities yet available (Bull *et al*, 2020). In fact, studies have shown that increased time spent in SB has resulted in increased cardiometabolic risk factors, all-cause mortality, type 2 diabetes, metabolic syndrome and functional limitations (Gennuso *et al*, 2013; Rezende *et al*, 2014). It is hypothesised that replacing time spent in SB by PA of any type or intensity could have health benefits for all population types (Bull *et al*, 2020). This systematic review demonstrated that limited studies have been completed evaluating the SB levels of people with an intellectual disability with only 25 studies qualifying for inclusion. The overall results of the review which represent 9,111 adults with an intellectual disability are stark, revealing that adults with an intellectual disability spend over 60% of their waking hours sedentary and take less than 6,500 steps per day on average. This compares to the general population where average step levels for adults aged over 65 years were over 6,500 while the overall adult average was almost 9,500 steps per day (Bohannon, 2007). However, these studies did not fully represent the intellectual disability population as people with a more severe or profound disability or mobility limitations were often excluded. Harris and colleagues (2019) identified comparable levels of SB of more than 70% in the intellectual disability adult population. Furthermore, divergent approaches and methods were used in studies to determine the SB levels and it

proved difficult to ascertain definitive conclusions as a result. In the studies, a wide range of devices were used for measurements ranging from accelerometers and pedometers for OM to self-report questionnaires. The devices included Actigraph, ActivPAL, Actiwatch and Caltrac accelerometers, Omron pedometers, a Personal Activity Monitor and a Sensewear armband. The Actigraph, which was used in 40% of the studies, was the most popular device used to assess SB levels. However, the accuracy of data obtained from the placement of the Actigraph device on the hip has been queried due to potential postural restraints at this location (Aguilar-Farías *et al.*, 2014; Kim *et al.*, 2015). Self-report measures, which comprised of either interviews, questionnaires or surveys to determine the SB information were used in five studies but of concern was two studies which compared the IPAQ to accelerometer data and found that the self-reported IPAQ underestimated the time spent in SB (Matthews *et al.*, 2011; Moss *et al.*, 2018). Overall, there is little consistency in the assessment of SB in adults with an intellectual disability across studies. While different methods are often used for measurement, steps are reported across a lot of the studies.

A total of 11 studies used steps as a measure of the SB levels. It is widely recognised that a minimum of 10,000 steps a day is required to maintain health (Wattanapisit *et al.*, 2017). However, these studies showed that few adults with an intellectual disability attain these recommendations and brings into question if these levels are achievable for this population. Dixon-Ibarra and colleagues (2013) showed that only 10% (n=4) of younger adults (18–49 years) and 3% (n=1) of older adults (50+) with intellectual disability achieved the recommended 10,000 steps per day. Another study, with a smaller sample size of 19 adults with an intellectual disability showed that only 15% of the participants achieved 10,000 steps/day, while several had <5000 steps per day, which can be indicative of a sedentary lifestyle according to some experts (Tudor-Locke *et al.*, 2013; Woods *et al.*, 2018). However, Finlayson and colleagues' study described 27% of the 62 participants that performed 10,000 steps per day which was higher than seen in other studies (Finlayson *et al.*, 2011). Overall, these studies show that a minority of adults with an intellectual disability are achieving the 10,000 steps per day recommended for health. This compares to the adult general population where an average of 9,448 steps per day was seen which reduced to an average of 6,565 steps per day for those aged over 65 years (Bohannon, 2007).

The WHO uses time and not steps to promote its PA recommendations for health. The recommendation for all populations, including those with an intellectual disability is to

partake in a minimum of 150 minutes of MVPA per week (WHO, 2019). Two studies proposed that to meet this minimum activity level, a step equivalent of 7,100 and 7,700 steps per day respectively is necessary (Tudor-Locke *et al.*, 2011; Cao *et al.*, 2014). The calculated pooled mean steps per day for this systematic review and meta-analysis was between 6,430 and 6,555 respectively, which is over 10% short of the WHO time recommendations, emphasising that the activity levels of adults with an intellectual disability are inadequate for achieving the health benefits associated with minimum activity levels. The health implications for not achieving these minimum activity levels have been shown to be far-reaching including increases in all-cause mortality, diabetes, cardiometabolic and metabolic risks (Biswas *et al.*, 2015; Edwardson *et al.*, 2012; Krishnan *et al.*, 2009). However, at least meeting the minimum recommended activity levels increases quality of life indicators as well as the positive perception of health status (Brown *et al.*, 2003). Of concern is that the IDS-TILDA study has shown that over 70% of participants did not meet the minimum PA recommendations and almost 80% were either overweight or obese (Burke *et al.*, 2017; McCarron *et al.*, 2017). Furthermore, multimorbidity rates of between 71–98% were identified (Kinnear *et al.*, 2018; McCarron *et al.*, 2013).

The relationship between sex and steps was researched by only four studies. In general, the research has shown that women with an intellectual disability have a greater health risk, for example due to morbid obesity and diabetes (Burke *et al.*, 2017; Hsieh *et al.*, 2014; Hsieh *et al.*, 2015). The meta-analysis pooled mean results indicated that women took 108.92 more steps per day than men. However, this was possibly due to the weighting of the Hilgencamp study, which had the largest number of participants of both sexes at 257, on the mean (Hilgencamp *et al.*, 2012). High heterogeneity in the forest plot, as demonstrated by an I^2 value of 79%, points to a large interstudy variability and the fact that the diamond touches the central axis indicates that the result may not be significant. However, when time spent in SB and the sex influence was investigated in a pooled analysis of six studies which had equal weighting, men spent less time in SB than their female counterparts. A systematic review on the influence of sex on SB determined there was no statistically significant difference in SB but the results showed that men with an intellectual disability were more physically active than women (Westrop *et al.*, 2019).

Time was another assessment type used to determine SB levels in the intellectual disability population. If it is assumed that approximately nine hours per day (=540 minutes) are spent sleeping, then 900 minutes are available for activity out of a total of 1,440 minutes per day

(Carlson, 2016). From the studies that used time as a measure for SB, the calculated pooled mean time was 599.9 minutes which was equivalent to 66.6% of available time spent in SB. This was less but still like the time of 606.31 minutes or 67.4% calculated using the mean-of-means formula, which was interesting considering the forest plot heterogeneity value was 99% which indicates that high variability could be present between the studies. This is a large amount of time to spend in SB and could potentially have severe health implications, especially considering that many adults with an intellectual disability have underlying health conditions. The IDS-TILDA showed that hyper-tension had a prevalence of over 35% and overweight/obesity of 89% (O'Brien *et al*, 2021; Ryan *et al*, 2021). Saunders and colleagues (2020) determined that the effect of increased time in SB on cognitive function, depression, functional capabilities and quality of life were extensive. In fact, the detrimental effects of sitting on health and its associations with all-cause mortality are widely recognised (Chau *et al*, 2013). Melville and colleagues (2015) reported similar SB levels of 65.5% in a walking intervention study which had 102 participants and expressed grave concern at the potential detrimental effects that could result if this continued. Of even more concern is that newer studies are showing even higher levels of SB in the intellectual disability population, for example 72% and almost 80% of time sedentary has been observed (Oviedo *et al*, 2017; Bellicha *et al*, 2020). Hence the evidence suggests that time in SB more than 60% is commonplace for adults with an intellectual disability which is a serious concern when the potential health repercussions are considered.

Inconsistent results were observed when the influence of age on SB was investigated in four studies. Two studies discovered that age had no influence on the SB levels of the intellectual disability cohorts (Oviedo *et al*, 2017; Woods *et al*, 2018). However, Dixon-Ibarra and colleagues (2013) found that older adults with an intellectual disability took significantly less steps than younger adults. Similarly, the Dutch HA-ID study found that lower levels of PA were significantly related to older age, but that age was not a predictor for SB levels (Hilgenkamp *et al*, 2012).

Positive active aging is promoted globally in an attempt to reverse the tendency for people to slow down as they age but in general it is under the guise of self-determination and self-management (DoH, 2015; Donoghue *et al*, 2016). While this may be viable in the general population it is not always possible for adults with an intellectual disability who may rely on the guidance and support of family and carers to attain positive ageing. This systematic review and meta-analysis has demonstrated that adults with an intellectual disability have a

very sedentary lifestyle overall which is consistently worse at the weekends compared to midweek (Dixon-Ibarra *et al.*, 2013; Finlayson *et al.*, 2011; Oviedo *et al.*, 2017). The possible negative health consequences of this SB is a critical concern and merits further research immediately. In addition, the role of the support infrastructure in promoting positive aging for adults with an intellectual disability needs to be investigated.

The final assessment type used to evaluate SB levels in the intellectual disability studies was screen time. The mean pooled observed screen time calculated from this meta-analysis was 3.42 hours per day, but this was calculated from two of only three studies which used screen time as a measure of time spent in SB and the Hsieh study had a much higher weighting of >96% due to the larger sample size so may have skewed results downwards (Hsieh *et al.*, 2017). In the general population, negative health effects were associated with more than three hours sitting in activities such as watching television and working, but watching television was especially harmful for CVD and diabetes (Periera *et al.*, 2012). A direct relationship was also observed for TV watching and other adverse health effects (Thorp *et al.*, 2011). The main screen time activity found for participants in the IDS-TILDA study was TV viewing with <20% regularly using a computer ((McCarron *et al.*, 2017). This is concerning as combined with the higher levels of diabetes, multimorbidity, obesity and overall poorer health already experienced by people with an intellectual disability, this TV screen time could lead to a further degradation in their health (McCarron *et al.*, 2013; Gawlik *et al.*, 2018; Tyrer *et al.*, 2019).

People with a more severe or profound intellectual disability are prone to more complex health issues, multimorbidity and have mobility limitations (McCarron *et al.*, 2015; Van Timmeren *et al.*, 2016). Unfortunately, this systematic review reveals that those with a more severe intellectual disability, the most vulnerable and potentially at increased risk for SB, were excluded from 60% of the included studies. This exclusion not only omits a large sector of the intellectual disability population whose voice will remain unheard but subsequently may underestimate the time spent in SB. Moreover, a lot of studies specified in the inclusion criteria that participants needed to be independently ambulatory (Temple & Walkley, 2003; Temple, 2007; Peterson *et al.*, 2008; Dixon-Ibarra *et al.*, 2013; FitzGerald & Hahn, 2014; Johnson *et al.*, 2014; Ryan *et al.*, 2014; Oviedo *et al.*, 2017; Chow *et al.*, 2018; Harris *et al.*, 2019; Oviedo *et al.* 2019) and other studies excluded those with severe mobility issues (Hilgenkamp *et al.*, 2012; Bergström *et al.*, 2013; Melville *et al.*, 2015; Carlson, 2016; Ghosh, 2020). In fact, 64% of the studies in this systematic review excluded those who were not

sufficiently able-bodied. This means that it is not possible to obtain a complete picture of the SB habits of adults with an intellectual disability because large segments of the population are excluded.

2.5 Conclusion

This systematic review demonstrates that adults with intellectual disability are more sedentary than their peers in the general population and high levels of time spent in SB are prevalent, even though measurement techniques and methodologies were inconsistent across studies. This was confirmed by findings across all the studies in this systematic review.

2.6 Chapter 2 key findings

Even though studies used divergent measurement techniques and were very heterogenous, this meta-analysis and systematic review demonstrated that SB levels were widespread in the intellectual disability adult population.

It revealed that even though women on average took more steps per day than men, males spent less time being sedentary per day than females.

Chapter 3

Physical health effects of sedentary behaviour (SB) on adults with an intellectual disability: a scoping review.

Chapter summary

This chapter describes the scoping literature review which was designed to establish the effects of SB on the physical health of adults with an intellectual disability. Sedentary behaviour is defined as any waking behaviour characterized by an energy expenditure of ≤ 1.5 METs while in a sitting, lying or reclining posture. An extensive search was executed in six databases: EMBASE, Medline, CINAHL, PsycINFO, ASSIA and Web of Science . Following screening, eighteen articles remained for inclusion in the review. A thematic analysis using the Braun and Clarke six step process resulted in the identification of seven broad health areas. Studies showed a prevalence of obesity, multimorbidity and metabolic syndrome as well as elevated levels of SB in adults with an intellectual disability. This literature review demonstrated that SB could be a contributor to the poor health which is common in adults with an intellectual disability. However to date the body of evidence does not confirm a cause-and-effect relationship.

Publication

Lynch, L., McCarron, M., Eustace-Cook, J., Burke, É. and McCallion, P., 2022. Physical health effects of sedentary behaviour on adults with an intellectual disability: a scoping review. *Journal of Intellectual Disabilities*, p.17446295221107281. First published online June 12, 2022. Available at <https://doi.org/10.1177/17446295221107281>.

The student was responsible for article conceptualisation, investigation, analysis, methodology, draft preparation and final review and editing.

3.1 Introduction

In order to understand the physical health effects of SB, it is important to understand what health is and what it means to be healthy. The constitution of the WHO states that health does not just refer to the absence of disease but is a complete state of social, physical and mental well-being and represents a fundamental right for all (WHO, 1995). Conversely, a cross-sectional study found that people with physical disabilities felt their disability did not define their state of health but rather that an absence of illness was what made them healthy (Nazli, 2012). The perception of being healthy does not necessarily correspond with reports on health conditions. Health cannot be objectively measured as it is defined by an individual's perceptions and values. Over 73% of adults with an intellectual disability who participated in IDS-TILDA perceived their health as 'very good' or 'good' despite multimorbidity levels in excess of 71% (McCarron *et al*, 2013; Lynch, 2021). This perception of good health was retained and sometimes exceeded across the ten years of the study (McCarron, 2011, 2014, 2017; Lynch, 2021). In general adults with an intellectual disability have shorter life spans than their counterparts in the general population, dying approximately 19 years earlier and from different causes (McCarron *et al*, 2015; Cooper *et al*, 2020). A Brazilian proxy-based study of adults aged 35-60 years showed that after five years, despite the relatively young age profile, adults with intellectual disability had more physical and mental health issues than controls (Guilhota *et al*, 2016). Worldwide, Ischaemic heart disease was the primary cause of death in the general population (Khan *et al*, 2020). A leading contributor to heart disease is overweight and obesity which was observed in almost 80% of a cohort of adults with intellectual disability but although these CVD risk factors were prevalent, heart disease was not the main cause of death (McCarron *et al*, 2017). Instead, for adults with an intellectual disability choking and respiratory infections were the leading causes of death (WHO, 2020; Cooper *et al*, 2020). However the shorter lifespan combined with the considerable multimorbidity rates observed in the intellectual disability population compared to the general population warrant further research and attention to cardiovascular risk factors such as SB and physical inactivity are essential until a greater understanding of these behaviours is obtained.

As seen earlier, while both SB and physical inactivity are typified by low energy expenditure they are different and should be addressed separately. A review of reviews on the effects of SB on health found that SB could be an important contributor to health irrespective of PA levels (Rezende *et al*, 2014). In fact in the general population, there is evidence to suggest

that increased sedentary time is associated with greater risks for all-cause mortality, an increase in metabolic risk factors, the incidence of CVD, type 2 diabetes risks and certain types of cancer (Biswas *et al*, 2015; Edwardson *et al*, 2012; Krishnan *et al*, 2009; Chomistek *et al*, 2013; Lynch *et al*, 2018). Hence while studies on the general population indicate that there may be health issues associated with increased time in SB, only limited information is available for adults with an intellectual disability. The aim of this literature review was to understand the physical health effects of SB in the adult intellectual disability population.

3.2 Methods

3.2.1 Research question

The PICO approach was used to define the research question for this literature review as follows:

P [Population or problem]: Adults aged 18+ with an Intellectual Disability

I [Intervention or exposure]: Sedentary behaviour level in line with the definition of SB

C [Comparison]: Individuals with all levels of intellectual disability living in residential, institutional or hospital settings, community group homes, with family or independently

O [Outcome]: Physical health effects of sedentary behaviour

The research question to be addressed was:

‘What are the physical health effects of sedentary behaviour on adults with an intellectual disability?’

3.2.2 Search

The article eligibility criteria used for this review was formulated using PICO and is summarised in table 3.1. Although the focus of the review is SB, both SB and inactivity were included in the search concepts to ensure all articles were captured.

Table 3. 1: Article eligibility criteria

	Inclusion criteria	Exclusion criteria
Population	Adults aged 18+ with an intellectual disability	All children and adults without an intellectual disability
Study Design	RCTs, cohort, case-control & qualitative	Reviews of any type
Language	English	Non-English
Subject	Health effects of SB or inactivity	
Timeframe	None up to April 2021	None

- Information sources

A subject librarian assisted with performing the search for this literature review. The following six databases were searched:

- EMBASE
- Medline
- CINAHL
- PsycINFO
- ASSIA
- Web of Science

In addition, any reviews about health and SB that were discovered during the search process were searched for appropriate references.

- Search strategy

The search strategy was refined using PICO and executed using three concepts. Concept 1 (C1) was SB and physical inactivity. Concept 2 (C2) was intellectual disability and learning disability. Concept 3 (C3) was impact, result, consequence, effect or response. All six databases were searched for each concept using Medical Subject headings (MeSH) terms and keywords and the Boolean operator OR was applied to broaden the search. An example of the search string used for Embase is shown in table 3.2. The results of each concept search were then combined using the Boolean operator AND. This was repeated in the other databases. This combined article list was then screened for final article inclusion.

Table 3. 2: Embase search string

Concept	Index	Keywords
C1: Sedentary behaviour & physical inactivity	'sedentary lifestyle'/exp	"sedentary life*" OR "sedentary behavi*" OR "physical* inactiv*" OR "inactive life*" OR "immobile life*" OR sitting OR "reclin* posture*" OR "lying posture" OR "sedentary time"
C2: Intellectual disability or learning disability	'intellectual impairment'/exp OR 'mental deficiency'/exp OR 'mentally disabled person'/exp	'intellectual disabilit*' OR 'intellectually disab*' OR 'learning disabilit*' OR 'mental handicap*' OR 'mental retard*' OR 'mentally disabl*' OR 'learning disorder*' OR 'mental deficien*' OR 'mental deficit*' OR 'mental* impair*' OR 'intellectual impair*' OR 'Trisomy 21*' OR 'down syndrome*' OR 'Down syndrome*' OR 'Down / s syndrome*' OR 'downs syndrome*' OR 'Trisomy 21*' OR 'Mongol*' OR 'down disease*' OR 'Downs syndrome' OR 'translocation 15 21 22' OR 'trisomy twenty one' OR 'trisomy twenty-one' OR 'intellectual impair*' OR 'intellectually impar*' OR 'intellectual deficit*' OR 'intellectual dysfunction' OR 'Coffin-Siris Syndrome' OR 'Cri-Du-Chat Syndrome' OR 'De Barsey Syndrome' OR 'De Lange Syndrome' OR 'Down Syndrome' OR 'Kleefstra Syndrome' OR 'Prader-Willi Syndrome' OR 'Schinzel-Giedion Syndrome' OR Phenylketonuria
C3: impact, result, consequence or response	No appropriate index terms	Impact* OR result* OR outcome* OR upshot* OR respons* OR conseq* OR conclus* OR effect* OR affect* OR aftermath* OR repercuss* OR eventual OR aftereffect* OR finish* OR fallout OR react* OR "follow up*" OR follow-up* OR chall* OR detriment* OR barrier*

- Screening process

A PRISMA flow diagram was used to illustrate the article screening process, see figure 3.1. The articles output from the search were imported into Covidence, which was used as the

screening management tool. Duplicates were removed and all articles were screened by title and abstract by the assessor, who then executed a full article review on twenty-seven articles. These twenty-seven articles consisted of 6 articles unearthed from reviews and 21 articles from the original search. This screening process was verified by another assessor. Data from the twenty-seven articles was summarised in an excel spreadsheet . The headings used in this data extraction spreadsheet are shown in table 3.3.

Table 3. 3: Data extraction spreadsheet headings

Article No
Article Detail
No of Participants
Study Focus
Assessment type
Measurement device
Country
Age
Sex
Level of intellectual disability
Year
Study Type
Outcome
Statistical results
Living Arrangements
Sedentary or inactivity
Conclusions
Findings
Comment

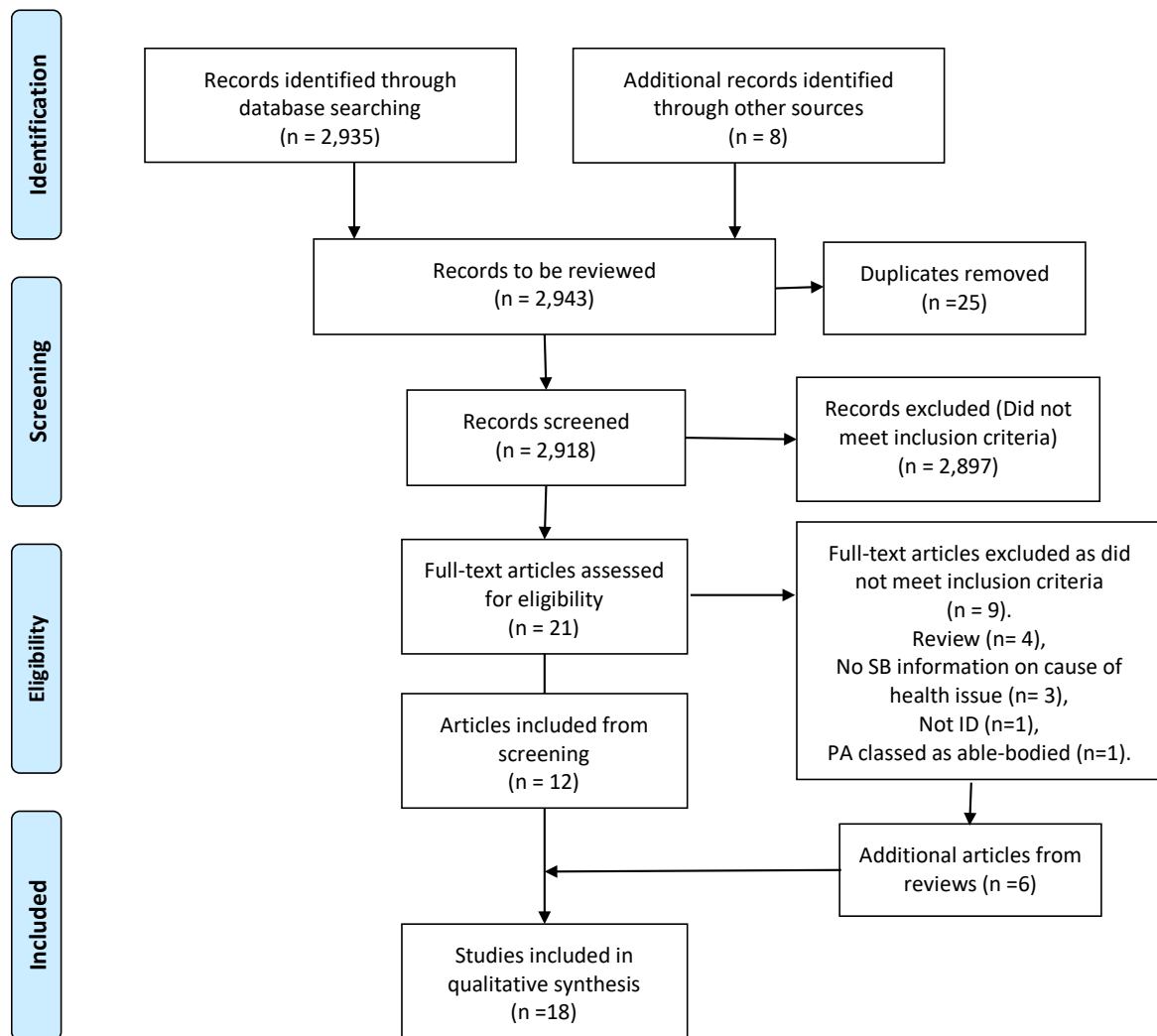


Figure 3. 1: Prisma search

- Data Synthesis

A qualitative synthesis of the final articles was performed and a thematic analysis using the Braun and Clarke Six Step process was completed as shown in table 3.4 (Braun and Clarke, 2006). The first step involved the researcher building familiarity with the articles and data through several readings of each article, identifying the main aspects of each study and creating and completing the data extraction tool. This enabled a succinct review for each article in order to conduct step two. As patterns emerged and the topics became evident the researcher used colour coding to highlight similar topics and then moved to identify the broader themes. These themes were fine-tuned until seven umbrella themes remained.

Table 3. 4: Six step thematic analysis process

Step number	Process	Explanation
1	Data familiarisation	Complete data immersion
2	Generate initial codes	Topics, patterns of data
3	Search for themes	Broader theme identification
4	Review of themes	Theme refinement
5	Define and name themes	Categorise. Include sub-themes if required
6	Produce report	Complete write-up

(Braun and Clarke, 2006)

3.3 Results

A total of 18 articles were successfully screened into this review. These articles are summarised in table 3.5. Overall, seven broad health themes were identified using the Braun and Clarke process as shown in table 3.6, which shows the data source for the study, the number of participants and whether PA/inactivity or SB were used as determinants. Some overlap in themes may be observed, for example obesity is a risk factor in metabolic syndrome and multimorbidity. Although inactivity is different to SB, it was included in the search to ensure that all relevant studies were captured because the terminology has been inconsistently used in articles before the definition for SB was refined (Tremblay *et al*, 2015). Sedentary behaviour was used in eight articles to compare to physical health outcomes, with only three articles solely using SB for comparison, while physical inactivity or PA levels were considered in fifteen articles. Thus the exclusion of inactivity or PA in this review would have resulted in an incomplete description of the state of the science, as over 50% of the articles would have been excluded. Eleven articles utilised some form of physical or OM. The number of participants with intellectual disability represented in the articles in this review was 9,830.

Table 3. 5: Final article summary

Article No	Article Detail	No of Participants	Study Focus	Assessment type/measurement	Strengths and/or weaknesses	Country
1	Wells, M.B., Turner, S., Martin, D.M. and Roy, A., 1997. Health gain through screening — coronary heart disease and stroke: developing primary health care services for people with intellectual disability. Journal of Intellectual and Developmental Disability, 22(4), pp.251-263.	120	Review of risk factors related to cardiovascular disease among people with intellectual disabilities	Health check and questionnaire with focus on family history and other CVD risk factors. Questionnaire also used to assess PA levels	No objective activity measurement, not a validated PA questionnaire and no information on amounts of time spent being active or inactive	UK
2	Havercamp, S.M., Scandlin, D. and Roth, M., 2004. Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. Public health reports, 119(4), pp.418-426.	946 in intellectual disability group. (1,598 in disability group & 4,358 in no disability group). 6,902 total.	Purposes of this study were to identify disparities between adults with developmental disabilities and non-disabled adults in health and medical care & compare this pattern of disparities to the pattern of disparities between adults with other disabilities and adults without disabilities.	Data on the health of adults with developmental disabilities living in North Carolina (NC) were compared with data from the 2001 NC Behavioral Risk Factor Surveillance System (BRFSS) survey, a random telephone survey of adults & the NC national core indicator survey	Large sample size which covered all levels of intellectual disability but due to telephone survey may not be fully representative. No objective measurements and no quantifiable amounts of PA.	USA

3	Carmeli, E., Bachar, A. and Barchad, S., 2007. Biochemical assessments of total antioxidant status in active and nonactive female adults with intellectual disability. Research in Sports Medicine, 15(2), pp.93-101.	21	To compare relationship between longterm PA and inactivity and plasma antioxidative status i.e. vitamin and enzyme levels in female adults with an intellectual disability	The antioxidant defence system measured was superoxide dismutase (SOD), catalase(CA), glutathione peroxidase(GPX), vit A & vitamin E. Chromatography with UV detector, liquid chromatography & tests by Randox labs	Small sample size & focussed on females. Compared sedentary controls with PA group. All from residential care setting. No details on level of activity or ID specified. All measured results were significantly better in active group (P<0.05)	Israel
4	de Winter, C. F., Magilsen, K. W., van Alfen, J. C., Penning, C., & Evenhuis, H.M. (2009). Prevalence of cardiovascular risk factors in older people with intellectual disability. American Journal on Intellectual and Development Disabilities, 114(6), 427–436.	470	Aims of (a) determining the prevalence of cardiovascular risk factors in older people with intellectual disability and (b) identifying the relation of these occurrences with Down syndrome & level of intellectual disability	Medical history through interview and chart review. Also physical examination	Large sample size but skewed towards females (73%/27%). 68.3% did no exercise i.e. did not do 150mins of MVPA per week. All intellectual disability levels but more severe & moderate. Did not talk about SB.	Holland
5	Moss, S.J., 2009. Changes in coronary heart disease risk profile of adults with intellectual disabilities following a physical activity intervention. Journal of Intellectual Disability Research, 53(8), pp.735-744.	100	To determine the CHD risk profile of adults with intellectual disability residing in a care facility & determine the effect of a PA intervention on the CHD risk profile of the residents.	Questionnaire and physical assessments of body fat, BMI, BP, non-fasting glucose and cholesterol, cardiorespiratory fitness test.	Active classed as MVPA min once per week. Most common risk factors for CVD were inactivity and overweight. Being active was 1 or more sessions of MVPA per week	South Africa

6	de Winter, C. F., Magilsen, K. W., van Alfen, J. C., Willemsen, S. P., & Evenhuis, H. M. (2010). Metabolic syndrome in 25% of older people with intellectual disability. Family Practice, 28 (2), 141-144	470	Studied the prevalence of the metabolic syndrome in the older population with intellectual disability and its association with patient characteristics	Waist measurement, fasting blood sample, BP. Semi-structured interview to assess daily PA level. PA criteria was to meet WHO requirement 5 X 30mins MVPA per week.	Large sample size which had significantly higher metabolic syndrome than general population. Mild intellectual disability even higher. No PA relationship detected. 3x more females than males due to setting being ex-nunnery. No SB measures	Holland
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7	Haveman, M., Perry, J., Salvador-Carulla, L., Walsh, P.N., Kerr, M., van Schrojenstein Lantman-de Valk, H., Van Hove, G., Berger, D.M., Azema, B., Buono, S. and Cara, A.C., 2011. Ageing and health status in adults with intellectual disabilities: results of the European POMONA II study. <i>Journal of Intellectual and Developmental Disability</i> , 36(1), pp.49-60.	1,253	1. What are the age-specific differences regarding type of residence, social relations, and state of employment for adults with intellectual disability in this European study? 2. Are there systematically and statistically significant differences between age groups with regard to lifestyle risk factors such as smoking, alcohol, and physical activity? 3. Which of the 17 medical conditions measured by the POMONA Checklist of Health Indicators (P15) are more prevalent in older age (55–64, 65 and older) compared to younger age groups?	The POMONA Health Interview Survey and Evaluation Form (P15) comprises items related to demographic characteristics of respondents, health status, health determinants, and health systems.	51.8% of total sample sedentary but 65+ years 60.9% sedentary. 41.4% of total sample do light activities for 4 hours per week. Good sample size but across European and cross-sectional not longitudinal. conclusions not generalisable as country samples were from pilots and unrepresentative of the intellectual disability population in each country	Cross-European study. Data from 14 countries
8	De Winter, C.F., Bastiaanse, L.P., Hilgenkamp, T.I.M., Evenhuis, H.M. and Echteld, M.A., 2012. Overweight and obesity in older people with intellectual disability. <i>Research in developmental disabilities</i> , 33(2), pp.398-405.	945	Provide info on overweight and obesity on a large sample of people with intellectual disability looking at prevalence and association with various factors like PA	Physical activity assessed wearing pedometers for 2 weeks. > 7500 steps classes as sufficient PA. Weight, height and waist-hip measurements and body fat taken	Part of large HA-ID study. Representative of population of older adults, 50+years. Obesity 25.6% vs 9.6% in general population. Atypical antipsychotics associated with obesity	Holland

9	Vis, J.C., de Bruin-Bon, R.H., Bouma, B.J., Backx, A.P., Huisman, S.A., Imschoot, L. and Mulder, B.J., 2012. 'The sedentary heart': Physical inactivity is associated with cardiac atrophy in adults with an intellectual disability. International journal of cardiology, 158(3), pp.387-393.	182	Aim of this study was to investigate Left ventricular volumes and mass in a physically inactive population of adults with an intellectual disability, including subjects with DS.	Echocardiography was performed with a portable GE VIVID I in all included subjects and PA was measured by a questionnaire, Short Questionnaire to Assess Health-enhancing PA (SQUASH)	Adults with and without DS compared to inactive controls. 115 DS vs 26 without DS. PA level in adults with intellectual disability was 2X less than controls. SQUASH form not validated for persons with intellectual disability. iLVM positively related to SQUASH score	Netherlands
10	Haider, S. I., Ansari, Z., Vaughan, L., Matters, H., & Emerson, E. (2013). Health and wellbeing of Victorian adults with intellectual disability compared to the general Victorian population. Research in Developmental Disabilities, 34(11), 4034–4042.	897	Aims are to describe and present results from the Victorian Population Health Survey of People with an Intellectual Disability 2009 (VPHS-ID 2009), the first population level survey in Victoria, Australia & to compare the health and wellbeing of people with Intellectual Disability to the general Victorian population.	telephone interviews with proxy respondents	Administrative database used to identify participants may under-represent population. Sufficient PA was 150+mins of MVPA. SB was 5X more in intellectual disability compared to general population.	Australia

11	Hsieh, K., Rimmer, J.H. and Heller, T., 2014. Obesity and associated factors in adults with intellectual disability. Journal of Intellectual Disability Research, 58(9), pp.851-863.	1,450	Examined the relationships between nonmodifiable and modifiable risk factors/antecedents for obesity by addressing four primary research questions	Obesity determined by BMI. Hours of TV-watching per day. PA was measured with a question 'How many days a week is 30' MVPA done?'	Baseline data from Longitudinal Health and Intellectual Disabilities study (LHIDS) but only 1 point in time. Obesity related to MVPA and no of hours watching TV. Morbid obesity 2X in younger adults.	USA
12	Geijer, J.R., Stanish, H.I., Draheim, C.C. and Dengel, D.R., 2014. Bone mineral density in adults with Down syndrome, intellectual disability, and nondisabled adults. American Journal on intellectual and developmental disabilities, 119(2), pp.107-114.	99 (but 33 non-intellectual disability)	Purpose of this study was to assess the BMD in adults with intellectual disability, with and without DS, and investigate whether BMD is associated with PA levels. Further aimed to determine whether differences exist in the BMD among three groups	BMD and activity levels. DXA scan and NHANES III Physical Activity Survey was used to assess walking activity	Good cross-sectional, comparative design. Time walking was measure of PA used, bouts, minutes in bouts, total walking time and total PA. Total PA time significantly less in both intellectual disability groups. In DS group total bouts walking significantly related to BMD but not in others.	USA

13	Carmeli, E., Bachar, A., Rom, O. and Aizenbud, D., 2015. Oxidative stress and nitric oxide in sedentary older adults with intellectual and developmental disabilities. In Pathophysiology of Respiration (pp. 21-27). Springer, Cham.	23. 12 in sedentary group and 10 in active group	Aim of the study was to investigate the serum levels of global OS and NO metabolites (NOx) in sedentary and non-sedentary older adults with intellectual disability	6 mL of venous blood samples were collected after an overnight fasting and were drawn into 'vacutainer' 10 mL tubes for metabolite assays	Focus on moderate to profound and living in residential care. Sedentary group bedbound or wheelchair so most of day spent in SB. Age range 50-60yrs. Specificity of serum OS values questioned.	Israel
14	Bryant, L.D., Russell, A.M., Walwyn, R.E.A., Farrin, A.J., Wright-Hughes, A., Graham, E.H., Nagi, D., Stansfield, A., Birtwistle, J., Meer, S. and Ajjan, R.A., 2018. Characterizing adults with Type 2 diabetes mellitus and intellectual disability: outcomes of a case-finding study. Diabetic Medicine, 35(3), pp.352-359.	147	In this paper we present data characterizing the study population in terms of diabetes control, health, and access to diabetes management services and support.	Interview to establish diabetes management & supporter's role in diabetes management & identify preferences for assistance with diabetes management.	Participants had mild to moderate intellectual disability & living in the community. 14% did no activity & 26% did some every day. Intensity not assessed. People using insulin excluded.	UK

15	Harris, L., McGarty, A.M., Hilgenkamp, T., Mitchell, F. and Melville, C.A., 2018. Correlates of objectively measured sedentary time in adults with intellectual disabilities. Preventive medicine reports, 9, pp.12-17.	152	aim of this study is to add to the available evidence by investigating correlates of objectively measured SB in adults with intellectual disabilities.	A secondary analysis of pooled baseline data from two RCTs of lifestyle behaviour change programmes. One RCT focused on weight management (n= 50; Harris et al., 2015; Harris et al., 2017) and the second one on increasing PA	Objectively measured SB was 72.9% & obesity based on height/weight measures. Physical and mental problems significantly related to SB time. Health assessments by questionnaire.	Scotland, UK
16	Kim, J. Y., & Yi, E. S. (2018). Analysis of the relationship between physical activity and metabolic syndrome risk factors in adults with intellectual disabilities. Journal of Exercise Rehabilitation, 14 (4), 592-597	17	this study intends to measure the PA of adults with disabilities using an accelerometer to confirm the relationship of their activity levels with biochemical variables and examine variables that can predict physical activities to provide basic data for use in exercises and programs to improve the PA levels of disabled adults	PA measured using an actical. Muscular strength was measured using a digital dynamometer	Mild and moderate Intellectual disability levels. Avg age was 29.88yrs. More men than women (13vs4). PA objectively measured. PA positively correlated with total cholesterol and LDL	Korea

17	Tyrer, F., Dunkley, A.J., Singh, J., Kristunas, C., Khunti, K., Bhaumik, S., Davies, M.J., Yates, T.E. and Gray, L.J., 2019. Multimorbidity and lifestyle factors among adults with intellectual disabilities: a cross-sectional analysis of a UK cohort. Journal of Intellectual Disability Research, 63(3), pp.255-265.	920	The primary purpose of this study was to determine the prevalence of multimorbidity in a population of adults with intellectual disability. We also aimed to identify risk factors, including lifestyle factors, for multimorbidity in adults with intellectual disability.	anthropometric measures (height, weight and blood pressure), blood samples and additional demographic and lifestyle data. The case record form included collection of data on chronic conditions. Questionnaire for gathering SB and PA information	SB related to multimorbidity. PA assessed as < or > 5x per week. Sitting question answer of 'sometimes or never' meets guidance of not sitting for extended periods. Younger adults 57% multimorbid vs 4% in general population of similar age.	UK
18	Murthy, S. and Hsieh, K., 2021. Examining Association Between Reported High Cholesterol and Risk Factors in Adults With Intellectual and Developmental Disabilities (IDD): A Five-Year Follow-Up. Intellectual and Developmental Disabilities, 59(2), pp.112-122.	1618. 925 completed for all 5 years	This study examined whether being physically inactive, having obesity, and/or having diabetes were predictors of reported high cholesterol over a 5-year span among adults with intellectual & developmental disabilities. It also explored whether there were any mediating effects of diabetes on the relationship between obesity and high cholesterol	Longitudinal Health and Intellectual and Development Study (LHIDDS) survey. Proxy reporting.	Outcome measure of study was high cholesterol. Physical inactivity was a '1' or '0' where '0' was doing some form of MVPA. High cholesterol significantly increased with age.	US

Table 3. 6: Health themes & measurement

	Health condition	Article topic	Article author	Data source	No of parts	Activity or SB
1	Metabolic syndrome	Prevalence of metabolic syndrome	De Winter et al, 2010	Anthropometric interview	470	PA
		Metabolic syndrome risk factors	Kim & Yi, 2018	objective measurements	17	PA
2	Overweight & Obesity	Overweight & obesity	De Winter et al, 2012	pedometer	945	inactivity
		Obesity & factors	Hsieh, Rimmer & Heller 2014	Survey	1,450	SB
3	Multimorbidity & diabetes	Multimorbidity	Tyrer et al, 2019	Anthropometric, bloods & form	920	PA & SB
		Diabetes	Bryant et al, 2018	interview	147	inactivity
4	Cardiovascular	CVD Risk factors	Wells et al, 1997	Questionnaire & health check	120	PA
		CVD Risk factors	Moss, 2009	Measurements & questionnaire	100	PA
		CVD Risk factors	De Winter et al, 2009	Interview & chart review	470	inactivity
		CVD Risk factor: Cholesterol	Murthy & Hsieh, 2021	Proxy reporting	1,618	inactivity
		Cardiac atrophy	Vis et al, 2012	Questionnaire & ECG	182	SB
5	General health	Health status	Havercamp, Scandlin & Roth 2004	Telephone survey	946	PA
		Health status	Haveman et al, 2011	survey	1,253	SB & inactivity
		Health status	Haider et al, 2013	Proxy interview	897	SB & PA
		Correlates of sedentary time	Harris et al, 2018	Objective measurements & question	152	SB
6	Bone mineral density	Bone mineral density	Geiger et al, 2014	Survey & DXA scan	99	PA
7	Body oxidation	Antioxidant status	Carmeli, Bachar & Barchad, 2007	Bloods	21	PA vs SB
		Oxidative stress & Nitric oxide	Carmeli et al, 2015	Bloods	23	SB vs PA

3.3.1 Metabolic syndrome

Metabolic syndrome is the presence of a collection of coronary risk factors which increase the risk of heart disease, stroke and diabetes (Swarup *et al*, 2021). A metabolic syndrome prevalence of 25% was found in a Dutch older intellectual disability population of 470 people but a significant relationship was not found between physical inactivity, as specified by the WHO, and metabolic syndrome ($p=0.26$) (WHO, 2020). However, the observed levels of metabolic syndrome in this intellectual disability population were significantly higher than those observed in the general Dutch population, especially for those with mild intellectual disability but females were overrepresented by a ratio of 3:1 (de Winter *et al*, 2010). A Korean study with seventeen participants with mild and moderate intellectual disability showed that metabolic syndrome risk factors of total cholesterol and LDL-cholesterol levels were significantly positively correlated to objectively measured PA levels. In addition, the study which had 3-times more men than women, found that blood sugar level (HbA_{1c}) was a predictor for PA (Kim *et al*, 2018).

3.3.2 Overweight and obesity

A Dutch study as part of the large cross-sectional study, HA-ID, which investigated overweight and obesity in older adults with intellectual disability, defined physical inactivity as taking less than 7,500 steps per day. Observed obesity levels were higher than in the general population (25.6% vs 9.6%) and a significant relationship between inactivity and obesity as measured by waist circumference and higher body fat levels was found. These observed elevated levels of central obesity are a concern due to the potential increase of cardiovascular risks and link to metabolic syndrome (de Winter *et al*, 2012). Engagement in moderate PA and hours spent watching TV were factors significantly associated with obesity levels in a longitudinal study on adults with intellectual disability. Physical activity and sedentary levels were assessed by a single question and showed that almost one third of participants did not do any MVPA. While the obesity levels in the intellectual disability cohort ranged from 26%-54% higher than those seen in the general population, the morbid obesity levels observed in the younger adults were twice that seen in the general population (Hsieh *et al*, 2014).

3.3.3 Multimorbidity & diabetes

In a UK study multimorbidity, which was defined as having two or more chronic conditions which negatively impact health and had a prevalence of 61.2%, was found to have significant associations with self-reported SB and doing less activity in a week, in a group of adults with intellectual disability. Obesity was the most common multimorbid condition seen with over 68.5% of participants being either obese or overweight (Tyrer *et al*, 2014). Of concern is that younger adults with intellectual disability were more than fourteen times likely to be multimorbid than similar age groups in the general population (57.1% vs 4%).

An interview-based cross-sectional study on 147 community-living participants with mild to moderate intellectual disability and type 2 diabetes, demonstrated that over 79% had additional co-morbidities: CVD (40%) and high cholesterol (16%) were the most prevalent. Sedentary behaviour levels were high with only 26% reporting some level of activity daily but intensities were not assessed. In addition, over 20% had higher than recommended HbA_{1c} levels and over 87% were overweight or obese (Bryant *et al*, 2018).

3.3.4 Cardiovascular

Wells and colleagues (1997) used health check and PA questionnaires to garner PA levels and CVD risk factors in a cross-sectional study with 120 participants. Over 51% of intellectual disability participants had done some form of moderate intensity activity in the preceding four weeks, compared to over 93% in a control group while over 48% of the intellectual disability participants had done no moderate intensity activity. There was a greater incidence of high body mass index (BMI) in the intellectual disability group, who were significantly heavier than the control group. In addition several intellectual disability participants had abnormal cholesterol levels. The study concluded that people with intellectual disability had higher risk factors for CVD and stroke than the general population. However, the study had no objective activity measures, the PA questionnaire was not validated and there was no information available on the amount of time spent being active. Moss and colleagues (2009) looked at changes in coronary heart disease after a PA intervention to assess risk. Pre-intervention results indicated that over 85% of the participants were inactive (i.e., they did not do any MVPA) and 67% were overweight or obese. However being active was classified as doing one or more session of MVPA a week which does not comply with WHO guidelines. Higher than recommended levels of glucose concentrations were observed in 28% of participants which could lead to increased risks of

heart disease (Moss *et al*, 2009). Cardiovascular risk factors were investigated in a 2009 Dutch study on 470 older adults of all levels of intellectual disability but which had more females and more participants with moderate to severe intellectual disabilities. Results showed that while over 68% of participants had insufficient exercise levels, central overweight levels of 70.4%, hypertension of 36.8% and diabetes rates of 8.7% were similar to levels seen in the general population. However hypercholesterolemia levels were higher at 31.8% and SB was not investigated (de Winter *et al*, 2009). A recent longitudinal study showed that obesity and diabetes were significant predictors of high cholesterol and potentially heart disease in adults with intellectual disability. In this sample 925 participants, 57.2%, completed a five-year follow-up. Almost 28% of participants were inactive, 36% were obese and 7.1% had diabetes. However, this study did not realise a significant relationship between elevated cholesterol and inactivity but measures of activity were by self-report and doing any form of activity would have registered as being active (1=inactive, 0=not inactive) (Murthy and Hsieh, 2021).

A 2012 study investigated the effect of physical inactivity on cardiac atrophy in people with an intellectual disability. Results indicate that cardiac size is significantly smaller in people with an intellectual disability compared to controls and that this cardiac atrophy was acquired through lifestyle habits such as more time in SB. The left ventricular (LV) mass index was inversely correlated with level of intellectual disability and positively related to PA levels and LV stiffness was significantly higher in adults with an intellectual disability compared to the control group. Physical activity levels of people with an intellectual disability were almost 2-times less than the controls ($p < 0.001$) (Vis *et al*, 2012).

3.3.5 General health

Havercamp and colleagues, (2004) found that compared to adults with no disabilities, adults with intellectual disability were significantly more likely to have fair or poor general health status and be sedentary, with over 33% reportedly having had no exercise in the previous month. However there were no OM or quantifiable amounts of time in activity or SB specified. This 2004 study, which had a large sample size and was representative of all levels of intellectual disability, did not show any significant difference in the obesity or overweight status of the different groups which differs from later studies. Haider and colleagues (2013) found that, adults with intellectual disability had SB levels that were almost five times that of the general population (31.1% versus 5.3%), were perceived to have more 'fair' or 'poor'

health, to have diabetes and were significantly more likely to be obese or underweight compared to the general population but concluded that this may be an under-representation due to the intellectual disability participants being identified from an administrative database. A pan-European cross-sectional study assessing the health of people with intellectual disability found that more than half the sample did little or no PA and were classed as sedentary and 41.4% did light activities for about four hours per week. The study discovered that activity levels decreased with age and the number of people with intellectual disability diagnosed with diabetes, osteoporosis and hypertension increased with age but conclusions were not generalisable as samples were small and unrepresentative of the intellectual disability population in each country (Haveman *et al*, 2011).

A study assessing the correlates of SB found that physical and mental problems, assessed by a 'yes' or 'no' answer to a question, were significantly associated with OM of SB in a group of 152 adults with intellectual disability of all levels. This average measured SB was found to be 72.9% (Harris *et al*, 2018).

3.3.6 Bone Mineral Density

A study comparing bone mineral density (BMD) levels between individuals with DS, intellectual disability and non- intellectual disability showed that individuals with DS had significantly less BMD than the other two groups. In addition, both intellectual disability groups had significantly less PA minutes per week but there was only a significant relationship between PA, as determined by walking levels, and BMD levels in the DS group which could pose increased risks of osteoporosis (Geijer *et al*, 2014).

3.3.7 Body oxidation

Research has implicated oxidative stress (OS), which is caused by an imbalance between free radical and antioxidant activity, in disease progression (Shruthi *et al*, 2021). Nitric oxide (NO) is an example of a free radical and is an inflammatory. Although the specificity of serum OS values has been questioned, a study showed significant elevated levels of serum global OS and NO levels in a group of sedentary adults with moderate or profound intellectual disability in residential care, as compared to an active control group (Carmeli *et al*, 2015). A second study which investigated the differences in plasma total antioxidant status using vitamin and enzyme levels between active and inactive female adults from a residential

setting with unspecified intellectual disability levels, found that plasma vitamin levels were significantly lower in the inactive group, indicating that PA could have a protective effect on the antioxidant defence system but activity levels were not specified (Carmeli and Bachar, 2007).

3.4 Discussion

Sedentary behaviour has only recently been recognised as a significant contributor to poor health outcomes (WHO, 2020). This literature review provides an insight into the emergence of SB as a significant risk factor for multiple diseases that affect adults with an intellectual disability and thus on the overall physical health of this population. It underscores the requirement for detailed studies investigating specific health problems for adults with intellectual disability and their relationship to SB using OM. The results of this literature review have demonstrated that there is a scarcity of research into the effects of SB on the physical health of adults with an intellectual disability, with only eight articles directly investigating the effects of SB on any form of physical health, despite SB prevalence being identified at over 60% in adults with an intellectual disability (Lynch *et al*, 2020) and the fact that in the general population SB has been shown to have such detrimental effects (Owen *et al*, 2014; Vasancari *et al*, 2017; López-Valenciano *et al*, 2020).

Globally the leading cause of death is ischaemic heart disease and stroke and overall deaths due to diabetes increased by 70% in the 20 years from 2000 to 2019 (Vos *et al*, 2020; WHO, 2020). Coincidentally levels of SB also increased for European adults in the same timeframe and have been linked to increased disease risk and health problems including CVD, type 2 diabetes, obesity and some cancers (Owen *et al*, 2014; Vasancari *et al*, 2017; López-Valenciano *et al*, 2020). The leading cause of death worldwide is CVD and adults with an intellectual disability have increased risk factors for CVD as demonstrated by significantly higher BMI, greater obesity and inactivity levels, lack of moderate intensity PA, and elevated cholesterol levels (Wells *et al*, 1997; de Winter *et al*, 2009; WHO, 2020; Murthy and Hsieh, 2021). Furthermore, cardiac atrophy, which is a decrease in the myocardial mass, and can be associated with adverse health outcomes, was observed in adults with intellectual disability who exercised significantly less than the controls (Chyrchel *et al*, 2018; Vis *et al*, 2012).

According to the US Department of Health, metabolic syndrome is the term used to describe a cluster of risk factors which can lead to health issues like heart disease and diabetes. Abdominal obesity, high triglyceride levels, high blood pressure and low HDL-cholesterol are examples of risk factors which can contribute to metabolic syndrome (US department of health, 2020). Irrespective of activity level, increased time and fewer breaks in SB were found to be significantly related to a metabolic syndrome rate of 48.6% in a group of US older adults who were sedentary for over 65% of measured time spent wearing an accelerometer (Bankoski *et al*, 2011). There were no similar studies in the intellectual disability community looking specifically at SB and metabolic syndrome and although higher levels of metabolic syndrome were seen in a Dutch intellectual disability population, no significant relationship was found with PA and SB was not investigated (de Winter *et al*, 2010). No significant relationship was found between high cholesterol and inactivity despite 36% of the 925 participants being obese while an inverse relationship was observed between levels of diabetes, osteoporosis and hypertension and activity levels as an intellectual disability cohort aged (Murthy and Hsieh, 2021; Haveman *et al*, 2011). Similarly, the WHO's definition of metabolic syndrome requires the presence of at least three risk factors i.e., insulin resistance and two risks of either obesity, dyslipidaemia or hypertension (Alberti and Zimmet, 1998). While these risk factors are highly prevalent in the intellectual disability population, studies evaluating them collectively are rare so it is difficult to ascertain the actual prevalence of metabolic syndrome. However, obesity and overweight, key risk factors in metabolic syndrome, have been shown to be a critical problem in intellectual disability studies. For example, 68.5% of intellectual disability participants were either overweight or obese while another intellectual disability study showed 87% of participants were overweight or obese and morbid obesity levels were twice that in the general population (Bryant *et al*, 2018; Hsieh *et al*, 2014; Tyrer *et al*, 2014). Ryan and colleagues (2021) found that overweight and obesity levels were in excess of 69% in a cohort of older adults with intellectual disability and that those who were obese were nine times more likely to have respiratory issues, which was the largest cause of death for this population (O'Leary *et al*, 2017). In another study, elevated obesity levels were significantly related to activity levels, but sedentary levels were not investigated (de Winter *et al*, 2012). Moss and colleagues (2009) discovered that 67% of their study participants were obese with 28% having elevated glucose levels, while over 85% did not achieve recommended PA levels. Equally, sedentary levels of five times the general population were seen in an intellectual

disability cohort who were significantly more likely to be overweight (Haider *et al*, 2013). A 2004 study also found that people with intellectual disability were more sedentary than the controls but conversely there were not significant differences in weight status (Havercamp *et al*, 2004). Despite the overall negative health effects of obesity, a study found that obesity had a protective effect for osteoporosis, a degenerative disease which increases bone fragility, where obese adults had higher BMD than normal-weight participants (Qiao *et al*, 2020).

Bone mineral density is a measure of the strength and integrity of bones and low measures are indicative of the presence of osteoporosis (Kanis *et al*, 1994). A cross-sectional study highlighted the poor bone status of a cohort of adults with intellectual disability, where over 30% and 40% had osteopenia and osteoporosis respectively, indicating an increased risk of fracture due to diminished bone integrity (Burke *et al*, 2019). Another study which compared post-fracture mortality rates between privately insured adults with and without an intellectual disability showed that those with an intellectual disability were at a greater risk of mortality a year after the event occurred emphasising the importance of improving the bone health of adults with an intellectual disability (Whitney *et al*, 2019). The National Health and Nutrition Examination Survey (NHANES) study showed a negative association between time spent sedentary and femur BMD, independent of PA level in neurotypical women (Chastin *et al*, 2014). A study which compared PA and BMD for a group of adults with and without intellectual disability, found that adults with an intellectual disability had lower BMD and that there was a significant relationship between BMD and PA level only in adults with DS, who consequently had an increased risk of osteoporosis (Geijer *et al*, 2014). While DS is a known contributor to decreased BMD it is a concern that all adults with intellectual disability had low BMD and warrants further investigation of risk factors (Angelopoulou *et al*, 1999). Thus bone health appears to be an issue for adults with intellectual disability irrespective of aetiology and while a causal relationship has not been explored with SB, it is something that warrants investigation.

Oxidative Stress is caused by an imbalance in the body whereby an excess of reactive products (free radicals) can lead to cell and tissue damage and consequent progression of diseases like diabetes and hypertension (Taniyama and Griending, 2003; Pizzino *et al*, 2017). Two studies investigated the oxidative status of people with intellectual disability, one looking at SB and the other at PA. Comparisons between sedentary and active groups

showed raised levels of free radicals were present in the sedentary group (Carmeli *et al*, 2015). The second study concluded that PA had a protective effect on the body's antioxidant status when higher plasma vitamin levels were discovered in an active group of adults with intellectual disability compared to an inactive group, although the level of PA was unspecified (Carmeli and Bachar, 2007). Antioxidants such as vitamins and minerals are capable of neutralising these damaging free radicals and protecting the body from disease (Dal and Sigrist, 2016). Unfortunately, the dietary intake for people with intellectual disability has been noted to be poor, with high energy foods and less nutrient-dense selections prevalent, irrespective of their living circumstances, so they may not be getting the required antioxidants from food to combat the negative effects of SB (Adolfsson *et al*, 2008; Hamzaid *et al*, 2020).

Multimorbidity is defined as having two or more chronic health issues (van den Akker *et al*, 1996). Chronic health conditions, also known as noncommunicable diseases, last for more than one year and require ongoing medical care (CDC, 2021). The primary chronic conditions of CVD, respiratory disease, cancer and diabetes account for 80% of deaths, with the main contributors of disease coming from the environment, behavioural, physiological and genetic factors (WHO, 2016). Adults with intellectual disability are at a greater risk of having more chronic health conditions and more likely to lead a sedentary lifestyle (Havercamp *et al*, 2004). A multimorbidity rate of 71% was observed in the IDS-TILDA longitudinal study, where hypertension and gastrointestinal disease were ubiquitous (McCarron *et al*, 2013). Sedentary levels were found to be significantly correlated with multimorbidity in a group of adults with intellectual disability while another study showed that over 79% of adults with intellectual disability who had diabetes, also had other health issues like high cholesterol and CVD (Tyrer *et al*, 2014; Bryant *et al*, 2018). Although multimorbidity and SB appear to be more widespread in adults with intellectual disability, limited studies have investigated the link, while in the general population these two aspects of health have been studied and a relationship well established (Lewis *et al*, 2016; Vankampfort *et al*, 2017; Thorp *et al*, 2011). In addition, the Irish Longitudinal Study on Aging (TILDA) proposed that a linear dose-dependent association between chronic health conditions and sedentary minutes per day existed (Kandola *et al*, 2020).

An observation in some studies was that people with a milder intellectual disability who lived more independently were more at risk of unhealthy behaviours and needed more guidance on health risks (de Winter *et al*, 2009). People with intellectual disability have significantly

poorer health and health outcomes than their peers in the general population (Emerson et al, 2016). In addition, some studies found that people with intellectual disability were more likely to perceive themselves as being in 'poor' or 'fair' health (Haider *et al*, 2013; Havercamp *et al*, 2004). Furthermore, in a group of adults with intellectual disability, perceived physical and mental problems were significantly associated with sedentary levels of 72.9% (Harris *et al*, 2018). Thus this population's self-perceived and measured ill-health could be related to elevated sedentary levels. However while the information showing a contributory effect between SB and poorer health in the intellectual disability population is not conclusive, existing studies have shown that higher levels of SB are present in the intellectual disability population, who predominately feel they are not in good health and have more issues being overweight and obese, have excessive chronic health conditions and suffer from metabolic syndrome.

3.5 Conclusion

This literature review has demonstrated that SB could be a contributor to the poor health which is common in adults with an intellectual disability. The limited studies have shown a prevalence of obesity, multimorbidity and metabolic syndrome as well as elevated levels of SB. However the body of evidence, which was primarily focussed on cross-sectional studies to date does not confirm a cause-and-effect relationship.

3.6 Chapter 3 key learnings

Extensive SB and poor health exist in the intellectual disability population but a causal relationship has not been established yet.

Chapter 4

Description of the overall methodology used in this study including the research design, all data sources, any ethical considerations required and the IDS-TILDA study.

Chapter summary

This chapter outlines the methodology for this study into the effects of SB on the physical health of adults with an intellectual disability, including the research design, all data sources and required ethical considerations. A comprehensive description of the IDS-TILDA study is provided which includes the objective health measures which includes objective measurement (OM) of PA and SB. All data sources, participant numbers and the refresh strategy are explored. The ethical considerations including the four principles of autonomy, beneficence, non-maleficence and justice are explained as they apply in this study.

4.1 Introduction

A sound methodology plan is necessary to ensure data accuracy and integrity in the completion of high-quality research and consequently facilitate sound policy decisions (Kothari, 2004). The longitudinal exploration for this study will reduce the scarcity of information present in the area of aging with an intellectual disability and sedentariness and facilitate direct comparison with the general population TILDA study. Both self-report and OM were used to interrogate the sedentary levels of adults with an intellectual disability. This chapter explains the methodology used in the study and why.

4.2 Epistemological research philosophy

Research philosophy describes the way research data is collected, analysed and used. The term epistemology comes from the Greek terms *epistēmē* (which means knowledge) and *logos* (which means reason). Epistemological research is understanding how knowledge about a subject is created and the philosophical underpinnings that guide the researcher (Moon & Blackmore, 2014). The research undertaken should be relevant to the research question and thorough in its execution. To that end this study is based on the pragmatic research approach. Pragmatism is based on the fact that a combination of different types of

research may be used to provide an understanding of the phenomena under investigation (Morgan, 2014). This approach enabled the researcher to be innovative in their approach and choose the most suitable methods for data acquisition to find the best solution to answer the research question (Shah *et al*, 2018)). In this case OM of SB were obtained through objective health measures and subjective measurements were obtained through interview questionnaires longitudinally to gather appropriate information to address the research question. A pragmatic approach means the researcher was able to use multiple sources of data to gain an understanding of the SB of those with intellectual disability. In addition the researcher was able to interpret self-reported and objectively measured physical health measures and relate them to the aforementioned SB.

4.3 Research Design

This study is a quantitative exploration using a longitudinal research design. Physical activity and sedentariness as well as functional capabilities and comorbidities were examined for correlations.

4.4 Intellectual Disability Supplement to the Irish Longitudinal Study on Aging

This research project stands within the IDS-TILDA study, a national longitudinal study investigating the health and wellbeing of older adults with intellectual disability and how they age (McCarron *et al*, 2017). Disparities in the ageing experience in the intellectual disability population, through the IDS-TILDA study, are identified and compared to that of the general population TILDA study. The IDS-TILDA study exemplifies research elements into successful, healthy aging and the factors that contribute to longevity in the intellectual disability population. IDS-TILDA has been in existence in Ireland for over twelve years and in this time has collected health, lifestyle information and physical measurements, every three years (defined as a wave) from a random sample of older adults with intellectual disability (McCarron *et al*, 2017). The core underpinnings of IDS-TILDA are inclusion, choice, empowerment, person-centred, best-practice, the promotion of people with an intellectual disability and to provide a positive contribution to people with an intellectual disability (McCarron *et al*, 2021). Appendix 4.1 shows the IDS-TILDA values frame.

The conceptual framework for IDS-TILDA illustrates the diverse array of data sources, with six umbrella themes, which was constructed in line with the TILDA domains to facilitate comparisons between studies, see figure 4.1. The themes of interest for this study were Physical Health and Behavioural. In the Physical health section, data from the self-report, functional ability, measures of physical performance and the objective health measures were studied while in the Behavioural section the exercise data were evaluated.

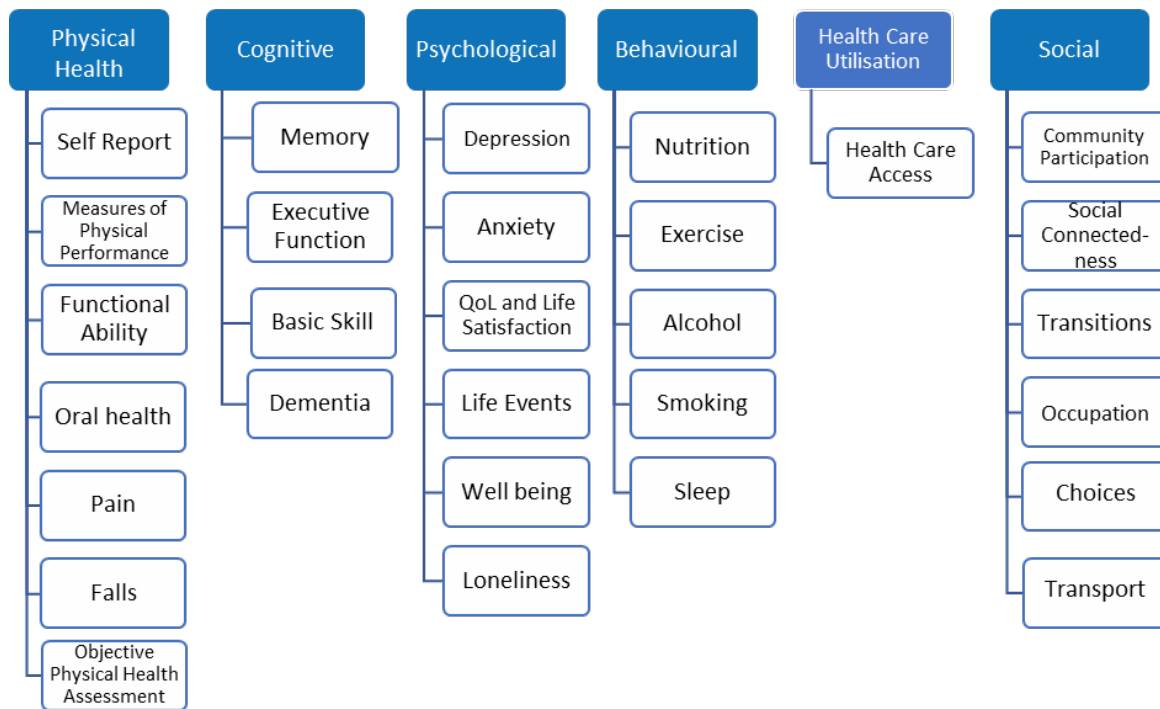


Figure 4. 1: IDS-TILDA Conceptual Framework

Individuals over the age of 40, across all levels of intellectual disability and residential settings were randomly selected from the National Ability Support System (NASS) database to participate in the study. Details of the overall recruitment process for the IDS-TILDA study are available (McCarron *et al*, 2022). The same cohort were followed through the first three waves of data collection. The data collection for Wave 1 ran from 2009-2011, Wave 2 2012-2014, Wave 3 2016-2017 and Wave 4 from 2019-2021. Due to loss to follow up, attrition due to death, and the fact that people had predominantly aged out of the younger cohort, the sample was refreshed at Wave 4, in 2019 in conjunction with the Health Research Board. There is recognition in the refreshment strategy that changing national policies and practices over the period of IDS-TILDA data collections such as de-congregation and day programming reform, that not all areas of representativeness of the original sample characteristics can be

preserved. Nevertheless, through the refreshment strategy, representativeness was significantly improved in both the present and for the future. The left side of figure 4.2 illustrates the change in participant numbers across the four waves of data collection for this study, highlighting the reasons for changes, while the right side of the figure shows the numbers who participated in each sedentary assessment that this study used.

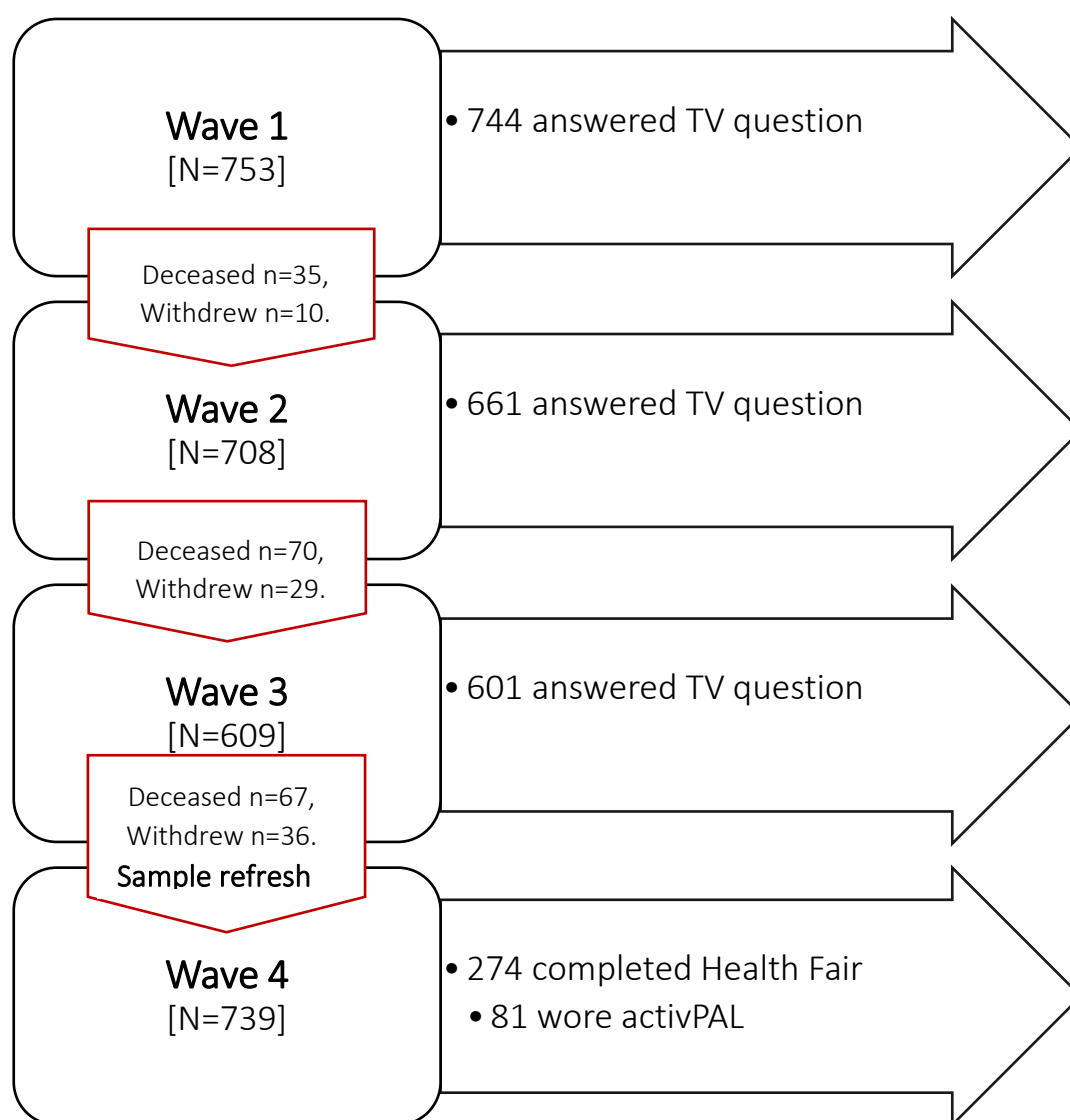


Figure 4. 2: Wave 1 to 4 participant numbers, how they changed & assessments completed

4.5 Ethical considerations

Due consideration was given to the ethical implications of this project from the onset. Ethical approval was obtained from the Faculty of Health Sciences, Trinity College Dublin (TCD) and all service providers involved in the study, as shown in appendix 4.2 to 4.5. It is inherent that

this research carried the responsibility to protect the confidentiality and privacy of all participants. The sample cohort for this study was small with highly recognisable information therefore making the data publicly available is in breach of confidentiality. Easy read materials and consent forms were used to facilitate informed consent. Participants were able to withdraw consent at any time. If a participant was unable to provide consent independently, a proxy who knew the person in excess of six months could be used. This proxy assent was facilitated by the Health Research Consent Committee. The four ethical principles as defined by Beauchamp and Childress were used in the design of the study (Beauchamp and Childress, 2001). These principles are autonomy, beneficence, non-maleficence and justice.

- Autonomy

Autonomy means the ability to make independent decisions. A participant's involvement was completely voluntary, and they could withdraw at any time. Support workers or key workers who accompanied the participant explained the optimal communication method of the individual which was invaluable if the individual's verbal language was limited.

- Beneficence

Beneficence means doing something for the good of others. Participants were informed that their participation in the research and the results would potentially contribute to quality-of-life improvements for people with intellectual disability. This was operationalised using easy-read explanatory material when participants are invited to participate in the Health Fair, the OM element of the study, but also when explaining the procedures during data collection. Throughout the data collection process, compassion, empathy and understanding was demonstrated by the researchers while taking OM. Participants were constantly reassured throughout the process. Augmented language was used where necessary with the support of the key worker to ensure optimal communication. If participants were unsure or exhibited any signs of discomfort the measure was ceased immediately.

- Non-maleficence

Non-maleficence in the context of this research meant that no harm would come to participants while undertaking the assessments. While all the assessments were designed to be safe, risk assessments for each individual participant were undertaken before every

assessment as participant safety and comfort was paramount. This risk assessment included observation of movement on arrival, asking questions of the individual about their ability to engage and if a support carer was onsite, seeking their knowledge of the individual and support. Measures were immediately ceased if there was any indication of discomfort.

- Justice

Justice means fairness. For this research justice equated to fair treatment and confidentiality for all the participants at all times. This was demonstrated by rigorous data management, for example the storage of completed recording sheets in locked cabinets in locked rooms and strict computer protocols, which adhered to all General Data Protection Regulation (GDPR) requirements. Every participant who was invited to participate in the Health Fair was given a unique identification number and a PIN number which were used for identification purposes. Thus, all data were pseudonymised and adhered to strict GDPR guidelines. Confidentiality was maintained throughout the Health Fair and subsequently with the resulting data management, through robust data protection methods, in adherence with the new regulations. All mandatory training in these data protection procedures was completed by the researcher. See appendix 4.6 and 4.7 for certificates. All GDPR guidelines were stringently followed throughout the study. This GDPR compliance is demonstrated in the IDS-TILDA data statement. See appendix 4.8.

- Informed consent

A process of informed consent was instigated in the Health Fair. This meant that consent was obtained from all participants which was explained and facilitated using easy-to-read accessible material to support understanding. This facilitated voluntary consent which meant that all information was provided in an understandable format in advance and on the day, to facilitate the participant's understanding and ability to willingly proceed. Each participant was asked for their consent on arrival at the Health Fair and once consent was obtained the participant received a wristband to indicate this. A system of process consent was used whereby consent was reaffirmed before each assessment. A participant's involvement was completely voluntary at all stages of the Health Fair and they could withdraw at any time or skip any assessment they were not comfortable doing. Support workers or key workers who accompanied the participant explained the optimal communication method of the individual which was invaluable if the individual's verbal

language was limited. Appendix 4.9 shows an example of a consent form. Appendix 4.10 shows an example of an easy read booklet for measuring weight.

4.6 Study data sources

There are multiple elements to the IDS-TILDA data collection process, four questionnaires and the objective health measures. The questionnaires consist of the Pre-interview Questionnaire (PIQ), the Computer Assisted Personal Interview (CAPI), the Carer's Questionnaire and the End-of-life Questionnaire. For this research study, the PA, SB levels and health measures were of interest. This study used two primary sources for its data, self-reported data from the PIQ and CAPI questionnaires and OM obtained from the Health Fair. Demographic information was obtained from the CAPI. The level of intellectual disability was categorised into mild, moderate and severe/profound. Living circumstances were categorised into living at home/independently, living in a group home or residential care. The body mass index (BMI) classifications were in accordance with the WHO (2000) and include underweight, normal, overweight and obese categories.

4.6.1 Pre-interview questionnaire

The PIQ incorporated demographic, chronic health, medication, sexual health questions, PA and mental health. This was sent out a minimum of one week in advance of the main interview to give the participant sufficient time to complete, seek help to complete or access their doctor's records to support completion. For Wave 4 the PIQ consisted of ninety-nine questions over 14 sections. Table 4.1 shows the PIQ sections with the relevant sections for this study highlighted in bold. BMI was obtained from the PIQ if OM were not available.

Table 4. 1: Pre-interview questionnaire sections

Section Title – Questions asked on the following areas:
Free Time: leisure activities and what people do
Self-reported Height and weight
Medical tests & screening: participation in the bowel health screening for example
Women's Health such as screenings like mammography
Health Services Used: including attendance at OPD or doctor's appointments
Satisfaction level with Health Services used
Cognition
Behaviours that challenge (using scale)
Medications: All medicines used including, supplementation
Sources of income: their pension or disability supports
Transport: how they navigate their community
Living circumstances: what their
Activities of daily living & helpers: ADLs and IADLS as well as volunteering
How was filling out questionnaire: evaluation

4.6.2 Computer Assisted Personal Interview

The CAPI interview was the primary face-to-face interview and consisted of fourteen sections. It was completed with the participant, or a proxy or a combination of both as a supported interview which provided all participants the opportunity to participate. Table 4.2 illustrates the CAPI sections, where the sections used in this study are highlighted in bold. The CAPI was completed at a site of the participants choosing, usually their own residence. However for Wave 4, due to COVID-19 restrictions from mid-March 2020, 180 of the total number of participants were interviewed by telephone and/or video. The CAPI incorporated social, environmental, health, functional limitations and domains including PA. The CAPI data from all four waves and the PIQ data from Wave 3, which fall under the self-report section, were used to support a robust interrogation of SB thereby contributing to answering the research question and meeting the objectives.

Table 4. 2: CAPI sections.

No	Section Title	Content
1	Cover screen & demographics	Residence & moves
		Faith/Spirituality
2	Cognitive Health	Memory
3	Social Participation	General Activities
4	Social Connectedness	Closeness Scale
5	Personal Choices	Quality of Life
		Satisfaction with life scale
6	Ageing Perceptions	
7	Occupation	
8	Learning and Technology	Technology
9	Physical Health	Overall health
		Eyesight
		Eye Disease
		Hearing
		General Communication
		Oral Health
		Heart Conditions
		Other Health Conditions
		Eating and Drinking
		Foot Health
		Falls
		Fear of Falling
		Falls Efficacy
		Steadiness and Fractures
		Pain
		Constipation
		Bowel Incontinence
		Bladder Incontinence
		Medication
10	Mental Health	Glasgow Depression Scale
		Glasgow Anxiety Scale
		Vitality Scale
		The Schedule for Meaning in Life Evaluation (SMiLE)
11	Behavioural Health	Physical Activity
		Perception of Physical Activity and Sport
		Smoking
		Alcohol
12	Evaluation Questions	
13	Final Checks	
14	Final Status	

4.6.3 Self-reported data

Self-reported data were used to investigate the SB levels of an adult population with an intellectual disability as part as the IDS-TILDA study across three waves of data collection. The SB information was garnered from a TV question, see table 4.3.

Table 4. 3: Self-reported data sources

Data source	Wave	Note
TV question	1, 2, 3 (CAPI)	In Social Participation section. Rested in W4

- TV Question

As part of the CAPI interview a question was asked on the amount of time spent watching television or DVDs, i.e.

‘Over the past 30 days, on average, how many hours per day did [you/he/she] sit and watch TV or DVD’s ?’

The answers ranged from none, less than one hour, between one and 3 hours, between three and five hours to more than five hours. Historically the amount of time spent watching TV or DVDs has been used as a surrogate measure for SB. The TV question was included as part of the CAPI in Wave 1 to 3 of the IDS-TILDA study but rested in Wave 4.

4.6.4 Objective health measures and the Health Fair

Historically activity levels and SB were evaluated using self-reported, proxy questionnaires (e.g. IPAQ and RAPA) or diaries. However, the accuracy, reliability and validity of these self-reported results may be questionable (Atkins *et al*, 2012; Reilly *et al*, 2008). Objective health measures are necessary to accurately understand the contributions of SB to health and wellbeing (Deprez *et al*, 2018). The Health Fair is an expansive suite of 22 objective health measurements, termed the ‘Health Fair’ to avoid negative connotations. Results from previous waves have driven the addition of more comprehensive assessments encompassing biological markers and new measures. Reasonable adjustments were made for each measure to ensure maximum comfort and engagement (Burke *et al*, 2020). Wave 4 also included the OM of SB and activity levels using an activPAL device. The researcher was

the project manager for the Wave 4 Health Fair which included organising and providing training to the research nurses, working closely with the services and nurses to schedule appointments, liaising with suppliers to obtain and maintain equipment as well as co-ordinating sample collection, analysis and results, while managing the results data in compliance with GDPR guidelines. The researcher participated in the Health Fair data collection and functioned as a backup research nurse. The increased number of health measures in Wave 4 meant that on top of the reasonable adjustments required for the intellectual disability population being assessed, due care and consideration had to be given to ensure the appropriate running order of assessments in order to minimise inconvenience and maximise comfort for each participant.

- Piloting the objective measures for Wave 4

The researcher co-organised a pre-pilot and pilot studies for the Health Fair process to ensure it ran efficiently and safely with minimal inconvenience to participants. The aim of the pre-pilot was to finalise the data recording tool, ensure the flow of assessments was organised in an efficient and accurate manner and to test the user friendliness of the easy-read accessible explanatory material. The pilot was run to verify changes made after the pre-pilot review and to test the consistency and quality of each research nurses' data collection process following training. The pre-pilot was conducted with fifteen individuals with life experience of intellectual disability and similarly the pilot was conducted with ten individuals who provided their feedback on the overall process, their experience and opinion on the materials used. Following the pilots, and the review of the feedback and quality assessment of the Health Fair, the order of objective assessments was changed to improve efficiency and station layouts were redesigned to maximise time and offset any potential delays. Consequently the Health Fair was organised into three stations, with one research nurse at each station. Each station was run simultaneously and was organised to take a similar amount of time, approximately 30 minutes. The running order of assessments at each station was structured to ensure participants could start and finish at any one of the three stations. Table 4.4 shows the health measures completed at their respective stations.

Table 4. 4: Wave 4 Health Fair objective health measures organised by three stations

Station 1	Station 2	Station 3
Oral health check	Hand grip strength test	Waist to hip ratio
MUAC	Blood pressure check	Height
Repeated Chair stand test	Hair sample	Weight
QUS test	Blood drop sample	Nutrition Assessment
Foot assessment	Cognitive Assessment	Mobilograph
Calf Measure		ECG- Kardia
Timed up and go test		2-minute step test
Balance Assessment		Oximeter
ActivPAL Application		

- Public and patient involvement

Representatives of the intellectual disability population have been intricately involved at every stage of the study development to ensure inclusion and full participation. This started with the design of the Health Fair easy-read documentation, where participants gave feedback on the documentation ease-of-use. A total of 15 people partook in the Health Fair pilot and pre-pilots. They gave constructive inputs about the health measures, station layout and the research nurses. This feedback was vital to the optimum Health Fair design.

- Objective measurements

The overwhelming advantage of OM is the confidence in measurement results due to the removal of any potential bias (Strath *et al*, 2013). A review of reviews which included all articles concerned with the measurement of PA levels up to 2014, discovered that self-reported measures were used the most at 42%, followed by OM at 38% and pedometers at 11% but concluded that OM should be included for the optimum evaluation of activity levels (Dowd *et al*, 2018). While the characteristic over-reporting in self-reporting instruments of PA may restrict belief in results, subjective measurements can provide contextual details of the activity that are not obvious from objective measures, while being a minimum burden to people and giving instant results and therefore prove useful (Strath *et al*, 2013; Shoemaker *et al*, 2021).

Independent OM are required to accurately determine SB levels and overcome potential limitations from self-reported data where activities may be omitted or exaggerated due to incorrect recollection (Price *et al*, 2020). While this may be true in older adults, it could be

even more relevant in an aging population with intellectual disability. Research postulates that the gold standard for measuring energy expenditure is the Doubly Labelled Water (DLW) assessment, whereby Hydrogen and Oxygen isotopes are ingested by the study participant and their elimination measured over a period of weeks, but this method is expensive and would not be suitable for large groups (Speakman *et al*, 2019). Motion sensors, which range from pedometers, accelerometers and inclinometers to wearable technologies, are the most valid for the determination of PA. Due diligence should be executed to ensure the most appropriate device is selected, considering practicality, cost and suitability of purpose. Wearables such as Fitbits are relatively cheap and accessible but accuracy for research has been questioned (Feehan *et al*, 2018). However agreement was found between the Fitbit and the Actigraph accelerometer for 7-day overall activity measurement but not the IPAQ (Brewer *et al*, 2017). Devices for this study were evaluated primarily on their ability to measure SB. Thus accelerometers were the primary focus.

Accelerometers are easy to use, compact devices that can generate lots of information on PA by the measurement of movement and acceleration with outputs of steps, energy expenditure and activity counts. Although expensive, accelerometers are accurate and capture both the intensity and duration of activities (Keadle *et al*, 2017). As tools they are recognised as being a valid and accurate way to evaluate PA levels but accelerometers do not consider posture so may miscategorise standing times as sedentary (Garatachea *et al*, 2010; Aunger and Wagnild, 2022). Pedometers which are cheap and easy to use in large studies and capture cumulative ambulatory activities by measuring step count, correlate well with accelerometers where walking is the primary source of activity, for example with sedentary older adults but do not capture the intensity or duration of activities and issues with inaccuracy occurred in frail older adults with gait issues and slower walking speeds (Crespo *et al*, 1996; Tudor-locke and Myers, 2001; Tudor-locke *et al*, 2002; Cyarto *et al*, 2004; Sugden *et al*, 2008). It is proposed that lack of muscle activity which negatively impacts metabolic effects is the basis for SB issues and consideration should also be given to posture when considering device selection (Tikkanen *et al*, 2013). For example standing still involves lower-limb muscle engagement and has a different physiological impact on the body compared to sitting idly. Inclinometers, such as the activPAL are accelerometers that also give the positioning context so are the device of choice for measuring SB (Aunger and Wagnild, 2022).

A number of accelerometer devices were evaluated to measure SB in Wave 4 of the IDS-TILDA study. These devices were assessed for suitability, reliability, accuracy for measuring sedentary and activity levels and ease of use. Finally, the devices needed to be minimally intrusive for participants with an intellectual disability. An important requirement for the device was for it to be ubiquitous and transparent in its use. Advice and discussions were held with experts in the field, including a physiologist, who had experience using accelerometers for different populations. The activPAL was used extensively to assess SB in older populations and proved to be a reliable, convenient and accurate measure in large studies so was an ideal choice for this study (Kozey-Keadle *et al*, 2011; Lyden *et al*, 2012; Granat, 2012; Edwardson *et al*, 2017; Giurgiu *et al*, 2020; Bellettiere *et al*, 2021; Carlson *et al*, 2021; Aunger and Wagnild, 2022). Following a review of the available literature, the accelerometer chosen to be used in the IDS-TILDA study was the activPAL due to its user friendliness, wearability and accuracy (Lyden *et al*, 2012; Allothman *et al*, 2020

- ActivPAL

The activPAL is a miniature, wearable accelerometer, which is worn constantly over 7 days. It is minimally encumbering to the wearer and designed to quantify free-living daily activities. While attached to the mid-thigh it senses limb position and activity every 20th of a second using the acceleration of the wearer's thigh posture. The activPAL is able to differentiate between sitting and lying as the algorithm calculates the angle of rotation on the y-axis which detected the thigh angle of rotation (PAL Technologies, 2019). Thus, the activPAL can reliably discriminate periods of upright activity from seated or lying activities and can classify three types of activity: sitting/lying, standing and stepping (Lyden *et al*, 2012). Lying is further classified into primary and secondary lying by the activPAL. Primary lying characterises the longest amount of time spent lying down in any one day and would usually represent nightly sleep time, while secondary lying signifies other time spent lying down (Pal Technologies, 2019). When examining SB posture is important because standing is distinct from being sedentary. This postural component affirms that the activPAL is the device-based standard for assessing SB (Bellettiere *et al*, 2021). The activPAL was found to be extremely reliable at assessing posture and motion with a mean percentage difference of 0.19% seen between measured and observed sedentary activities (Grant *et al*, 2006). Daily activities are classified in terms of time spent lying, sitting, standing and stepping and the number of sit-to-stand actions performed can be captured (PAL Technologies, 2019).

The activPAL allows for the stepping rate (cadence) of upright activities be accurately recorded allowing the intensity of a person's PA to be quantified (Sellers *et al*, 2016). Hence an accurate depiction of the wearer's activity profile may be obtained using complex analysis routines called 'Intelligent Activity Classification' where acceleration and inclination are considered. The four-megabyte memory capacity ensures the activPAL can record activities for more than seven days and the validation algorithm allows for a number of non-wear hours in a day (PAL Technologies, 2019). A sophisticated software suite, which is comprised of three pieces of software, PALConnect, PALAnalysis and PALBatch, accompanies the activPAL and the output may be obtained in a spreadsheet format or graphically. Examples of graphical activity representations are shown in figures 4.3 and 4.4, where the different colours represent separate activity intensities. Red is for stepping, green standing, yellow sitting and blue for lying down. Table 4.5 shows an example of variables captured.

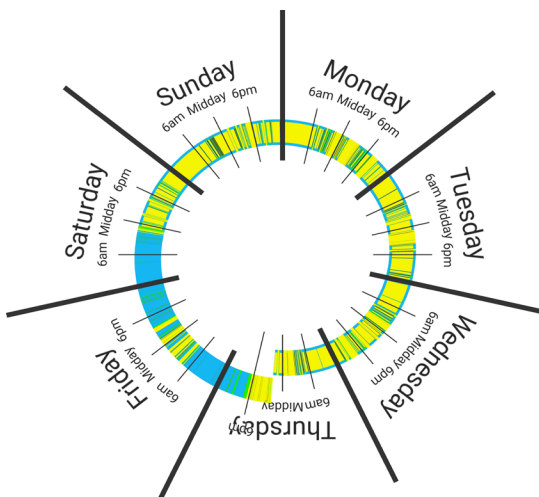
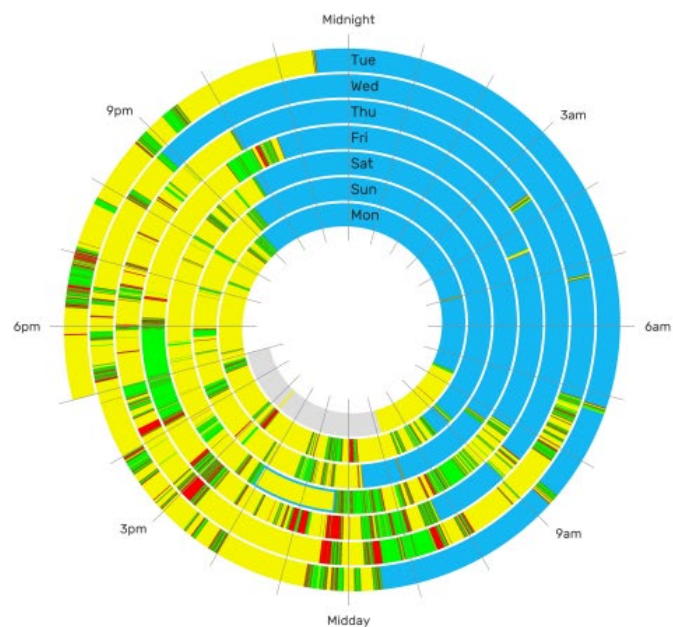


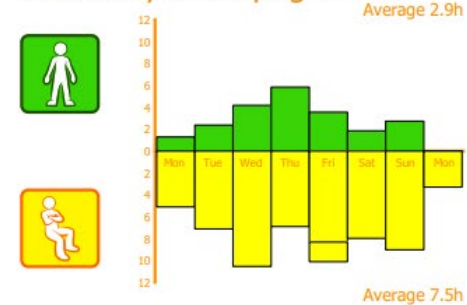
Figure 4. 3: Example of activPAL activity graph output



Number of Steps



Sedentary and Upright Time



Lying Time



Figure 4. 4: activPAL out for a participant with 6 valid day's results

Table 4. 5: activPAL variables

activPAL variable
Day of Week
Date
Valid Day
Inverted wear correction
Alignment (%)
Total Time (m)
Total Number Steps
Event type (Activity Classification)
Number Cycling Steps
Upright Time(m)
Standing Time(m)
Total Stepping Time(m)
Cycling Time(m)
Sitting Time(m)
Seated Transport Time(m)
Primary Lying Time(m)
Secondary Lying Time(m)
Non-Wear Time(m)
Number Sit To Stand Transitions
Number Stand To Sit Transitions
Activity Score(MET.h)
Number Sitting Bouts >30m
Number Sitting Bouts >60m
Time Spent In Sitting Bouts >30m
Time Spent In Sitting Bouts >60m
Stepping Time(m) (Cadence>=100)
Stepping Time(m) (Cadence>=100, duration>1m)
Number Steps (Cadence>=100)
Number Steps (Cadence>=100, duration>1m)

- activPAL dependent variables

The primary activPAL variables to be explored for this study were METs, sit-to-stand transitions and mild, moderate and vigorous activity time as assessed by stepping cadence, time, steps, total sedentary time, sitting and lying time.

A single MET is the resting energy expenditure. MET intensities are compared with resting metabolic rate (RMR). The activPAL MET values are representative of average daily energy expenditure (EE). Physical activity level (PAL) is the ratio of total daily EE to resting energy expenditure (i.e. $PAL = TEE/BMR$), where resting EE depends on age, gender, body size and composition and represents from 45-70% of total daily energy expenditure. Physical activity level represents a person's total daily energy expenditure and will vary predominately based on an individual's lifestyle and activity levels (United Nations University and World Health Organization, 2004). See table 4.6 for typical PAL values.

Table 4. 6: Activity classification by PAL

Category	PAL value
Sedentary or light activity lifestyle	1.4 - 1.69
Active or moderately active lifestyle	1.7 - 1.99
Vigorous or vigorously active lifestyle	2 - 2.4

(United Nations University and World Health Organization, 2004)

A PAL of greater than 1.7 is associated with reduced risk of CVD, diabetes, some cancers and overweight/obesity (Saris *et al*, 2003). In fact the WHO and FAO recommend PAL values of greater than 1.75 for health (United Nations University and World Health Organization, 2004). The activPAL output is the energy expenditure per day in MET/H. If this is divided by 24 it gives the average PAL value.

The minimum number of METs for MVPA per week recommended for health is 600, an average of 86-METs/day (WHO, 2020). Thus a person with an average daily MET value of less than 86 would be classed as inactive. However it is difficult to ascertain what the minimum number of METs to define SB is. The step-based activity criteria is summarised in table 4.7.

Table 4. 7: Activity classification by step level

Number of steps/day	Activity level
<5,000	Sedentary
5,000-7,499	Low active
7,500-9,999	Somewhat active
10,000-12,499	Active
>12,500	Highly active

(Tudor-Locke et al, 2008)

The activPAL step output was also summarised by cadence level, steps per minute, whereby different cadences represented different activity levels. Table 4.8 summarises the cadence and the associated activity intensity level.

Table 4. 8: activPAL activity type by step cadence level

Step activity classification	Cadence
Mild	<75
Mild (low activity)	75-100
Moderate	100-125
Vigorous	>125

The activPAL MET/h output is a measure of the average daily EE.

- activPAL setup and implementation

The researcher engaged with PAL Technologies in the use of the activPAL devices and associated software suite and attended training in June 2019 with PAL Technologies in Glasgow and learned how to fully operate the activPAL and its software suite which included charging, coding, set-up and analysing the device data. Following this training the researcher was responsible for the activPAL device setup, attaching and removing activPAL devices as well as the collection, downloading and amalgamation of all the data. All set-ups for the pilots and objective measures as well as successfully training the research nurses on the procedure was the responsibility of the researcher.

Due to the complex nature of using the activPAL, the process for its use required careful management for both nurses and participants before and during implementation. A detailed protocol on the activPAL use and application was written, see appendix 4.13. Easy read documents were created for the participants to ensure that they fully comprehended the procedure. Consent forms were specifically designed for the activPALs and an easy-read

sheet was created to give to participants post-activPAL application to explain its use and care. The procedure flow for the activPAL is shown in figure 4.5.

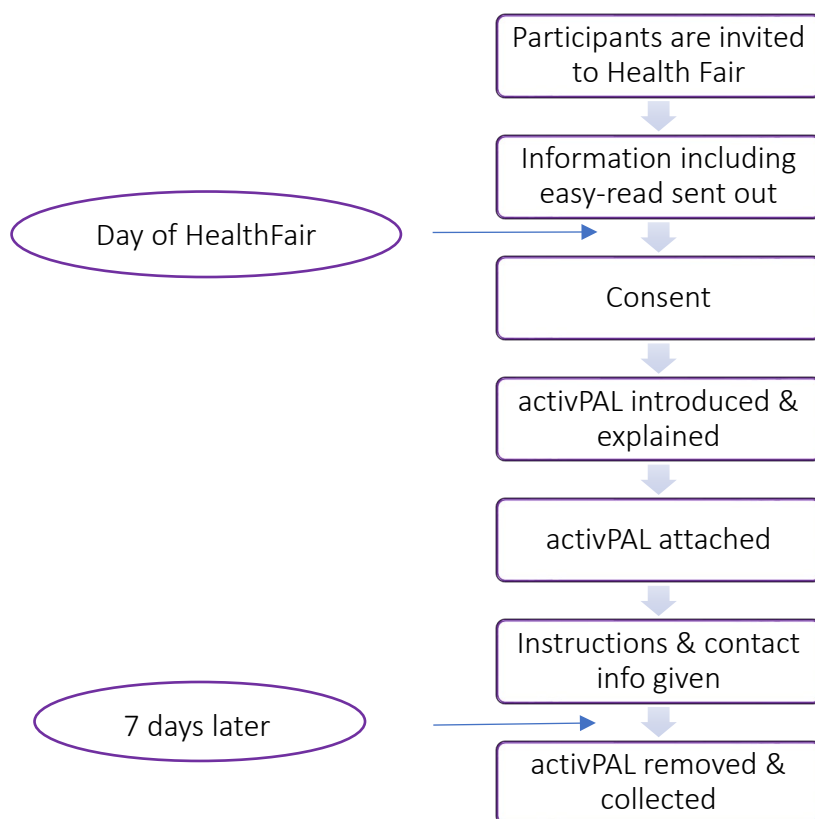


Figure 4. 5: activPAL procedure in Health Fair

Originally participants were asked to look after the activPAL due to its high cost and fragility but unfortunately this resulted in some participants removing it when they got home and putting it in a safe place to protect it. Concern was expressed at the end of January 2020 that the uptake for activPALs was low at 28% (n=41/146). After brainstorming it was decided to try and incentivise people to use them by offering water bottles. Before the water bottles arrived, the nurse on the activPAL station was asked to try and encourage people to wear the activPAL. She started saying 'Do you like to dance?' and mimicking dancing motions. This appeared to relax participants. Participants who were regular swimmers did not agree to wearing the device as the activPAL needed to be removed if immersed in water. The perception was that those with a mild intellectual disability were more hesitant to accept the activPAL but this was not observed in the results.

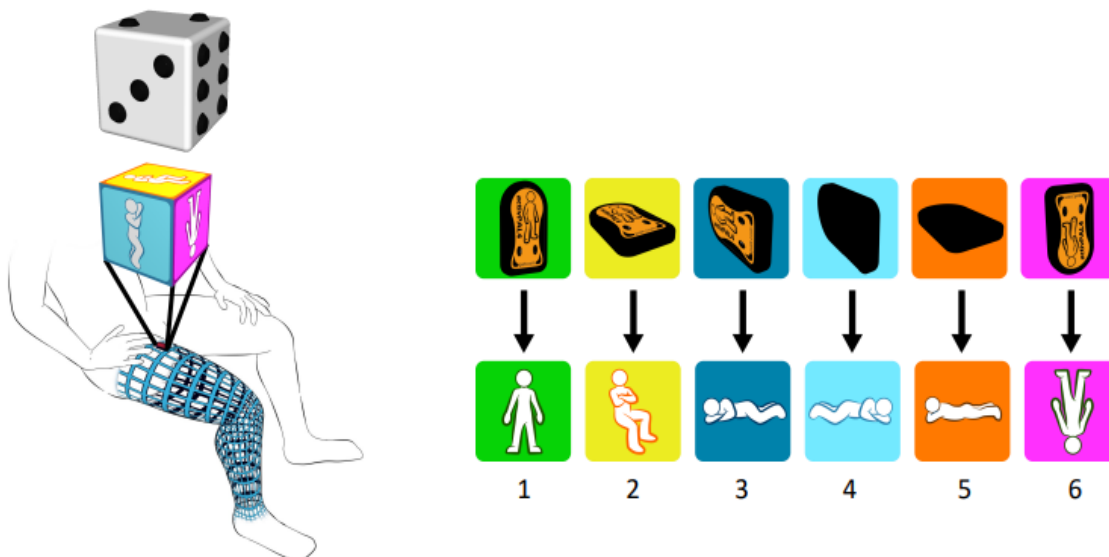
- ActivPAL valid days wear

According to PAL Technologies, the activPAL uses an automated validation algorithm called MORA to decide if a day of wear may be classified as valid or not. Hence a valid day is a day which meets the wear-time criteria which is based on the total recording time, non-wear criteria and dice-face criteria. The recommended protocol for valid days is 24-hours but other algorithms may be applied according to the type of use. For example, if a study is based on a waking day protocol the shorter 10-hour protocol may be used. Thus, part days are recorded but they are not classed as valid as it does not make sense to class a day as valid where the activPAL stopped recording at midday (12 hours wear) where 8-hours of this wear was in bed. Table 4.9 shows the activPAL wear protocol.

Table 4. 9: activPAL wear protocol

Timespan	Non-movement allowed
24-hour protocol	allow up to 4 hours continuous stillness
14-hour protocol	allow up to 10 hours continuous stillness
10-hour protocol	allow up to 14 hours continuous stillness

Figure 4.6 shows the six dice-face orientations. The activPAL device orientations are mapped onto six sides of a cube. For every 15-second measurement, the average expected thigh orientation and location is calculated and validated by an algorithm (Pal Technologies, 2023).



(Pal Technologies, 2023)

Figure 4. 6: activPAL device orientation illustrated using dice-face criteria.

- Number of days accelerometer wear

The literature has differing opinions on the number of day's recordings required to be able to accurately predict PA or SB. Generally, it is proposed that devices be worn for at least seven days, but studies differ in the required measured days (Hagströmer *et al*, 2007). Adolescent females for example require more measurement days due to the large variability seen in their lifestyles (Dowd *et al*, 2017). A study with ambulatory adults recommended five days data, with tighter confidence intervals observed if a weekend-day was included as less intra-person variability was observed at the weekend (Aguilar-Farias *et al*, 2019). Hart and colleagues (2011) deemed that three days accelerometer data were necessary to reliably predict PA levels in older adults but for SB five days data were recommended. In contrast Prescott and colleagues found three days to be adequate to accurately determine SB in a group of adults receiving haemodialysis but propose that less variance was seen because these adults had less functional capacity and more comorbidities, while some studies discovered variances were due to individual's changing their behaviours (Aadland and Ylvisåker, 2015; Prescott *et al*, 2020). Studies that considered participants with only one day's measurement of SB yielded similar results to studies with five or more days measurement data (Matthews *et al*, 2008). Similarly NHANES showed that one day was sufficient for accurately predicting PA behaviour and that the inclusion of weekend data biased results (Wolff-Hughes *et al*, 2016). Usually four valid days seems to be the acceptable level for population studies (Hagströmer *et al*, 2007; Healy *et al*, 2011; Migueles *et al*, 2017). However consideration must also be given to the population being assessed. Kocherginsky and colleagues (2017) found that increasing age was related to the number of days the accelerometer was successfully worn for in a group of older adults and that two or three valid days gave comparable results to seven day's wear, suggesting that longer wear days may be burdensome for older adults. For those with an intellectual disability, four days wear has been recommended but there is a lack of standardised protocols and few studies comply (Leung *et al*, 2017).

For the purposes of this study, the protocol asked participants to wear the activPAL device for seven consecutive days (except if performing water-based activities they were requested to remove and then replace). Because adults with intellectual disabilities usually prefer routine and residential settings are more often routine-based, minimum day-to-day variance was expected so all valid days were included in the initial analysis, which is supported by an

array of literature, see for example, O'Donovan *et al*, 2017; Anderson *et al*, 2013 and Keller *et al*, 2022.

- Study participant numbers stratified by activPAL use

Not all participants kept the activPAL device in situ for the recommended 7 days, subsequently six days was the maximum valid days wear time seen. Over 73% (n=53/72) of the activPAL participants wore the device for six days. Only 7% (n=5/72) wore it for one or two days. Table 4.10 shows the numbers of days wear and participant numbers.

Table 4. 10: Number of valid days activPAL device wear for participants

No of Valid days wear	No. of participants	Percent of participants
1	2	2.8
2	3	4.2
3	1	1.4
4	6	8.3
5	7	9.7
6	53	73.6

- Participant mobility status compared through activPAL measurements

The researcher explored the individual participant's mobility to investigate if it impacted step levels or sedentary time in relation to activPAL use. Almost 17% of the activPAL participants (n=12/72) had some type of mobility restriction noted while doing the Health Fair, which prevented them participating in the Two-Minute Step Test assessment. The mobility issues for each of the 12 participants is shown in table 4.11. The mean daily step count for the 60 participants who had no noted mobility issues was 6% higher than the overall group: 5,290 compared to 5,016 steps per day, while the mean for the 12 participants who had noted mobility issues was 3,663, 17% lower than the total group's mean step count.

Table 4. 11: Mean daily steps of activPAL participants with noted mobility issues (n=12)

Participant	Physical limitation	Mean daily steps
1	Wheelchair user	52
2	Very unsteady on feet	369
3	Unable to stand independently	816
4	Unspecified medical condition	1346
5	Wheelchair user	1682
6	Wheelchair user	2218
7	Using oxygen	4440
8	Tremors, uses walker and unsteady	4804
9	Physical disability	5719
10	Unable due to mobility	7165
11	On oxygen	7227
12	Limited mobility	8122

The inter-group difference (between the total group and those with no mobility limitations) in mean daily sedentary hours was 1%, 9.79 (SD±2.85) versus 9.88 (SD±2.91) hours. Those who had noted mobility challenges were 9.5% less sedentary than the total group, 9.34 (SD±2.63) versus 9.79 hours. Table 4.12 presents the overall mean sedentary time for all activPAL participants with or without mobility issues.

Table 4. 12: Mean sedentary time for all participants and those with and without mobility issues

	N	Min. (minutes)	Max. (m)	Mean (m)	SD (m)	Min. (hours)	Max. (h)	Mean (h)	SD (h)
Total participants	72	213.95	922.86	587.27	171.26	3.57	15.38	9.79	2.85
Able bodied	60	213.95	922.86	592.58	174.63	3.57	15.38	9.88	2.91
Mobility issues	12	333.90	866.20	560.68	157.50	5.57	14.44	9.34	2.63

The participants with noted mobility issues took less steps than their more able-bodied peers but spent less time sedentary overall. This may be due to staff or carers being more focussed on keeping these people moving due to higher dependency and the requirement for more assistance. In fact even without mobility restrictions people with an intellectual disability require additional support to ensure PA is accessible (Melville *et al*, 2015). Furthermore those with mobility issues would more than likely have physiotherapy plans in place which specified movements. Physiotherapy has been successfully used to increase PA levels and reduce falls in a cohort with an intellectual disability (Crockett *et al*, 2015). Conversely a study which used a dichotomous mobility variable found that being immobile

was a predictor of lower levels of PA but no participant in this study was classified as completely immobile (Finlayson *et al*, 2009).

- Sit-to-stand transitions

The pattern of SB accumulation was also considered i.e., the number and pattern of sedentary bouts. Studies indicate that shorter bouts were associated with more favourable cardiometabolic biomarkers and longer bouts have negative effects (Bellettiere *et al*, 2017). The number of times the transition from sitting to standing was made was measured and provided vital information on the physical status of participants.

- Researcher training

The researcher completed the comprehensive IDS-TILDA field researcher training and qualified as a field researcher. This expansive training included ethical considerations, gaining consent, managing workloads, GDPR and CAPI administration and contributed to understanding the data collection tools and the type of data collected. Appendix 4.14 shows the training content.

4.6.5 Co-morbidity measure

Comorbidities are coexisting medical disorders which may manifest as chronic illness or disease and can impact a person's response to sickness and eventual longevity (Klabunde *et al*, 2000). The more chronic conditions present the higher the mortality risk after hospital admission (Iezzoni *et al*, 1994). Rather than focus on single health issues or multimorbidity, it was decided that a comorbidity index (CI) would better reflect the health status and mortality outlook of study participants. A CI is a summary measure of the comorbidities present and as an indicator of the disease burden was better for predicting mortality than individual comorbidities (Austin *et al*, 2015). A number of indexes were evaluated for suitability with older adults with an intellectual disability, many of which use the International Classification of Diseases (ICD) to categorise comorbidities. The most commonly used indexes evaluated for use were the Charlson Comorbidity Index, Elixhauser Comorbidity Measure and Whitney Comorbidity Index. See appendix 4.15. The Cumulative Illness Rating Scale (CIRS-G) comorbidity index was chosen for this study due to its use of

body systems for identifying health conditions which was more easily applied to this population, as well as its proven use, see appendix 4.16.

- Cumulative Illness Rating Scale

The Cumulative Illness Rating Scale (CIRS) is a 14-item scale developed to provide a means to quickly assess physical impairments, through disease burden and severity. It is the most commonly used scale for older adults (Mistry *et al*, 2004). Each scale item relates to a specific organ and body system. Scoring is based on a degree of severity scale from 0-4 where 4 is the worst case (Linn *et al*, 1968). A number of modifications were made to optimise the scale for use in an older population resulting in the CIRS-G scale (Salvi *et al*, 2008). The scores are used in two ways, the first as a total comorbidity score which can be a maximum score of 56 and the second is by severity index (CIRS-SI). The CIRS-SI was calculated by dividing the comorbidity score by the total number of categories with a score >1. The resulting scores were divided into two categories, where CIRS-SI ≤ 2 represented low-severity and CIRS-SI >2 represented the high-severity index group (Salvi *et al*, 2008). The CIRS system was accurate at predicting the 18-month survival of hospitalised older adults (Salvi *et al*, 2008). A study which assessed the comorbidity status of adults with autism and intellectual disability found the CIRS-G was suitable and accurate in this population (Miot *et al*, 2019). Another study concluded that results from the CIRS-G were repeatable and reliable when used in geriatric patients who may have psychiatric issues (Miller *et al*, 1992).

In addition, the 14 individual health conditions as defined by the body systems and the number of health conditions present were investigated.

4.6.6 Functional capability

A comprehensive method to assess participant's functional independence and capacity in everyday activities was required. The Barthel Index (BI) is a simple, reliable scale for measuring clinically relevant performance in activities of daily living (ADLs) which can be easily translated into a person's physical capability and functional status. The original scale consisted of 10 items, with a maximum score of 100 for someone who was totally independent (Carroll, 2011). A modified version of the BI with a maximum score of 20 was utilised for the IDS-TILDA participants (O'Connell *et al*, 2019). The 10 items evaluated by the BI are mobility, stairs, dressing, bathing, eating, transfer (getting in or out of bed), toileting, bladder continence, bowel continence and grooming, see appendix 4.17.

4.6.7 Literature review risk factors

Scoping literature reviews were executed to determine risk factors for increased TV viewing and SB in the general and intellectual disability populations. Any risk factors identified were mapped to IDS-TILDA variables from the CAPI sections of social participation, social connectedness, personal choices, occupation, physical health, mental health and behavioural health. The risk factors identified are shown in table 4.13.

Table 4. 13: Risk factors for increased TV viewing & sedentary behaviour from literature reviews

Risk factors for increased TV viewing & sedentary behaviour (from literature reviews)
Age
Blue-collar employment
Depression
Divorced/separated
Drinker
Enjoyment of TV
Good hearing
Higher income
Late bedtime & late riser
Less active, less leisure time PA, less MVPA
Less neighbourhood lighting, scenery and lack of shops
Living alone, Unmarried/single women
Living independently or with family
Lower aerobic fitness
Lower education level
Lower income
Medication
Mild/moderate intellectual disability
Mobility issues
More energy dense diet, higher salt intakes & eating more
More independence
More neighbourhood crime & litter
More soft drinks
No children
No educational program
No epilepsy
Non-immigrant
Overweight/Obesity/higher BMI
Poorer health, chronic diseases & increased bad health outcomes
Residence type
Rural living or Live in nonmetropolitan area
Smoking
Social norms
TV size
Unemployment/retirement
Women who did not drive

Risk factor categories were consolidated or omitted to avoid erroneous results. To simplify fizzy drink consumption, a new 4-category variable (versus the existing 8-category variable) was created and reversed for regression. Further consolidation of BMI and fizzy drinks to two-categories was required when the adjusted multinomial was completed to eliminate

errors. Education level was consolidated from eight to three overall categories primary, post-primary and none for analysis. A new four-category variable was created to represent four different bedtimes, which was consolidated 2-categories and life satisfaction from 3- to 2-categories due to an uneven distribution across categories. The Glasgow Depression Scale was used to assess whether participants were suffering from depression or not. A score of 13 or higher indicated depression. The results were divided into those who scored <13 and 13+. The Glasgow Anxiety Scale was used to assess if participants suffered from anxiety. A score of 15 or over indicated anxiety. Results were divided into those who scored <15 and 15+. Employment, and training and education were investigated separately and then merged to create a new 'occupation' variable, as experience has shown that employment versus attending day service classification may be blurred in this population e.g. people may refer to day service as work (McGlinchey *et al*, 2013). The standard IDS-TILDA responses for self-reported health status ranged from excellent to poor (5-categories). These self-rated health categories were consolidated into three categories of fair/poor, good and excellent/very good. The time up in the morning was consolidated into two variables, before and after 7am. The psychotropic variable comprised of five different types of medications: antipsychotics, anxiolytics, sedative and hypnotics, antidepressants and mood stabilisers. A four-category variable based on the number of psychotropics taken per day was initially created and further consolidated to two categories. Similarly the hearing variable was consolidated to three-categories. The difficulty in social participation variable had 13-subsections ranging from health to not liking or feeling awkward in social situations. All individual subsections were investigated initially and finally consolidated to 2-categories of had difficulty and did not. Similarly the difficulty getting around the community variable was consolidated to 3-categories (does not travel, had difficulty and did not have difficulty), from five categories which ranged from footpath design and lack of street crossings to signage issues and no access to recreational areas to feeling unsafe.

4.7 Data Management

Throughout the Health Fair, the researcher co-ordinated and managed the data collection by the four trained field nurses. All the physical health measures were captured on hardcopy recording tools, with one tool per station. These recording sheets were created using the run order for each station of the Health Fair as the template. The participant's PIN number

was the only identifier on the sheet. The researcher manually checked the completed recording sheets to ensure the results were recorded in accordance with specified guidelines and any inaccuracies were fed back to the research nurses. These recording sheets were stored securely in numerical order, by participant ID number, on site at Trinity in a locked filing cabinet in a secured, locked room, only accessible with the direct permission of the Principal Investigator and data manager of the IDS-TILDA study.

The researcher was responsible for the management of this data. On completion of the data collection, the researcher inputted the data collected, extracted all the third-party data, including nutrition data from the INTAKE24 software, cardiovascular information from the Kardia and Mobilograph devices and the activPAL activity measures and inputted all into a dataset created in SPSS using the Wave 2 dataset as a template. The researcher was responsible for the quality assessment of all the inputted data which involved comparing hardcopies to inputted data. The researcher also performed all data cleaning and worked closely with the IDS-TILDA statistician in preparation for amalgamation with the master IDS-TILDA dataset and analysis.

4.8 Statistical analysis plan

All data were cleaned and quality checked prior to starting analysis. Data normality was explored to assist with choosing which statistical test would be the most appropriate for use. This was done using the Kolmogorov–Smirnov tests where a significant p-value ($p < 0.05$) indicated that the null hypothesis was false and data were not normally distributed and using histograms (Mishra *et al*, 2019). Any potential outliers were examined carefully. Dependent variables were investigated and merged if necessary to facilitate an even distribution for regression analysis.

Bivariate investigations were completed with all the dependent variables and the covariates of age, sex, level of intellectual disability, aetiology, living circumstances and BMI as well as any risk factors that were identified in the scoping reviews. Pearson chi-square was used for categorical variables, ANOVA for normally distributed continuous variables and Kruskal-Wallis for non-normally distributed continuous variables. Any significant associations identified where $P < 0.05$ as well as p-values up to 0.2 went forward to the next stage of analysis due to potential confounder influences and to ensure all relevant categories were captured in the final model (Mickey and Greenland, 1989).

Multicollinearity was examined to ensure there was no inter-variable dependency which could skew results using Tolerance ($1-R^2$) where a larger number was better and Variance Inflation Factor (VIF) the inverse of tolerance which should be less than 10. A Tolerance of less than 0.1 meant the correlation with other variables was high, suggesting multicollinearity.

Regression analysis was used to ascertain the effects of all the significant independent variables on the dependent variable. Even if the normality assumption was breached, linear regression remained a valid statistical test instead of nonparametric tests which can be very sensitive to outliers (Li *et al*, 2012). A binary logistic regression was undertaken if the dependent variable had two categories. Otherwise a multinomial regression was executed. Linear regression was used for continuous dependent variables. Significant variables where $p < 0.05$ were examined for consideration in the final model.

For the regression analyses, variables were transformed so that each variable was compared to the best possible case; those who were overweight/obese and underweight were compared to those who were normal weight, mild level of intellectual disability was used as the reference for intellectual disability, independent/family living circumstance was used as the reference category for residence type, less than 50 years was the reference for age and normal the reference for BMI. Choosing the optimum model is a balance between using the least amount of appropriate variables that best fits the data and can predict the outcome accurately, knowledge of the area and a criterion-based approach (Faraday, 2002). Practical considerations like the cost of measurement and applicability were also included. The optimum model would predict and/or explain the relationship in the data. The remaining independent variables were assessed and excluded from further analysis if redundant information was included. Final models were adjusted for the covariates of age, gender, level of intellectual disability, aetiology and residence type irrespective of significance levels.

Unstandardised Beta, where a one-unit change in the independent variable is associated with a change in the dependent variable, while all other independent variables were held constant, was reported as well as adjusted odds ratio (AOR). Odds ratios less than one (i.e. $EXP(B) < 1$) which indicate a scenario that is less likely, were transformed to reflect the whole number.

Relationships were also explored using Chi-square automatic interaction detection (CHAID), a decision tree matrix which uses chi-square to determine significant relationships. The

Classification and Regression Tree (CRT) was also examined. The output from CHAID and CRT were easy to interpret graphical categorisations of significant variables which explained the dependent variable, while in multinomial regression the output was a table with detailed results for individual independent variables. Data may be nonparametric for CHAID and CRT.

If two categories were present sensitivity and specificity were examined. Sensitivity and specificity are probabilities associated with a test where sensitivity is the true positive test result i.e. disease presence, in this case people who are truly inactive and specificity is the probability of a true negative result i.e. people who are truly active. IBM SPSS V26 was used to perform all of these statistical analyses.

4.8.1 Correlations

For completeness, two-variable correlations were examined using Spearman's rho, Pearson's correlation coefficient, the Interclass Correlation Coefficient (ICC) and if viable Bland-Altman plots. The ICC correlated between the same classes of data (Liljequist *et al*, 2019). The Pearson correlation coefficient was used because of its use with continuous data and because its use for only parametric data is questioned, it was also used for non-parametric data (Bollen and Barb, 1981; Sedgwick, 2012). Correlation coefficient values and how to interpret their results are shown in tables 4.14 and 4.15.

Table 4. 14: Correlation coefficient values and their meaning

Size of coefficient	Interpretation
0.90 to 1.00	Very high correlation
0.70 to 0.89	High correlation
0.50 to 0.69	Moderate correlation
0.30 to 0.49	Low correlation
0.00 to 0.29	Little if any correlation

(Zady, 2000)

Table 4. 15: Spearman's rho correlation scale

Coefficient range	Correlation strength
0.0 - 0.1	Negligible
0.1 - 0.39	Weak
0.4 - 0.74	Moderate
0.75+	Strong

(Schober *et al*, 2018)

- Bland-Altman plots

Bland-Altman plots are used for continuous variables and are used to determine systematic differences between measurement techniques and identify bias and outliers, where bias is systematic error related to the measurement. The difference between the two measures and the mean of the two measures were calculated. Data normality of the mean-difference variable was a requirement for Bland-Altman plots (Doğan, 2018). A one-sample t-test was completed on each of the difference-of-measures being investigated, where significant p-values indicated that there was a difference between measures and it was not appropriate to do Bland-Altman. However if $p > 0.05$, then the range within which the 95% confidence interval of the measurement differences should lie were calculated (mean difference $\pm 1.96 \times$ standard deviation of the difference) (Giavarina, 2015). To test how close the mean value was to zero, a linear regression was run, with the difference as the dependent variable and the mean as the independent variable. If the unstandardised Beta is not close to zero and a significant p-value results, this indicates that there is a difference between the measurements and proportional bias was present. Values closer to zero indicate better agreement between measurement techniques but measurements between the 95% CI lines would be deemed acceptable (Bland and Altman, 1986).

4.8.2 Model fit

The model fit was examined using the Akaike Information Criterion (AIC) where a lower AIC value was indicative of a better model fit. It gave an estimation of prediction error and was used with due consideration given to context with other variables. In addition, Nagelkerke and Adjusted R-squared were used to assess how much of the model variance could be explained by the independent variables.

4.8.3 Missing data

Missing data were given appropriate consideration as it could impact the validity and statistical power of results. Valid percentages were presented in all calculations to exclude missing data. If available the option in SPSS which allowed missing variables to be excluded on a pairwise basis i.e. only excluded if the data for the specific analysis is missing, was used. The three types of missing data are MCAR (missing completely at random) where data is unpredictably missing, MAR (missing at random) where the missingness is related to other variables in the dataset and NMAR (not missing at random) where the data cannot be ignored as the missingness is related to the variable itself and may lead to biased results

(Kang, 2013; Bhaskaran and Smeeth, 2014; Tabachnick and Fidell, 2014). Little's test for MCAR was used to test the missingness type. A nonsignificant value would indicate that the null hypothesis could not be rejected and data were MCAR and data imputation could proceed. Missing data below 5% may be ignored (Tabachnick and Fidell, 2014). All levels of missingness and their respective categories were reported.

- Multiple Imputation Chained Equation

Multiple imputation Chained Equation (MICE) was executed to impute missing values to investigate the effect on the correlation values and improve the reliability of the model, through reducing bias due to missing data, using overall distributions to improve data integrity and accuracy of results. Studies have found that discarding data where complete cases were not available introduced bias compared to using multiple imputation techniques (Biering *et al*, 2015; Nissen *et al*, 2019). Generally imputed datasets are thought to give more accurate results (Pham *et al*, 2019; Muller *et al*, 2022). The MICE procedure, using five iterations, was used to impute missing values across the datasets. This methodology uses two steps to compute the missing values. Multiple copies of the dataset are made and missing data is filled in based on observed values after which the estimates are pooled for the completed datasets (Lee *et al*, 2016). The MICE model, an iterative series of predictive models, performs multiple predictions for each missing value using logistic regression and random sampling, based on the existing data and its distribution, which are filled in a number of times until they converge and leads to lower standard error values. Biering and colleagues (2015) showed that multiple imputation is a valid way to manage bias due to missing data in longitudinal studies.

Only variables with up to 20% missingness were included to preserve data accuracy (Peng *et al*, 2006; Azur *et al*, 2011). The literature is inconclusive regarding acceptable levels of missing data, ranging from 5-10%, so that study validity is unaffected, but overall the mechanism causing the missing data is more important rather than the percentage missing (Tabachnick and Fidell, 2007). If data imputation was completed all analysis was repeated and results compared.

4.8.4 Sample size

A power analysis was completed for each individual part of the study to determine the sample size required to predict a statistically significant result. Assuming an effect size of 80%, a significance level of 0.05 and a number of variables (M) in the final model, the number of participants required was:

$$N \geq 50 + 8 * M.$$

However when the number of variables exceeds seven, this rule of thumb formula overestimates the required sample size (Green, 1991).

4.9 Conclusion

This chapter detailed the methodology used for this overall study. The IDS-TILDA longitudinal study was introduced showing the research design, sampling strategy and ethical considerations. The Pragmatism research philosophy used for this study was elucidated. All data sources and types of analysis used were detailed.

Chapter 5

An investigation into the risk factors for increased TV viewing in the intellectual disability population and the identification of a framework to structure results.

Chapter summary

This chapter details three literature scoping reviews that were executed to identify and structure the risk factors for increased TV viewing and consequent SB in the intellectual disability population. The first literature search identified a framework, the Systems of Sedentary Behaviour (SOS) which could be used to structure and summarise any identified risk factors. The other literature searches were executed for the general and intellectual disability populations to determine predictors or determinants of increased TV viewing. Finally, the identified predictors were mapped to variables from IDS-TILDA and summarised on the SOS framework.

5.1 Introduction

An activity compendium showed that watching TV had the lowest metabolic output of all sitting activities for example knitting, or reading (Ainsworth *et al*, 1993). In fact a study found that one's metabolic rate actually decreased when watching TV (Klesges *et al*, 1993). Extended TV viewing was found to substantially displace energy expenditure from PA, especially in the MVPA exercise category, which caused some authors to suggest that negative health effects associated with TV viewing may in fact be due to inactivity (Matthews *et al*, 2018). TV viewing is the predominant measure of leisure-time SB and a common SB across all age groups, with Irish and US adults watching 2.5 and 3.5 hours/day respectively (Dunstan *et al*, 2005; Gershuny *et al*, 2005; Clark *et al*, 2009; ATUS, 2021; TAM Ireland, 2023). Time spent watching TV has been extensively used as a self-reported measure for assessing the SBs of the general population across the globe because it is a common sedentary activity which people regularly engage in, often for extended periods (Dunstan *et al*, 2005; Healy *et al*, 2008; Chang *et al*, 2008; Veerman *et al*, 2012). Studies have shown that watching more than 2 or 3-hours TV a day can reduce life expectancy by 1.38 years and 2 years respectively while watching an average of over 6 hours TV per day reduced life expectancy by almost 5 years (Katzmarzyk and Lee, 2012; Veerman *et al*, 2012). For adults aged over 25 years an

increase of one hour TV viewing per day reduced life expectancy by over 20 minutes, which was similar to the effect of smoking two cigarettes (Veerman *et al*, 2012). Furthermore, a significant dose-response relationship was observed between watching TV and metabolic risk factors including systolic blood pressure and waist circumference for active Australian adults (Healy *et al*, 2008). In addition, increased odds of sarcopenia occur in older adults who watched in excess of two hours of TV per day (de Souza *et al*, 2022). Despite this research, it was proposed that TV viewing may not be the most accurate measure of overall SB as it is only one potential aspect (Crawford *et al*, 1999). Until recently, studies have focussed on TV viewing as the primary proxy measure for SB. However, with the evolution of mobiles as multidimensional devices, streaming services and the increase of computer and IPAD use, TV viewing alone may be insufficient to capture all relevant data and thus the levels and effects of SB may be underestimated. For example, a Brazilian study found that younger adults engage in more diverse screen activities (Silva *et al*, 2021). There is limited evidence on the prevalence of the screen behaviour of adults with intellectual disability even though time watching TV has been associated with poorer health outcomes.

Increased time spent watching TV has been shown to have detrimental health effects especially concerning CVD, diabetes and increased prevalence of metabolic syndrome, with significant weight gain associated with watching more than five hours per day compared to less than three hours per day (Dunstan *et al*, 2005; Wijndaele *et al*, 2009; Wijndaele *et al*, 2010; Pereira *et al*, 2012). Furthermore a Japanese study on older adults found that increased TV viewing was associated with higher levels of obesity/overweight irrespective of activity levels (Inoue *et al*, 2012). Indeed TV viewing appears to be an autonomous contributor and risk factor for MetS in adults, irrespective of activity levels or types (Chang *et al*, 2008). If adults spend more than four hours per day (excluding working) watching TV or on a computer, twice the odds of having MetS was observed and the health benefits of meeting the minimum MVPA was attenuated (Ford *et al*, 2005). Similarly, an Australian cross-sectional study found that for each one hour increase in TV viewing there was a 12% and 26% increase in MetS in men and women respectively, but if at least 30 minutes of MVPA was performed a day this reduced the prevalence of MetS by 11% and 28% (Dunstan *et al*, 2005). However this activity level is more than the minimum activity recommendation for health benefits recommended by the WHO (WHO, 2020).

A couch potato syndrome in respect to TV viewing posited that increased calorific intake occurred when watching TV; studies suggested that increased snacking of energy-dense, high-fat, low-nutritional value food ensued (Brown and Witherspoon, 2002; Snoek *et al*, 2006; Thomson *et al*, 2008). This mindless eating could be partially explained by exposure to the widespread advertising of unhealthy snack foods on TV which contributed to more food consumption in adults and children, especially in those who were overweight or obese (Powell *et al*, 2007; Harris *et al*, 2009; Kempset *al*, 2014). It is unknown if obesity is a predictor of TV viewing habits and SB or a result of this SB. However, a contributor to obesity could be the reduced energy expenditure while watching TV and/or an increased calorific intake while engaging in TV watching or a combination of both. Aside from the potential genetic, cultural or socioeconomic effects, the primary cause of the global obesity problem is an energy imbalance, where calorie intake is greater than energy expenditure, resulting in fat deposition, not least contributed to by the type of mindless eating behaviour seen while watching TV (Koplan and Dietz, 1999).

Before a literature review could be performed on the correlates of increased TV viewing and consequent SB, a method to structure and frame the results was required. A framework that took a multi-level approach which covered all environmental, individual and interpersonal factors was sought. Thus a holistic approach needed to be adapted for health behaviours to become mainstream, in this case to understand the risk factors so that TV viewing and consequently SB may be reduced. The aim of this chapter was to present the modifiable and non-modifiable contributing factors of increased TV viewing, which were discovered in two separate literature scoping reviews, using the IDS-TILDA dataset and framed using a comprehensive structure.

5.2 Framework identification

A scoping literature review was completed to identify a framework to define and structure the risk factors associated with increased TV watching and a means to clearly represent the state of the science for TV viewing determinants for the intellectual disability population. Two suitable frameworks which had a focus on SB were evaluated for use: the Ecologic model of four domains of SB and the Systems of Sedentary behaviour (SOS) Framework (Owen *et al*, 2011; Chastin *et al*, 2016). The Ecological Framework focussed on transport, leisure, occupation and household while the SOS framework took a clustered approach applicable across the life course, with each cluster representing an aspect of daily life from

the environment, politics, social, home and cultural to individual factors. While both frameworks were investigated for use in this study to determine the most appropriate means for representing the SB of people with an intellectual disability, after careful consideration and consultation with experts it was felt that the cluster categorisation of the SOS framework, which was somewhat similar to the IDS-TILDA framework themes, would facilitate ease of use within the intellectual disability arena and give more clarity in representing results. It was therefore used as a guide in the identification and mapping of variables, as well as to frame the results. The clusters are not autonomous and there may be interaction across the life course. In addition it was felt that the SOS model would be more appropriate for people with an intellectual disability, for example some of whom may not have occupations. Originally when the SOS Framework was constructed, the area deemed to be the most important by its creators was institutional settings (Chastin *et al*, 2016). However limited studies on institutional settings and no studies on politics and economics were found. Figure 5.1 illustrates the SOS framework.

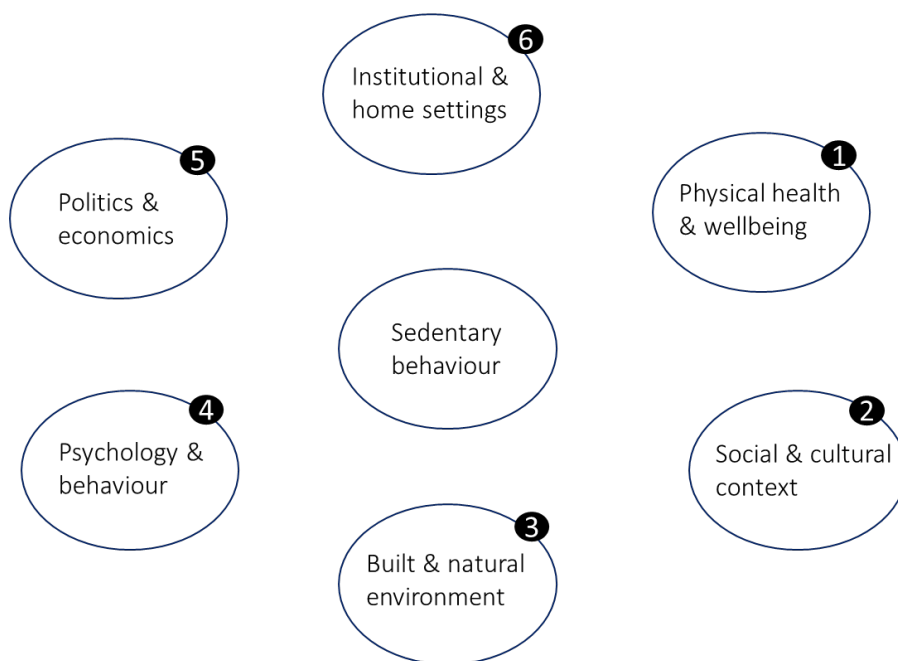


Figure 5. 1: Systems of Sedentary behaviour Framework (Chastin *et al*, 2016)

The six clusters of the SOS framework are explained below (Chastin *et al*, 2016).

1. Physical Health and wellbeing

This relates to an individual or group's health and wellbeing and general health status. Individual factors like BMI, age and sex were captured in this cluster. It also covered systems for provision of health care or health enhancing facilities.

2. Social and cultural context

The social and cultural context for an individual/group refers to the social environment that they reside in and their cultural education and experience. It encompassed education, income, socio-economic status and employment status.

3. Built and natural environment

This relates to the overall physical environment that individuals/groups lived in. It included the weather, rural or urban location as well as type of neighbourhoods.

4. Psychology and behaviour

The psychology and behaviour cluster captured motivations, attitude, self-efficacy and general behavioural habits like PA.

5. Politics and economics

Politics and economics related to the political and economic situation that an individual experienced in their civic engagement and covered local, national and international areas.

6. Institutional and home settings

This captured all information in relation to home or institutions that individuals/groups interacted with like living circumstances.

5.3 Identifying and establishing the variables

A scoping literature review was completed to identify potential risk factors for increased TV viewing in two phases. The first focussed on the general population risk factors and the second on risk factors for increased TV viewing in the intellectual disability population. A number of risk factors for increased TV viewing were identified from the literature and some crossovers were identified between the two population groups. The scoping review found few studies investigated multiple levels of influence on TV habits which incorporated

environmental as well as individual factors. However one general population systematic review determined multifaceted correlates of increased TV viewing, from individual and behavioural factors like diet and activity level, socioeconomic factors like education level and employment status, interpersonal factors like social and family status to environmental factors which included neighbourhood attractiveness (O'Donoghue *et al*, 2016). Overall the predominant area for research into the correlates of TV viewing was individual effects, with a large focus on obesity/BMI in both groups. Studies investigating TV viewing risk factors were five times greater in the general population than in the intellectual disability population (26 in the general population versus 5 in the intellectual disability population). The 26 general population studies which identified risk factors for increased TV viewing are summarised in table 5.1, along with the correlates of reduced and increased TV viewing identified in each study.

Table 5. 1: Studies identified from literature for correlates of TV viewing in general population

Publication	Correlate of high TV	Correlate of low TV
Salmon <i>et al</i> , 2000	Overweight	
Hu <i>et al</i> , 2003	Obesity	
Salmon <i>et al</i> , 2003; Clark <i>et al</i> , 2010	Lower education	
	Rural living	
	unemployment	
	Enjoyment of TV	
Bowman, 2006	Overweight	
	Unemployed or retired	
	Lower income	
	Less educated	
	More energy dense diet	
Sugiyama <i>et al</i> , 2007; Kozo <i>et al</i> , 2012		Walk-friendly environment
King <i>et al</i> , 2010	Less active	
	Higher BMI	
	Poorer health	
	Lower incomes	
	Divorced/separated	
	More neighbourhood crime	
	Less neighbourhood lighting	
	Less neighbourhood scenery	
Touvier <i>et al</i> , 2010	Retirement	
Van Dyck <i>et al</i> , 2010	Age	
	BMI	
	TV size	
		higher educational level
		Self-efficacy
		Pros about reducing TV time
Granner & Mburia-Mwalili, 2010	BMI	
	Eating more	
		Higher self-rated health status
Teychenne <i>et al</i> , 2012	Less educated & overweight women	
Rhodes <i>et al</i> , 2012	Age	
	Higher BMI	
	Unemployment/retirement	
	Less leisure time PA	
		Having children in the home
Coogan <i>et al</i> , 2012		Higher socioeconomic status
Ding <i>et al</i> , 2012		Higher education level
		Neighbourhood walkability
		Employment status (negatively related)
		Sense of community
Kikuchi <i>et al</i> , 2013	Less educated men	
	Underweight men	
	Overweight	
	Less MVPA	
	Women who lived alone	
	Women who did not drive	
Strong <i>et al</i> , 2013	Walking in the dark	
	Street litter	
	Lack of shops	
Stamatakis <i>et al</i> , 2014		Higher socioeconomic level
		Higher education level
Xie <i>et al</i> , 2014	Higher BMI	
Uijtewilligen <i>et al</i> , 2015	Male sex	
	Smoking	
	Lower aerobic fitness	
	Higher skinfold measures	
	More independence	
Hadgraft <i>et al</i> , 2015	Men in blue-collar jobs	
	Men with higher BMI	

Herman & Saunders, 2016	Single women	
	Women with higher energy intake	
	Higher income	
	Female sex	
	Older age	
	Less educated	
	Lower income	
	Inactive	
	Smoker	
	Overweight/obese	
O'Donoghue <i>et al</i> , 2016	Single	
	Blue-collar employment	
	Non-immigrant	
	Unmarried/single women	
	No children	
	Social norms	
	retirement	
	unemployment	
		Higher Education level
		employment
		neighbourhood walkability
		walking and cycling facilities
		attractiveness
		socioeconomic demographic of
		neighbourhood
		Safety of neighbourhood
	BMI	
	Medication	
	Chronic diseases	
		Female sex
		For women PA outside work
	Enjoyment of TV	
	Age	
	Income	
	Bad diet	
	Smoker	
		Inverse relation with PA & TV
Chang <i>et al</i> , 2018	Lower educational level	
	Live alone	
	Live in nonmetropolitan area	
	overweight	
Werneck <i>et al</i> , 2018	unemployed	
	Living alone	
	Smoker	
	Drinker	
	Men with higher salt intake=diet	
Silva <i>et al</i> , 2021	Young or older aged adults= age	
	Obesity	
	Lower education level	
	Bad diet	
	Unemployed	
	More soft drinks	
	Depression	
	Increased bad health outcomes	
	Less likely to do PA	

Five studies which identified TV viewing correlates for people with an intellectual disability are summarised in table 5.2, which shows the articles and correlates of increased and reduced TV time examined.

Table 5. 2: Intellectual disability TV viewing correlates identified from the literature

Publication	Correlate of high TV	Correlate of low TV
Mikulovic <i>et al</i> , 2014	Late bedtime & late riser	Early bedtime & early risers
Hsieh <i>et al</i> , 2014	Obesity	
Hsieh <i>et al</i> , 2017	Low level of PA	
	Mild/moderate ID	
	Living independently or with family	
	Male sex	
	obesity	
	unemployed	
	No educational program	
		Severe/profound ID
		epilepsy
		Psychotropic medication
		Living in group home
Melville <i>et al</i> , 2018	Mild ID	Epilepsy
	Living independently or with family	
	Mobility issues	
	Did not have epilepsy	
	Good hearing	
	Male sex	
	Obesity	
Oppewal <i>et al</i> , 2018	Residence type	
		Severe/profound ID

5.3.1 General population risk factors

The general population literature scoping review identified ten risk factors for increased TV watching: individual factors of age, BMI, sex, lifestyle including health status, socio-economic status and behaviours such as smoking and drinking, physical activity, attitude and behaviour such as self-rated health, mental health status, self-efficacy and a sense of community, and social and cultural where lower incomes and education levels were linked to increased TV viewing, environmental like neighbourhood quality, and domestic setting factors including marital and status and whether children were in the home.

Age was positively associated with TV hours (Rhodes *et al*, 2012). According to Herman and Saunders (2016), adults aged more than 75-years were 5-times more likely to report watching more than two-hours TV/day compared to younger adults, and those who were non-immigrants watched a minimum of two hours/day of TV.

A higher BMI appeared to be related to increased TV viewing, with the odds of someone who was overweight/obese watching greater than two hours TV being significantly more

than underweight individuals (Bowman, 2006; King *et al*, 2010; Rhodes *et al*, 2012; Kikuchi *et al*, 2013; Xie *et al*, 2014; Smith *et al*, 2015; Herman and Saunders, 2016; Silva *et al*, 2021). In fact each two-hour increment per day was associated with a 23% increased obesity risk (Hu *et al*, 2003). TV time was positively associated with BMI and eating more in US women while other studies found age and BMI were positively associated with TV viewing time (Granner and Mburia-Mwalili, 2010; Van Dyck *et al*, 2010; Chang *et al*, 2018). Those who watched four hours or more of TV per day were four times more likely to be overweight (Salmon *et al*, 2000). Conversely a Japanese study on older adults found that underweight men watched prolonged TV (Kikuchi *et al*, 2013). Thus the evidence on TV watching for SB and BMI is inconclusive. Neither is it clear whether TV viewing and SB cause obesity or vice-versa (Ekelund *et al*, 2008). A longitudinal study proposed that a higher BMI was a determinant of a sedentary lifestyle but could not definitively say that SB resulted in BMI changes (Mortensen *et al*, 2006).

It has been suggested that a sex difference exists when it comes to TV viewing. Some studies showed that women watched significantly more TV than males while others showed the opposite (Rhodes *et al*, 2012; Xie *et al*, 2014; Uijtdewilligen *et al*, 2015). A cross-sectional study which used screen use outside of worktime as a measure of SB, found that men had an increased risk of metabolic syndrome (MetS) with more self-reported time spent watching TV, independent of whether they achieved the minimum PA recommendations (Sisson *et al*, 2009). Conversely another cross-sectional study showed only women had a significant relationship with increased TV time and MetS, while both sexes saw metabolic risks decreased by two-thirds if the minimum amount of vigorous PA was achieved (Bertrais *et al*, 2005). TV viewing was representative of a more sedentary lifestyle overall and reduced levels of PA in women but not men, where each additional hour of TV viewing from baseline for women resulted in an 8.6-minute reduction in PA per week, five years later (Sugiyama *et al*, 2008; Lakerweld *et al*, 2011). Furthermore, TV viewing time in excess of 10-hours/week was significantly related to having obesity and diabetes in women, the risk of which increased by 14% for every two-hour increase in TV viewing and inactive women who watched more than 14-hours TV/week had an increased prevalence of MetS compared to those women who watched less TV (Hu *et al*, 2003; Dunstan *et al*, 2005). In fact, women who watched more TV were more likely to have unhealthy diets, do less exercise, smoke, and drink alcohol (Hu *et al*, 2003). Overall the effect of sex on TV is inconclusive.

The behavioural factors captured from the general population literature review could be summarised in four areas, lifestyle, activity, attitude and behaviour. Lifestyle factors of smoking, drinking, higher salt intakes, soft drink intake, less vegetable intake and lower activity levels were associated with increased TV viewing (Uijtdewilligen *et al*, 2015; Herman and Saunders, 2016; Werneck *et al*, 2018; Silva *et al*, 2021). Poor health outcomes were linked to more TV watching (King *et al*, 2010; Rhodes *et al*, 2012; Silva *et al*, 2021). Increased TV viewing time was related to less leisure time PA, including MVPA, suggesting a substitution-effect (Rhodes *et al*, 2012; Kikuchi *et al*, 2013). Heavy TV use was associated with being more likely to not participate in PA (Silva *et al*, 2021). Inactivity was associated with watching more than two hours TV/day (Herman and Saunders, 2016).

People who suffered from depression and had negative health outcomes were more likely to watch more TV while those who had higher self-efficacy and self-rated health watched significantly less TV (Granner and Mburia-Mwalili, 2010; King *et al*, 2010; Van Dyck *et al*, 2010; Silva *et al*, 2021). Other studies found that predictors of prolonged TV viewing were enjoyment of TV and perceived barriers to PA of cost, weather and work commitments as well as the inability to drive (Salmon *et al*, 2003; Clark *et al*, 2010; Kikuchi *et al*, 2013).

Lower education levels, lower incomes, retirement and unemployment were associated with increased TV time (Salmon *et al*, 2003; Bowman, 2006; Clark *et al*, 2010; King *et al*, 2010; Touvier *et al*, 2010; Ding *et al*, 2012; Rhodes *et al*, 2012; Kikuchi *et al*, 2013; Silva *et al*, 2021). When education level was used as a socioeconomic gauge for women, there was an inverse relationship between education level and social cohesion and TV viewing and less-educated women were more likely to enjoy watching TV and be overweight (Teychenne *et al*, 2012). A longitudinal study determined that children whose father had a lower socioeconomic occupation were more likely to watch at least three-hours TV/day when middle-aged (Smith *et al*, 2015). Higher socioeconomic status and attained education level was negatively associated with TV time but positively associated with work-related SB (Stamatakis *et al*, 2014). A sex-effect on the combined consequences of work-related sitting with TV viewing behaviours was proposed, where men with blue-collar jobs and increased BMI and women who had higher energy intake and were single were associated with more TV viewing (greater than 1.5-hours/day) but for both sexes those on higher incomes were three-times more likely to exhibit high TV viewing and high work-related sitting behaviours (Hadgraft *et al*, 2015). Older adults with lower educational attainment or unemployed were more likely to watch higher levels of TV (Herman and Saunders, 2016; Chang *et al*, 2018). A

four-year follow-up study found that a sense of community had a marginal link with reduced TV time (Ding *et al*, 2012).

Neighbourhood walkability was inversely related to TV time but another study found that the neighbourhood socioeconomic status was inversely related to time watching TV (Sugiyama *et al*, 2007; Coogan *et al*, 2012; Ding *et al*, 2012; Kozo *et al*, 2012). Similarly people who lived in neighbourhoods with bad lighting and scenery, more crime and litter and lack of shops were significantly more likely to watch more TV (King *et al*, 2010; Strong *et al*, 2013). Living in nonmetropolitan and rural areas was associated with increased TV time (Salmon *et al*, 2003; Clark *et al*, 2010; Kikuchi *et al*, 2013; Chang *et al*, 2018). Interestingly, the size of a person's TV was found to be positively related to TV time (Van Dyck *et al*, 2010).

People who were either divorced, separated or single were more likely to watch two-hours or more TV/day but having children in the home was associated with watching less TV (King *et al*, 2010; Rhodes *et al*, 2012; Herman and Saunders, 2016). Adults, irrespective of sex, who lived alone watched significantly more TV (Kikuchi *et al*, 2013; Chang *et al*, 2018; Werneck *et al*, 2018). For young Dutch adults, higher independence was one of the primary determinants for increased TV viewing (Uijtdewilligen *et al*, 2015).

5.3.2 Intellectual disability population risk factors

For people with an intellectual disability, factors identified were physical health and wellbeing, social and cultural context, attitude and behaviour and institutional and home settings. High screen behaviour was common in the few available intellectual disability studies (Oppewal *et al*, 2018). BMI especially obesity was associated with higher TV time (Hsieh *et al*, 2014; Melville *et al*, 2018). Those who had mobility issues, good hearing, male sex or were obese were more likely to engage in high screen time while people with epilepsy or who took psychotropic medication had inverse relationships with hours of TV watched (Hsieh *et al*, 2017; Melville *et al*, 2018). However a systematic review found inconclusive results for sex, mobility, BMI, physical health and genetic syndromes (Oppewal *et al*, 2018). The level of intellectual disability was linked to increased TV time where adults with a borderline or mild/moderate intellectual disability were more likely to engage in higher screen time than those with a more severe/profound level (Hsieh *et al*, 2017; Melville *et al*, 2018). Similar to the general population literature, an adult with intellectual disability was significantly more likely to watch more TV if they were unemployed or had no educational

program (Hsieh *et al*, 2017). Sedentary behaviour as assessed by TV watching habits was significantly related to the time people with an intellectual disability went to bed and rose at, with early risers and earlier bedtimes related to less TV watching and sedentary activity (Mikulovic *et al*, 2014). Inconclusive results were seen for relationships between mental health issues and TV viewing habits (Oppewal *et al*, 2018). Some literature illustrated that those living independently or with family watched more TV than those in other residence types and were therefore more sedentary but results were not consistent across studies (Hsieh *et al*, 2017; Melville *et al*, 2018).

Due to the dearth of research on TV viewing in the intellectual disability arena, the risk factors discovered in the general population search were also explored in this study and were mapped to an IDS-TILDA variable equivalent where available. Table 5.3 summarises the additional general population and intellectual population literature correlates that were identified from the scoping literature reviews (excluding age, sex, BMI and intellectual disability level) and the equivalent IDS-TILDA variable they were mapped to.

Table 5. 3: Mapping of the additional literature-derived correlates of TV viewing and IDS-TILDA variable

High TV correlate (Gen)	High TV correlate (ID)	Wave 3 IDS-TILDA variable
Lower educational level	No educational program	Question 'Do you attend/do any of the following?-In education or training' & 'Attend day service/activation in the community'& 'What is highest level of education?'
Live in nonmetropolitan area/ Rural living		County of residence
Unemployment/retirement/ Blue-collar employment	unemployed	Question ' <i>Which one of these would you say best describes your current employment situation?</i> '
TV size or Enjoyment of TV		Information not available
Eating more/ Bad diet/Men with higher salt intake/ More energy dense diet/ More soft drinks		Food questions in CAPI & 'Fizzy drinks' question'
Lower income/ Higher income		Wave 2
Self-rated health		'Would you say your health is?'
Live alone/ More independence/ No children/ Unmarried/single/ Divorced/separated	Live independently or with family	Marital status
Street litter/ Lack of shops/ More neighbourhood crime/ Less neighbourhood lighting/scenery		For Wave 3 used 'Difficulty getting around community' and 'safe in community'
Less MVPA/inactive/ Less likely to do PA/ Less leisure time PA/Less active/ Lower aerobic fitness	Low level of PA	IPAQ, RAPA *
Women who did not drive		No one drives
Smoker		Wave2
Non-immigrant		Everyone non-immigrant
Social norms		n/a
Medication	No Psychotropic medication	No single variable available.
Bad health/ Poorer health/ Chronic diseases/ Depression		Health questions *
Drinker		Question ' <i>How often if at all, do you go to the pub for a drink?</i> '
	Late bedtime & late riser	Question ' <i>During the past month, when have you usually gone to bed? Time to bed Wave 3' & 'When have you usually gotten up in the morning?'</i> '
	Mobility issues	Question ' <i>Have you difficulty walking 100 yards?</i> '
	Good hearing	Question ' <i>Do you use any of the following aids or appliances to help you with your hearing?-Hearing aid (all the time)?'</i> '

* These will be addressed in later chapters

5.4 Mapping onto the Systems of Sedentary Behaviour Framework

Each of the identified themes and their corresponding risk factors from the literature searches were mapped onto the appropriate cluster from the SOS framework. The nine identified general population themes were captured in five clusters on the SOS framework: physical health and wellbeing, social and cultural context, built and natural environment, psychology and behaviour and institutional and home settings, as seen in figure 5.2. Figure 5.2 illustrates the general population risk factors for increased TV viewing uncovered in the literature scoping review, mapped onto the corresponding SOS cluster classification, where the factors highlighted in bold had IDS-TILDA equivalent data available. The four general themes identified from the intellectual disability search were captured in four SOS clusters: physical health and wellbeing, social and cultural context, psychology and behaviour and institutional and home settings. The IDS-TILDA equivalent variables for the identified correlates were mapped onto the appropriate SOS clusters. Figure 5.3 shows the SOS framework with the correlates of TV viewing discovered in the intellectual disability literature shown in green. Any IDS-TILDA variable that corresponded to correlates found in either the intellectual disability or general population literature are shown in red. These variables provided the basis for the analysis of the self-reported and objectively measured SB in the intellectual disability population that are addressed in this study.

5.5 Conclusion

A comprehensive set of risk factors for increased TV viewing and SB for the intellectual disability adult population was identified and summarised using the SOS framework. This provided a basis for the analysis into the overall SB of the adult intellectual disability population.

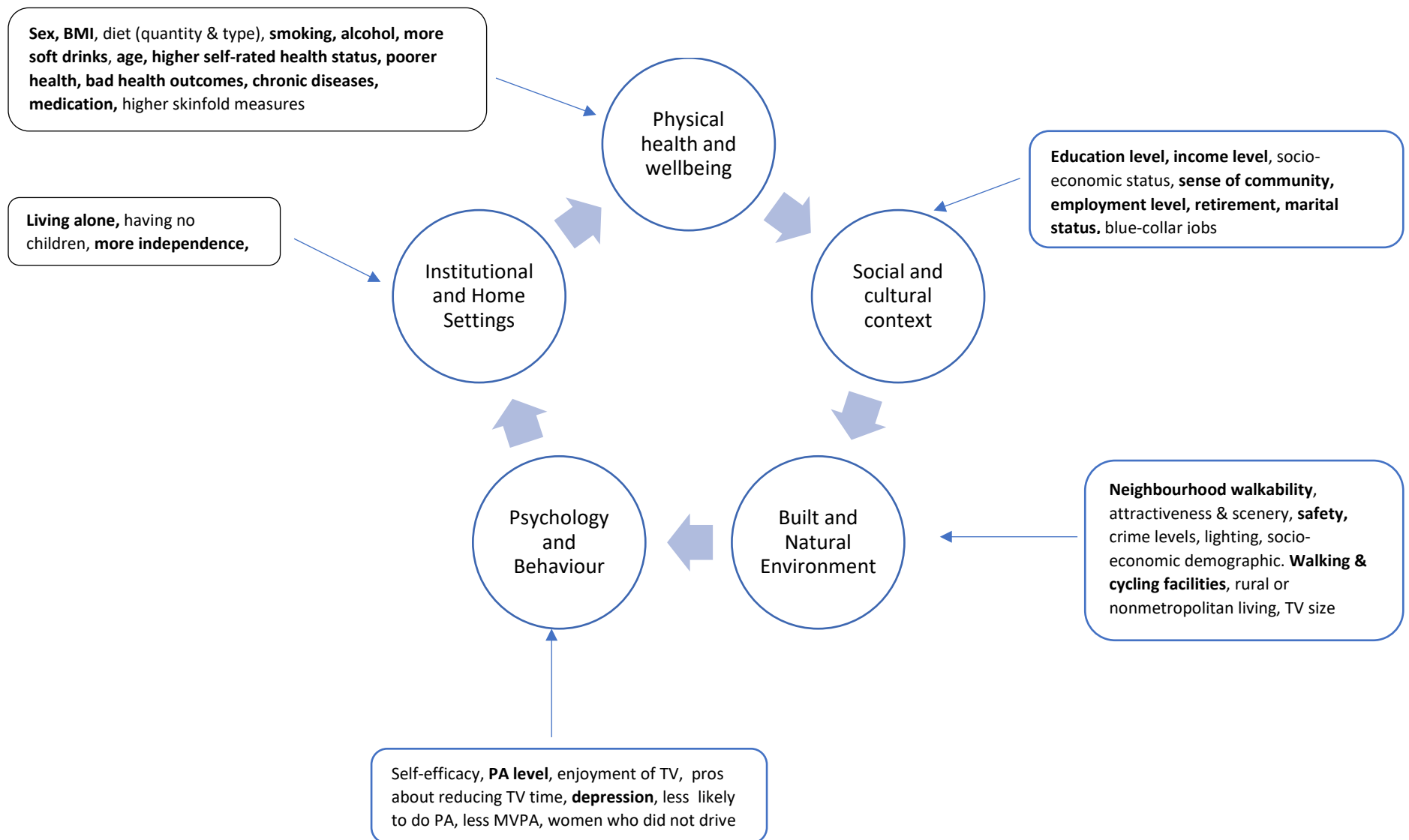


Figure 5. 2: SOS model with determinants for TV viewing: general population

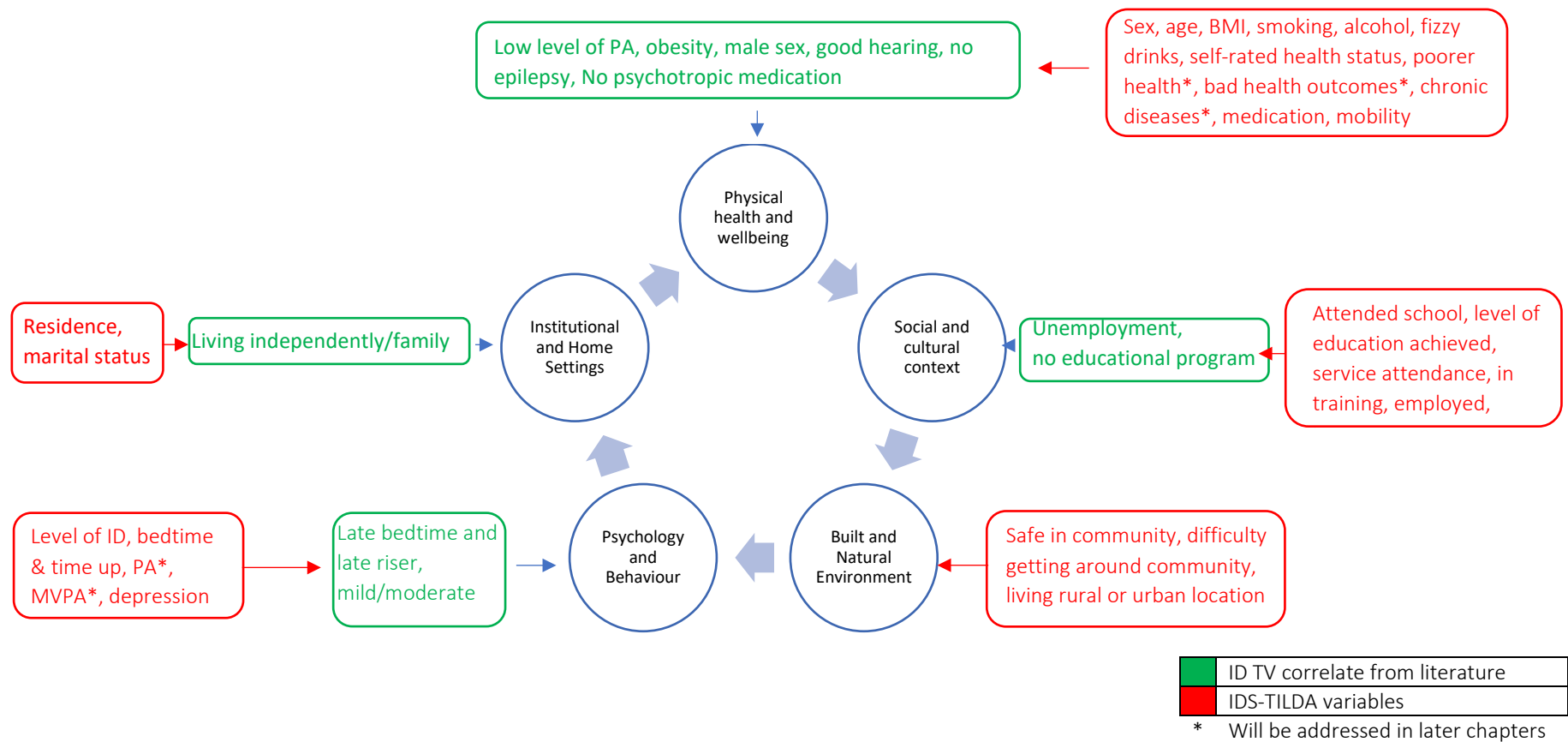


Figure 5. 3: Correlates of increased TV viewing using SOS framework for intellectual disability population showing IDS-TILDA variables

Chapter 6

A longitudinal exploration of self-reported TV behaviours as a surrogate for sedentary behaviour in older adults with an intellectual disability from the IDS-TILDA study.

Chapter summary

This chapter presents the findings of the investigation into the self-reported TV habits of people with an intellectual disability, where time watching TV was used as a proxy for sedentary behaviour (SB). Risk factors, as identified previously, which were mapped onto IDS-TILDA variables and the standard covariates, were explored to determine their viability as contributors to increased TV viewing and SB. Details of the analysis plan are given. Multinomial logistic regression and Chi-squared Automatic Interaction Detector Analysis (CHAID) are explored and compared. Multiple Imputation Chained Equation (MICE) was used to impute missing values in the original dataset. All analyses were rerun using the imputed dataset and findings examined for difference to the original. A novel framework, the Systems of Sedentary Behaviour, was used to structure results.

6.1 Introduction

This chapter examined the self-reported TV habits of adults with an intellectual disability, where TV time was used to represent SB. Risk factors for both the general population and intellectual disability population identified in chapter 5 were explored. As demonstrated earlier, there is very limited record for the investigation of TV habits and SB within the intellectual disability population. Therefore the aim of this study was to examine the self-reported TV habits of older adults with intellectual disability using the IDS-TILDA dataset and to determine modifiable and non-modifiable contributing factors.

6.2 Methods

6.2.1 Study design and participants

This study was positioned within IDS-TILDA. From the total sample of 753 participants in Wave 1, 744 (98.8%) answered the TV question. For Wave 2 93.4% (n=661/708) and in Wave 3 98.6% (n=601/609) participants answered the TV question. However given that direct longitudinal comparisons were necessary, only those who participated in all three waves were included in the analyses. The final numbers included were 603 (99%) for Wave1, 576 (94.5%) for Wave2 and 601 for Wave3. The difference in numbers is due to some not answering the questions in every wave.

6.2.2 Data sources

The data sources for this study came from two questionnaires, the Pre-interview (PIQ) and the Computer Assisted Personal Interview (CAPI).

6.2.3 Outcome measure

The TV watching habits of participants was garnered by asking the following TV question

‘Over the past 30 days, on average, how many hours per day did you sit and watch TV or videos? Would you say ...?’.

Response categories ranged from none, <1, 1-3, 3-5 and >5 hours/day (five categories). While the five category TV question answers formed the basis for analysis, this information was also categorised into two categories: < three hours and > three hours TV viewing. This three-hour sitting threshold to classify SB was based on evidence that sitting for more than three hours/day had detrimental effects specifically for CVD and diabetes (Clark *et al*, 2009; Patel *et al*, 2010; Periera *et al*, 2012).

6.2.4 Framework

The Systems of Sedentary Framework (SOS) was used to structure the results of this study in a concise and adaptable manner (Chastin *et al*, 2016). The SOS model groups multiple levels of influence on health behaviours into six clusters. These different levels of influence ranged from environment and policy to social, individual and interpersonal factors.

6.2.5 Statistical analysis

Statistical analysis was executed as described in chapter 4. Both the two- and five-category TV watching variables were used as the dependent variable in the initial bivariate

investigations but only the five-category analysis yielded any consistent significant results and was carried forward to the regression analyses. The dependent TV variables and independent variables were grouped as categorical variables in all statistical models. Pearson chi-square was used to explore bivariate associations between time watching TV and the independent variables: sex, age, level of intellectual disability, aetiology, living circumstances and BMI as well as any correlates that were identified through the literature reviews and mapped to IDS-TILDA variables.

The Akaike information criterion (AIC) was used to compare models and determine the best model fit for predicting high TV watching.

Multicollinearity was investigated to ensure no inter-variable dependencies were present.

Relationships were explored using crosstabulation, and subsequently examined further by either a binary or multinomial regression to examine the overall model fit, explain the contribution of each of the independent variables and explore any further significant associations. The dependant variable of how many hours TV/videos were watched and the significant independent variables were used in the regression models. Results for all standard covariates were computed on a wave-by-wave basis and for direct comparison the same participants were examined longitudinally. Wave 3 data were used for the complete analysis for all variables and adjustments were made for significant variables. Analyses were repeated after missing value imputations were completed and results compared.

6.2.6 Sample size

The minimum sample size required to provide meaningful results for this TV viewing and SB investigation was 122.

6.2.7 Missing data

The researcher thoroughly investigated all the missing values in this study. Originally, eight variables had in excess of 10% missing data: 28.9% for the question asking if people had difficulty getting around their neighbourhood with over 68% missing from the subsections; in excess of 50% missing from the level of education question and in excess of 31% for BMI. See appendix 6.1. Little's Test for MCAR was not suitable as data were categorical so the researcher investigated the missing data. The 31.4% missing BMI data were investigated and converted to a binary missing/not missing variable and compared to level of ID and residence. This missing/not missing variable was significantly related to level of ID and

residence type (Pearson chi-square $p < 0.001$ for both) indicating that the BMI data were MAR. Similarly the level of education had extensive missingness. On inspection of the data, those who had no or another type of education were mis-classed as missing. When this was amended the number missing reduced to 14.3% ($n=87$). This education level variable was converted to a binary missing/not missing variable and compared to level of ID, where a Pearson chi-square $p=0.003$ indicated that there was a correlation and that the missing data were MAR. Finally the 28.9% missing data from the difficulty getting around the community question was investigated and found to be due to the large number of people who did not travel around the community ($N=163$). When this was considered the missingness decreased to 2.1% ($N=13$). Furthermore 192 participants answered positively to the question on experiencing difficulty getting around the community which explained the level of missingness in the subsections of the question and the subsections were then excluded. Before a missing value imputation could be computed, a missing data pattern analysis was completed which showed that only three variables had complete data, see figure 6.1.

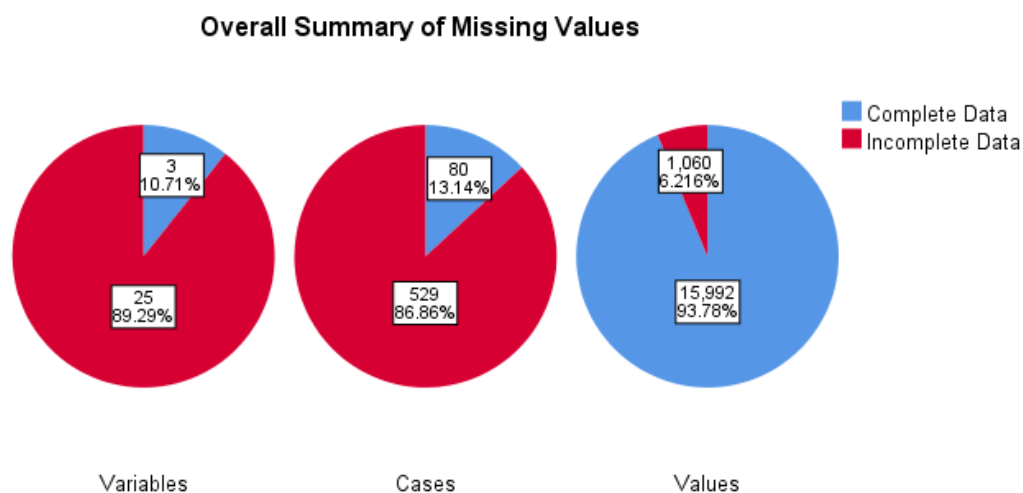


Figure 6. 1: Overall summary of missing values for 27 independent variables & dependent TV-variable Multivariate Imputation by Chained Equations (MICE) was used to deal with up to 20% missing data, specifically MAR and MCAR (Azur *et al*, 2011; Tabachnick and Fidell, 2014). Post-MICE the missing data were zero, see figure 6.2.

Overall Summary of Missing Values

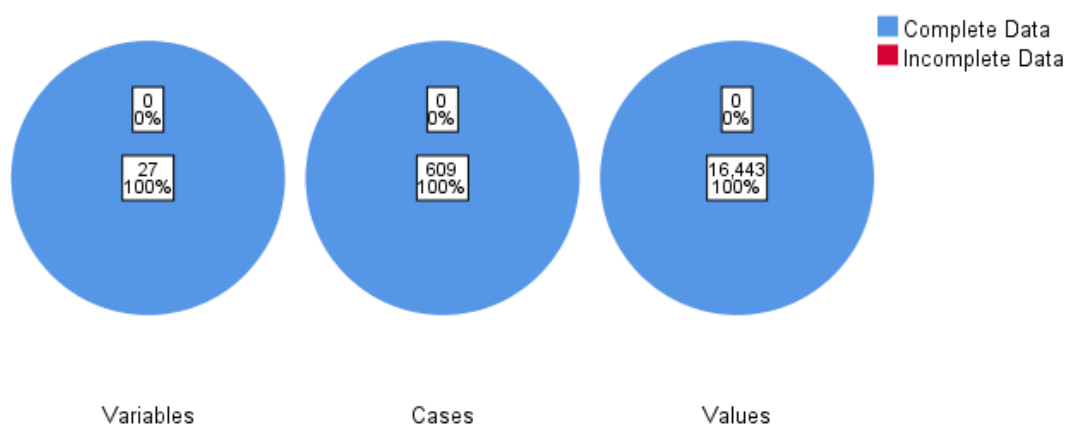


Figure 6. 2: Post MICE summary of missing values for 26 independent variables & dependent TV-variable.

Although negligible differences were observed between the mean and standard deviations for the MICE computations compared to the original variables, multiple regression analyses were repeated to ensure data integrity.

6.3 Results

6.3.1 Demographic profile of the participants across the three waves

The total demographic profile of participants who participated in all three waves is shown in table 6.1. The average age of participants was 54.75 in Wave1, 57.1 in Wave2 and 59.3 years in Wave3. The predominant intellectual disability level was moderate at approximately 42%. There were more female participants than males at 55%. Unless otherwise stated, data reported was for the same 609 participants across waves.

Table 6. 1: Wave 1-3 participant demographic profile for total participants in all three waves and same 609 participants.

Profile characteristics		Wave 1(N=753)		Wave 2 (N=708)		Wave 3 (N=609)		Wave 1 (n=609)		Wave 2 (n=609)	
		n	%	n	%	n	%	n	%	n	%
Sex	Male	335	44.5	312	44.1	269	44.2	269	44.2	269	44.2
	Female	418	55.5	396	55.9	340	55.8	340	55.8	340	55.8
Age**	<50	274	36.4	197	27.8	72	11.8	254	41.7	180	29.6
	50-64	344	45.7	356	50.3	381	62.6	278	45.6	313	51.4
	65+	134	17.8	148	20.9	156	25.6	77	12.6	113	18.6
	Min (years)	44	n/a	44.6	n/a	48	n/a	41	N/a	44	N/a
	Max (years)	90	n/a	92.32	n/a	95	n/a	90	N/a	92	N/a
	Mean (years)	54.8(SD±9.6)	n/a	57.1(SD±9.3)	n/a	59.13 (SD±8.8)	n/a	53.18(SD±8.8)	N/a	55.87(SD±8.8)	n/a
Aetiology	Down Syndrome	147	19.52	138	19.5	109	17.9	109	17.9	109	17.9
Level of ID*	Level ID not verified	58	7.7	17	2.4	17	2.8	17	2.8	17	2.8
	Mild	167	22.2	158	22.3	139	22.8	139	22.8	139	22.8
	Moderate	323	42.9	304	42.9	259	42.5	259	42.5	259	42.5
	Severe or Profound	205	27.2	192	27.1	163	26.8	163	26.8	163	26.8
Living circumstances	Independent/Family	129	17.1	115	16.2	95	15.6	106	17.4	103	16.9
	Community group home	264	35.1	307	43.4	246	40.4	230	37.8	266	43.7
	Residential Care	356	47.3	284	40.1	268	44	273	44.8	240	39.4
BMI ⁺	Underweight	12	1.6	20	2.8	3	0.5	5	0.8	14	2.3
	Normal	217	28.2	177	25	56	9.2	171	28.1	152	25
	Overweight/Obese	355	47.1	395	55.8	232	38.1	301	49.4	359	58.9
TV viewing ⁺⁺	None	138	18.3	124	17.5	77	12.6	103	16.9	105	17.2
	Less than 1 hour TV/day	139	18.5	116	16.4	95	15.6	117	19.2	102	16.7
	1 to 3 hours TV/day	295	39.2	294	41.5	269	44.2	240	39.4	260	42.7
	3 to 5 hours TV/day	123	16.3	87	12.3	123	20.2	104	17.1	71	11.7
	5 hours or more TV/day	49	6.5	40	5.6	37	6.1	39	6.4	38	6.2

*Total 48 missing ID level, ** Age missing W2 (3), + BMI missing W1 (132), W2 (84), W3 (191), ++ TV missing W1 (6), W2 (33), W3 (8)

6.3.2 TV habits examined across two- and five-categories.

The overall participant TV habits were examined by two (less than and greater than 3 hrs) and five categories across the waves. The two-category summaries demonstrated that only 18.9% (n=109/576) to 26.6% (n=160/601) of participants self-reported to watch more than 3 hours TV/day and thus were classed as sedentary. However if the TV categories were examined by five categories it demonstrated that over 40% of participants watch between 1-3 hours TV/day, see table 6.2.

Table 6. 2: Wave1-3 TV viewing descriptives by two- and five-categories

TV watching per day	categories	Wave 1		Wave 2		Wave 3	
		n	%	n	%	n	%
2 Categories	>3hrs	143	23.7	109	18.9	160	26.6
	<3hrs	460	76.3	467	81.1	441	73.4
5 Categories	None	103	17.1	105	18	77	12.8
	<1hr	117	19.4	102	17.5	95	15.8
	1-3hrs	240	39.8	260	44.7	269	44.8
	3-5hrs	104	17.2	71	12.2	123	20.5
	5hrs+	39	6.5	38	6.5	37	6.2

Table 6.3 shows the mean TV hours stratified by demographic characteristics. Overall all categories saw increases in mean TV viewing time across the waves. On average both sexes watched more TV in Wave 3. Out of the 609 participants who participated in all three waves, Wave1 females watched 1.8% more TV than the total females in the Wave1 sample. Those living at home or independently consistently watched more TV on average than those in group homes or residential care. Living circumstances changed over the three waves; the number living independently/with family decreased from 17.6% (n=106) in Wave 1 to 15.8% (n=95) in Wave 3, while the numbers living in community group homes (CGH) and residential care fluctuated. Participants in CGH increased from 38.1% in Wave1 to 44.1% (n=266) in Wave2 (to decrease in Wave3 to 41% (n=246)), while residential care decreased from 45% (n=273) in Wave1 to 40% (n=240) in Wave2 to 45% (n=268) in Wave3.

Those with a more severe or profound intellectual disability consistently watched less TV than those with a mild or moderate intellectual disability level. There appeared to be a trend for those with a higher BMI to watch more TV on average but this trend was not as obvious in Wave 3.

Table 6. 3: Mean number of TV hrs watched per day stratified by demographic characteristics.

Profile characteristics		Mean No. of Hours per day		
		Wave 1	Wave 2	Wave 3
Sex	Male	2.72	2.78	2.88
	Female	2.81	2.73	2.94
Age	<50	2.76	2.74	2.93
	50-64	2.71	2.77	2.9
	65+	2.78	2.71	2.93
Aetiology	Down Syndrome	2.76	2.7	2.82
Level of ID	Level ID not verified	2.53	2.87	3.13
	Mild	2.98	2.96	3.07
	Moderate	2.9	2.87	3.05
	Severe or Profound	2.27	2.32	2.53
Living circumstances	Independent/Family	3.09	3.28	3.14
	Community group home	2.89	2.7	2.93
	Residential Care	2.5	2.47	2.82
BMI	Underweight	1.8	2.31	3
	Normal	2.7	2.46	2.9
	Overweight/Obese	2.83	2.88	3.08

6.3.3 Risk factor exploration

Examinations of risk factors for increased TV viewing were completed in two phases. The first phase involved bivariate examination of covariates of sex, level of intellectual disability, aetiology, residence, age and BMI and the second phase examined those covariates identified from the literature review, using IDS-TILDA variables.

- Phase 1: standard co-variables

Initial investigations were performed using crosstabs where Pearson chi-square values of <0.05, to ensure 95% confidence in results, were used to identify significant associations between the independent variables and the different TV categories. The resulting Pearson chi-square p-values from these analyses are summarised in table 6.4 for all three waves of data collection. Any significant relationships are highlighted in bold and any p-values up to 0.2 are in italics, as these will be carried forward to the next stage of analysis. Level of intellectual disability and residence type had significant associations across all 3 waves for the 5 TV categories. In addition Wave 2 showed significant associations for BMI for 5 categories of TV and residence and ID level for 2 categories. Further analyses were required to understand exactly how the statistically significant variables could predict the dependant

variable TV time. Multinomial logistic regressions were required to investigate the five TV categories and binary logistic regression for the two-category TV dependent variable.

Table 6. 4: Wave 1-3 Pearson chi-square p-values for independent factors & TV categories

	Wave 1⁺		Wave 2⁺		Wave 3⁺	
	2 categories TV	5 categories TV	2 categories TV	5 categories TV	2 categories TV	5 categories TV
Sex	0.907	0.747	0.739	0.968	0.398	0.839
ID level	<i>0.158</i>	<0.001	0.038	<0.001	0.294	<0.001
Aetiology	0.910	0.232	<i>0.193</i>	0.329	0.629	0.802
Residence	0.533	<0.001	0.001	<0.001	0.531	<0.001
Age	<i>0.184</i>	0.475	0.696	0.599	0.238	0.586
BMI	0.373	0.394	0.386	<0.001	0.346	<i>0.104*</i>

*Expected count>20%. Monte-Carlo used. ⁺ = Chi-square p-value

- Level of Intellectual disability

Appendix 6.2 to 6.4 shows the bivariate comparison for level of intellectual disability and five TV watching categories for Waves 1-3 using multinomial regressions, where the reference category was mild intellectual disability. Those with a severe/profound intellectual disability were significantly less likely to watch any TV except in Wave 3 where no relationship was observed for the less than one-hour category. However in Wave 3 those with moderate intellectual disability were over 3 times more likely to watch < 1hour TV [AOR=3.3; p=0.017, 95%CI 1.2-8.8]. When the level of intellectual disability was investigated against two categories of TV for Wave2, those who were severe/profound were almost twice less likely to watch >3hours TV [p=0.044, 95%CI 1-3.8], see appendix 6.5.

Wave 3 data were imputed and calculations were rerun with the missing values included. Results were similar to the original Wave 3 results, with slightly tighter confidence intervals. For all three waves, those with a severe/profound intellectual disability were approximately 4-6 times less likely to watch TV across all categories from 1 hour to > 5 hours [COR=5.9; p<0.001, 95%CI 2.9-11.9; COR=5; p<0.001, 95%CI 2.1-10.4; COR=4.5; p=0.005, 95%CI 1.5-12.3]. In addition those with a moderate level were 3 times more likely to watch < 1hour TV/day [COR=3; p=0.019, 95%CI 1.2-7.7]. Appendix 6.6 shows the detailed imputed multinomial results. Table 6.5 illustrates the significant results from the wave 3 imputed multinomial analysis.

Table 6. 5: Significant relationship for imputed intellectual disability data & 5-category TV

Wave	Level of ID	TV category	p-value*	COR	1/COR	CI**
3 Imputed Data	Severe/profound	1-3hrs	<0.001	0.169	5.9	2.9-11.9
		3-5hrs	<0.001	0.214	4.7	2.1-10.4
		>5hrs	0.006	0.232	4.3	1.5-12.3
	Moderate	<1hr	0.019	3	n/a	1.2-7.1

*P set at <0.05. ** CI is 95%

○ Living circumstances

All bivariate comparisons for the influence of residence on TV watching were compared to those living independently/with family. Across the three Waves, those who lived in residential settings were consistently less likely to watch TV. Appendix 6.7 to 6.9 shows the original dataset results. For Wave2, the two TV categories indicated that those in residential and CGT were more than 2 times less likely to watch >3hrs TV/day [COR=2.2; p=0.006, 95%CI 1.3-3.7; COR=2.8; p<0.001, 95%CI=1.6-4.8], see appendix 6.10. Although there was no missing living circumstance data some TV data were missing so the multinomial regression was repeated with the imputed data for Wave 3. Results were similar to the Wave 3 results with missing data. Those in residential settings were approximately 2-4 times less likely to watch 1 to up to >5 hours TV/day compared to those who lived independently/with family [COR=4.3; p=0.001, 95%CI 1.8-11; COR=2.8; p=0.037, 95%CI 1.1-7.9; COR=3.8; p=0.021, 95%CI 1.2-12.4]. Furthermore those in CGH were almost 4 times less likely to watch >5 hrs TV/day [COR=3.8; p=0.041, 95%CI 1.1-14.7]. Table 6.6 summarises the significant results for residential settings and the wave 3 imputed five-categories of TV.

Table 6. 6: Summary of significant relationships for residence and 5-categories TV

Wave	Residence	TV category	p-value*	COR	1/COR	CI**
3 Imputed	Residential	1-3hrs	0.001	0.233	4.3	1.8-11
		3-5hrs	0.037	0.360	2.8	1.1-7.9
		>5hrs	0.021	0.263	3.8	1.2-12.4
		>5hrs	0.041	0.263	3.8	1.1-14.7

*P set at <0.05, ** CI is 95%.

- BMI

Those who were overweight/obese in Wave2 were more than 3 times more likely to watch TV in every category [COR=3.3; $p<0.001$, 95%CI 1.742-6.254; COR=3.8; $p<0.001$, 95%CI 2.232-6.382; COR=3.6; $p<0.001$, 95%CI 1.756-7.445, $p=0.012$, 95%CI 1.278-7.424], see appendix 6.11. The Pearson chi-square p-value for BMI (after imputation) was <0.001 . Hence further investigation was warranted. Although the multinomial regression showed no significant relationships with any TV category those who were underweight had a p value <0.2 so BMI progressed to the next analysis stage.

- Phase 2: literature review risk factors
 - Descriptives

Descriptives of the potential risk factors uncovered from the literature review by the Wave3 participants are shown in table 6.7.

Table 6. 7: Literature review risk factor descriptives for Wave3 IDS-TILDA participants

Risk Factor	Risk status	Factor	N	n	%	Missing
Marital Status	Single		603	595	98.7	6
	Partner			6	1	
	Married			2	0.3	
Fizzy drinks	4+/day		554	4	0.7	55
	5/week-3/day			62	11.2	
	1/month-4/week			266	48	
	Never			222	40.1	
Sense of community	A lot		582	247	40.6	27
	A little			212	36.4	
	None			123	21.1	
Employment	Employed		601	218	36.3	8
	Unemployed			383	63.7	
Education/training	yes		607	16	97.4	2
	no			591	2.6	
Day service	yes		607	345	56.8	2
	no			262	43.2	
Education level	Post primary		522	76	14.6	87
	primary			283	54.2	
	none			163	31.2	
Occupation	yes		607	454	74.8	2

	no		153	25.2	
Diff. getting around community	Does not travel	596	163	27.3	13
	Yes difficulty		192	32.2	
	No difficulty		241	40.4	
Wheelchair user	yes	602	78	13	7
	no		524	87	
Difficulty walking 100yards	yes	601	225	37.4	8
	no		376	62.6	
Epilepsy	yes	603	215	35.7	6
	no		388	64.3	
Smoker	yes	600	77	12.8	9
	no		523	87.2	
Alcohol	yes	600	247	41.2	9
	no		353	58.8	
Hearing	Excellent/V.good	598	358	59.9	11
	Good		174	29.1	
	Fair/poor		56	9.4	
	Deaf		10	1.7	
SR Health	Fair/poor	604	87	14.4	5
	Good		243	40.2	
	v.good/excellent		274	45.4	
Time to bed	before 7pm	576	12	2.1	33
	7-9.30pm		134	23.3	
	9.30-11:59pm		414	71.9	
	After 12am		16	2.8	
Time up	Before 7am	591	72	12.2	18
	After 7am		519	87.8	
Psychotropic medication	None	549	208	37.9	60
	1 to 3		286	52.2	
	4 to 6		52	9.5	
	7 to 10		3	0.5	

○ Bivariate associations

Crosstabulations were used to explore the bivariate associations between these covariates and TV watching to determine any significant relationships. Pearson chi-square p-value was used to gauge the level of significance. Investigations were completed using two- and five-categories and the imputed five-categories of TV viewing. Any p-values up to 0.2 were brought forward to the next stage of analysis. Appendix 6.12 shows the results for all calculations. Table 6.8 shows the results of the crosstabulations for the imputed five-category TV variables and each of the identified risk factors.

Table 6. 8: TV viewing correlates Pearson chi-square p-values for the 5cat imputed dataset

Correlate	p-value (5cat) imputed data
Marital status*	0.224*
Fizzy drinks (4cat)*	0.007*
Sense of community	<0.001*
Employment	<0.001*
Education/training*	0.001*
Attend day service	<0.001*
Highest level of education (3cat)	0.061*
Occupation	0.433*
Difficulty getting around community: main question	<0.001*
Difficulty getting around community: unsafe**	n/a
Difficulty getting around community: footpaths**	n/a
Difficulty getting around community: no street crossings**	n/a
Difficulty getting around community: signage issues**	n/a
Difficulty getting around community: access recreational areas**	n/a
Mobility: wheelchair user	0.001*
Mobility: difficulty walking 100 yards (4 cat)	n/a
Mobility: difficulty walking 100 yards (2 cat)	<0.001*
Epilepsy	0.002*
Smoker	0.794*
Drink alcohol	0.266*
Hearing	0.036*
3 cat SR health	0.003*
Time to bed*	0.03*
Time up in morning*	0.05*
Psychotropic medication	0.127*

*95% confidence interval

○ Bivariate Regressions

Only the imputed results are reported here. No significant relationship was seen in the imputed multinomial regression for alcohol, hearing, occupation or self-rated health and TV viewing.

■ Fizzy drinks

Appendix 6.13 shows the original data multinomial regression for fizzy drink consumption. The imputed data multinomial regression showed that those who drank from five fizzy drinks/week up to three/day were almost 3 times more likely to watch less than 1hrs TV/day and almost 10 times more likely to watch more than 5 hours TV/day [COR=2.8; p=0.032, 95%CI 1.1-7.1; COR= 9.8; p<0.001, 95%CI 3.1-30.5] but with tighter confidence intervals.

- Sense of community

Appendix 6.14 shows the original data multinomial for sense of community. The calculations with imputed data showed approximately 2.5-5 times less TV viewing up to 5hours TV/day for those who felt no sense of community at all [COR=3.5; p=0.001, 95%CI 1.7-7.4; COR=4.8;mp<0.001, 95%CI 2.6-9.1; COR=2.5; p=0.009, 95%CI 1.3-5.1].

- Employment

Appendix 6.15 shows the original data multinomial for employment and TV watching. The imputed data showed that those who were unemployed were approximately 2 times less likely to watch between 1-5 hours TV/day [COR=2.8; p=0.001, 95%CI 1.6-4.9; COR=2; p=0.031, 95%CI 1.1-3.8].

- Day service

Over 55% of participants attended day service. Appendix 6.16 shows the original multinomial for day service attendance and TV watching. The imputed data had the same results where those who did not attend day service were 1.9 times less likely to watch 1-3hrs TV/day [COR=1.9; p=0.022, 95%CI 1.1-31].

- Education level

The education level question was rested in Wave3 so Wave 2 results were used. Table 6.9 shows the education level breakdown. The imputed multinomial regression showed that those who had no education were over 4 times less likely to watch 1-3 hours TV/day than those who had some type of education [COR=4.1; p=0.002, 95%CI 1.7-10].

Table 6. 9: Highest education level achieved by participants

Education Level	Number (%)
None	163 (31.2)
Primary	283 (54.2)
Secondary	9 (1.7)
Other *	67 (12.9)

*2 had a primary degree, 3 had diploma/certificate, 62 answered 'other' but no details provided

- Occupation

Appendix 6.17 shows the original multinomial for occupation and TV watching category.

- Difficulty getting round community and feeling safe

Appendix 6.18 shows the original multinomial for difficulty getting around the community and TV watching category . No significant relationship was observed with TV viewing time and any of the five subsections for the difficulty getting around the community question. The imputed data showed that those who did not travel or had difficulty travelling around the community were 3-6 times less likely to watch any category of TV compared to those who had no difficulty getting around their community [COR=3.6, p=0.002, 95%CI 1.6-7.9; COR=2.8, p=0.012, 95%CI 1.3-6.3; COR=6, p<0.001, 95%CI 3-12.1; COR=3.1, p=0.002, 95%CI 1.5-6.2; COR=4.7, p<0.001, 95%CI 2.2-10.2; COR=2.8, p=0.01, 95%CI 1.3-6; COR=4, p=0.005, 95%CI 1.5-11.2; COR=3.6, p=0.015, 95%CI 1.3-10].

- Mobility

Mobility was assessed in two ways; by the question 'Difficulties that might stop you doing physical activity? - Wheelchair user' and 'Level of difficulty - walking 100 yards'. The wheelchair chi-square p-value while marginally larger than 0.05 (p=0.079) warranted further investigation. Appendix 6.19 shows the regression analysis for wheelchair users and TV categories. Conversely the imputed wheelchair data did not show any significant relationship with TV.

The question on difficulty walking 100-yards was analysed by four and two categories. Appendix 6.20 shows the original data for difficulty walking 100yards and 5-categories TV. The imputed difficulty walking 100-yards question yielded similar results to the original i.e. those who had difficulty were approximately 2 times less likely to watch up to 3-hours TV/day [COR=2, p=0.032, 95%CI 1.1-3.7; COR=2.2, p=0.003, 95%CI 1.3-3.7].

- Epilepsy

Results of the multinomial for epilepsy are shown in appendix 6.21. Similarly the imputed data showed that those with epilepsy were approximately 2 times less likely to watch between 1-5 hours TV/day [COR=2, p=0.007, 95%CI 1.2-3.4; COR=2.6, p=0.002, 95%CI 1.5-4.7].

- Alcohol

The original multinomial for alcohol and TV watching is shown in appendix 6.22. The imputed dataset showed that participants who drank alcohol in the last six months were 2

times more likely to watch up to five hours of TV compared to those who did not drink [COR=2.5, p=0.004, 95%CI 1.4-4.8; COR=1.9, p=0.018, 95%CI 1.1-3.4; COR=1.9, p=0.039, 95%CI 1-3.5].

- Self-rated health

Appendix 6.23 shows the self-rated health and TV watching original multinomial results.

- Time to bed and time up

Those who got up after 7am were 3-times more likely to watch between 3-5 hours TV, compared to those who got up before 7am [COR=3.3, p=0.017, 95%CI 1.241-8.627], see appendix 6.24.

- Psychotropic medication

The imputed data showed that those who took between 1-6 medications per day were over 2 times less likely to watch 1-3-hours TV/day [COR=2, p=0.021, 95%CI 1.2-3.7; COR=2.3, p=0.046, 95%CI 1-5.4].

6.3.4 Multinomial regression with five categories of TV viewing and significant variables

Multicollinearity was investigated to ensure there were no inter-variable correlations. All VIF values were less than two and the minimum tolerance is 0.68 indicating minimal inter-variable correlation, see appendix 6.25.

The objective was to find a model which could predict increased TV viewing in the intellectual disability population. Calculations were completed for original and imputed datasets but only the imputed results are detailed here. Adjusted odd ratios (AOR) control for all the predictor variables in a model. To explore the predictability of the full set of variables a Forced Entry Method is the default used in SPSS, where all predictor variables were input (Pallant, 2020).

- Imputed dataset

A total of fifteen variables had significant relationships with TV viewing and could be carried forward to the imputed full model: alcohol, fizzy drinks, wheelchair, part of the community, employment, education/training, day service attendance, difficulty getting around community, difficulty walking 100yards, epilepsy, self-rated health, up after 7am, smoker,

psychotropic medications and hearing excluding the standard covariates. Wheelchair use was covered in the walking 100yards variable while alcohol and fizzy drink consumption were deemed as consequences and not causes of TV watching so removed. The covariates of age, sex, living circumstances, intellectual disability level and aetiology were forced back into the model for an initial final model consisting of sixteen variables. Finally the education/training variable was removed to eliminate errors because only 3% of people answered yes to the binary question which could not be consolidated without errors. The Nagelkerke for the imputed model was 30.2%. Appendix 6.25 shows the significant results from the imputed multinomial regression. Appendix 6.26 shows the significant factors for decreased TV viewing. There were three significant risk factors for increased TV viewing from the imputed model. Those with a moderate intellectual disability were approximately 3-4 times more likely to watch less than one-hour and up to five-hours TV/day [AOR=4, p=0.008, 95%CI 1.4-11.4; AOR=2.5, p=0.043, 95%CI 1-6.3; AOR=2.9, p=0.030, 95%CI 1.1-7.6]. Participants who rose later than 7am were 4-times more likely to watch 3-5hours TV/day [AOR=4.1, p=0.011, 95%CI 1.4-11.8]. Finally those who had difficulty walking 100yards were 3-times more likely to watch over 5-hours TV/day [AOR=3.1, p=0.026, 95%CI 1.2-8.3].

The risk factors for increased TV viewing from the imputed model were the same as those from the original model i.e. having a moderate intellectual disability, getting up after 7am and difficulty walking 100yards.

○ Model fit

Stepwise regression was used to find the optimum model but results indicated the best model was used for both datasets. The AIC was used to compare the original and imputed models to determine the best combination of predictor variables for high levels of TV viewing in the intellectual disability population. Table 6.10 shows the final 14-variable original model and the imputed 16-variable model AIC results. Lower AIC values indicated a better model fit but more variables may impact AIC values.

Table 6. 10: Model fit for 14-variable original model & 16-variable imputed model & 5-category TV dependent variable

Model type	AIC value
14-variable original model	1378.1
16-variable imputed model	1713.8

6.3.5 Chi squared automatic interaction detector (CHAID)

A CHAID decision tree was used to investigate the predominant risk factors for increased TV viewing and the 16-variable imputed dataset. Appendix 6.28 shows the 14-variable original dataset CHAID. Figure 6.3 shows that CHAID decision tree for the 16-variable imputed dataset. Similar to the original data, the algorithm determined three terminal nodes for TV watching prevalence. The first node (Node 0) indicated that the average TV time/day was approximately 2.9-hours for all 609 participants ($p < 0.001$). The terminal nodes, 1 and 2, showed that intellectual disability was the only significant predictor for high TV time. Over 72% of participants with a mild/moderate intellectual disability watched on average 3.05 hours TV/day while almost 28% with a severe/profound intellectual disability watched on average 2.5-hours/day. Thus the CHAID analysis showed no difference in predicting risk factors for increased TV watching for the original and imputed datasets.

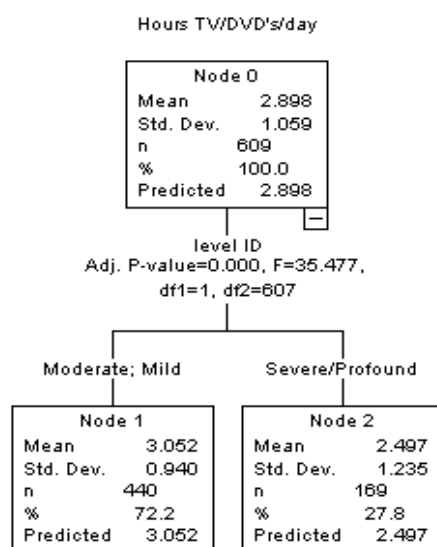


Figure 6. 3: CHAID for imputed dataset 16-variable model & 5-categories TV

6.4 Adapted SOS Model

The risk factors identified from the multinomial regression and CHAID analyses were summarised in an SOS model. Figure 6.4 shows the adapted SOS model with the significant correlates of increased TV viewing in the intellectual disability population, as identified by CHAID and multinomial logistic regression, with and without data imputation. The final model addressed two out of the proposed six clusters i.e. physical health and well-being and psychology and behaviour.

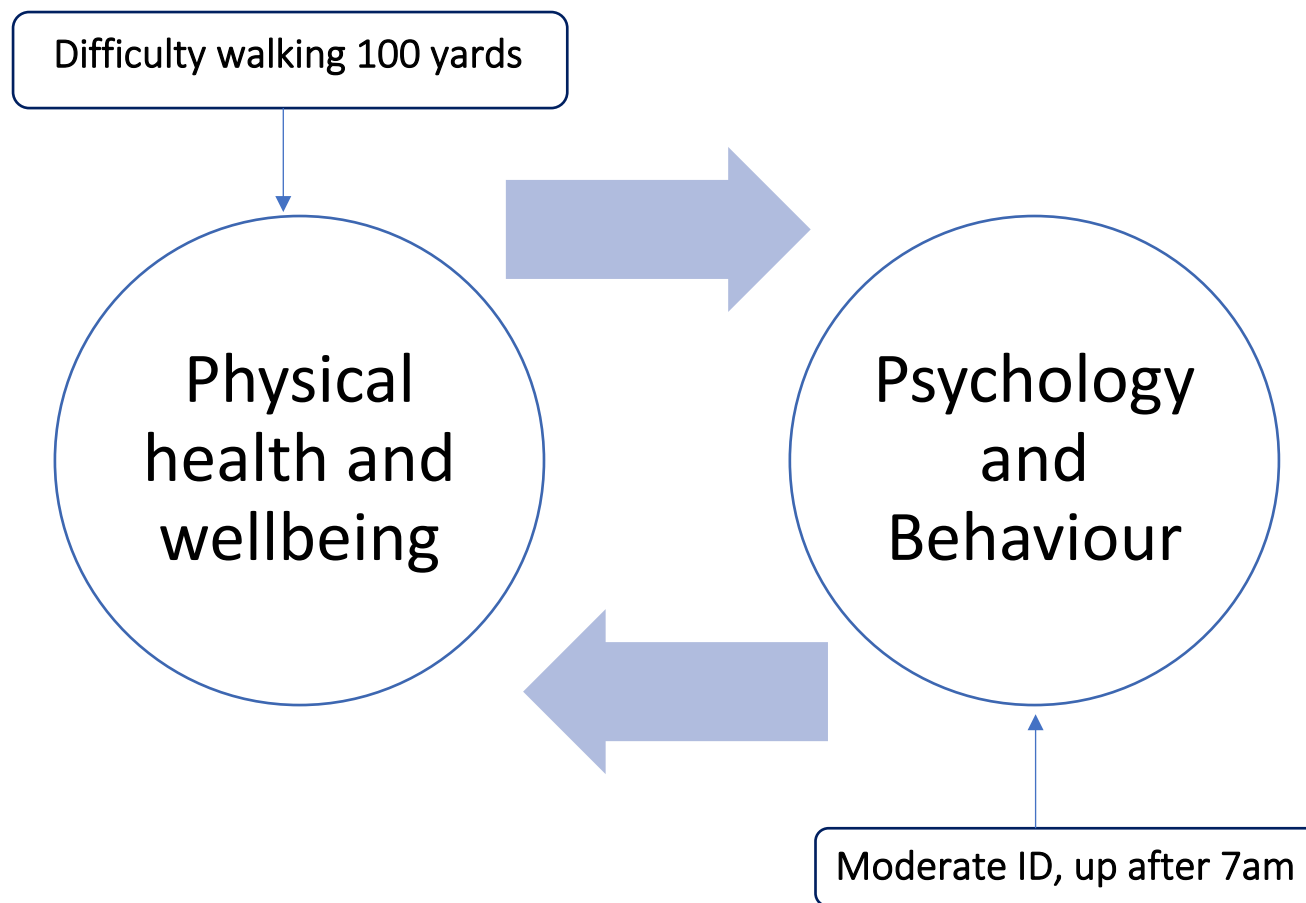


Figure 6. 4: SOS framework showing total final correlates of increased TV viewing for intellectual disability population

6.5 Discussion

The objective of this analysis was to determine significant risk factors that contributed to increased TV viewing among individuals with an intellectual disability, where TV was used as a surrogate for SB. In addition to the standard covariates, other potentially contributing factors were examined and framed using the Systems of Sedentary Behaviour (SOS) framework, which also supported the structuring of all the results. A total of thirty-one variables were investigated by the researcher as potential contributors to increased TV viewing and consequent SB. The literature showed inconsistent TV time categories were used for quantifying excessive TV watching, where classifications varied from greater than two- to greater than four-hours/day versus the five-categories used in this study. In the majority of variable categories investigated in this study, over 40% of participants watched between 1-3 hours of TV/day, although significant relationships were not always observed. Thus the researcher focussed on the five TV categories for more meaningful results.

This study's analysis of the TV data from Wave 1-3 showed results consistent with the existing intellectual disability literature. While sex was highlighted as a correlate in the literature, it did not present as a significant contributor to increased TV viewing in any wave in this study (Hsieh *et al*, 2017; Melville *et al*, 2018). No studies investigated aetiology and TV viewing but this study deemed it was not a significant contributor to TV time. Similarly age was not proposed as a correlate of TV viewing in the intellectual disability literature and no significance was found in this analysis, although general population studies found that older adults watched more TV (Herman and Saunders, 2016; Chang *et al*, 2018; Werneck *et al*, 2018). The literature purports that lower PA levels are related to higher TV time and this was confirmed by this study, where those who did no or minimal PA were more likely to watch more TV (Hsieh *et al*, 2017). Although obesity was a theme observed in most studies, this study only saw the wave 2 bivariate investigation indicate that those who were overweight/obese were more likely to watch more TV than those of normal BMI (Hsieh *et al*, 2014, 2017; Melville *et al*, 2018).

Intellectual disability level was deemed as a contributor to increased TV time in the literature and this relationship was confirmed in this study across all three waves, but significant relationships were only observed when five-categories of TV watching were interrogated (Hsieh *et al*, 2017; Melville *et al*, 2018). Those with a more severe/profound intellectual disability were less likely to watch TV than those with a mild/moderate level. People with a

more severe/profound intellectual disability were found to be less sedentary when TV was used as a proxy measure but this may be because those with a more severe impairment may watch less TV due to potential sensory, communication and cognition impairments (Oppewal *et al*, 2018). For individuals with an intellectual disability autonomy and choice may not fully exist, which reduced as they aged, and is possibly more the experience of those with a more severe/profound intellectual disability in group homes (Smith *et al*, 2005). The requirement for carers to guide their activities may be constant across the life course and the influence of these carers will be critical to reducing SB including TV watching (Buys *et al*, 2012). These carers need to be educated and facilitated to encourage the reduction of SB and integrate PA as a vital part of everyday life (Cartwright *et al*, 2017).

Living circumstance was highlighted as a significant correlate to TV viewing time in some literature (Hsieh *et al*, 2017). This was verified in this study where it was noted that higher TV levels were observed in those who reside independently/with family and the lowest levels of TV viewing in those living in residential care. This is possibly because people living independently may have more control over the TV than those in residential care, have more choice or simply are the only one watching so there are no disputes over what is on. However, it also may indicate a higher level of dependency of those in residential care. In fact this study found a moderate positive relationship between level of intellectual disability and living circumstance. Hence these residents were less likely to have control over the TV, or possibly those in residential care have greater health needs and were more likely to depend on others to support them in their activities. Whether it is TV watching or otherwise, it is noted in the literature that those in residential care were more likely to have more structured days than those living independently/with family which could explain less TV hours watched (Esteban *et al*, 2021). Furthermore, those living independently may have more difficulty integrating into the community and TV may provide a convenient entertainment option (McCausland *et al*, 2018). Significant relationships were seen when the five TV categories were analysed with over 50% of those living independently/with family watching 1-3-hours TV/day. In the final model living circumstance did not emerge as a predictor to increased TV viewing.

Drinking more fizzy drinks was associated with more TV time in the general population and similarly the data in this study concurred, with participants who reported watching more than five-hours TV/day, being ten times more likely to drink three fizzy drinks/day (Silva *et*

al, 2021). However it is unlikely that drinking more fizzy drinks caused one to watch more TV but rather that watching more TV may result in drinking more fizzy drinks, whether that is due to advertising or another factor, possibly a refreshment or treat whilst watching TV. Nevertheless, an association was observed and mindless snacking is a factor in modern society which may play a role in a sedentary lifestyle. In other words a combination of fizzy drinks and TV watching may pose a lethal combination for an individual's health and a factor that support staff need to be aware of. However, with consideration to fizzy drink consumption and perhaps an association with BMI, another factor that plays a role in SB, no relationship was identified with any fizzy drink category. Similarly while only 40% (n=247/600) of participants drank alcohol, alcohol consumption was seen as a significant correlate to watching more than five-hours TV a day which confirmed the general population literature and may reflect trends within the population of relaxing with a drink watching TV in the evening, a trend that increased many-fold during COVID lockdowns (Werneck *et al*, 2018; Alpers *et al*, 2021). Whilst these alcohol consumption figures were for the general population, no data is available for people with intellectual disability, but it is not unrealistic to say that they may have followed similar patterns. No relationship was observed between smoking and TV habits although the general population saw significant direct relationships (Uijtdewilligen *et al*, 2015; Werneck *et al*, 2018). Previously noted in the first wave of the IDS-TILDA study was the negligible smoking and drinking levels among the intellectual disability population (McCarron *et al*, 2011). Another factor noted in this study was that late risers watched more TV, which concurred with the intellectual disability literature (Mikulovic *et al* 2014). Perhaps this reflects people living more independently or unemployment or having more flexible schedules so do not need to get up early and have more free time to dedicate to watching TV. Furthermore watching TV at night was shown to affect sleep quality which may lead to disrupted sleep and sleeping in later (Xie *et al*, 2020).

In the general population those with lower levels of education watched more TV (Salmon *et al*, 2003; Clark *et al*, 2010; Van Dyck *et al*, 2010; Chang *et al*, 2018). However this study showed no significant relationship. Similarly attending any type of education or training was not significantly related to TV watching habits. Leaving home to go to work or service was not seen as a significant contributor to TV viewing in this study but those not attending day service and who were unemployed were less likely to watch excessive TV. Both the general population and intellectual disability literature found that unemployment and not attending

education were significantly related to high TV time (Touvier *et al*, 2010; Rhodes *et al*, 2012; Hsieh *et al*, 2017; Chang *et al*, 2018). This could be attributed to having more free time and lacking the resources, motivation or confidence to do other activities. Humans require purposeful activity for health and longevity and if this is not present more SB, as demonstrated by increased TV time, could ensue (Musich *et al*, 2018). However these results could also reflect the intellectual disability level of participants which was positively correlated with occupation in this study. Those with higher disability levels were significantly more likely to be unemployed.

Participants who had epilepsy were less likely to watch TV in this study which confirmed results seen in the literature (Hsieh *et al*, 2017; Melville *et al*, 2018). This could be due to sensitivity to fast-moving, flashing images. Taking psychotropic medication was seen as a contributor to less TV in the literature and this was confirmed in the bivariate analysis in this study (Hsieh *et al*, 2017). This could be explained by side-effects of psychotropic medications which may cause drowsiness.

Self-reported health is increasingly being viewed as a valid health-status indicator and potential mortality predictor (Miilunpalo *et al*, 1997). No intellectual disability studies were found which looked at self-perceived health status and TV habits but in the general population this was found to be inversely related to TV hours watched (Granner and Mburia-Mwalilli, 2010). Conversely, this study showed that those who rated themselves as having poor or fair self-rated health were less likely to watch TV compared to those with excellent self-rated health. The literature shows that self-rated health can be an indicator of morbidity and functional status of older adults in the general population, as well as an independent indicator of the body's inflammatory status (Ocampo, 2010; Christian *et al*, 2011). Thus those who had low self-rated health may have more health issues and higher levels of intellectual disabilities and a consequent inability to watch more TV.

While Ding and colleagues (2012) in their general population study found a marginal link between having a sense of community and reduced TV viewing, this study showed that those who felt less part of their community were less likely to watch TV. This could be due to the presence of mental health conditions like loneliness and depression. Mental health problems like loneliness are often present in those with an intellectual disability which are predictable from functional limitations and perceived societal negative perceptions (Wormald *et al*, 2019). In fact people with an intellectual disability were restricted

integrating into their community primarily due to requiring assistance and reduced physical and health abilities (McCausland *et al*, 2018). An enhanced sense of community and strong social support has a protective effect for mental health problems like loneliness (Prieto-Flores *et al*, 2011; Chung *et al*, 2022).

General population studies found that community settings like safety and walkability were significant contributors to TV viewing habits but to date this was not investigated in the intellectual disability literature (King *et al*, 2010; Kozo *et al*, 2012; O'Donoghue *et al*, 2016). This study showed that safety was not a significant contributor to TV viewing but those who had difficulty getting around the community were less likely to watch TV, the largest contributor of this difficulty coming from reduced independence and requiring assistance to travel.

People with mobility issues were deemed to watch more TV in an intellectual disability population (Melville *et al*, 2017). This study showed that those in a wheelchair were less likely to watch more TV, which was confirmed by those who had difficulty walking 100yards. This may be partially explained by the fact that wheelchair use and level of intellectual disability are positively correlated with each other. Those with a more severe/profound intellectual disability level were more likely to have mobility issues and as seen earlier, those who had a severe/profound intellectual disability watched less TV.

Both the CHAID and multinomial regression methods of analysis concurred that intellectual disability level, specifically moderate level, was a significant contributor to increased TV viewing. However the methods then diverged on other significant contributors to the dependent variable. The multinomial regression highlighted difficulty walking 100yards and rising later as a further significant risk factor. This difference between analyses was not entirely unexpected (Şata and Elkonca, 2020). Both techniques were used to determine the most significant predictors of an outcome. CHAID used chi-square to determine the optimal split at each step in the analysis but for each split the sample size reduced so other significant variables may be excluded from the model. The output was graphical and easy to interpret. Once multicollinearity was not present, multinomial logistic regression gave a tabular output with clear indications of the contribution of each variable by means of odds ratio. Overall the results between both methodologies concur which has previously been noted (Rudolfer *et al*, 1999; Shiran *et al*, 2021). Thus results from both models should be included in the final model for the risk factors of increased TV viewing.

The final SOS model which highlighted the significant risk factors for increased TV viewing in the intellectual disability population consisted of three variables: moderate intellectual disability level, rising after 7am and difficulty walking 100yards. This was the first time that difficulty walking 100yards was identified as a significant contributor to increased TV viewing and ergo SB. This model provided a simple guide for identifying those most at risk for increased TV viewing and consequently SB.

6.6 Conclusion

The analysis of TV habits from this study generally agrees with the limited literature available on the correlates of increased TV viewing time among those with intellectual disability. However, ultimately this study highlighted an insufficiency in the literature to understand the TV habits of those with an intellectual disability and therefore firmly use this measure as a surrogate for SB. Even so, the levels of TV watching were significant and may be an indicator of elevated SB in some elements of the intellectual disability population. However further investigation using other tools and OM is warranted. This study provided novel insights into new correlates of TV viewing for the intellectual disability population. One strength of the study was the adaptation of a new framework to structure the risk factors for TV viewing and ergo SB. Intellectual disability level, specifically those with a mild or moderate level, appeared to be the most significant independent contributor to TV viewing and consequent SB of older adults with an intellectual disability. TV viewing and the SOS model could provide the key determinants for reducing the sedentariness of this population. Being inclusive of all factors, specifically a difficulty walking 100yards and rising after 7am, the model can support the identification of the most significant contributors to SB that need to be considered. Future research should include environmental, institutional, economic and political information that will support individuals with intellectual disability, carers and staff gain knowledge and awareness of SB and its effects on people's lives.

6.7 Chapter 6 key learnings

The way a question is asked will have a bearing on the accuracy of answers and people may not realise how much TV they are actually watching, without relating it to specific programs or times. For future waves of IDS-TILDA field researchers will delve deeper into the TV question, asking more specific questions about movies, soaps or time periods spent watching TV so as to prevent an underestimation of TV time watched and consequent SB time. Objective measurements will facilitate the accurate measurement of SB.

Chapter 7

To measure the relationship between objectively measured sedentary behaviour and age, sex, level of intellectual disability, aetiology, living circumstances, comorbidities and functional capabilities.

Chapter summary

This chapter presents the findings of investigations into the objectively measured SB of older Irish adults with intellectual disabilities, as measured by the activPAL, and relationships with age, sex, level of intellectual disability, aetiology, living circumstance, functional and comorbidity status. In total eleven sedentary variables were examined. The total daily sedentary level was a sum of the sitting, secondary lying and seated transport activity. The functional capability was assessed using the standardised Barthel index (BI) as a continuous and categorical variable. Each participant's health status was evaluated using the Cumulative Illness Rating Scale for Geriatrics (CIRS-G) and individual health conditions. Descriptives, including BI and CIRS-G scores for the covariates were completed for the total study participants and compared to the activPAL participants. Results showed that more uninterrupted time in SB led to reduced functional capacity and an increase in comorbidities like upper GI conditions, while raised total sedentary time was associated with more endocrine conditions. More time in shorter bouts of SB saw increases in BI scores and a reduction in CIRS-G scores as well as a reduction in respiratory conditions. Increased sit-to-stand transitions was associated with better everyday functionality and increased energy expenditure.

7.1 Introduction

Sedentary behaviour is a 21st century phenomena and increases with each passing decade (López-Valenciano *et al*, 2020). In recent years SB has emerged as a significant risk factor for health but the exact amount that is detrimental is unknown as demonstrated by the 2020 World Health Organisation's advice to minimise the amount of time in SB and to replace this sedentary time with PA of any type or intensity to reduce its harmful health effects (Friedenreich *et al*, 2020; WHO, 2020). Sedentariness is a risk factor for mortality, independent of MVPA (Koster *et al*, 2012). However a meta-analysis which included over one million people found that the subjective measurement of SB was detrimental to all-cause mortality when people were sedentary for more than seven hours a day, which compared to OM where nine hours a day was the cut-off, but higher levels of MVPA may attenuate the risk (Ku *et al*, 2018). While longevity has increased globally, health status has remained constant meaning that people are living longer but not necessarily better lives (WHO, 2023). While there is a myriad of different contributors to ill-health which can culminate in older age, the reduction of SB and increase in PA are proven contributors to healthier living and mortality reduction (US Department of Health and Human Services, 2018). Research has shown that PA can attenuate the harmful effects of SB which exerts extra pressure and cost on an already fragile health system (Ekelund *et al*, 2019; Heron *et al*, 2019). In fact in 2016 alone, estimates show the UK cost of SB approximated to a minimum of £700 million, with potentially 69,000 lives lost, while Finish figures estimated the cost of elevated SB in 2017 as €1.5billion and France in 2016 in excess of €1billion (Heron *et al*, 2019; ; Kolu *et al*, 2022; Nguyen *et al*, 2022; Noël *et al*, 2022). Similarly Canadian 2021 figures showed CVD and type-2 diabetes were the most expensive chronic diseases and the overall cost of excessive SB was approximately €2billion (Chaput *et al*, 2023). It is critical to have an accurate understanding of SB through precise measurement before appropriate targeted interventions may be designed.

7.1.1 Sedentary behaviour measurement

Sedentary behaviour may be assessed by subjective or objective means. While self-reported measurements can provide contextual information and are a cost-effective way for population surveillance, they may unwittingly neglect vital information about sitting behaviours through omission or lack of follow-up questions, and social approval and desirability may bias answers (Adams *et al*, 2005). In addition inter-questionnaire reliability

and validity is not always high (Helmerhorst *et al*, 2012). Furthermore the classic under-reporting of SB levels from self-report measures means that confidence in deriving conclusions may be low (Shoemaker *et al*, 2021). The first review which investigated the measurement of SB in adults with intellectual disabilities found that while almost 50% of identified studies used some form of OM, research was required to understand the specific cut-offs for this population, and the accuracy of self-report and proxy questionnaires should be examined (Melville *et al*, 2017). The global activity guidelines for health which were developed by an expert panel in 2020, including for people with an intellectual disability, surmised that more research was required to understand the effects of activity types and levels on comorbid conditions and risks of noncommunicable diseases in this cohort (DiPietro *et al*, 2020). Close consideration should be given to the application and population before choosing the most appropriate tool to ensure scientific rigor. As seen earlier, aside from suitability and applicability for the intellectual disability population, the primary driver for choosing an OM tool for this study was the accurate measurement of SB, so that precise comparison may be made with its effect on physical health.

7.1.2 Health

Overall advances in medicine, healthcare and decreasing birth rates have resulted in increased life expectancy (WHO, 2015; 2023). Aging is associated with adverse health but research has shown that chronological age is not always the best reflection of an individual's health status and that bad health in older age is not a foregone conclusion (Lowsky *et al*, 2014). In fact healthy aging is a complex phenomenon with influences ranging from physical factors to resilience and quality of life (Salamene *et al*, 2021). While generally people are living longer, people with an intellectual disability are still dying 20 years earlier than their peers in the general population (O'Leary *et al*, 2018; Doyle *et al*, 2021). Certain fitness elements contribute more throughout the life course. The musculoskeletal system for example is critical for maintaining longer functional independence in older adults, while cardiovascular fitness has an inverse relationship with all-cause mortality (Hunt, 2003; Imboden *et al*, 2018). In the general population the primary cause of death is ischaemic heart disease while circulatory and respiratory diseases are the main causes of mortality in the intellectual disability population (Hosking *et al*, 2016; WHO, 2019). Multimorbidity is a contributor to increased risk of premature death (Nguyen *et al*, 2020). Overall those with intellectual disability experience poorer health, higher dependency and earlier mortality

than their peers in the general population. Sedentary behaviour could be a contributing factor. Therefore it is imperative to use objectively measured SB to accurately examine if it influences health or functional capabilities.

7.1.3 Establishing health status and functional independence utilising comorbidity indices and measures of dependence

To facilitate inter-study comparison and establish if there is a relationship between health status and SB, standardised measures of health like comorbidity indexes (CI) are necessary. They provide a single measure of an individual's health or dependence status, based on the survival outcome and not the treatment of diseases (Austin *et al*, 2015). A single score representing disease severity makes the process of stratifying people by illness category easier but these cumulative measures depend on the variables that make up the overall index so due care must be given to evaluating each individual illness or disease and categorising it correctly (Roffman *et al*, 2016). While the Charlson Comorbidity Index (CCI) is extensively used, the CIRS-G has also been used widely in the geriatric and intellectual disability population (Tekin *et al*, 2001; Boi *et al*, 2012; Villagrassa *et al*, 2018; Miot *et al*, 2021). The CIRS-G consists of 14-body systems which cumulatively can accurately represent the overall health of an individual.

Functional independence, which is an individual's ability to function autonomously and safely in their personal environment, is a complex arena encompassing an individual's physical and cognitive capacity as well as their health knowledge, typically characterised by the ability to perform activities of daily living (ADLs) predominately self-care and mobility (Molenaar *et al*, 2020). The Barthel Index (BI) uses an ordinal scale to quantify performance in ten specific ADLs as a measure of functional independence and is recommended as the standard measure of disability (Wade and Collin, 1988). It is used extensively in the intellectual disability and general populations so inter-study comparisons may be easily made (Hilgencamp *et al*, 2011; Schoufour *et al*, 2014; Burke *et al*, 2019; Chen *et al*, 2019; O'Connell *et al*, 2019; Hirose *et al*, 2022; Lin and Tseng, 2022).

7.2 Method

7.2.1 Data sources

Data for this study was obtained from the Computer Assisted Personal Interview (CAPI), Personal Interview Questionnaire (PIQ) and Health Fair, the objective health measure suite included in Wave 4, details of which were discussed in chapter 4. As part of the Health Fair an activPAL device was offered to participants to track activity and sedentary levels. The data from the activPAL was used to determine the SB of participants.

- activPAL outcome measure

The SB variables obtained from the activPAL measurements consisted of a total sedentary value which incorporated sitting and lying time and the PAL value, which was representative of a person's daily energy expenditure compared to their basal metabolic rate (Westterterp, 2013). In addition the number of bouts greater than 30 and 60 minutes and the time in the five different sedentary bouts measured by the activPAL was investigated as follows:

- Less than 30minutes
- More than 30minutes & less than 60minutes
- More than 60minutes & less than 120minutes
- More than 120minutes & less than 240minutes
- More than 240minutes

The health status of participants was obtained by calculating a 14-item comorbidity index, the CIRS-G using data from the CAPI and PIQ. Functional capabilities were assessed by the BI, which was calculated using variables from the PIQ.

7.2.2 Cumulative Illness Rating Scale - Geriatric

The CIRS-G comorbidity index was chosen to represent the comorbidities of this study participants because it has been successfully used extensively with both older adults and those with an intellectual disability. Appendix 4.7 shows the index. Each of the individual 14-variables, which represented a body system for the CIRS-G index were mapped onto the appropriate IDS-TILDA variables, see figure 7.1.

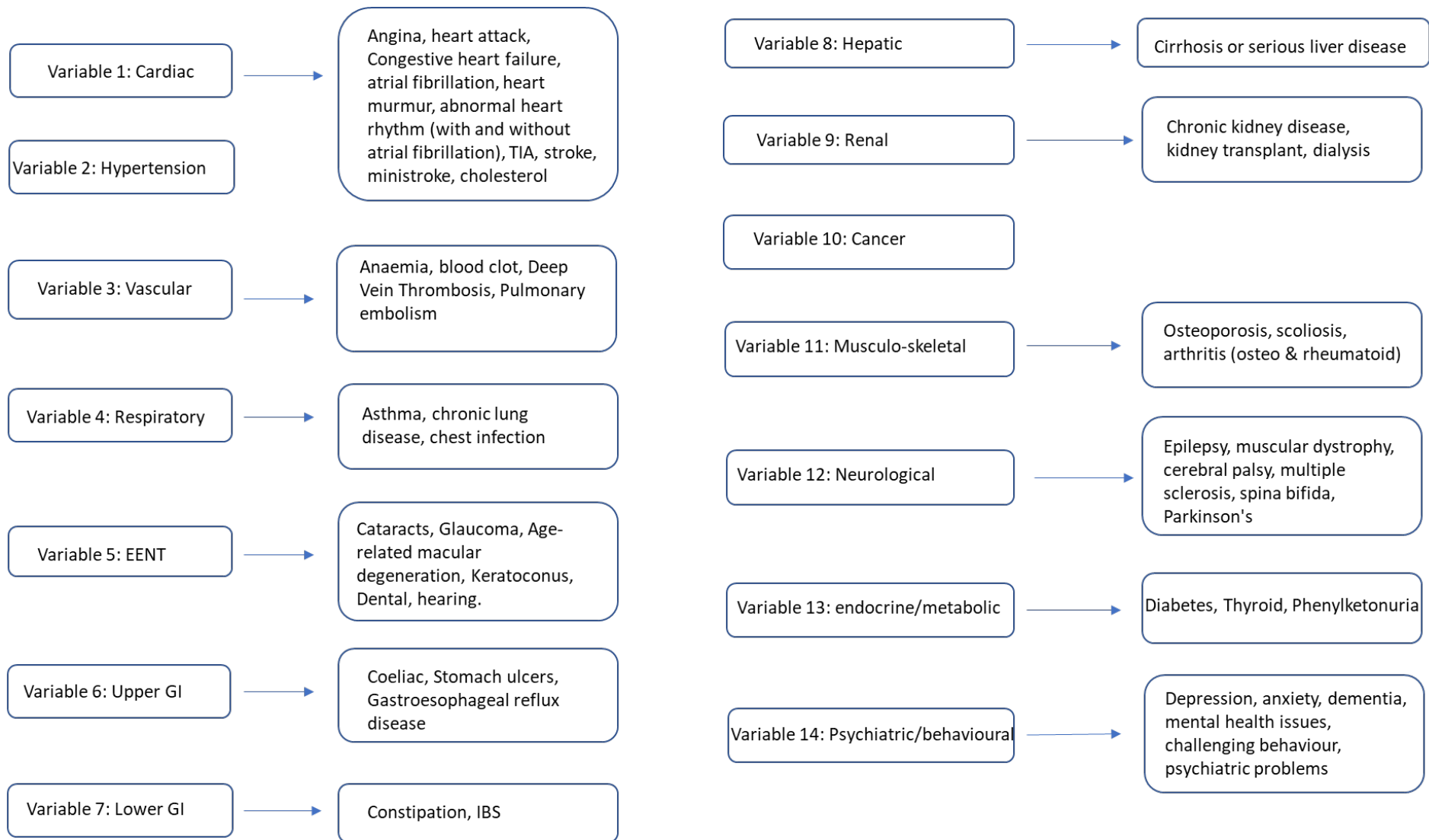


Figure 7. 1: Cumulative Illness Rating Scale 14-variables with equivalent IDS-TILDA variables

Each body system consisted of several different health conditions. These individual conditions were summed and an ordinal scale created using this summed index variable for each of the fourteen variables to reflect the level of severity of each condition. This scale was mapped to the CIRS-G severity scale 0-4, where four was extremely severe/life-threatening and 0 was none (no conditions). For example the Endocrine/metabolic variable consisted of diabetes, thyroid and phenylketonuria (PKU). All three conditions would be the maximum for this variable but not necessarily life-threatening unless uncontrolled. The total scale value was calculated by summing the value of each condition for a maximum score of 56 (14 conditions x4 (maximum score for each condition)). The other genitourinary variable (ureters, bladder, urethra, prostate, genitals) was excluded because of the unavailability of all variables and the lack of significance of these diseases in this group and replaced by a cancer variable (McMahon and Hatton, 2021). Lastly the ear, eye, nose and throat (EENT) condition included any dental issues. The individual body conditions and their respective CIRS-G categories based on the number of conditions present in each are presented in table 7.1. Lower CIRS-G scores indicate less comorbidities and better health.

The severity index score, CIRS-SI, was also calculated. This CIRS-SI score represents the disease burden, the total number of conditions that have a score greater than two, i.e., are at the two highest severity levels for each of the individual body conditions. Total severity score values of less than or equal to two are classified as low severity and values greater than two are classified as high severity.

Table 7. 1: CIRS-G scale mapped onto IDS-TILDA variables & number of health conditions associated with each level. Categories with the same scale are merged in some cases.

CIRS-G body system category	Equivalent IDS-TILDA variable	CIRS-G scale	No. of conditions
Cardiac	Heart attack [myocardial infraction],	0	0
	atrial fibrillation, angina, congestive	1	1 to 2
	heart failure, heart murmur,	2	3 to 4
	abnormal heart rhythm (with &	3	5 to 6
	without atrial fibrillation), TIA, stroke, mini stroke & cholesterol	4	7
Hypertension	Self-reported high blood pressure	0	0
		2	1
Vascular	Anaemia, blood clot, Deep Vein	0	0
	Thrombosis, Pulmonary	1	1
	Embolism	3	3
Respiratory,	Asthma, chronic lung disease, Chest infection.	0	0
		1	1
		2	2
		3	3
EENT	Cataracts, glaucoma, age-related	0	0
	Macular degeneration, keratoconus,	1	1 to 2
	Dental, hearing	3	3 to 4
Upper GI	Coeliac, stomach ulcers,	0	0
Lower GI	Gastroesophageal reflux disease.	1	1
	Constipation, IBS	2	2
Hepatic	Cirrhosis or serious liver disease.	0	0
Cancer	Cancer of any type	3	1
Musculo-skeletal	Osteoporosis, Scoliosis, arthritis (osteo & rheumatoid)	0	0
		1	1
		2	2
		3	3
Neurological	Epilepsy, muscular dystrophy, Cerebral palsy, multiple sclerosis, Spina bifida, Parkinson's	0	0
		1	1
		2	2
		3	3
Renal	Chronic kidney disease, Kidney transplant, dialysis	0	0
		1	1
		3	2
Endocrine/metabolic	Diabetes, Thyroid, Phenylketonuria	0	0
		1	1
		2	2
Psychiatric/behavioural	Depression, anxiety, dementia, Mental health issues, Challenging behaviour, Psychiatric problems	0	0
		1	1
		2	2 to 3
		3	4

7.2.3 Barthel Index

The overall BI scores were categorised based on the total results which were self- or proxy-reported or a combination of both, see table 7.2. The original BI was augmented to better reflect the study population (O’Connell *et al*, 2019). Appendix 4.8 shows the modified BI, where lower scores represented poorer physical function capacity.

Table 7. 2: Barthel Index category of functional status based on scores

Score	Category
0 to 4	Total dependence
5 to 12	Severe dependence
13-18	Moderate dependence
19	Mild dependence
20	Total independence

7.2.4 Statistical analysis

Statistical analysis was completed as described in chapter 4. Table 7.3 shows the dependent variables normality test results.

Table 7. 3: Dependent variable Kolmogorov-Smirnov tests results

Variable	Test results	Distribution type
Time sitting	P(72)=0.05, p=0.2	Normal
Primary lying	P(72)=0.084, p=0.2	Normal
Total sedentary time	P(72)=0.091, p=0.2	Normal
Bouts >30minutes	P(72)=0.130, p=0.004	Nonparametric
Bouts >60minutes	P(72)=0.231, p<0.001	Nonparametric
PAL	P(72)=0.076, p=0.2	Normal
Barthel score for total study participants	P(739)=0.133, p<0.001	Nonparametric
Barthel score for 72 activPAL participants	P(72)=0.151, p=0.001	Nonparametric
CIRS score for all participants	P(739)=0.113, p<0.001	Nonparametric
CIRS score for activPAL participants	P(72)=0.169, p<0.001	Nonparametric

In addition the Kolmogorov-Smirnov tests for normality showed that bouts less than 30-minutes and up to 60-minutes were normally distributed (p=0.2) while the longer bouts were not (p<0.05) so required nonparametric statistical tests. Bivariate explorations were completed with all the activPAL sedentary variables, the Barthel and CIRS-G indices and the

standard covariates to determine if a significant relationship was present that needed detailed analysis. These bivariate investigations between the independent variables, including covariates, and dependent variables were explored using ANOVA for normally distributed continuous dependent variables and Kruskal-Wallis for the nonparametric continuous variables. Chi-square was used to investigate categorical variables. Any variables with p-values up to 0.2 were investigated further by either linear regression for continuous dependent variables or multinomial logistic regressions for categorical variables with more than two categories, to understand the type and strength of relationships. If categories had insufficient data they were consolidated or transformed to binary variables to avoid errors, and regressions executed. The number of bout categories were consolidated into three categories to eliminate errors. Multinomial logistic regressions were executed with the number of bouts at greater than 30 and 60 minutes and the standard covariates. The Barthel categories were consolidated into two categories (moderate to total dependence and mild dependence to total independence) to eliminate errors from the regression analysis when the PAL variable was investigated and all variables were divided by ten to give a more meaningful result, due to the tight range of the PAL variable.

The use of Pearson's correlation coefficient for only parametric data has been questioned so it was used for all data, Spearman's rho for nonparametric and Interclass Correlation coefficients for normally distributed data to examine any relationships between the Barthel and CIRS-G indexes and the sedentary variables of total sedentary time, sitting time, primary lying time and PAL (Bollen and Barb, 1981). The strength and direction of relationships were evaluated.

- Multicollinearity

Multicollinearity was investigated with all models and variables using Tolerance and VIF. No inter-variable interaction was observed except when the individual health variables were investigated. Multicollinearity was found between the cirrhosis and renal variables. See appendix 7.1. Excluding the renal instead of the cirrhosis variable resulted in a marginally better model fit ($R^2_{adj}=0.141$ versus 0.139).

7.2.5 Missing values

As before missing data were investigated to ensure the statistical validity of results would not be impacted. Up to 5% missingness would not affect the statistical power of results

(Bennett, 2001; Tabachnick and Fidell, 2014). A missing value analysis was completed on the dependent comorbidity and functional indexes. The maximum missingness observed was 4.2% (n=3). Hence data imputation was not necessary, see appendix 7.2.

7.3 Results

7.3.1 Demographic study profile

Table 7.4 presents the demographic profile of the study participants by the total (N=739) and the activPAL subgroup participants (n=72). Overall there were more women than men within this current study (53.6%, n=395/739 versus 46.5%, n=344/739 respectively) and similarly more women participated in the activPAL at 66.7% (n=48/72). The mean age of participants was 58.5 (SD± 10.1) years versus the mean age of those who engaged with the activPAL was 60.6 (SD±9.6) years. In total ten people with Down syndrome (13.9%, n=10/72) engaged with the activPAL compared to a total of 145 people (21.9%, n=145/739) in the total sample. The majority of people were within the obese category (69%) both within the overall sample (n=399/739) and those who engaged with the activPAL (n=49/72). For both groups most people had a moderate level of intellectual disability (42.5%, n=293/729 and 50%, n=34/72) and lived in CGH (49%, n=358/739 and 47.9% n=34/72).

Table 7. 4: Overall demographic profile of participants and those who engaged with ActivPAL.

	Overall study		ActivPAL	
	N	%	N	%
Total participants (N)	739		72	
Sex				
Male	344	46.5	24	33.3
Female	395	53.5	48	66.7
Down Syndrome	145	21.9	10	13.9
Level of ID				
Level ID not verified	13	1.9	2	2.9
Mild	204	29.6	25	36.8
Moderate	293	42.5	34	50
Severe or Profound	192	27.9	7	10.3
Age				
Age (<50)	135	18.3	9	12.5
Age(50-64)	407	55.1	40	55.6
Age(65+)	197	26.7	23	31.9
Age yrs(min)	37	n/a	41	n/a
Age yrs(Max)	89	n/a	87	n/a
Age yrs(Mean)	58.51(SD±10.13)	n/a	60.57(SD±9.6)	n/a
Living circumstances				
Independent/Family	126	17.3	11	15.5
CGH	358	49	34	47.9
Residential Care	246	33.7	26	36.6
BMI				
BMI: Underweight	11	1.8	0	0
BMI: Normal	199	32.7	22	31
BMI: Overweight/Obese	399	69.5	49	69

Missing obs: Living circumstances n=9, level ID n=37, BMI n=130.

activPAL missing: Living circumstances & BMI n=1, level ID n=4.

- Examination of activPAL calculated sedentary time

The total sedentary time as calculated by the activPAL is classed as the sum of the time sitting, secondary lying and seated transport. Participants spent an average of 8.14 (SD±2.83) hours/day sitting and an average of 9.63 (SD±2.4) hours asleep. The total mean daily sedentary time was 9.79 (SD±2.85) hours. Secondary lying time was on average less than 0.5 (SD±0.71) hour/day while the average seated transport time was 1.2 (SD±1.6) hours/day. Table 7.5 shows the activPAL sitting, lying and total sedentary time.

Table 7. 5: activPAL measured daily sedentary behaviour summary (sitting, sec. lying & transport) (n=72)

		Sedentary behaviour in minutes (mins)					Sedentary behaviour in hours (h)				
		Min. (mins)	Max. (mins)	Mean (mins)	Std. (m)	Dev.	Min. (h)	Max. (h)	Mean (h)	Std. (h)	Dev.
Total	Sedentary Time	213.95	922.86	587.27	171.26		3.57	15.38	9.79	2.85	
	Sitting Time	62.98	909.54	488.21	170.10		1.05	15.16	8.14	2.83	
	Seated Transport Time	0.00	625.55	73.28	92.89		0.00	10.43	1.22	1.55	
	Secondary Lying Time	0.00	197.49	25.77	42.76		0.00	3.29	0.43	0.71	
	Primary Lying Time	275.67	1058.49	577.89	144.18		4.59	17.64	9.63	2.40	

Seated transport and secondary lying were non-normally distributed so non-parametric tests were required. Figure 7.2 shows a histogram of the total sedentary time.

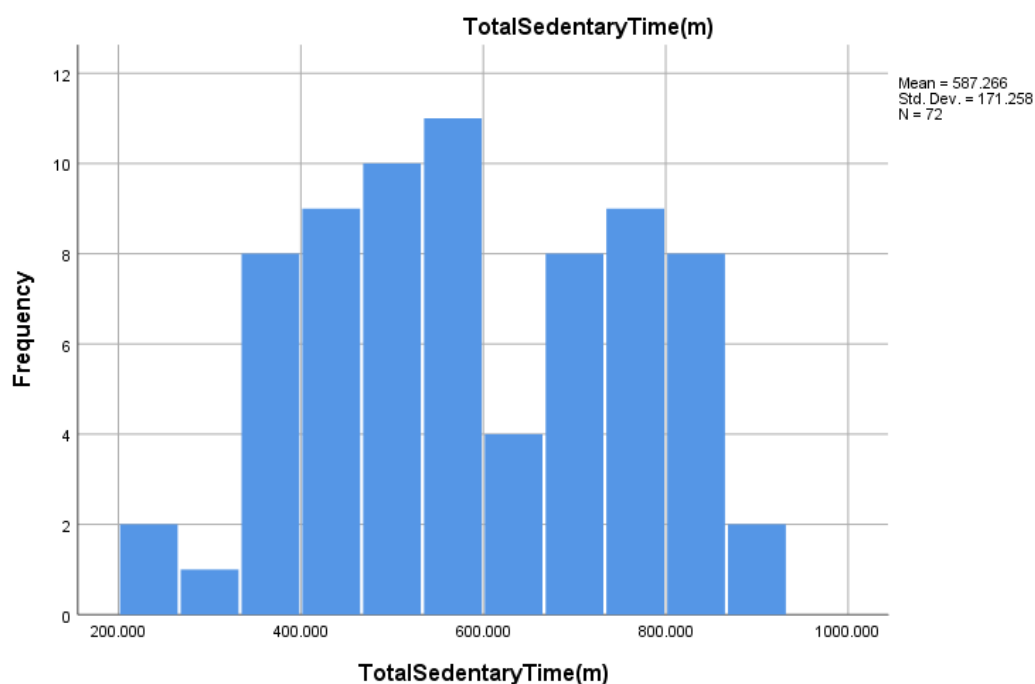


Figure 7. 2: Total sedentary time (sitting, secondary lying & transport) for activPAL

The individual SB was examined by level of intellectual disability. Those with a severe/profound intellectual disability had the highest level of mean total sedentariness of 708 minutes/day ($SD \pm 147$ minutes) which consisted of 528 minutes ($SD \pm 214$ minutes) sitting time and slept the longest at 646 minutes/night ($SD \pm 153$ minutes). Those with a moderate intellectual disability spent more time in bed at night than those with a mild level (582,

SD $\pm$ 165 versus 550, SD $\pm$ 118 minutes respectively). However those with a moderate intellectual disability spent less time sitting (469, SD $\pm$ 178 versus 482, SD $\pm$ 130minutes) and the most time lying down during the day (31, SD $\pm$ 54minutes compared to 20, SD $\pm$ 21minutes) compared to those with a mild and severe intellectual disability. Those with a severe/profound intellectual disability spent over 2.5 times more time in seated transport compared to those with a mild level (160, SD $\pm$ 223minutes versus 60, SD $\pm$ 61). See full description in figure 7.3 below.

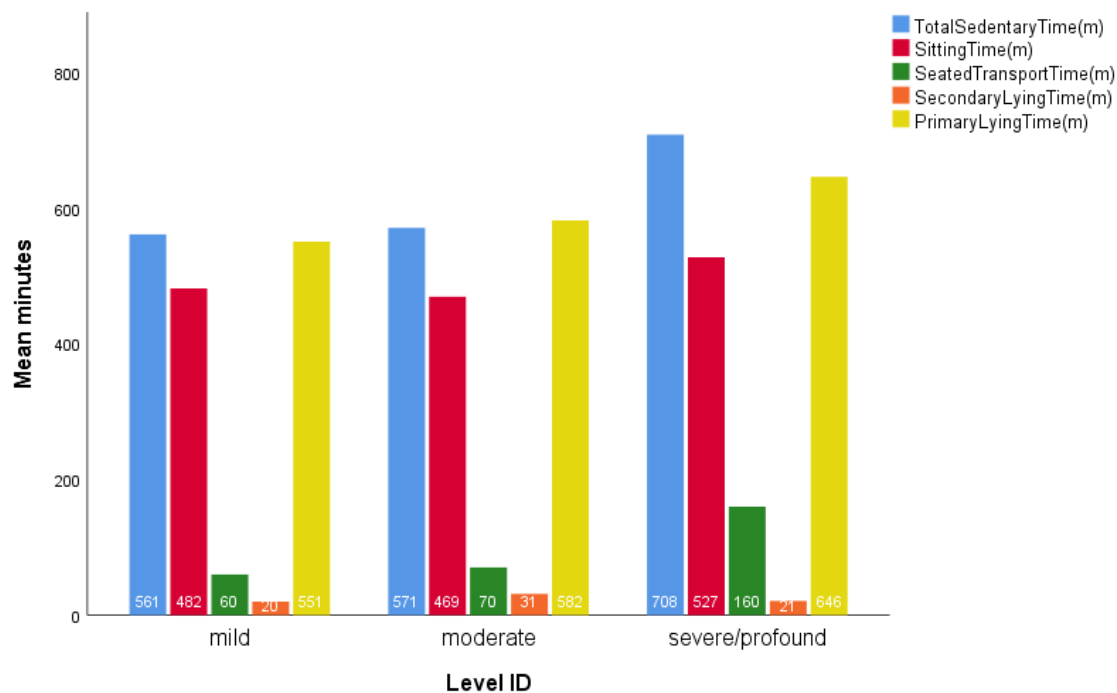


Figure 7. 3: Mean activPAL sedentary behaviour time & type by level of intellectual disability

Women with a moderate and severe/profound intellectual disability spent approximately 4% and 20% more time in total daily SB (576 versus 552minutes and 829 versus 660minutes) than their male counterparts but this reversed for a mild intellectual disability where men spent 11% more time sedentary (606 versus 540minutes). Figure 7.4 presents sedentary time by minutes stratified by level of intellectual disability.

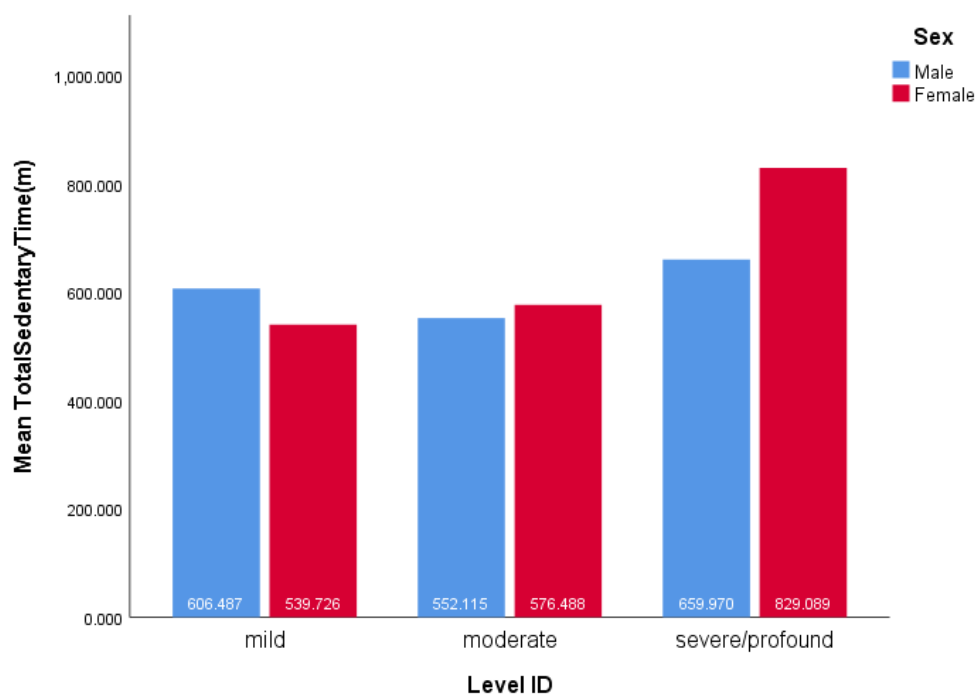


Figure 7. 4: Mean activPAL sedentary time by level of ID and sex

Examining activPAL measurements stratified by living circumstances, it can be seen in figure 7.5 that those who lived in residential settings (605, $SD \pm 201$ minutes) were more sedentary than those who lived in CGH (587, $SD \pm 158$ minutes) or independently/with family (549, $SD \pm 153$ minutes).

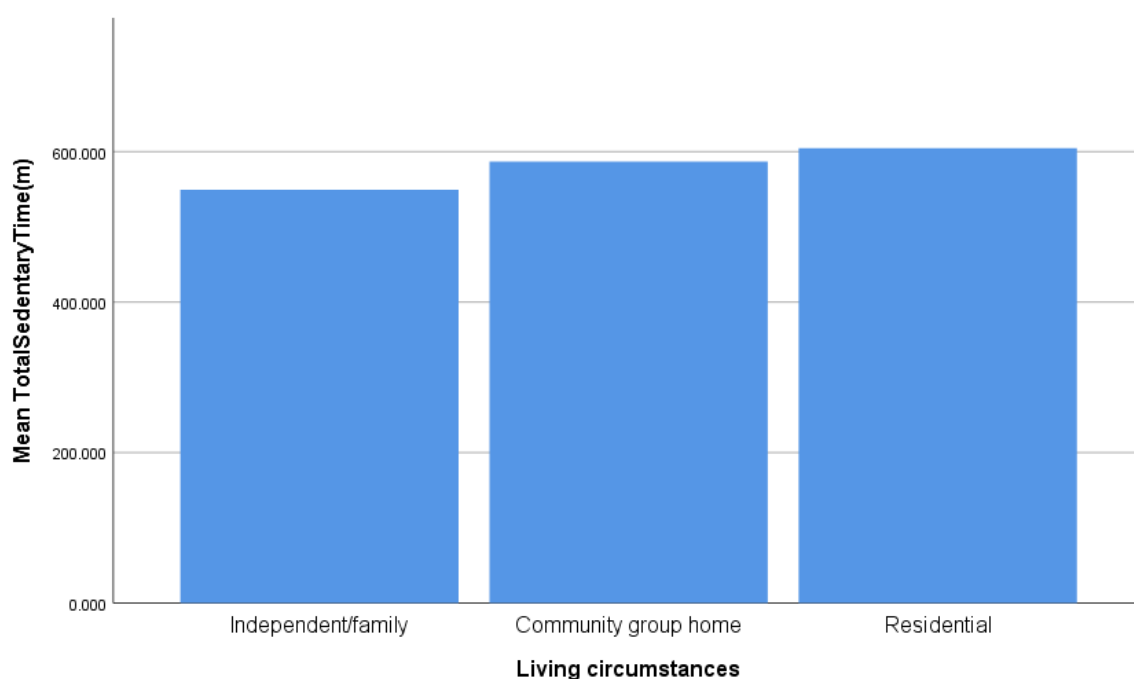


Figure 7. 5: Mean activPAL sedentary time in minutes by living circumstance

- Examination of the different time periods spent sedentary

Sedentary bouts refer to uninterrupted time periods spent in SB and are measured in minutes. The activPAL output shows sedentary bouts in five different lengths of time as shown in table 7.6, which shows the total mean time spent in the respective sedentary bouts for participants. The maximum amount of time observed, 486 minutes (SD±92), was spent in bouts of less than 30 minutes. The mean time in each bout decreased as the bout time increased, with the least time spent in bouts greater than four hours.

Table 7. 6: Overview of total Sedentary bout descriptions for all activPAL participants (N=72)

Sedentary bout category time	Sedentary bouts measured in minutes			
	Minimum	Maximum	Mean	Std. Deviation
< 30 minutes	29.0	486.1	236.0	92.0
> 30 mins < 60 minutes	0.0*	325.0	136.8	72.3
> 60 minutes < 120 minutes	0.0*	321.5	120.6	88.7
> 120minutes < 240minutes	0.0*	321.4	76.1	75.7
> 240 minutes	0.0*	220.9	17.8	47.1

*If average is <1 it is rounded down to 0

- Number of sedentary bouts greater than 30 and 60 minutes

The number of sedentary bouts greater than 30 and 60 minutes are summarised in table 7.7. Over 40% (n=29/72) of the participants had no bouts greater than 60-minutes. The maximum number of bouts greater than 60-minutes observed was five and only one person did this.

Table 7. 7: Number of participants and their number of sedentary bouts >30 and >60minutes

No. of bouts	Bouts >30-mins		Bouts >60-mins	
	n	%	n	%
0	5	6.9	29	40.3
1	7	9.7	17	23.6
2	11	15.3	14	19.4
3	12	16.7	9	12.5
4	10	13.9	2	2.8
5	5	6.9	1	1.4
6	12	16.7	-	-
7	6	8.3	-	-
8	2	2.8	-	-
9	2	2.8	-	-

- Examination of sedentary bouts stratified by covariates

Sedentary bouts were then examined stratified by the covariates of age, sex, level of intellectual disability, aetiology, living circumstance and BMI, see table 7.8. Those who were younger than 65-years spent more time in bouts of less than 30-minutes (264 versus 205 minutes) while those older than 65 spent more time in the longer bouts of 30-60 minutes (169 versus 158) and 120-240 minutes (232 versus 189). Both men and women presented with comparable results, the biggest difference being that men spent more time in bouts of greater than 240-minutes (417 versus 355minutes). The level of intellectual disability sedentary bout profile was similar except that those with a more severe intellectual disability spent more time in longer bouts, 497-minutes in greater than 240-minute bouts compared to 362-minutes of those with a mild level. Aetiologies other than DS spent more time in all sedentary bouts except for the greater than 240-minute (360 versus 476minutes). The living circumstances showed that those in residential settings had more time in the longer bouts, especially greater than 240-minutes (399 versus 349minutes for those living more independently). Those who were overweight/obese also spent more time in bouts greater than 60-minutes (184 versus 170-minutes) and 120-240-minutes (220 versus 170-minutes) than those who had a normal BMI.

Table 7. 8: Mean time in activPAL sedentary bouts stratified by the six covariates

	Mean bout time (minutes)				
	<30	30-60	60-120	120-240	>240
Total participants (N)					
Sex					
Male	246(SD $\pm$ 99)	164(SD $\pm$ 81)	188(SD $\pm$ 103)	182(SD $\pm$ 106)	417(SD $\pm$ 140)
Female	244(SD $\pm$ 95)	160(SD $\pm$ 76)	176(SD $\pm$ 86)	214(SD $\pm$ 115)	355 (SD $\pm$ 162)
Down Syndrome	230(SD $\pm$ 120)	128(SD $\pm$ 59)	113(SD $\pm$ 87)	140(SD $\pm$ 80)	476 (SD $\pm$ 118)
Other aetiology	248(SD $\pm$ 92)	167(SD $\pm$ 79)	191(SD $\pm$ 88)	213(SD $\pm$ 114)	360 (SD $\pm$ 157)
Level of ID					
Mild	250(SD $\pm$ 84)	150(SD $\pm$ 66)	181(SD $\pm$ 93)	168(SD $\pm$ 88)	362 (SD $\pm$ 183)
Moderate	251(SD $\pm$ 95)	163(SD $\pm$ 76)	168(SD $\pm$ 82)	215(SD $\pm$ 115)	365 (SD $\pm$ 115)
Severe or Profound	227(SD $\pm$ 147)	175(SD $\pm$ 98)	226(SD $\pm$ 130)	230(SD $\pm$ 137)	497 (SD $\pm$ 158)
Age					
Age (<65)	264(SD $\pm$ 83)	158(SD $\pm$ 72)	184(SD $\pm$ 94)	189(SD $\pm$ 112)	377 (SD $\pm$ 148)
Age(65+)	205(SD $\pm$ 110)	169(SD $\pm$ 88)	176(SD $\pm$ 87)	232(SD $\pm$ 110)	374 (SD $\pm$ 178)
Living circumstance					
Independent/Family	231(SD $\pm$ 69)	118(SD $\pm$ 35)	166(SD $\pm$ 49)	228(SD $\pm$ 130)	349 (SD $\pm$ 119)
CGH	266(SD $\pm$ 70)	182(SD $\pm$ 80)	165(SD $\pm$ 85)	185(SD $\pm$ 90)	366 (SD $\pm$ 152)
Residential Care	220(SD $\pm$ 126)	153(SD $\pm$ 79)	207(SD $\pm$ 110)	222(SD $\pm$ 128)	399 (SD $\pm$ 181)
BMI					
Normal/Under.	265(SD $\pm$ 101)	176(SD $\pm$ 79)	170(SD $\pm$ 82)	170(SD $\pm$ 105)	378 (SD $\pm$ 137)
Overweight/Obese	235(SD $\pm$ 93)	155(SD $\pm$ 77)	184(SD $\pm$ 96)	220(SD $\pm$ 113)	377(SD $\pm$ 167)

Missing obs: Living circumstance (9), level ID (37), BMI (130).

activPAL missing: Living circumstance & BMI(1), level ID (4).

- Metabolic equivalent and Physical Activity Level

As seen previously, the MET values measured by the activPAL were all of low intensity, with the equivalent PAL indicating that all participants were in the sedentary to light activity range, mean 1.35, range 0.32. (Note PAL=MET/24).

- activPAL graphical output

The activPAL software facilitates a graphical representation of an individual's activity levels in a spiral or linear form. Figure 9.6 to 9.8 illustrate three spiral images of ranges of activity levels. As described in table 8.10, the red indicates stepping activity, the green standing, yellow sitting and blue lying down (sleeping time). Figure 7.6 shows a participant who performed an average of over 12,000 steps/day and 42 sit-to-stand transitions. Figure 7.7 shows a participant who took a mean of over 7,000 steps per day and 75 sit-to-stands. Figure

7.8 shows a participant who was in a wheelchair and had less than 100 steps per day and 10 sit-to-stands. Visually the differences between participants and their respective activities are evident. The increased standing time (green) of participant 2 compared to that of participant 1 or 3 is easily observed. Similarly participant 3 spent much more time in the primary lying position, no time stepping and most of their waking time in a sitting position compared to the other participants.

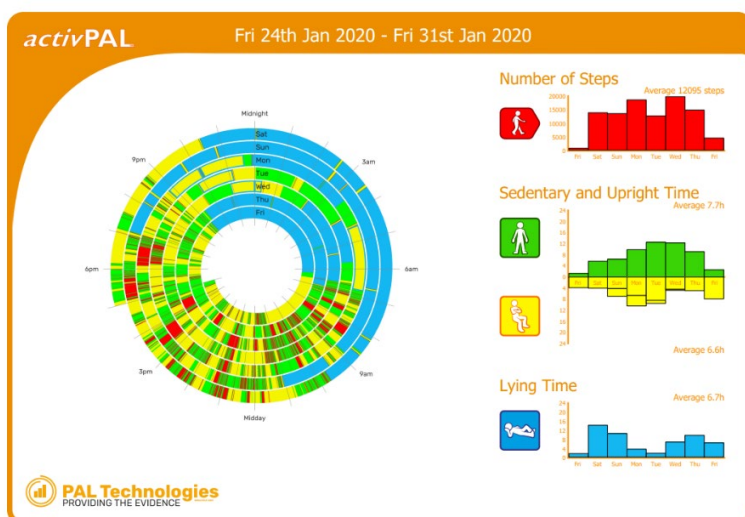


Figure 7. 6: activPAL spiral of participant with mean >12,000 steps/day

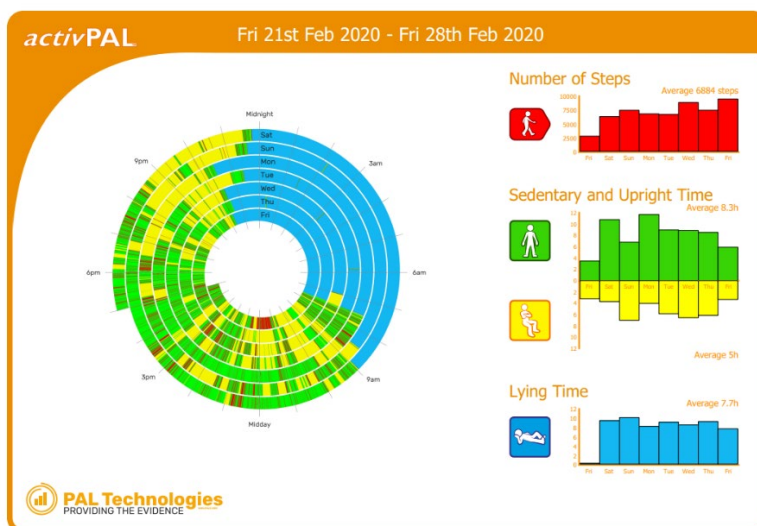


Figure 7. 7: activPAL spiral of participant with mean >7,000 steps/day

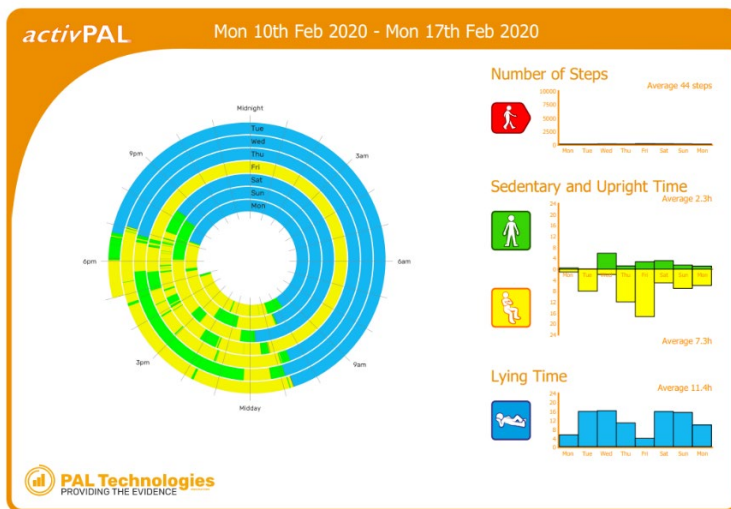


Figure 7. 8: activPAL spiral of participant who in a wheelchair

Figure 7.9 to 7.11 show the linear representation of the same activPAL output for the same participants. Figure 7.9 shows the participant who took a mean of over 12,000 steps per day. As seen in the spiral graph, this person did a lot of stepping as evidenced by the red colour and minimal sitting (yellow). Figure 7.10 shows the participant who took more than 7,000 steps per day, where again a significant amount of red is present on the graph while the wheelchair participant in figure 7.11 had minimal stepping and standing and spent the predominant amount of days sitting (yellow) or lying (blue).

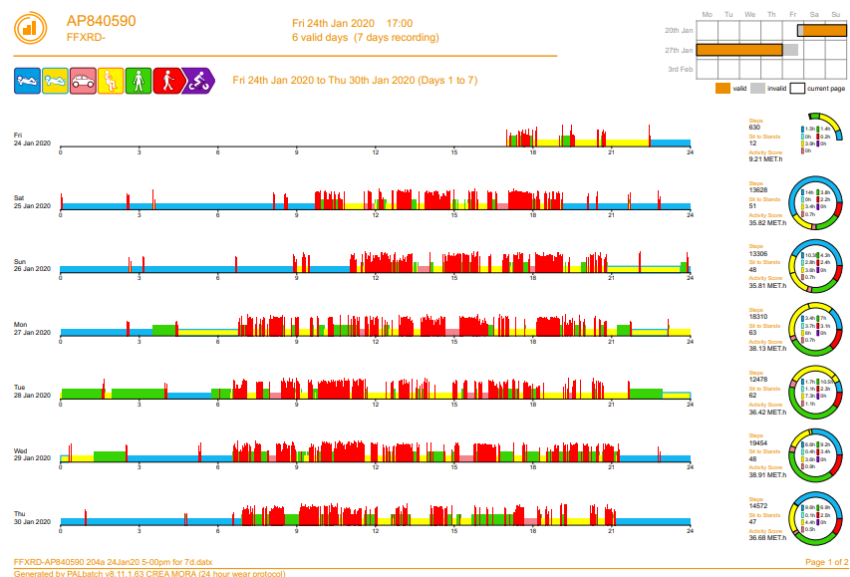


Figure 7. 9: activPAL linear graph of participant who had mean >12,000 steps per day

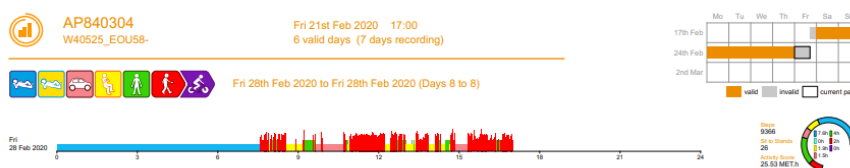
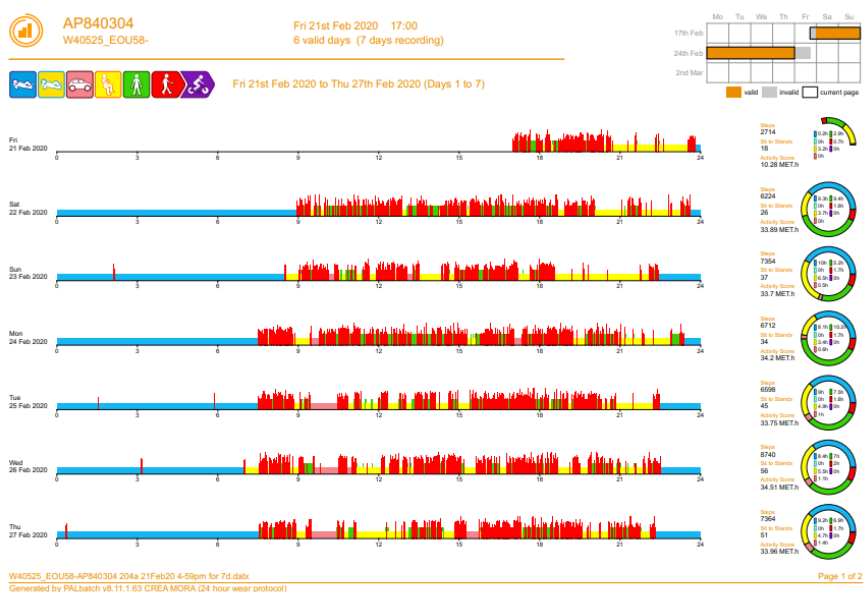


Figure 7. 10: activPAL linear graph of participant who had mean >7,000 steps per day



Figure 7. 11: activPAL linear graph of participant who was in a wheelchair

- Examination of participant functional capacity using the Barthel index

The BI results for the total sample (N=739) were compared to the 72 activPAL participants and presented in table 7.9. A higher score is indicative of more functional independence. When the BI scores were organised by category of dependence, over 14% of both groups were classified as totally independent. Almost 9% (n=59/739) of the total study group had total dependence compared to 1.4% (n=1/72) in the activPAL group. Over 75% of participants in both groups had at least a moderate dependence level.

Table 7. 9: Comparison between Barthel scores for the total sample (N=739) versus activPAL sample (n=72) according to dependence level

Dependence category*	BI Score	Overall participant values per category		Overall activPAL participant values per category	
		n	%	n	%
Total dependence	0 to 4	59	8.7	1	1.4
Severe dependence	5 to 12	191	28	15	21.7
Moderate dependence	13 to 18	263	38.6	36	52.2
Mild dependence	19	70	10.3	7	10.1
Total independence	20	98	14.4	10	14.5

*Missing obs. n=58 and 3 respectively, not all participants answered all questions to compile BI

Table 7.10 shows the activPAL participant's BI mean category and scores by covariates. The mean Barthel score for functional independence for the total 739 study participants was 13.63 (SD±5.5), compared to the 72 activPAL participants who had a mean score of 15.28 (SD±4.1). The mean Barthel category for the total participants was 2.94 (SD±1.14) compared to 3.14 (SD±0.97) for the activPAL participants. A negative gradient was observed by intellectual disability level where those with a mild level had higher independence as measured by the BI score (3.5 versus 2.6) and category level (16.8 versus 12.3) compared to those with a more severe level. Similarly those who lived more independently had more functional independence having a BI category of 4, versus 2.5 of those who were in residential care.

Table 7. 10: Barthel Index score & category descriptives for activPAL participants (N=72)

	Barthel Index mean		n	%
	Category	Score		
Total participants (N=739)	2.94 (SD±1.14)	13.63 (SD±5.5)		
activPAL participants (N=72)	3.14 (SD±0.97)	15.28 (SD±4.1)		
Sex				
Male	3	15.46	24	33.2
Female	3.22	15.18	45	66.8
Down Syndrome	3.7	17.6	10	16.7
Other aetiologies	3.05	14.88	59	83.3
Level of ID				
Mild	3.5	16.77	26	43.5
Moderate	2.91	14.55	33	47.9
Severe or Profound	2.57	12.29	7	8.6
Age				
Age (<65)	3.35	16.2	46	71
Age(65+)	2.74	13.43	23	29
Living circumstance				
Independent/Family	4	18.27	11	19.4
CGH	2.24	16.28	32	50.3
Residential Care	2.52	12.56	25	30.3
BMI				
Underweight/normal	2.89	14.74	19	25.6
Overweight/Obese	3.27	15.55	49	74.4

- Examination of participant health conditions using Cumulative Illness Rating Scale index

Prior to calculating the CIRS-G scale scores, the number of individual health conditions that each participant had was investigated. Table 7.11 presents the number of chronic health conditions identified among those participants who engaged with the activPAL. As can be seen, 1.4% (n=1/72) reported 11 doctor's diagnosed conditions, with only one person, 1.4%, reporting none. In total 31 people (43.1%) had 5 or more conditions with over 98% (n=71/72) of participants having at least one chronic health condition.

Table 7. 11: Number of health conditions that participants exhibited

No of chronic health conditions	No. of participants (N=72)	
	n	%
0	1	1.4
1	4	5.6
2	16	22.2
3	12	16.7
4	8	11.1
5	7	9.7
6	9	12.5
7	3	4.2
8	5	6.9
9	4	5.6
10	2	2.8
11	1	1.4

The CIRS-G comorbidity conditions for the activPAL sample are shown in table 7.12. The most common comorbidities for the activPAL participants were psychiatric/behavioural (78.6%, n=55/72), cardiac (48.6%,n=35/72) and endocrine/metabolic (41.7%, n=30/72) .

Table 7. 12: Comorbidity conditions according to the CIRS-G categorisation showing activPAL participants

Comorbid condition	activPAL participants	
	n	w/condition %
Psychiatric/behavioural	55	78.6
Cardiac	35	48.6
Endocrine/metabolic	30	41.7
EENT	24	33.3
Musculo-skeletal	23	31.9
Hypertension	22	30.6
Lower GI	22	30.6
Neurological	21	29.2
Respiratory	14	19.5
Upper GI	11	15.3
Vascular	3	4.2
Renal	2	2.8
Cancer	1	1.4
Hepatic	1	1.4

Next the total CIRS-G scores for the 72 activPAL participants were calculated as described in section 7.2.2. Table 7.13 illustrates the activPAL participant's CIRS-G determined scores and

the number of participants at each score (N=72). Over 54% (n=39/72) had 1-4 specific body-system problematic health conditions, 31% (n=23/72) had 5-8 and over 12% (n=9/72) had 9-12 negative health conditions associated with specific body systems. Only one participant had no health conditions similarly identified from overall doctor's reported chronic health conditions.

Table 7. 13: CIRS-G scores for activPAL participants and the number at each score level

CIRS-G Score	No. of participants scored	
	n	%
0	1	1.4
1	5	6.9
2	10	13.9
3	15	20.8
4	9	12.5
5	6	8.3
6	5	6.9
7	6	8.3
8	6	8.3
9	2	2.8
10	3	4.2
11	3	4.2
12	1	1.4

The mean CIRS-G scores were then calculated for the activPAL participants. The mean CIRS-G score for the activPAL sample (N=72) was 4.85 (SD± 2.9, range 0-12). These were stratified by demographics, as seen in table 7.14. Males had lower CIRS-G scores than females (4.1 versus 5.2). Those with a moderate intellectual disability had the largest burden of conditions as demonstrated by a higher CIRS-G score (5.3) compared to those with mild (4.4) and severe/profound levels (4.7). A graded differential was observed with CIRS-G scores and living circumstance, which decreased as residence became more independent (4.35 for those living independently/with family versus 6.35 for those in residential settings). Participants with DS had lower CIRS-G scores than those with other aetiologies (4.3 versus 4.94) and people who were overweight/obese had lower scores than those with a normal BMI (4.5 versus 5.4).

Table 7. 14: CIRS-G score stratified by activPAL participant demographics (N=72)

Demographics	CIRS-G Scale		
	score	n	%
Sex			
Male	4.13	24	28.4
Female	5.21	48	71.6
Aetiology			
Down Syndrome	4.30	10	12.3
Other aetiologies	4.94	62	87.7
Level of ID			
Mild	4.44	27	36.1
Moderate	5.26	34	53.9
Severe or Profound	4.71	7	9.90
Age			
<65 years	4.14	49	58.2
65+ years	6.35	23	41.8
Living circumstance			
Independent/Family	3.45	11	10.9
CGH	4.26	34	41.7
Residential Care	6.35	26	47.4
BMI			
Underweight/normal	5.36	22	34.5
Overweight/Obese	4.57	49	65.5

○ CIRS-G Severity score (CIRS-SI)

The CIRS-SI was calculated for each activPAL participant. Over 61% (n=44/72) of the participants were classified as having a high severity comorbidity burden, i.e. had a score of ≥ 2 . The mean severity score was 2.4 (SD $\pm$ 2.1), see table 7.15.

Table 7. 15: CIRS-SI severity score for activPAL participants

Severity level	activPAL participants	
	n	%
Low severity	28	38.9
High severity	44	61.1

7.3.2 Bivariate associations using activPAL sedentary variables and standard covariates

- Sedentary variables

Bivariate relationships were explored between the activPAL sitting, primary lying, total sedentary time and PAL measurements and the covariates of age, sex, level of intellectual disability, aetiology, BMI and living circumstance using ANOVA, see appendix 7.3. The only statistically significant relationship observed was with aetiology and total sedentary time where $p=0.032$, but the level of intellectual disability was borderline significant with PAL ($p=0.059$).

- Sedentary bouts

Bivariate associations were explored with the standard covariates, the five different sedentary bouts and the number of bouts over 30 and 60-minutes. ANOVA was used for investigations on the normally distributed shorter bouts, Kruskal-Wallis for the nonparametric bouts greater than 60-minutes and Pearson chi-squared for the number of bouts classified by category. Statistically significant results were seen for age and the time spent in bouts less than 30-minutes, aetiology and bouts between 60 and 120-minutes and living circumstance and the number of bouts greater than 30-minutes, implying that there is an association that warrants further investigation, see appendix 7.4 for full results.

7.3.3 Bivariate associations using activPAL sedentary variables and Barthel index

The BI as a continuous score and categorically broken down into two and five categories was used as dependent variables to investigate the relationship with the four activPAL SB variables of sitting, primary lying, PAL and total sedentary time. The five-category variable ranged from total dependence to total independence and the two-category variable was divided between moderate to total dependence and mild dependence to total independence to ensure categories were evenly distributed for analysis. Kruskal-Wallis was used to investigate the correlations between the non-parametric BI variables and the sedentary variables. For full results see table 7.16. Significant relationships are highlighted in bold. The total time in SB and the PAL were significantly related to both the BI continuous and categorical variables. In addition the sitting time was significantly related to the overall BI score and borderline significant for the BI 5-category variable ($p=0.055$).

Table 7. 16: Bivariate correlations using Kruskal-Wallis p-values for Barthel index & sedentary variables

	Sitting time (mins) p-value	Primary (mins) p-value	Lying (mins) p-value	Tot sedentary time (mins) p-value	PAL p-value
Barthel index (score)*	0.021	0.235		0.019	0.024
Barthel index (5 category)*	0.055	0.119		0.018	0.001
Barthel index (2 category)*	0.303	0.242		0.070	<0.001

*Kruskal-Wallis

- Bivariate correlations for Barthel index and sit-to-stand transitions, sedentary bout length and number of sedentary bouts

Table 7.17 shows the bivariate correlations explored using Pearson, Spearman's rho and the Interclass correlation coefficients (ICC) with the BI score and the number of sit-to-stand transitions. Significant low-level correlations were observed with Pearson and Spearman's rho ($p < 0.05$). No correlation was seen with the ICC. Bivariate correlations for the BI score, sedentary bout length and the number of sedentary bouts greater than 30 and 60 minutes were completed using Spearman's rho and Pearson correlation coefficient to determine the type and strength of relationships of the nonparametric data. All bout lengths had significant relationships with the BI score except for the 30 to 60-minute bouts. Moderate correlations (greater than 0.4) were observed for the less than 30-minute and 120–240-minute bouts while weak negative correlations were seen for the 60-120-minute and greater than 240-minute bouts, meaning these may not be significant contributors to people's functional capacity. The number of bouts greater than 30 minutes showed a weak negative correlation with the BI while the bouts greater than 60-minutes showed a moderate negative correlation, all indicating that they may impact BI scores and consequent functional status i.e. as the number of bouts increased the BI score and consequent functional capacity decreased.

Table 7. 17: Bivariate correlations of Barthel index with sit-to-stands, sedentary bout length and number of sedentary bouts

Correlation coefficient	No of Sit-to-stands	No of bouts						
		<30m	>30m & <60m	>60m < 120m	>120m & <240m	>240m	>30mins	>60mins
Pearson coefficient	0.279	0.44	-0.015	-0.332	-0.438	-0.306	-0.225	-0.41
Pearson p-value	0.02	<0.001	0.912	0.005	<0.001	0.011	<i>0.063</i>	<0.001
Spearman coefficient	0.311	n/a*	n/a*	-0.38	-0.414	-0.243	-0.242	-0.396
Spearman p-value	0.009	n/a*	n/a*	0.001	<0.001	0.044	0.045	0.001
ICC coefficient	0.146	0.074	-0.004	n/a**	n/a**	n/a**	n/a**	n/a**
ICC p-value	0.258	0.376	0.506	n/a**	n/a**	n/a**	n/a**	n/a**

*Normally distributed, **nonparametric

7.3.4 Bivariate associations with the Cumulative Illness Rating Score & severity & covariates

Both age ($p=0.005$) and living circumstance ($p=0.003$) emerged as significant contributors to the CIRS-G score in the bivariate explorations, see appendix 7.5.

Spearman's rho, Pearson and the ICC were used to assess correlations between the sedentary variables and the CIRS-G index scores. No significant relationships were observed with any of the sedentary variables and either CIRS-G or CIRS-SI but the Pearson p-value for PAL was borderline significant at 0.063, see table 7.18.

Table 7. 18: Spearman's rho, Pearson & ICC correlations for CIRS-G score & sedentary variables

Coefficient	Sitting time (mins)	Primary (mins)	Lying	Tot sedentary time (mins)	PAL
Pearson coefficient	0.064	-0.002		0.067	-0.22
Pearson p-value	0.592	0.985		0.578	0.063
Spearman's rho	0.037	-0.003		0.055	-0.194
Spearman's rho p-value	0.76	0.981		0.646	0.102
ICC coefficient	0.004	0		0.005	-0.02
ICC p-value	0.493	0.5		0.492	0.534

Bivariate correlations for the CIGS-G index score and sedentary bouts were completed using Spearman's rho and Pearson correlation coefficient to determine the type and strength of relationships. Weak but significant relationships were seen for bouts less than 30-minutes and 120-240-minute bouts, as well as the number of bouts greater than 60-minutes long. As the time in 30-minute bouts increased, the CIGS-G score decreased while a positive relationship was seen with the time in 120-240-minute bouts and the number of bouts greater than 60-minutes, see table 7.19.

Table 7. 19: Bivariate correlations for CIRS-G & length & number of sedentary bouts

	<30m	>30m & <60m	>60m < 120m	>120m &<240m	>240m	No of bouts	
						>30mins	>60mins
Pearson coefficient	-0.279	-0.076	0.161	0.308	0.106	0.184	0.296
Pearson p-value	0.018	0.527	0.176	0.008	0.375	<i>0.121</i>	0.012
Spearman coefficient	n/a*	n/a*	0.147	0.269	0.082	0.2	0.28
Spearman p-value	n/a*	n/a*	0.217	0.023	0.494	0.092	0.017

*=normally distributed

7.3.5 Regression analysis of activPAL sedentary variables and covariates

- Total sedentary time and covariate regression

A linear regression model with the activPAL total sedentary time as calculated by the CREA algorithm showed that aetiology was a significant contributor for increased sedentary time. Specifically those who had aetiologies other than DS were more likely to be 39-minutes/day more sedentary [B=39.6, p=0.023, 95%CI 5.7-73.6]. The stepwise regression model which only had the aetiology variable remaining showed similar results [B=39.97, p=0.015, 95%CI 8.2-71.8]. However, the confidence intervals were very wide indicating high levels of variability, see table 7.20 and 7.21.

Table 7. 20: Linear regression full model for activPAL total sedentary time and covariates

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% CI for B	
	B	Std. Error	Beta			Lower	Upper
(Constant)	484.094	196.093		2.469	0.016	91.712	876.475
Age	2.343	47.651	0.006	0.049	0.961	-93.006	97.691
Sex	-13.453	48.797	-0.036	-0.276	0.784	-111.095	84.189
Level ID	-3.137	47.503	-0.009	-0.066	0.948	-98.191	91.918
Aetiology	39.627	16.952	0.297	2.338	0.023	5.706	73.548
BMI	-3.257	12.335	-0.034	-0.264	0.793	-27.939	21.426
Living circumstance	-23.588	34.539	-0.094	-0.683	0.497	-92.700	45.524

Table 7. 21: Stepwise linear regression reduced model for activPAL total sedentary time and covariates

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% CI for B	
	B	Std. Error	Beta			Lower	Upper
(Constant)	406.378	74.850		5.429	0.000	256.848	555.907
Aetiology	39.972	15.925	0.299	2.510	0.015	8.158	71.786

R²_{adj}=0.075

- Sedentary bouts and covariate regression

Linear regressions were executed with all covariates and each of the sedentary bout times. Age had the only significant relationship with bouts of less than 30-minutes in the linear regression full model and was the only variable that remained in the stepwise regression. Table 7.22 shows that as the age category changed from over 65 to less than 65-years the time in sedentary bouts of less than 30-minutes increased by 61-minutes, meaning that the

younger age group spent more time in shorter sedentary bouts [$B=60.5$, $p=0.010$, 95%CI 14.7-106]. Only 8% of the variance in the bout time could be explained by the age variable, as indicated by the adjusted r-squared.

Table 7. 22: Linear stepwise regression for sedentary bout <30minutes & standard covariates

	Unstandardized Coefficients		Standardized Coefficients Beta	t	Sig.	95.0% CI for B	
	B	Std. Error				Lower	Upper
(Constant)	135.041	39.365		3.431	0.001	56.401	213.681
Age	60.451	22.901	0.313	2.640	0.010	14.700	106.201

$R^2_{adj}=0.084$

Similarly the stepwise model for bouts greater than 60 minutes and less than 120 minutes showed aetiology as the only significant variable. Table 7.23 shows those with other aetiologies spent 20-minutes more in 60-to-120-minute bouts compared to those with DS [$B=20.1$, $p=0.017$, 95%CI 3.7-36.5] but only 7% of the variance is explained by the model.

Table 7. 23: Linear stepwise regression for sedentary bout >60m & <120m & standard covariates

	Unstandardized Coefficients		Standardized Coefficients Beta	t	Sig.	95.0% CI for B	
	B	Std. Error				Lower	Upper
(Constant)	31.985	38.601		0.829	0.410	-45.129	109.098
Aetiology	20.053	8.213	0.292	2.442	0.017	3.646	36.460

$R^2_{adj}=0.071$

- Physical Activity Level and covariate regression

Table 7.24 shows how living circumstance emerged as a significant contributor to PAL from the stepwise regression reduced model. As the living circumstance became more independent, the PAL increased by an unstandardised Beta of 0.024 [$B=0.024$, $p=0.048$, 95%CI 0-0.048] but less than 5% of the PAL variance could be explained by the model ($R^2_{adj}=0.045$).

Table 7. 24: Linear stepwise regression reduced model for PAL & standard covariates

	Unstandardized Coefficients		Standardized Coefficients Beta	t	Sig.	95.0% CI for B	
	B	Std. Error				Lower	Upper
(Constant)	1.309	0.023		56.852	0.000	1.263	1.355
Living circumstance	0.024	0.012	0.245	2.019	0.048	0.000	0.048

$R^2_{adj}=0.045$

- Regressions with Barthel Index Score and sedentary variables

Table 7.25 summarises the significant linear regression results for the Barthel index with each of the activPAL sedentary variables. A linear regression for PAL with the continuous Barthel score showed a positive significant relationship ($p<0.001$) with $R^2_{adj}=0.25$ showing the PAL values accounted for almost 25% of variance in the Barthel dependent variable meaning that participants functional independence level could be partially explained by activity level. The results were divided by 10 because a full one-unit change in the PAL index is too large to make meaningful sense. Therefore for every 0.1 unit change in the PAL meant the Barthel score would increase by three [$B=3.1$, $p<0.001$, 95%CI 1.8-4.3].

A linear regression with the number of sit-to-stand transitions showed that a significant positive relationship existed, where every one-unit increase in the number of sit-to-stand transitions would result in a BI increase of 0.04 [$B=0.04$, $p=0.02$, 95%CI 0.006-0.074], implying that participants who performed more transitions were more functionally independent. However an adjusted R^2 of 6.4% means that over 93% of the variation in the model is not explained by the number of sit-to-stand transitions performed so they may not be the most accurate way to determine functional independence level.

Linear regressions were performed with the sedentary bouts and the BI continuous score. For every one-minute increase in time spent in bouts less than 30 minutes, a 0.02 increase in the BI score resulted [$B=0.019$, $p<0.001$, 95%CI 0.01-0.029]. Over 18% of the variance in the BI could be explained by the time spent in bouts <30minutes ($R^2_{adj}=0.182$). For every one-minute increase in bouts of 60-120-minutes, 120-240-minutes and greater than 240-minutes, a decrease of 0.02 [$B=0.015$, $p=0.005$, 95%CI -0.026 - -0.005], 0.02 [$B=0.023$, $p<0.001$, 95%CI -0.035- -0.012] and 0.03 [$B=0.026$, $p=0.011$, 95%CI -0.045- -0.006] was seen in the BI scores. However only the 120-240-minute bout time explained the variance in the BI to a good degree with an $R^2_{adj}=0.18$ compared to less than 10% for the other bout times.

Similarly the linear regression with the number of sedentary bouts greater than 60 minutes showed that for every one unit increase in the number of bouts, there was a corresponding decrease in the BI score of 2.3 [B=-2.308, $p<0.001$, 95%CI -3.6- -1.1] and almost 16% of variance could be explained by the number of bouts greater than 60-minutes.

Table 7. 25: Linear regression for the Barthel Index score & PAL, sit-to-stands, sedentary bout length and no. of bouts

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95%CI
	B	Std. Error	Beta			
PAL mean	30.479	6.323	0.507	4.820	0.000	17.86 - 43.1
Number Sit To Stands	0.040	0.017	0.279	2.374	0.020	0.006 – 0.074
Bouts < 30m	0.019	0.005	0.440	4.015	0.000	0.010 – 0.029
Bouts >60m & <120m	-0.015	0.005	-0.332	-2.876	0.005	-0.026 - -0.005
Bouts > 120m & < 240m	-0.023	0.006	-0.438	-3.989	0.000	-0.035 - -0.012
Bouts >240m	-0.026	0.010	-0.306	-2.630	0.011	-0.045 - -0.006
Number bouts >60m *	-2.308	0.627	-0.410	-3.680	0.000	-3.560 - -1.056

*=3 categories

- Regression for Barthel Index category, sedentary variables and covariates

A multinomial regression model with the Barthel 5-category variable showed that increased time in SB was significantly related to the level of functional independence, see table 7.26. Compared to those who were totally independent, those with a mild, moderate or severe dependence level were 1.006 to 1.008-times more likely to spend more time in SB [OR=1.006, p=0.02, 95%CI 1.001-1.015; OR=1.008, p=0.023, 95%CI 1.001-1.012; OR=1.008, p=0.008, 95%CI 1.002-1.014]. The variance in the Barthel dependent variable explained by the SB variable was 16.3% (Nagelkerke). The sitting variable showed equitable results with a Nagelkerke of 10.8%.

Table 7. 26: Multinomial regression for Barthel Index category and time in sedentary behaviour

modified BI category for wave 4		Sig.	OR	95% CI Exp(B) Lower Upper	
Total dependence	Intercept	0.636			
	TotalSedentaryTime(m)	0.872	0.999	0.983	1.015
Severe dependence	Intercept	0.016			
	TotalSedentaryTime(m)	0.008	1.008	1.002	1.014
Moderate dependence	Intercept	0.151			
	TotalSedentaryTime(m)	0.023	1.006	1.001	1.012
Mild dependence	Intercept	0.017			
	TotalSedentaryTime(m)	0.020	1.008	1.001	1.015

- Cumulative Illness Rating Score

Table 7.27 shows the significant linear regression results for sedentary bout time and number and the Barthel index with the CIRS-G scores. Significant relationships for bouts of less than 30-minutes and between 120-240-minutes were seen, where the time in shorter bouts was associated with less comorbidities and the time in the longer bouts was associated with more comorbidities, as measured by the CIRS-G. For every minute increase in bouts of less than 30-minutes, the CIRS-G score decreased by 0.01 [$B=0.009$, $p=0.018$, 95%CI -0.016 - -0.002] and over 18% of the variance in the CIRS-G scores could be explained by the time spent in bouts <30minutes ($R^2_{adj}=0.182$). Conversely for every minute increase in sedentary bouts of 120-240-minutes, the CIRS-G score increased by 0.012 [$B=0.012$, $p=0.008$, 95%CI 0.003-0.021].

The number of sedentary bouts were also investigated. A significant relationship was observed for the number of bouts greater than 60-minutes where, as the number of bouts increased, the CIRS-G score increased by 1.2 [$B=1.2$, $p<0.02$, 95%CI 0.28-2.1].

A significant relationship ($p<0.001$) was seen with the CIRS-G score and the BI score, where over 22% of the model variance could be explained by the BI score ($R^2_{adj}=0.222$). Table 7.27 shows for every one unit increase on the BI score, there was a corresponding 0.348 decrease in the CIRS-G scale meaning that participants who had more functional independence had less comorbidities.

Table 7. 27: Significant linear regression results for sedentary bouts & no of bouts & CIRS-G score

	Unstandardized Coefficients		Standardized Coefficients		t	Sig.	95.0% CI for B	
	B	Std. Error	Beta				Lower	Upper
Bouts < 30m	-0.009	0.004	-0.279		-2.432	0.018	-0.016	-0.002
Bouts > 120m & < 240m	0.012	0.004	0.308		2.711	0.008	0.003	0.021
No bouts >60m(3 cats)	1.201	0.463	0.296		2.591	0.012	0.276	2.125
BI score	-0.348	0.077	-0.482		-4.504	<0.001	-0.503	-0.194

- Regression of individual health variables and sedentary variables

Linear regressions were performed using the 14 individual health variables as independent variables and sedentary time and PAL as the dependent variables, to investigate if SB had an effect on individual health conditions. No significant associations were observed. Both models were then adjusted for the standard covariates. The 19-variable linear regression showed the endocrine variable had a significant relationship with sedentary time, where an increase in endocrine conditions was associated with a 105-minute increase in sedentary time [B=105, p=0.038, 95%CI 6.3-204]. Aetiology was the only remaining variable in the stepwise regression model, with other aetiologies being 39 minutes more sedentary than those with DS [B=39, p=0.019, 95%CI 6.7-71], as seen earlier.

The PAL linear regression full model showed the cardiac, upper GI and level of intellectual disability variables had significant relationships. Level of intellectual disability and cardiac remained in the reduced model after the stepwise regression was run. An increase in cardiac condition category corresponded to a decrease in PAL of 0.03, meaning those with more cardiac conditions were less active, while an improvement in intellectual disability category resulted in an increase in PAL of 0.04, see table 7.28.

Table 7. 28: Linear Stepwise regression for 13 individual health variables (excluding Renal), covariates & PAL mean

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% CI for B	
	B	Std. Error	Beta			Lower	Upper
(Constant)	1.288	0.041		31.25	0	1.205	1.37
Cardiac	-0.033	0.014	-0.28	-2.35	0.022	-0.061	-0.005
Level ID	0.035	0.017	0.25	2.099	0.04	0.002	0.069

R²_{adj}=0.106

The five different sedentary bouts were investigated with the 14 individual health variables via multinomial logistic regression models initially but required transformation to binary variables to avoid regression errors. Significant relationships were found with the respiratory, upper GI and psychiatric/behavioural variables and some sedentary bout times as shown in table 7.29. Participants who had more time in sedentary bouts less than 30 minutes and 30 to 60 minutes were significantly less likely to have respiratory diseases

[AOR=0.99, p=0.008, 95%CI 0.98-0.997; AOR=0.99, p=0.038, 95%CI 0.98-0.999]. Those who spent more time in sedentary bouts between 120-240-minutes were more likely to have upper GI problems [AOR=1.008, p=0.045, 95%CI 1-1.017]. Participants who had more time in 60-120-minute bouts were more likely to have psychiatric or behavioural issues [AOR=1.01, p=0.03, 95%CI 1.001-1.019]. The best model fit with a Nagelkerke of 17% was with time in bouts of <30minutes, with all other models having a Nagelkerke of <10%.

Table 7. 29: Logistic regression for health variables with sedentary variables

Health condition		Sig.	Exp(B)	95% C.I. for EXP(B)	
				Lower	Upper
Respiratory	Bouts < 30m	0.008	0.990	0.983	0.997
Respiratory	Bouts >30m & <60m	0.038	0.990	0.980	0.999
Upper GI	Bouts > 120m & < 240m	0.045	1.008	1.000	1.017
Psychiatric/behavioural	Bouts >60m & <120m	0.030	1.010	1.001	1.019

The number of sedentary bouts greater than 30 and 60-minutes was also investigated by multinomial logistic regression. The number of 30 and 60-minute bouts were consolidated to three and two categories respectively. The model showed that those who did 6-9 bouts greater than 30-minutes were almost 10-times more likely to have psychiatric behavioural conditions but the CI was very wide indicating caution must be taken interpreting results [AOR=9.8, p=0.034, 95%CI 1.3-80.4]. Almost 53% of the variance in the number of bouts greater than 30 minutes could be explained by the health conditions (Nagelkerke =52.7%). No significance was seen with the number of 60-minute bouts.

- Regression with the number of health conditions summary score

Linear regressions were executed with the number of health conditions as the independent variable and sedentary time, PAL and the number of bouts greater than 30-minutes and 60-minutes. No significant relationship was seen with sedentary time. Table 7.30 summarises significant results. The regression with PAL showed that the PAL decreased as the number of conditions increased meaning that as people had more health conditions, they were less active i.e. for every 1 unit increase in health conditions PAL decreased by 0.006 [B=-0.006, p=-.045, 95%CI -0.012-0]. The regression completed with the number of sedentary bouts greater than 30-minutes showed that as the number of health conditions increased the number of bouts greater than 30-minutes increased by 0.114 [B=0.114, p=0.04, 95%CI 0.005-0.222]. Similarly as the number of health conditions present increased the number of

sedentary bouts greater than 60-minutes increased by 0.085[B=0.085, p=0.012, 95%CI 0.019-0.15].

Table 7. 30: Regression for no of health conditions with PAL mean & no sedentary bouts >30 & 60-minutes

Dependent variable*	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% CI for B	
	B	Std. Error	Beta			Lower	Upper
PAL mean	-0.006	0.003	-0.237	-2.037	0.045	-0.012	0.000
No bouts >30m 2 cats	0.114	0.054	0.243	2.095	0.040	0.005	0.222
No of >60min bouts in 2 cats	0.085	0.033	0.295	2.580	0.012	0.019	0.150

*independent variable=no of health conditions

The models were adjusted for the covariates and only the total sedentary time had any significant relationship in the adjusted regression model where aetiology was the only significant variable in the full and reduced model, see table 7.31. As aetiology changed from those with DS to other aetiologies, the sedentary time increased by almost 40-minutes but confidence intervals were very wide [B=39.97, p=0.015, 95%CI 8.2-71.8].

Table 7. 31: Adjusted stepwise reduced regression model for all covariates & no of health conditions by total sedentary time

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% CI for B	
	B	Std. Error	Beta			Lower	Upper
(Constant)	406.378	74.850		5.429	0.000	256.848	555.907
Aetiology	39.972	15.925	0.299	2.510	0.015	8.158	71.786

7.3.6 activPAL model fit

The AIC was used to estimate the model fit for the activPAL dependent variables and the independent covariate variables. Lower relative AIC values are indicative of a better model fit. The total sedentary time reduced model had an improved AIC value of over half the original model, see table 7.32.

Table 7. 32: AIC full versus reduced model fit for activPAL total sedentary time & covariates

Model Type	Variables	AIC value
Full	total sedentary time & covariates	1084.22
Reduced	total sedentary time & covariates	417.88

7.3.7 Results summary

In summary, the statistically significant results that were found for health and functional capacity, as measured by the CIRS-G comorbidity index, individual health conditions and the Barthel Index, with various sedentary variables are as follows:

1. As the number of sedentary bouts greater than 60-minutes increased the BI decreased and the CIRS-G increased, meaning that longer bouts of sedentariness led to a decrease in functional capacity and an increase in comorbidities.
2. As the time in bouts less than 30-minutes increased, the Barthel score increased and the CIRS-G decreased which reversed for all the longer bouts, meaning more time in shorter bouts was related to increased functional independence and less comorbidities while time in longer bouts was related to decreased functional capacity and increased comorbidities.
3. As the PAL increased, the Barthel score and the number of sit-to-stand transitions increased, meaning those who were more active performed more sit-to-stands and had more functional independence.
4. A reduction in PAL corresponded to an increase in cardiac conditions so less active people had more cardiac conditions.
5. Increased sedentary time was associated with more endocrine conditions.
6. More time in shorter bouts of sedentary time saw a reduction in respiratory conditions, so breaking up sedentary time more frequently reduces respiratory conditions.
7. Increased upper GI conditions were seen with more time spent in longer bouts of sedentary time.
8. An increase in psychiatric conditions was seen with more time in bouts of 1-2-hours and more bouts of greater than 30-minutes.

7.4 Discussion

This chapter investigating the effects of objectively measured SB on the health of older adults with an intellectual disability contributed novel and thought-provoking results, which will be important in clinical practice. This study showed the average sedentary time for the activPAL participants was 9.8 hours/day which confirms previous literature results where mean sedentary time of approximately 8-11 hours/day was observed, which could have negative health impacts (Hagströmer *et al*, 2010; Melville *et al*, 2017; Harris *et al*, 2019; Ghosh *et al*, 2021; Lynch *et al*, 2021). General population studies observed lower but still elevated levels of SB. The US 2003-2004 NHANES study, saw an average of 7.7-hours/day in SB which increased to over eight hours/day by the 2015/2016 study cycle (Matthews *et al*, 2008; Ussery *et al*, 2018). Similarly, objectively measured SB in older adults increased from seven to nine hours/day in a group of active older adults (Sánchez-Sánchez *et al*, 2019; Madden *et al*, 2021). However objectively measured SB of over nine hours/day reduced to six hours when the same SB was self-reported, highlighting the importance of OM, as used here, for deriving accurate conclusions (Harvey *et al*, 2015).

The activPAL graphical activity output showed that the participant who had the most steps per day spent the least amount of time lying down. At first glance of the linear outputs a big difference was not obvious between the two participants who had in excess of 7,000 and 12,000 steps per day respectively. The person who took less steps stood more, had more sit-to-stand transitions and spent almost two-hours less sitting down. The literature proposed that 10,000 steps per day is generally accepted as the target for health benefits and older neurotypical adults are expected to perform 7,000-10,000 steps/day for health but for certain age-bands, an increase in the number of steps per day above a certain threshold does not affect all-cause mortality (Tudor-Locke *et al*, 2008; Hall *et al*, 2020; Paluch *et al*, 2022). For adults over 60-years this level was 6,000-8,000 steps per day while for those younger than 60, this threshold was 8,000-10,000. However given that people with an intellectual disability age prematurely compared to their general population peers, a lower step level as seen in this study, combined with frequent breaks in sedentary bouts may be sufficient to maintain health (O’Leary *et al*, 2018; Yates *et al*, 2020).

The PAL results seen in this study were indicative of a population who were in the sedentary to light activity range which verifies similar findings from Mc Keon and colleagues (2013) pilot study, which also observed low intensity activity levels even in those who achieved the recommended activity levels. Investigations with PAL and the standard covariates in this

study showed that residence type was the only statistically significant variable, illustrating that participants who lived more independently had relatively higher levels of energy expenditure, as indicated by larger PAL values. Similarly, the activPAL measured SB showed that participants who lived in residential settings were more sedentary than those living independently or with family, although the relationship was not statistically significant. It makes sense that those in residential settings were more sedentary as they may have higher needs and a higher reliance on support (Van der Weele *et al*, 2021). In fact people who lived in residential settings exercised less unless they had a caregiver who saw the benefit in exercising (Heller *et al*, 2002). Research has shown that a lack of support from caregivers and authority figures results in less activity and clear direction on how to reduce sedentary pursuits could help alleviate this sedentariness (Bodde and Seo, 2009). Unfortunately, staff shortages and sometimes a lack of staff motivation to support those with an intellectual disability to engage in more PA compound these sedentary issues (Temple and Walkley, 2003). Conversely when screentime was used as a proxy for SB and not objective measures, those who lived independently/with family were more sedentary, while another showed no significant relationship with SB, again emphasising the importance of objective measures (Hilgenkamp *et al*, 2012; Hsieh *et al*, 2017).

Results in this study showed that women, except for those with mild intellectual disability, were more sedentary than males but this conflicts with other studies which saw no sex differences in SB (Westrop *et al*, 2019; Ghosh *et al*, 2021). The only significant covariate from the regression analysis with any of the activPAL measured sedentary dependent variables was aetiology with the total sedentary time. Those with DS had significantly lower total time in SB compared to other aetiologies which concurs with the literature where those with DS were found to be more active and participated in more sport compared to other types of intellectual disabilities but usually did not meet minimum PA recommendations (Nordstrøm *et al*, 2013; Borland *et al*, 2020; Oreskovic *et al*, 2020). This increased activity could be due to organisations such as Down syndrome Ireland who are very active in providing families with support and advice on health, more so than other aetiologies who would not have such active non-governmental organisations. Furthermore in a systematic review Agiovlasitis *et al* (2020) concluded that those with DS were sedentary for approximately nine hours/day compared to almost ten hours measured in this study. In addition this study showed that those with other aetiologies spent over an hour more in bouts of 60-120-minutes than those with DS.

The activPAL OM determined that those with a severe/profound intellectual disability were more sedentary than those with mild and moderate levels which would make clinical sense as it is known that those with more severe levels of intellectual disability can present with more complex health, higher care requirements and less independence (Burke *et al*, 2017; Ahlström *et al*, 2022). Analogous results were observed in a UK study exploring the health of 152 participants with different levels of intellectual disability (Phillips and Holland, 2011). Though systematic reviews found people with a severe intellectual disability were less active, the sedentary element is not reported here as screen time was used as the proxy which is not an accurate representation of SB for those with a severe intellectual disability as seen earlier (Melville *et al*, 2018; Oppewal *et al*, 2018). Conversely, a secondary analysis of RCT data determined that intellectual disability level was not related to SB (Harris *et al*, 2018). Studies have shown that people with a severe/profound intellectual disability and those who are more sedentary are more likely to be multimorbid (Tyrer *et al*, 2019).

Overall high levels of comorbidities were observed in this study with over 43% presenting with 5 or more conditions compared to 22% in the general population TILDA study (Hernández *et al*, 2019). Over 93% (n=67/72) of participants had at least 2 chronic conditions compared to 71% observed previously in the IDS-TILDA study, but high variability i.e. ranges from 62% to 97% was seen in the literature (Mc Carron *et al*, 2013; Hermans and Evenhuis, 2014; Kinnear *et al*, 2018; Tyrer *et al*, 2019). The TILDA study showed that increased sedentary time was associated with having more than four chronic conditions (Kandola *et al*, 2020). The mean CIRS-G score observed here of 4.85 (SD±2.9) was 2-times lower than that seen with adults with autism spectrum disorder (ASD) and equivalent to scores seen in the general population of 4.7 (SD±3) (Miot *et al*, 2019; Wang *et al*, 2020). However the mean comorbidity severity score of 2.4 (SD±2.1) seen in this study was higher than that observed in the general population (1.2, SD±0.6), indicating that more people in this study had multiple conditions (Wang *et al*, 2020). The percentage of participants observed in the high comorbidity severity category in this study was less than that observed in Miot *et al*, 2019 (61%, n=44/72 versus 73%, n=46/63), which could be due to more diverse aetiologies seen here.

Older age (greater than 65) had the highest CIRS-G scores (6.35, SD±3.2) in this study, which concurred with the literature, where age was one of the primary risk factors for comorbidities and could provide a target for interventions (Hermans and Evenhuis, 2014; Miot *et al*, 2019; Benraad *et al*, 2020). Compared to the general population, chronic diseases

and comorbidities affect people with an intellectual disability at a younger age, and as observed in this study those under 65 also had multiple chronic health conditions, (4.14, $SD \pm 2.9$) but the disease burden was lower than the older age group. In addition, the results in this study showed that participants from residential settings had the highest CIRS-G scores as well as spending the most time sedentary, which would tie-in with their more complex healthcare requirements (Ahlström *et al*, 2022) .

Although a link with the number of chronic conditions and sedentary time was not observed here, significant associations were found for the individual conditions of endocrine, upper GI, respiratory, and cardiac conditions. Similar to El Mrayyan and colleagues, this study identified the most commonly observed comorbid condition was psychiatric/behavioural. An increase in psychiatric/behavioural conditions was found to be related to spending more time in sedentary bouts of 1-2-hours and performing more bouts of greater than 30-minutes for the participants in this study. As they age, those with an intellectual disability are 11-times more likely to have a psychiatric disorder if they are already diagnosed with a mood or anxiety disorder (El Mrayyan *et al*, 2019; van den Bemd *et al*, 2022). High levels of SB are observed in those with psychiatric problems, which is a concern given that psychiatric disorders appear to be one of the most common comorbid conditions for people with an intellectual disability, especially depression in those with ASD and an intellectual disability (Bratek *et al*, 2017; Kruisdijk *et al*, 2017; Singh *et al*, 2019; Mazza *et al*, 2020; Sáez-Suanes *et al*, 2021).

The second most common comorbidity seen in this study was cardiac which agreed with results from an Australian study where psychiatric and cardiac issues were the most common comorbidities after sensory disorders, with an average of four conditions present (Hussain *et al*, 2020). An equivalent range of conditions was observed in this study, but results were not directly comparable because a standard comorbidity scale was not used in the Australian study. Of concern is the evidence that people with an intellectual disability had a 24% increased risk of early onset cardiac issues, which was even higher in those with a more severe/profound intellectual disability (Wang *et al*, 2023). Although no significant relationship was seen with SB and the comorbidity index in this study, linear regressions with the individual health conditions, showed that the cardiac and endocrine variables were significantly related to the total sedentary time. In fact a one hour increase in SB or TV viewing resulted in a 5-8% increased chance of having a chronic health condition such as type 2-diabetes while replacing 30-minutes of sedentary time with activity of any type,

especially higher intensity, showed over 30% risk reduction (Guo *et al*, 2020; Li *et al*, 2021). This is concerning when the level of SB and chronic health presented in this study is considered, and a possible indication that SB could be contributing to higher levels of overall chronic health. This study observed a significant positive relationship with sedentary time and the number of endocrine conditions, which concurs with recent evidence that SB is a significant risk factor for both type-2 diabetes and CVD mortality (Honda *et al*, 2019; Katzmarzyk *et al*, 2019; Henschel *et al*, 2020; Zou *et al*, 2022; Peter-Marske *et al*, 2023). The type of SB should also be a consideration because 5-6 hours of screen time had the same negative impact on CVD as 10-11 hours of total sedentary time (Jingjie *et al*, 2022).

No significant relationship was seen here with cardiac issues and sedentary bouts of any length, even though some studies showed breaking up longer bouts of sedentary time was beneficial for CVD risk reduction (Yerramalla *et al*, 2022; Bell *et al*, 2023). However in this study shorter bouts were associated with reduced respiratory conditions, which is one of the leading causes of death in this population. Hence an intervention based on breaking up sedentary time could be of great benefit. The literature, including the TILDA study, showed that people with chronic lung disease and chronic obstructive pulmonary disease spent more time in SB and accrued this time in longer bouts (Cheng *et al*, 2020; Kandola *et al*, 2020).

The results seen in this study show that longer bouts were associated with more upper GI conditions which confirmed the evidence seen in the literature, where the risk of developing gastric ulcers was curbed by more ambulatory activity, compared to sedentary time, and inactivity and lack of exercise had a significant positive relationship with gastroesophageal reflux (Cheng *et al*, 2000; Rosenstock *et al*, 2003; Pitta *et al*, 2005; Murao *et al*, 2011; Çela *et al*, 2013).

The results here demonstrate that as the number of cardiac conditions increased, the PAL mean value decreased indicating more SB and less activity. Similarly PA has a modulating effect on high levels of SB for CVD risk and the strong indications that those who spent more total time and longer periods sedentary had increased odds of presenting with chronic health for example, type-2 diabetes, compared to those who were less sedentary and more active needs to be addressed, especially in those most at risk like the intellectual disability population (Bellettiere *et al*, 2019; Huang *et al*, 2021; Duran *et al*, 2022; Yerramalla *et al*, 2022; Han *et al*, 2023).

A negative relationship was observed with the number of comorbidities and functional capacity: the more comorbidities present the more functional dependence was seen in study participants. This concurred with the general population and intellectual disability literature where the level of functional capacity decreased as multimorbidity increased and the presence of heightened multimorbidity predicted future functional capacity declines (Ryan *et al*, 2015; Miot *et al*, 2019). The TILDA study demonstrated that reduced gait speed and grip strength were predictors of a decline in health due to multimorbidity while a review assessing links between functional capacity and multimorbidity proposed that it was a bi-directional link with many additional influences across the lifespan e.g. obesity and SB but the presence of an intellectual disability was found to be a bigger influence on balance than obesity (Ryan *et al*, 2018; Calderón-Larrañaga *et al*, 2019; Perez-Cruzado *et al*, 2021).

A standardised, globally recognised index like the BI to represent the functional capability of populations, means that cross-population comparisons may be easily facilitated and inter-test discrepancies eliminated (Wade and Collin, 1988). Results here have shown that SB is significantly related to functional independence, as determined by the BI, the implications of which are huge. Sedentary behaviour was significantly negatively associated with BI scores and hence higher dependency, while PAL levels were significantly positively related with the BI scores, which agreed with results seen in octogenarians where replacing SB with activity of any type or intensity improved functional capability as demonstrated through BI scores, while sedentary older adults had more functional limitations than their active counterparts (Tornero-Quiñones *et al*, 2020; del Pozo-Cruz *et al*, 2022). Specifically the negative effects on functional independence of excessive SB of over 15 hours per day seen in a group of older adults was moderated by time spent in MVPA, where 51-minutes/day of MVPA was deemed sufficient to compensate for sedentary adverse results (Alfonso-Rosa *et al*, 2022). Losing functional capacity leads to loss of independence and could have multiple consequences on increased care provision and costs, as well as the social and psychological wellbeing of individuals who could consequently be more isolated and have a reduced quality of life (Bozkurt *et al*, 2016). Indeed higher objectively measured sedentary time was associated with lower activity of daily living scores in community-dwelling older adults (Amaral Gomes *et al*, 2021). However the literature demonstrated that appropriate training programs integrated with reductions in SB can improve the functional capabilities of adults with an intellectual disability as measured by strength, cardiovascular improvement and

motor skills (Przysucha *et al*, 2020; Jouira *et al*, 2021; 2022; Sedaghati *et al*, 2021; Farías-Valenzuela *et al*, 2022).

This study demonstrates that as the number of sit-to-stand transitions increased, the BI increased. In other words, people with higher dependency have greater difficulty in standing, which has concerning implications to care provision. Indeed difficulty in going from sitting to standing was an indicator of decreased physical function in older adults and was a good indicator of when breaks in sedentary bouts occur because physical function may be improved by breaking up extended sedentary periods (Bohannon, 2012; Mañas *et al*, 2021; Wilson *et al*, 2021; Han *et al*, 2022). In fact, Manas *et al* (2021) propose that the potential to reduce or avoid frailty in older inactive adults may be dependent on breaking the cycle of SB. Thus if SB contributes to decreasing a person's ability to stand, carers and service providers need to instigate interventions to avoid this from happening.

A direct relationship with the number of sedentary bouts greater than 60-minutes and the CIRS-G index and a negative relationship with the Barthel index was observed in this study, which means that as people had more time in longer bouts of SB, their functional capabilities decreased and their number of comorbidities increased. The literature confirms these findings where increased breaks in SB were associated with lower waist measurements, reduced LDL-cholesterol, blood pressure, triglycerides and insulin in adults, while increased incidence of metabolic syndrome, frailty, psychiatric distress and mortality risk was associated with longer bouts of sedentariness (Carson *et al*, 2014; Honda *et al*, 2016; Kikuchi *et al*, 2021; Owari, 2021; Roe *et al*, 2023). In addition this study showed that more sedentary bouts less than 30-minutes was related to an increase in the BI score and a reduction of the CIRS-G score, so more frequent breaks in sedentary time was beneficial from a functional capability and comorbidity standpoint, which coincides with the literature where increased breaks in SB time were related to reducing metabolic risk factors (Healy *et al*, 2008). However a Portuguese study which found that older adult's physical function was negatively impacted by increased sedentary time, found that only 30-minutes of MVPA/day attenuated the sedentary effects on physical function and not breaks in sedentary time (Hetherington-Rauth *et al*, 2021).

7.5 Conclusion

This chapter demonstrated through OM, that older adults with an intellectual disability have worrying levels of SB of almost 10-hours/day. All eleven activPAL sedentary variables were thoroughly interrogated against the standard covariates and the Barthel and CIRS-G indexes. Significant negative relationships were observed with everyday functionality and the overall time spent in SB as well as longer bouts, but evidence suggests that more movement, especially multi-faceted may compensate for the unfavourable effects of extended SB. In fact results of this study show that less SB as evidenced by more sit-to-stand transitions, time in shorter bouts of SB and increased energy expenditure using PAL can improve functionality scores and health outcomes. Furthermore a reduction in PAL corresponded to an increase in cardiac conditions. Of concern is that over 93% of participants had two or more comorbid conditions. However more time spent in shorter bouts of SB saw improvements in respiratory conditions, which is the leading cause of death in this population and more time in longer bouts of sedentariness was related to the presence of more upper GI conditions. Hence reducing the amount of time people sit for long uninterrupted periods by introducing frequent breaks provides a simple, clinically feasible way to make a positive change that will provide health and functional improvements.

7.6 Chapter 7 key learnings

- Sedentary behaviour, which is widespread and at worrying elevated levels for adults with an intellectual disability, has negative connotations for their overall health, functional capacity and wellbeing.
- Simple changes like breaking up time spent being sedentary will be critical for improving health. It is the small, frequent daily changes that will have the biggest impact.
- Replacing SB with PA of any type or intensity would have health benefits.

Chapter 8

Systematic review and meta-analysis to determine the prevalence of sedentary behaviour in the intellectual disability population: revisited and updated

Chapter summary

This chapter describes the integration of this study's results into the original systematic review and meta-analysis which was originally completed to determine the prevalence of SB in the intellectual disability adult population. The original and new pooled results are summarised and displayed graphically in forest plots. Any differences are described.

8.1 Introduction

This chapter provides an update to the systematic review and meta-analysis which was executed to establish the prevalence of SB in the adult intellectual disability population as described in chapter 2. Once the full thesis analyses were complete, for thoroughness and after consultation with experts in the field, the advice was to return to the original meta-analysis data and feed back in this study's results to evaluate if they had any effect on the overall SB prevalence.

8.2 Method

The previous article data were grouped according to the SB assessment category used in each article. Out of the four original methods identified for quantifying SB, three were appropriate to use with this study as follows:

- Number of steps per day
- Amount of screen time per day
- Time in SB per day

As before, RevMan Review Manager Version 5.4.1 was used to summarise the data graphically using forest plots with this study's results added in. Each individual study's results is represented by a box, the size of which represents the study weighting in the overall meta-

analysis, and lines which denote the 95% confidence interval (CI). The variance between individual studies is represented by the heterogeneity value, I^2 .

8.3 Results

Table 8.1 summarises the original and new results. A total of four broad themes to assess SB and activity were investigated:

- total sedentary minutes by sex
- steps by sex and level of intellectual disability
- the mean-time sedentary per day
- the mean steps per day.

A manual mean-of-means calculation was also executed for the mean sedentary time and steps.

Table 8. 1: Summary of meta-analysis original results and results with new study data added in

Activity variable	Description of results	Original Result			New result		
			95%CI	I ²		95%CI	I ²
Sedentary minutes/day by sex	Men less sedentary than women	-234	-481, 126	57%	-206	-443, 309	53%
Sed. mins/day (minus Finlayson study)	Men less sedentary than women	-154	-294, -1.4	0	-144	-282, -5.2	0
Steps by sex	Women take more steps than men	1,089	-70, 288	79%	736	-76, 223	76%
Steps by level of ID	Moderate to profound took more steps than mild ID	1,906	1276, 2,537	0	1,848	1256, 2,439	0
Total sedentary minutes	Total mean sedentary minutes/day	600	520, 680	99%	599	523, 674	99%
Mean overall steps	Total mean steps/day	6,715	6086, 7344	88%	6,576	5962, 7190	89%

- Total sedentary minutes stratified by sex

The first aspect investigated was sedentary minutes per day, stratified by sex which was represented by seven studies. Data were divided by ten to make plot more readable. The forest plot for the original SR data showed that men had less sedentary minutes per day than women, the mean difference was -234 [95% CI, -481, 126], see figure 8.1. Moderate heterogeneity was present between studies as demonstrated by $I^2=57\%$. The pooling of this study's results resulted in a 12% reduction in step difference, although men were still less sedentary than women. The mean difference reduced to -206-steps/day [95%CI -443, 309]. Moderate heterogeneity remained although it decreased to $I^2=53\%$, see figure 8.2.

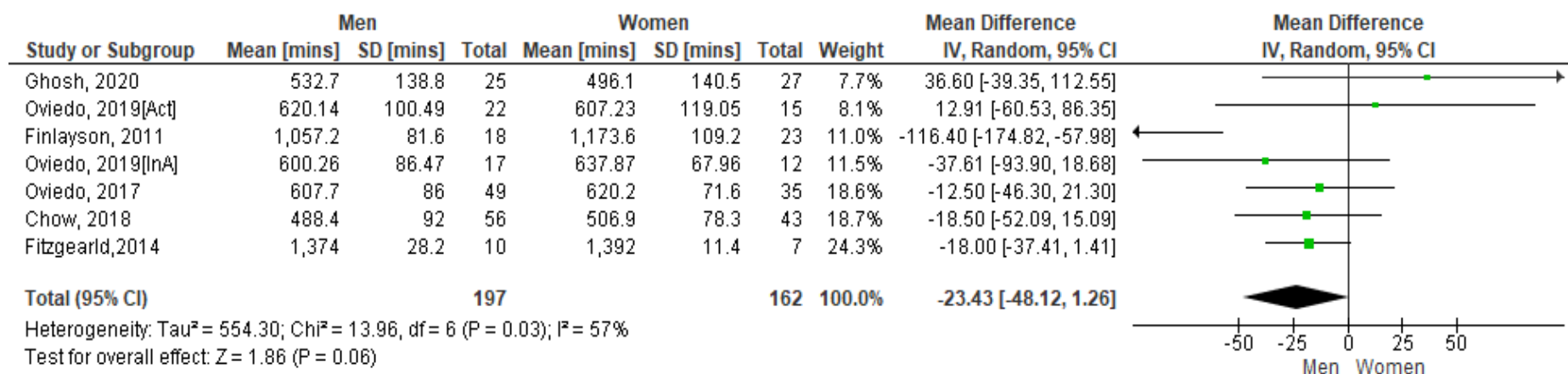


Figure 8. 1: Sedentary minutes by sex: Original data (divided by 10)

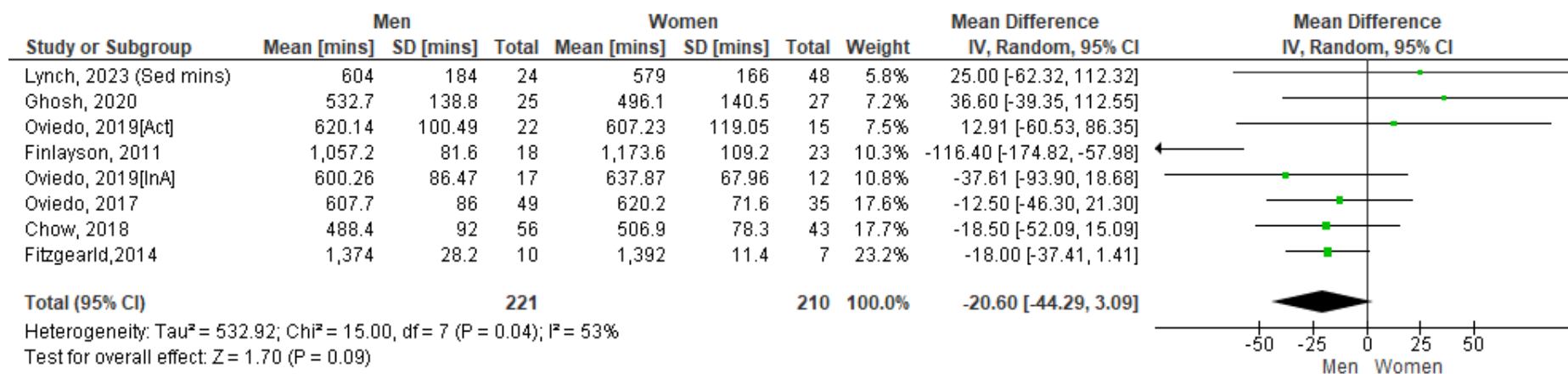


Figure 8. 2: Sedentary minutes by sex: new study added (divided by 10)

As before, the Finlayson study which appeared to be an outlier was removed from calculations. The original data forest plot still showed that men were less sedentary than women. The lower and upper points of the horizontal plane of the diamond, [95% CI, -294, -1.4] both lie to the left, meaning the resulting difference was significant, with a mean difference of -153.7, see figure 8.3. When this study's data were pooled with the original data, and the Finlayson study was excluded, the mean difference reduced to -144, less than 7% difference [95%CI -282, -5.2]. No heterogeneity was present with $I^2=0$, and the result remained significant, see figure 8.4.

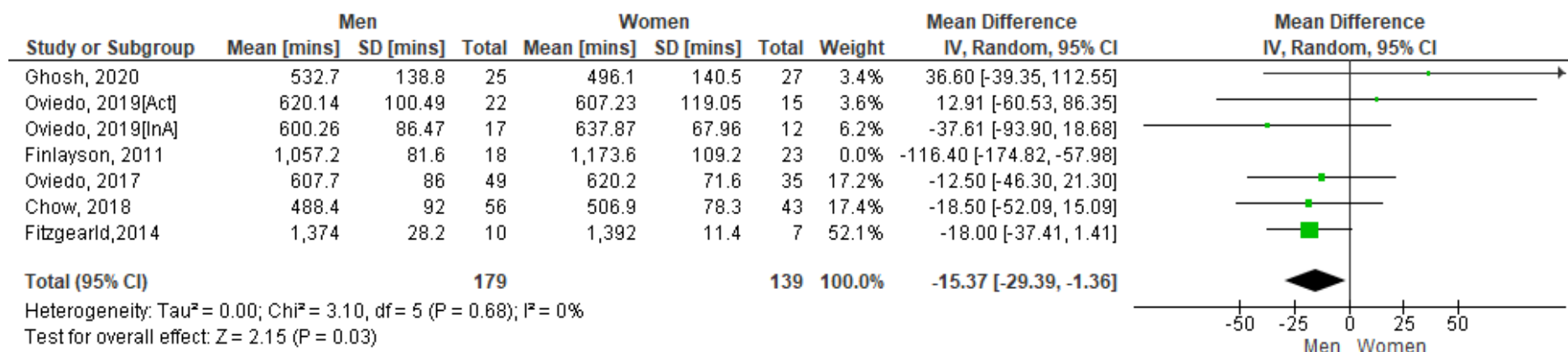


Figure 8. 3: Sedentary minutes by sex: original data (Divided by 10 & Finlayson excluded)

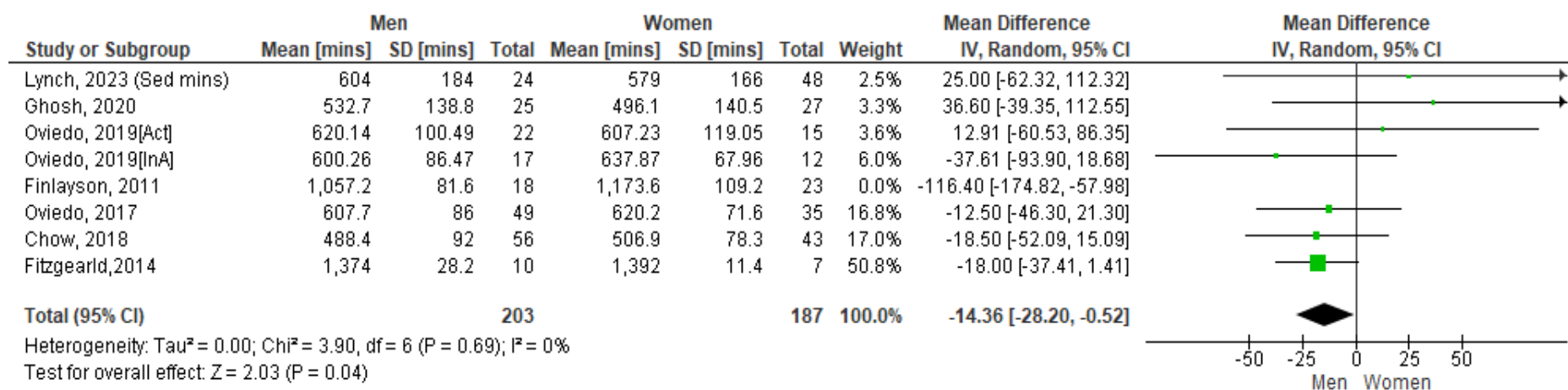


Figure 8. 4: Sedentary minutes by sex: new study added (Divided by 10 & Finlayson excluded)

- Step data stratified by sex

Figure 8.5 shows the original forest plot for steps stratified by sex as seen in four studies. According to the original plot females take more steps per day than males, which is contrary to some study results (Westrop *et al.*, 2019). The mean difference seen was 1,089 steps per day, 95% CI [-69.7, 287.6]. However, a high heterogeneity of $I^2 = 79\%$ was observed indicating it may not be appropriate to pool article results due to study differences (Higgins *et al.*, 2003). In addition, as the diamond shape touches the line of no effect the overall effect is not significant.

When the results of this study were added in, women still took more steps than men and the overall effect remained insignificant as the diamond shape crosses the line of no effect, see figure 8.6. The mean difference seen reduced by 32% to 736 steps per day, 95% CI [-76, 223] and although a high heterogeneity remained, it decreased to 76%.

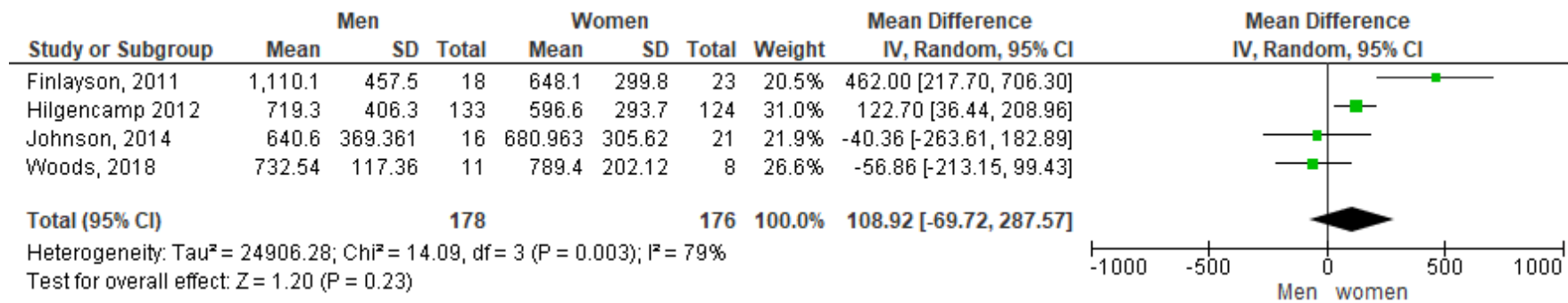


Figure 8. 5: Steps by sex: original data (divided by 10)

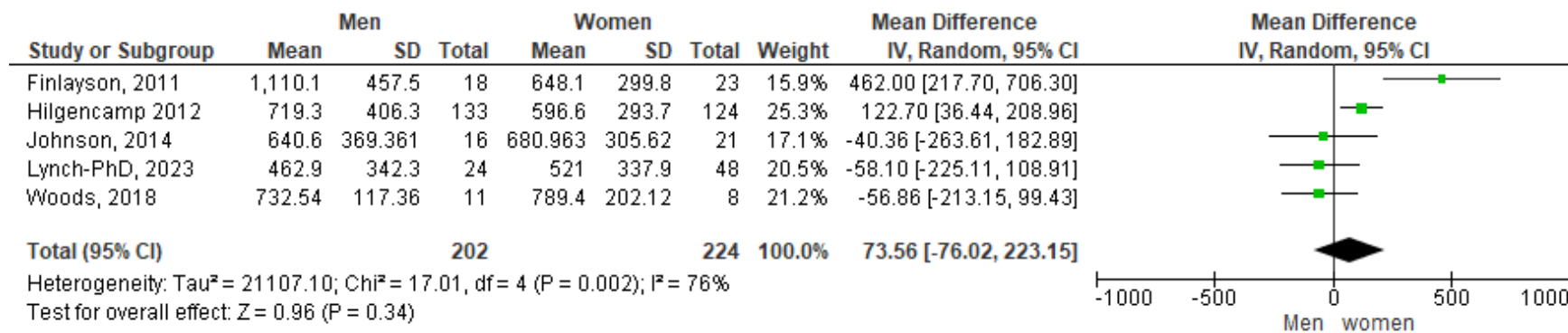


Figure 8. 6: Steps by sex: new data added (Divided by 10)

- Pooled step data stratified by intellectual disability level

The step stratification by intellectual disability level was pooled from two studies. The forest plot showed that those who had a moderate to profound intellectual disability took more steps than those of a mild level. The heterogeneity observed was zero between studies, which remained unchanged with the new study's data added in. The pooling of this study marginally reduced the step number by 3% from 1,906 more steps per day [95%CI 1274.5, 2537.2] to 1,848 [95%CI 1255.8, 2439.4], see figure 8.7 and 8.8.

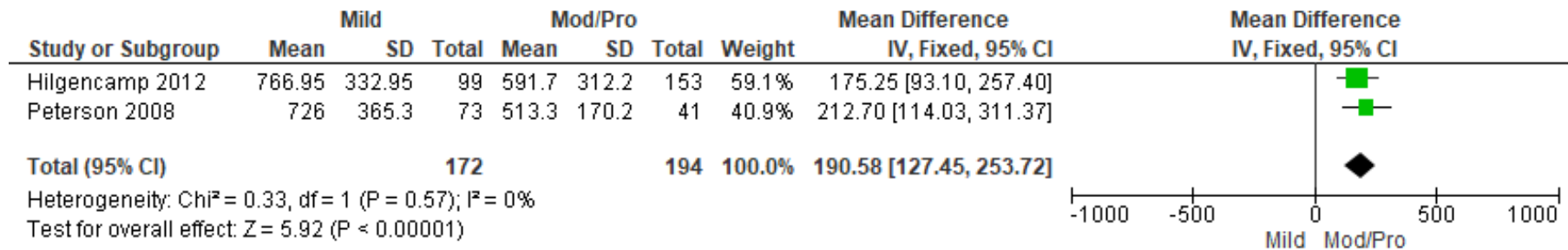


Figure 8. 7: Steps by ID level: original data (Divided by 10)

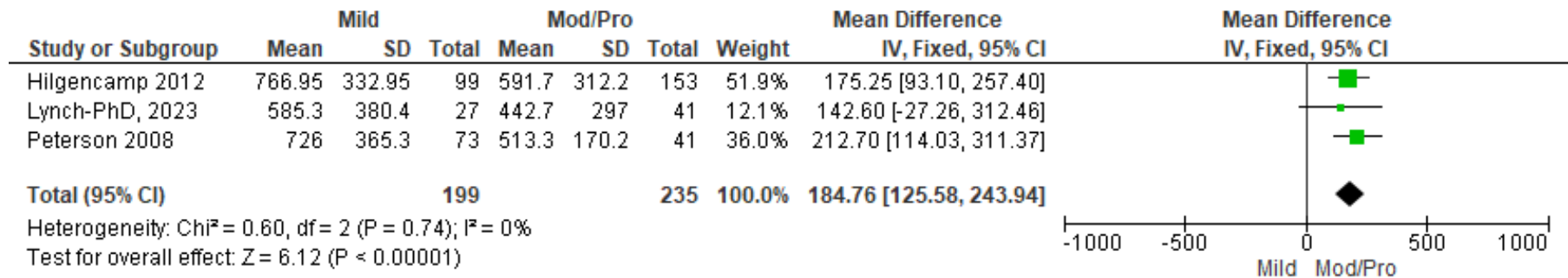


Figure 8. 8: Steps by ID level: new data added (Divided by 10)

- Pooled mean sedentary minutes

The original total sedentary minutes meta-analysis was completed with 13 studies, which resulted in a mean sedentary time of 600-minutes/day, 95% CI [520.3, 679.5] but the heterogeneity was $I^2=99\%$. The addition of this study to the meta-analysis resulted in a one-minute reduction to the sedentary time i.e. it reduced to 599 [95%CI 523.3, 673.6]. However heterogeneity remained high at $I^2=99\%$, see figure 8.9 and 8.10.

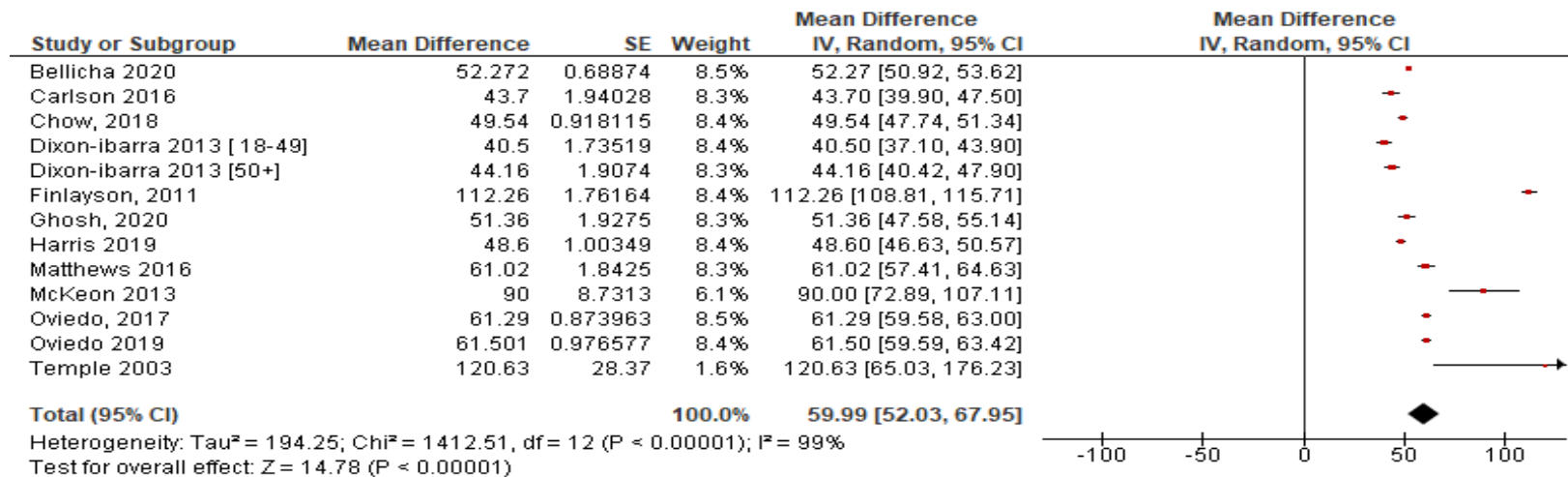


Figure 8. 9: Total mean sedentary minutes: original data (Divided by 10)

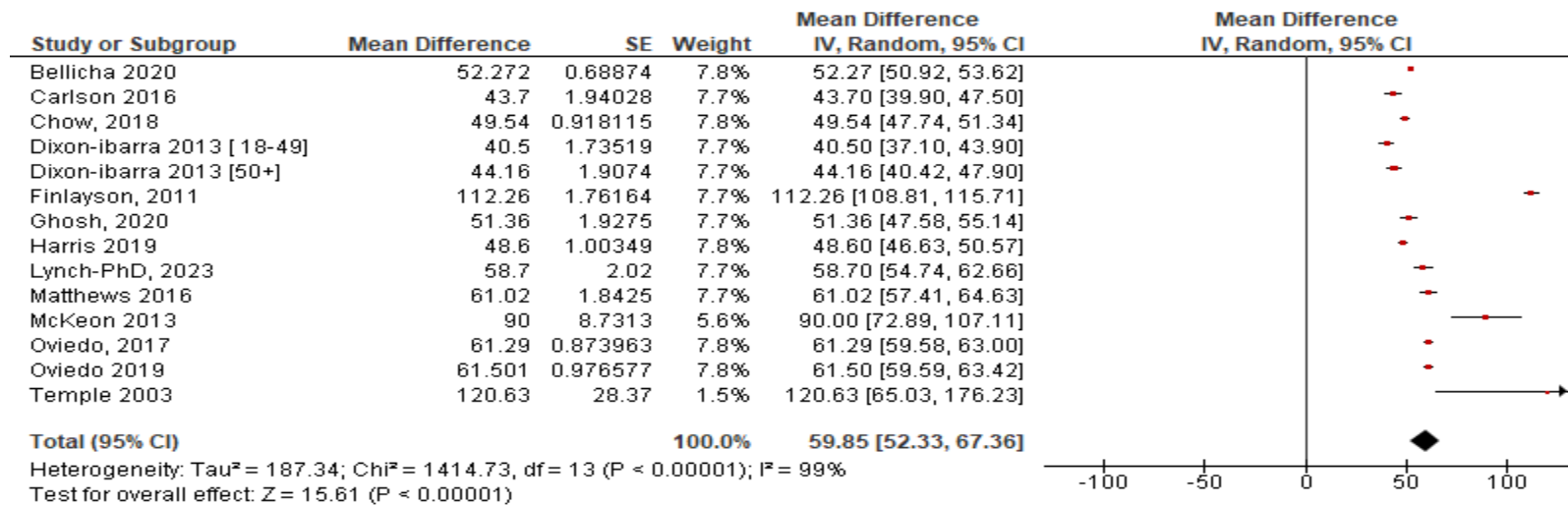


Figure 8. 10: Total mean sedentary minutes: new data added (Divided by 10)

- Pooled mean steps per day

The original data meta-analysis results gave a pooled study mean for twelve studies of 6,715 steps per day, 95% CI [6,086, 7,344]. The variability between studies was very high with $I^2 = 88\%$ indicating high heterogeneity, which may indicate that it is inappropriate to combine studies due to the potential variability in studies (Higgins *et al.*, 2003). When this study's results were pooled, the mean overall steps per day reduced by almost 10% to 6,576 steps per day, 95% CI [5,962, 7,190]. A high study heterogeneity remained with $I^2 = 89\%$, see figure 8.11 and 8.12.

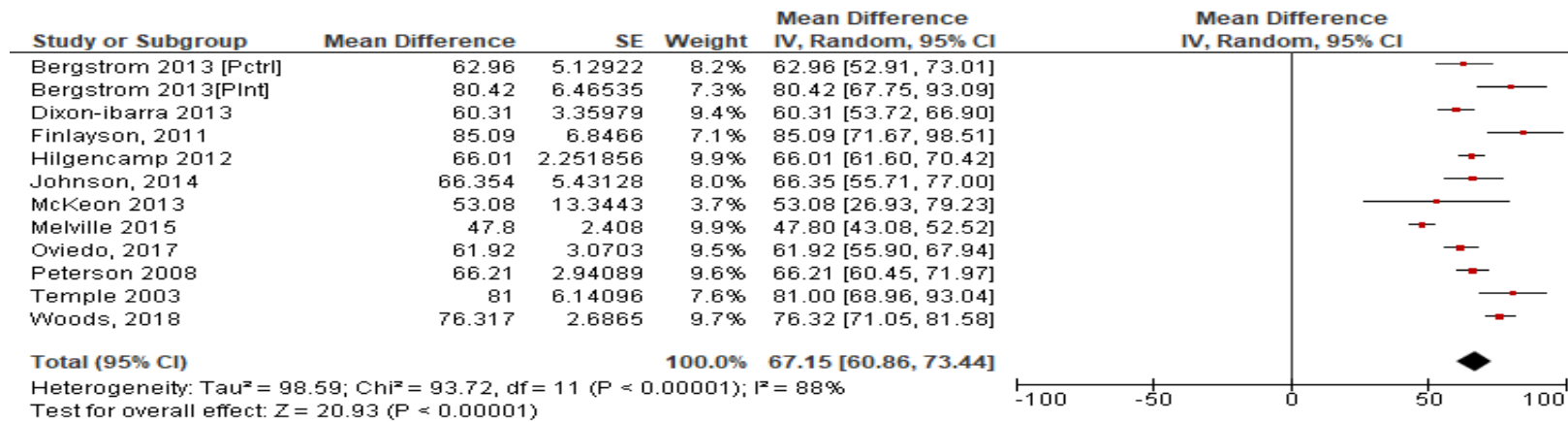


Figure 8. 11: Total mean steps: original data (Divided by 10)

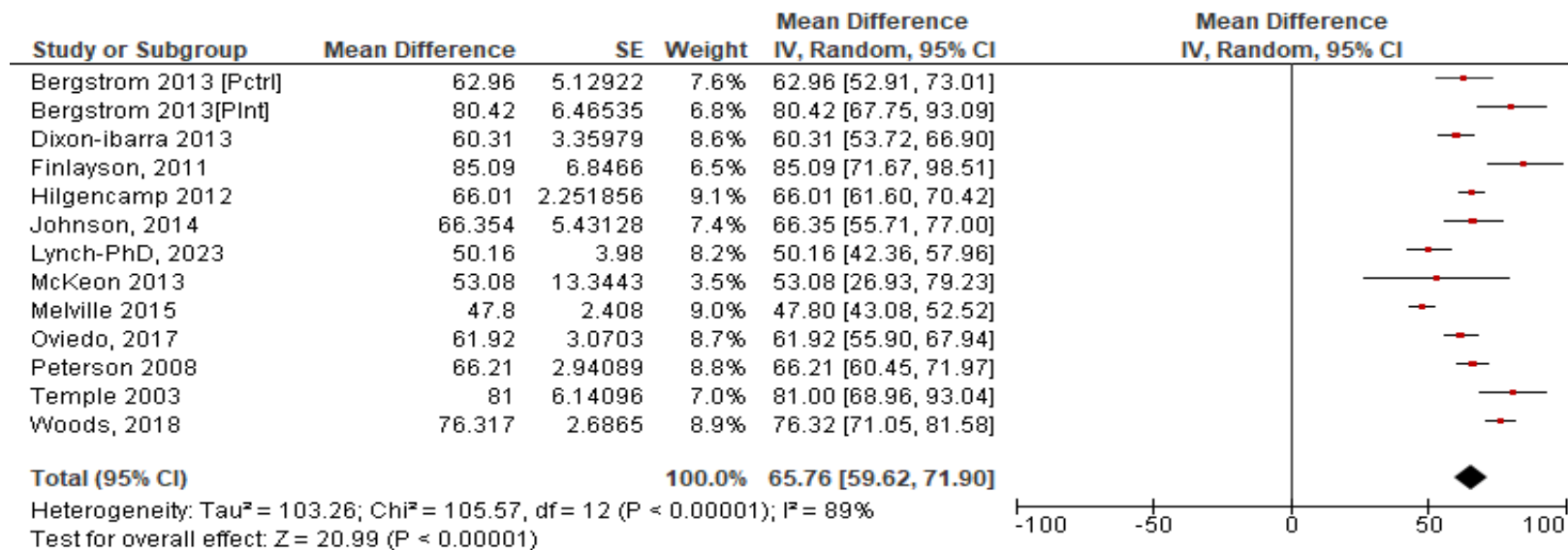


Figure 8. 12: Total mean steps: new data added (Divided by 10)

- Mean-of-means calculation

The formula used to calculate the mean of means was:

$$\frac{(m_1 \times n_1) + (m_2 \times n_2) + (m_3 \times n_3) + \dots + (m_{11} \times n_{11})}{n_1 + n_2 + n_3 + \dots + n_{11}}$$

$$n_1 + n_2 + n_3 + \dots + n_{11}$$

where m=Study means and n=Study sample size

- The calculated sedentary minutes mean-of-means including this study's data were 604.5 compared to 606.3 for the original meta-analysis, a reduction of 0.3%.
- The calculated mean-of-means steps per day for the original study was 6,555 steps/day compared to 6,446 with this study's data added in, a reduction of 1.7% steps per day.

8.4 Discussion

According to the original and new pooled forest plots, men spent less time sedentary than women but females took more steps per day than males, which conflicts with Westrop and colleagues (2019) systematic review which found that men were more active than women but the data on SB was inconclusive. However women's stride length is usually shorter than males which may explain the fact that they have more steps in the pooled analysis (Cho *et al*, 2004). Women with an intellectual disability have higher levels of obesity and poor health so they will need to be specifically helped to be more active (Burke *et al.*, 2017) .

Both the original and pooled results showed that those with a severe/profound intellectual disability took more steps than those with a mild level. A possible explanation may be that there are higher levels of challenging behaviour among those with more profound intellectual disability, for example in one study over 80% of those with a severe/profound intellectual disability exhibited challenging behaviour (Poppes *et al*, 2010). This challenging behaviour may manifest as hyper-activity e.g. pacing and it may be combined with being on the autistic spectrum which is accompanied by sensory and environmental sensitivities and impacts on individuals sitting quietly for long periods of time (Matson *et al*, 2008).

The mean pooled time in SB changed negligibly with the addition of this study's results, remaining elevated at approximately 10 hours per day. A reduction of 10% was seen from the original to the new pooled mean daily step data with the addition of this study's data but step level was still insufficient for health at approximately 6,500 per day.

8.5 Conclusion

The results from this study did not change the overall results of the systematic review to determine the prevalence of SB in the intellectual disability population, although small differences were observed. Men still spent less time sedentary than women but women took more steps than men, which may be due to smaller stride lengths. Those with a moderate to profound intellectual disability took more steps than those with a mild level but this may be due to the presence of challenging behaviours.

Un-sedentary for health

Summary and overview

This chapter presents a summary of the overall study findings, where each chapter's results are reviewed concisely. Recommendations to reduce SB in clinical practice and changes to policy and education are proposed. Areas for future research are recommended. This thesis entailed a systematic exploration into the SB of older adults with an intellectual disability using three self-reported measures and an objective measurement device. Overall this study shows that sedentary levels are high including watching TV and evidence emerging from this thesis demonstrates that sedentariness has negative effects on a number of health factors, such as cardiac conditions, as well as functional capabilities. Initially a systematic review and meta-analysis determined that adults with an intellectual disability were sedentary for over 60% of their waking hours however a literature review on the effects of SB on health could not establish a cause-and-effect relationship. An investigation using TV as a proxy for SB highlighted that TV may not be the optimum self-report tool for all levels of intellectual disability specifically those with a severe/profound level. The activPAL objective measures showed that all participants, even those who had greater than 10,000 steps per day, were classified in the sedentary to low active range. Unfortunately, whilst all movement is good, all activity observed within this study was at a low intensity level. Overall sedentariness of almost 67% was observed. More time in SB was associated with increased health and functional problems while those who moved more had better functional capabilities and less comorbidities which bodes well as evidence for future practice development. Positively more frequent breaks in sedentary time saw reduced endocrine and respiratory conditions whereas less activity was related to increased cardiac conditions. This thesis is one of the first studies using objective measures to investigate the effect of SB on the health of older adults with an intellectual disability and as such adds unique insights to the field. Results show that simply breaking up time in SB could possibly have positive health benefits, a positive implication for individuals with intellectual disability.

9.1 Introduction

This concluding section provides a brief summary and key findings of each thesis chapter. This chapter demonstrates how the research question ‘What is the prevalence of SB in adults with an intellectual disability and how does this affect their physical health?’ was answered and how the objectives were achieved. Recommendations for clinical practice, education, policy and future research are proposed. A summary of the study strengths and any limitations is provided.

9.2 Chapter overview

An outline of each thesis chapter is provided with a summary of the key findings.

9.2.1 Sedentary behaviour levels in adults with an intellectual disability: a systematic review and meta-analysis.

The systematic review and meta-analysis that were executed to determine the prevalence of SB in adults with an intellectual disability from peer-reviewed articles was examined. The researcher developed and published a protocol to guide the process. Almost 50 studies went forward for full review but only 25 were retained after rigid quality assessments by the researcher and another reviewer. Forest plots were used to summarise the data.

Key findings:

- There was a lack of consistency in the measurement and assessment of SB
- Average steps per day was 6,500
- Participants were sedentary for over 60% of their waking time

9.2.2 Physical health effects of sedentary behaviour on adults with an intellectual disability: a scoping review.

The peer-reviewed scoping review to determine the health effects of SB on the health of adults with an intellectual disability was expounded here. Almost 3,000 articles were reviewed for inclusion. Eighteen final articles were retained after quality assessment. The Braun and Clark method for thematic analysis was used to structure results.

Key findings:

- Seven broad themes were identified: metabolic syndrome, overweight and obesity, multimorbidity & diabetes, cardiovascular, general health, bone mineral density and body oxidation
- High levels of SB were identified in the intellectual disability population
- There was insufficient evidence in the literature to conclude that a causal relationship existed between SB and the health of adults with intellectual disability

9.2.3 Description of overall methodology used in this study including the research design, all data sources, any ethical considerations required and the IDS-TILDA study.

This methodology chapter described the methods that ensured the research question was answered comprehensively. The research design and philosophy were explained as well as the ethical principles that were integrated into the overall study. All data sources were expounded and the statistical procedures that were used were explained. Finally the IDS-TILDA study, a longitudinal study examining the health and wellbeing of adults over the age of 40 registered on the National Ability Support System was described.

9.2.4 An investigation into the risk factors for increased TV viewing in the intellectual disability population and the identification of a framework to structure results.

This chapter detailed the comprehensive investigation into the overall risk factors for increased TV viewing in adults with an intellectual disability and the Systems of Sedentary Behaviour (SOS) framework that was chosen to examine and structure results. The SOS model covered all environmental, individual and interpersonal factors so a comprehensive approach to risk factor management could be facilitated. A total of three scoping reviews were executed to gather the appropriate information, one for the model identification and the others for increased TV viewing risk factor identification in the general and intellectual disability populations. All identified risk factors were mapped on to clusters of the SOS model.

Key findings:

- Predominant research on SB was completed on the general population where nine themes for increased TV viewing were identified.

- The limited intellectual disability research primarily focussed on individual factors and four themes for increased TV viewing were identified.
- The SOS Framework was chosen to structure and summarise the relevant risk factors. It facilitated a systematic and concise way to interrogate the data which left it more applicable to practice.
- Over thirty risk factors were mapped onto corresponding IDS-TILDA variables for this investigation. These included education level, employment status and behaviours like smoking and drinking from the general population. Living circumstances, bedtime and mobility issues were some of the factors that emerged from the intellectual disability search.

9.2.5 A longitudinal exploration of self-reported TV behaviours as a surrogate for sedentary behaviour in older adults with an intellectual disability from the IDS-TILDA study.

A longitudinal exploration was completed across three waves, the equivalent of ten years, of IDS-TILDA data collection. Self-reported television watching time was used as a proxy for SB in this investigation. Participants were asked a single question, with a range of five choices, to assess the amount of TV watched on a daily basis. Novel risk factors for the intellectual disability population were explored and framed using the SOS framework.

Key findings:

- Higher levels of TV viewing were evident in those who lived more independently or with family compared to those in residential care settings.
- Drinking fizzy drinks and alcohol was associated with spending longer time watching TV.
- Late risers and those who had difficulty walking 100yards watched more TV.
- Those with a severe/profound level were deemed less likely to watch TV and hence be less sedentary by this method of assessment.
- Unemployed and participants who did not attend day service were less likely to watch TV.
- Participants with epilepsy, poor self-rated health or who felt less part of the community were less likely to watch TV.

- Those who had difficulty getting around the community due to requiring assistance and having reduced independence were also less likely to watch TV.

Overall risk factors for increased TV viewing from the adjusted model:

- Moderate intellectual disability
- Difficulty walking 100 yards
- Rising after 7am
- Two out of the six SOS framework clusters summarised the overall risk factors for increased TV viewing. These were physical health and wellbeing and psychology and behaviour.

TV may not be the most appropriate proxy for SB in the intellectual disability population, especially for those with a more profound level of intellectual disability but it may be suitable for those with a mild or moderate level.

9.2.6 Update to the systematic review and meta-analysis to determine the prevalence of sedentary behaviour in the intellectual disability population.

This mini chapter was orchestrated to include the results of this study into the original meta-analysis which was completed to establish the prevalence of SB in the adult intellectual disability population. Forest plots were updated with the new results using RevMan and the original and new pooled results were compared.

Key findings:

- Overall results of the original meta-analysis did not change but small differences were observed.
 - Women still took more steps than men but the addition of this study's data saw the mean difference reduced by 32% to 736 steps per day
 - Those with a moderate to profound intellectual disability still took more steps but the mean steps reduced by 3% to 1,848 with the new data added in
 - The overall sedentary times reduced by one minute when the new data were included.
 - Pooled mean steps per day reduced by 10% to 6,576 with the new data included.

9.2.7 To measure the relationship between objectively measured sedentary behaviour and age, sex, level of intellectual disability, living circumstances, comorbidities and functional capabilities.

The objectively measured SB results from the activPAL device was compared to the covariates of age, sex, level of intellectual disability, aetiology, living circumstances and BMI. Optimum standardised indexes to assess functional and comorbidity status of the participants were sought and compared to the SB measurements. The Barthel index (BI) was used to quantify functional status and the Cumulative Index Rating Score (CIRS-G) was used to assess comorbidity status.

Key findings:

- Average measured sedentary time was 9.8-hours/day which may reflect poor activity levels, and negative implications to health
- Those with a more severe/profound intellectual disability were more sedentary than those with other levels of intellectual disability
- Women were more sedentary than males (except for mild intellectual disability) which corroborates previous findings in the thesis
- Those with DS were less sedentary than other aetiologies, a possible explanation being that those with DS are exposed to activity opportunities more frequently, such as the Special Olympics, than others.
- Physical Activity Level (PAL) was indicative of a cohort in the sedentary to light activity range
- Those living more independently were more active which may imply that living in a less restrictive environment may provide more opportunity for movement
- Over 93% (n=67/72) of participants had at least two chronic conditions, which confirms that multimorbidity is highly prevalent among those with an intellectual disability, over double that seen in the Irish general population.
- Those over 65-years had the highest CIRS-G scores implying that they had the highest chronic illness burden. Elevated scores may be an indicator for 1-year mortality.
- A positive significant relationship was observed between more time spent in sedentary bouts greater than 60-minutes and the CIRS-G index so the more time people spent in uninterrupted sedentary time the higher the disease burden.

- A significant inverse relationship was observed between more time spent in sedentary bouts greater than 60-minutes and physical function as measured by the BI, implying that more time in SB resulted in a decrease of functional capability.
- This study's results showed the most common comorbidity was psychiatric/behavioural, which was also confirmed in the literature and was related to spending more time in sedentary bouts of 1-2-hours. A possible explanation for these high levels of SB maybe the corresponding medications particularly antipsychotic which have sedating properties.
- The second most common comorbidity condition was cardiac which coincided with the high levels of cardiac risk factors present i.e. obesity, inactivity and diabetes. Of interest was the low levels of conditions such as hypertension that have been noted among this cohort
- The number of cardiac conditions were negatively related to the PAL mean, meaning that those who were less active presented with more cardiac conditions.
- Endocrine health was significantly positively related to sedentary time. Sedentary behaviour was a significant contributor to diabetes which is more prevalent in the intellectual disability population compared to the general population. There were also high levels of thyroid disease, particularly among those with DS which impacts weight gain and sluggishness and could be a contributor to increased SB, thus requiring external encouragement to move.
- Shorter bouts of sedentary time were associated with less respiratory conditions, so breaking up sedentary time resulted in better respiratory health, the leading cause of death in this population.
- Longer bouts of sedentary time were associated with more upper GI conditions, which confirms what is seen in the literature where increased sedentary time and less activity contributed to gastric ulcers and gastroesophageal reflux as well as poorer gut motility and constipation.
- A negative relationship was observed between functional capacity and comorbidities meaning that as functional independence increased, the numbers of chronic health conditions decreased.
- Time in SB was negatively significantly related to functional independence and BI scores, indicating that more time spent sedentary resulted in less functional capacity.

- PAL scores were positively significantly related to functional independence and BI scores, signifying that more activity resulted in more functional capacity.
- The number of sit-to-stand transitions was directly related to physical function as measured by the BI, implying that as people moved more their functional capability improved.

9.3 Discussion

This study has uncovered novel information on the patterns and risk factors for sedentary behaviours among adults with an intellectual disability using self-reported TV habits as a proxy for SB and objective measurements of SB using an activPAL device. The risk factors for SB as determined from increased TV viewing were difficulty walking 100-yards, getting up after 7am and having a moderate intellectual disability. According to the activPAL objective measurements, women were more at risk of increased SB, as were those with a more severe/profound intellectual disability and those who had other aetiologies than Down Syndrome (DS).

This is the first study to identify difficulty walking 100-yards as a significant risk factor for SB. Other studies have not found that sitting time predicted mobility declines in general population older adults; instead, a decline in mobility has been cited as a cause of being more sedentary (Compernelle *et al*, 2020; Lee *et al*, 2020). Similarly, the literature has shown that getting up later is related to increased TV viewing and consequently more SB, which may reflect less structured schedules due to under and unemployment among people with intellectual disabilities (Mikulovic *et al* 2014). In addition, those with a severe or profound intellectual disability often have higher dependencies and health issues which may explain their higher sedentary levels as seen with the activPAL measurements (Burke *et al*, 2017; Ahlström *et al*, 2022). However using TV as a proxy for SB those with a severe/profound intellectual disability were less sedentary, which could be due to sensory or cognitive impairment issues restricting their ability to watch TV and helps explain findings that those with a moderate intellectual disability were more at risk of increased SB as determined by increased TV viewing (Hsieh *et al*, 2017; Melville *et al*, 2018; Oppewal *et al*, 2018). The study finding of a sex difference observed in the objective measurements of this study also differs from existing literature and the TV results found in this study on sex and SB which was primarily inconclusive (Westrop *et al*, 2019; Ghosh *et al*, 2021; Lynch *et al*, 2021). The literature concurs with the objective measurement results in this study that those with other

aetiologies are more sedentary than those with DS, which could be related to the numerous organisations focussed on activity promotion for those with DS e.g. Down Syndrome Ireland (Nordstrøm *et al*, 2013; Agiovlasitis *et al* 2020, Borland *et al*, 2020; Oreskovic *et al*, 2020). However using TV as a proxy for SB in this study did not show any relationship with aetiology and no other literature examined this relationship.

The total risk factors for increased SB in this study could be and were summarised in two of the SOS clusters, physical health and wellbeing and psychology and behaviour, see Figure 9.1. This summary model provides a more succinct, clear way of identifying those most at risk of increased SB than has previously been reported and offers an easily deployed focus for use in practice.

In addition, the objective measurements highlighted that increased SB was related to decreased functional capacity. A positive relationship was observed with comorbidity status and SB, where increased SB was related to having more comorbidities. A new discovery was that shorter sedentary bouts was related to the presence of less respiratory conditions. No intellectual disability literature has previously highlighted the relationship between SB and respiratory conditions in this way; instead, the literature has indicated that increased SB accumulated in longer bouts was associated with chronic lung disease and obstructive pulmonary disease (Cheng *et al*, 2020; Kandola *et al*, 2020).

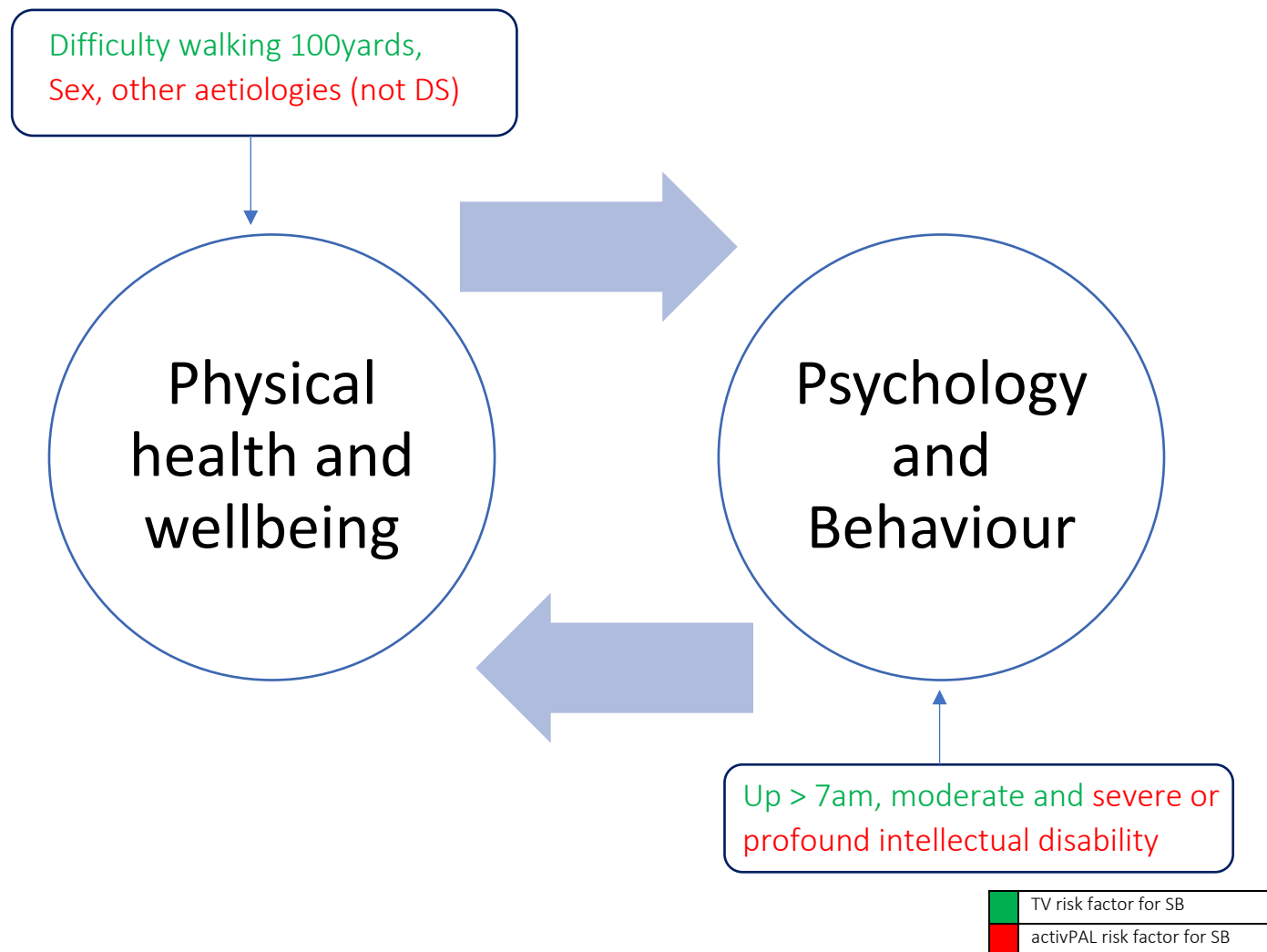


Figure 9. 12: Systems of Sedentary Behaviour model showing TV and activPAL risk factors for increased sedentary behaviour

9.4 Recommendations

Considering the results and implications from this study, a number of recommendations can be made across clinical practice, education, research and policy which could actively improve the sedentary levels in the intellectual disability population and consequently improve their functional independence and health status. In clinical practice these recommendations encompass a focus on improving functional motor skills which are the basis for all movement, the integration of frequent movement in group settings, collaborating with clinicians in the community who will ultimately be responsible for the health of people as they move to community settings, and empowering those with an intellectual disability to take ownership for moving more and sitting less.

9.4.1 Clinical practice

- Fundamental movement skill (FMS) development and maintenance

The literature showed that FMS proficiency was related to PA level and SB and it is critical that sufficient time and training be given to people with an intellectual disability to improve these basic skills, which provide a basis for all movement and activity throughout the life course.

- Addressing SB needs to begin early in life by building good activity habits and developing FMS which provide a lifelong basis for all movement and PA. Therefore specific tailored activity programs targeting children with intellectual disabilities should be established to develop their FMS and compensate for inherent differences in motor functions.
- Follow-on activity programs should be established for these children to further develop motor competence by practice and ingrain lifelong PA habits.
- People with an intellectual disability require more support. Carers and support workers may work in partnership with them to build sustainable, accessible and enjoyable activity options into their daily lives, by means of their person-centred care plan.

- Activity in day or residential group settings

Clear guidelines are urgently required to ensure that SB is minimised and engagement in more active activities is encouraged in group settings such as day service and residential settings. However the implementation of any PA programs for this population who often experience a lack of motivation and self-efficacy, need to include adaptations for cognitive and emotional limitations as well as ease of accessibility.

- The fact that those living more independently are more active should encourage staff and carers in residential settings to provide more opportunities for activity.
- A review of activities in group settings e.g. day service is necessary. It should be obligatory to include regular standing and/or more active pursuits in programs.
- People should be encouraged not to sit for extended periods for example using a Fitbit or some sort of a device to prompt people to stand up. Alternatively a game or basic movement break could easily be integrated into a schedule with minimal cost or disruption.
- Staff should encourage and assist people to stand and walk frequently, ideally every hour. The Trinity Centre for Ageing with an Intellectual Disability (TCAID) People with an intellectual disability as Physical Activity Leaders (P-PALs) program was a highly successful 3-country collaboration with over 100 individuals trained as leaders which could be used as a template to encourage movement e.g. by using videos from the programme. Furthermore, celebration days could be set-up like that organised in Trinity to celebrate a participant with DS being an Operation Transformation leader.

- Decentralised primary care in the community

The de-institutionalisation of people from residential to community settings has resulted in more reliance on community resources. Using the SOS model as a guide, the community medical profession including doctors, nurses, healthcare workers, physiotherapists and occupational therapists need to be made aware of those at the highest risk of increased SB i.e. those with a moderate intellectual disability and those with difficulty walking 100yards, who have certain behavioural life traits such as late risers, so that they may be specifically targeted for activity interventions.

- Activity should be prescribed to improve health outcomes and potentially reduce the excessive drug burden seen in this population. Generally doctors command respect and if they were to specify activity quantities and types there would be a higher chance of success. These activity recommendations could be integrated into care plans and treated like a drug prescription.
- Clinicians need to intervene as early as possible to encourage movement, more activity and less SB, ideally with children, to address FMS deficiencies.
- Frequent medication reviews are necessary in clinical practice to prevent overprescribing and overuse of drugs. Programs such as STOMP (Stopping over Medication of People with a Learning Disability, Autism or both with psychotropic medicines) which are used extensively in the UK to minimise overuse of medication, should be implemented in Ireland.
- There is a need to investigate the impact of SB on cognitive function as well as mental health overall. For example SB has been shown to negatively impact the sleep patterns of depressive adults. Therefore the elevated levels of psychological problems observed in this study which may be attributable in part to excessive SB, could be improved.

- Establishment of programs to encourage activity

The P-PALs program gave people with an intellectual disability the self-efficacy to direct classes and consequently encourage movement for themselves and their peers. There were also examples of people leading classes in a community setting. This type of approach to promoting PA and ownership of programmes and confidence in delivering PA programmes has been seen as a successful model elsewhere such as with the Pembrokeshire county council in 2022. Similarly, interventions in the general population which effectively reduced time in SB have been successful in maintaining activity levels up to four years later and should be given careful consideration for adults with an intellectual disability.

- Establish national accessible programs like P-PALS and guide and nurture people to own them.
- Identify and actively engage with organisations like Age & Opportunity that could support the rollout of these programs.

- Programs should be integrated into mainstream community programs where possible, to benefit both the general and intellectual disability populations.

9.4.2 Education on the detrimental effects of sedentary behaviour

Health promotion and education are necessary for the adult intellectual disability population, as well as their primary carers, support workers and healthcare professionals to help improve the SB situation. Policymakers, service staff, carers and people with an intellectual disability need to be educated on the detrimental effects of SB and provided with solutions to frequently break the habit of being sedentary. Carers and support workers can encourage more frequent activity and through their own behaviour can influence and lead by example for those whom they care. Education needs to be addressed for each group separately to address their differing requirements.

- Healthcare professional education
 - Undergraduate health programs particularly for nurses and doctors need to emphasise the negative effects of SB.
 - Methods to encourage the prescription of activity to those most at risk of SB should be outlined.
- Intellectual disability population education
 - Programs such as the Get Wise project at TCAID were setup to encourage those with an intellectual disability to understand their health better in an accessible way and included activities to support better health and wellbeing. These should be rolled out at a National level.
- Carers, staff and support worker education
 - Staff and carer training need to include education on the negative effects of SB.
 - Tactics to integrate regular movement into everyday life should be proposed.
 - Education needs to be provided on thyroid disease, especially for those with DS, and the fact that it may contribute to weight gain and lethargy, which may influence increased SB, and cause people to require more support and motivation to move.

- Carers and staff need to keep informed about programs such as Get Wise and P-PALs so they may best support those with an intellectual disability.

9.4.3 Policy

- Healthy Ireland Framework

The Healthy Ireland (HI) Framework mandates a program to improve the health and wellbeing of the entire Irish population. National teams have been established to drive programs for all sectors of Irish society to reduce the prevalence of chronic disease. A number of areas are targeted for example diet and exercise.

- In line with WHO recommendations, the reduction of SB should be at the forefront of this policy, together with specific activity recommendations.
- Those with an intellectual disability need to be included in the surveys and research in line with the inclusive health theme. A 'health for all' theme cannot exist if it does not include all segments of the population.
- Engage with National Policy Program lead, local authorities and local community development committees who are responsible for the implementation of the HI programs in the community.

- National Positive Ageing Strategy

The Department of Health (DOH) has a strategy to facilitate positive ageing in the Irish population, in line with the HI initiative, which was designed with inputs from a large number of organisations for older people (DOH, 2013). This policy promotes inclusion in society as well as health promotion and active participation in society. Retirement would be considered optional or staggered and older adults would be encouraged to continue in paid employment or volunteer work. The security and safety of older adults to remain independent is also a consideration.

- People with an intellectual disability need to be represented and included in these strategies. The consultation phase did not include any intellectual disability groups.
- Adults irrespective of their intellectual capacity need to move as they age.

- A Healthy Weight for Ireland – The Obesity Policy and Action Plan (2016-2025)

The strategy for obesity reduction was designed with other stakeholders, including children and young people (DOH, 2015). It has a life-course focus, specifically on children and families as well as on prevention, targeting inequalities like socio-economical. The overall strategy is multifaceted, taking a holistic approach to include education, work, community, older adults, media and primary care but food intake and PA are key aspects.

- The intellectual disability community were not involved in the consultation phase of this policy despite having equivalent or worse levels of obesity and overweight than the general population.
- In addition sedentariness should be a specified target of this strategic plan and not just PA.

- Cardiovascular health strategy

The strategy for cardiovascular health was setup for the detection, treatment and prevention of cardiovascular disease (CVD) in Ireland. It was a decade long program which expired in 2019 and was not renewed.

- Given that CVD is one of the leading causes of death in Ireland, this strategy needs to be re-established.
- People with an intellectual disability need to be specifically included in the newly established program.
- Sedentariness needs to be specifically targeted as part of the risk reduction strategy.

9.5 Opportunities for future research

- Studies should include all levels and types of intellectual disability and all mobility levels as well as OM to primarily assess SB levels and determine the exact prevalence of time spent in SB.
- Exploration and comparisons are warranted between the IDS-TILDA data IPAQ sitting question and TV question data.

- Comparisons between the RAPA questionnaire and activPAL objective measures need examination.
- Specific questions on mobile phones need to be included in questionnaires. Mobile phone use as a proxy for SB needs to be considered given the evolution of mobile phone use. Mobile phones are multifunctional devices from which TV and other streaming services are watched and games are played, aside from the video-calling capabilities and normal phone use.
- Novel opportunities exist to investigate the relationship between objectively measured SB with bone health, sleep and mental health, where limited studies exist with the intellectual disability population.
 - There are indications that SB has a negative effect on BMD, which can lead to osteopenia or osteoporosis which is highly prevalent in this population.
 - Sleep problems are common in people with an intellectual disability. Evidence suggests that SB may affect sleep quality and contribute to insomnia.
 - Poor mental health has been associated with SB and the associations found in this study with psychological issues warrants more detailed investigation.
- Other OM completed at the Health Fair on fitness and PA e.g. balance tests, could add to the exploration of SB and be used as possible indicators or predictors of the presence of excessive SB.
 - These additional measures in combination with the SB information could help establish the factors that impact on the physical fitness of people with an intellectual disability.
- Recommendations for IDS-TILDA should be that the activPAL should be worn for eight days to ensure that seven full day's measurement is obtained.
- Specific research focussing exclusively on SB and its effect on particular health aspects of adults with an intellectual disability like the excessive obesity levels, multimorbidity and metabolic syndrome are required. These studies should use OM for accuracy. Thus an in-depth understanding of the health effects of SB on adults with an intellectual disability may be achieved and suitable recommendations made to expedite change, health improvements and consequently improved quality of life for this vulnerable population.
- A detailed examination of SB effects on health stratified by PA level and type.

9.6 Planned activity

9.6.1 Planned publications

- An investigation into the risk factors for increased TV viewing in the intellectual disability population and the identification of a framework to structure results.
- A longitudinal exploration of self-reported TV behaviours as a surrogate for SB in older adults with an intellectual disability from the IDS-TILDA study.
- To compare the self-reported SB levels of older adults with an intellectual disability using the International Physical Activity Questionnaire (IPAQ) and Rapid Assessment of Physical Activity (RAPA) questionnaires
- To compare objectively measured activity levels with the self-reported IPAQ activity levels in older adults with an intellectual disability as part of the IDS-TILDA study. Sedentary behaviour was measured using an activPAL device.
- To measure the relationship between objectively measured SB and age, sex, level of intellectual disability, living circumstances, comorbidities and functional capabilities

9.6.2 Planned further work and post-doctoral targets

- Hone academic and research skills with a focus on SB in the intellectual disability population.
- The examination and comparison of the IDS-TILDA Wave 5 OM using the activPAL to verify the results seen in this study with a larger sample size.
- Grant applications will be sought to support the extension of this study.

9.7 Study strengths

- This study has a large nationally representative sample of participants of all ranges of intellectual disability, age and residence types from across Ireland.
- New areas have been investigated as part of the research into SB in older adults with an intellectual disability and novel risk factors discovered.
- Overall results imbue confidence as they are based on OM.

9.8 Study limitations

- While the TV question used in this study is similar to other TV questions used in research, and found to be of high reliability, the literature has found that people underestimated the amount of time they spent watching TV so it is possible that the above results are an underrepresentation of the actual amount of time spent watching TV. Thus the SB levels are most likely even higher in this cohort of older adults with an intellectual disability.
- Covid-19 caused the premature cessation of the Health Fair therefore not all participants had the opportunity to engage, which limited the sample.
- The systematic review illustrated that studies were not fully representative of the intellectual disability population as often do not include those who have mobility issues or those with more severe levels of intellectual disability.
- For the systematic review calculations, a sleep time of 9 hours per night was assumed, to coincide with the literature, but this was less than the sleep time objectively measured in this study and may not be an accurate representation of the sleep patterns overall.
- Adaptations and prompts suggested to researchers when administering the questionnaires were executed at the researcher's discretion .

9.9 Conclusion

This concluding chapter illustrates how the study research question ‘What is the prevalence of SB in adults with an intellectual disability and how does this affect their physical health ‘ was answered and the objectives achieved. The prevalence of SB in the intellectual disability population was initially determined through the literature with a systematic review and meta-analysis, through self-reported TV habits and finally with OM using an activPAL device. This scrutiny of the data in a systematic manner ensured that a thorough interrogation of all data were completed to warrant confidence in the final results and conclusions. The new results were pooled with the original meta-analysis to see if the new data had an impact on the overall pooled prevalence. To ensure thoroughness and the possibility of replication by other researchers, when identifying or establishing health status a scoping review was initiated, which provided evidence that SB could be a contributor to the bad health observed in the intellectual disability population. The health status of participants was evaluated in a number of different ways. To facilitate direct comparison with other studies a comorbidity index, CIRS-G and functional index, BI were used and these were compared to the OM of SB. In addition individual health conditions were examined against the objectively measured SB variables. A model, based on the SOS framework, is proposed to identify those most at risk of increased SB. This study demonstrated that people with an intellectual disability have high levels of sedentariness that can negatively affect their health. Extended time in SB was shown to have detrimental effects on functional independence and lead to increased chronic conditions. However reducing SB is not difficult. There are an infinite number of ways that people can replace time in SB with low levels of activity to enjoy health benefits which will not incur costs or require lots of planning. Standing up more often, ideally at least every hour is a simple solution to breaking the sedentary cycle but the overall message is to move more and more often.

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Appendix

Appendix 2.1

PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) checklist:
recommended items to address in a systematic review protocol* : **Sedentary behaviour levels in adults
with an intellectual disability: a systematic review protocol**

Section and topic	Item No	Checklist item
ADMINISTRATIVE INFORMATION		
Title:		
Identification	1a	Identify the report as a protocol of a systematic review: <i>Included in title</i>
Update	1b	If the protocol is for an update of a previous systematic review, identify as such: <i>NA</i>
Registration	2	<i>Registered with PROSPERO. Registration number: CRD42020177225</i>
Authors:		
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author. <i>This is included in the first section under the review title.</i>
Contributions	3b	Describe contributions of protocol authors: <i>Included after author details</i> and identify the guarantor of the review: <i>Dr Eilish Burke</i>
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments: <i>NA</i>
Support:		
Sources	5a	Indicate sources of financial or other support for the review: <i>Health Research Board Ireland Grant/Award Number: mcrrm-HRB-IDS-TILDA-2018-1 (208808.15703); Trinity College Dublin; Department of Health.</i>
Sponsor	5b	Provide name for the review funder and/or sponsor: <i>Health Research Board</i>
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol. <i>None</i>
INTRODUCTION		
Rationale	6	Describe the rationale for the review in the context of what is already known. <i>Included in Introduction, section 1.1</i>
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO): <i>Section 1.2</i>
METHODS		
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review. <i>See Section 2.1</i>
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage. <i>Section 2.3 Information sources</i>
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated. <i>See Section 2.4 Search Strategy</i>
Study records:		
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review. <i>See Section 3.1 Data Management</i>

Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis). <i>See Section 3.2 Selection Process</i>
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators. <i>See Section 3.3 Data Collection process</i>
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications. <i>See Section 3.4 Data items</i>
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale. <i>See Section 3.5 Outcomes and prioritisation</i>
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis. <i>See Section 2.4.3. Quality assessment and risk of bias</i>
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised. <i>See Section 3.6 Data Synthesis</i>
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2 , Kendall's τ). <i>TBC</i>
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression). <i>Section 3.6 Data synthesis and Section 3.7 Confidence in cumulative evidence</i>
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned. <i>See Section 3.6 Data synthesis. Thematic analysis.</i>
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies). <i>See Section 3.6 Data Synthesis</i>
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE). <i>Section 3.7 Confidence in cumulative evidence</i>

*** It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (cite when available) for important clarification on the items. Amendments to a review protocol should be tracked and dated. The copyright for PRISMA-P (including checklist) is held by the PRISMA-P Group and is distributed under a Creative Commons Attribution Licence 4.0.**

From: Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart L, PRISMA-P Group. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. BMJ. 2015 Jan 2;349(jan02 1):g7647.

Appendix 2.2

Quality Assessment Tool for controlled trials

- Study Quality Assessment Tools

Criteria:	Yes	No	Other (CD, NR, NA)*
1. Was the study described as randomised, a randomised trial, a randomised clinical trial or a RCT? 1.1 Was the method of randomisation adequate (i.e. use of randomly generated assignment)?			
2. Was the study described as a controlled trial? 2.2 Was the control group matched on relevant variables (age, sex, education, disorder)?			
3. Was the overall dropout rate from the study at endpoint 20% or lower of the number allocated to the intervention?			
4. Was the differential drop-out rate (between groups) at endpoint 15% points or lower?			
5. Was there high adherence to the intervention protocols for each treatment group? (defined as 75% attendance or more)			
6. Were other interventions avoided or similar in the groups?			
7. Were outcomes assessed using valid and reliable measures?			
8. Were outcomes measured consistently across all study participants?			

Criteria:	Yes	No	Other (CD, NR, NA)*
9. Did the authors report that the sample size was sufficiently large to be able to detect a difference in the main outcome between groups with at least 80% power?			
10. Were outcomes reported or subgroups analysed prespecified (i.e. identified before analyses were conducted)?			
11. For RCTs: Were all randomised participants analysed in the group to which they were originally assigned i.e. did they use an intention-to-treat analysis? 11.1 For controlled trials: was a recognised statistical method employed? (recognised methods defined as did-in-dif, regression discontinuity, propensity score matching, instrumental variables)			
Total score: Number of YES			
Overall Quality Rating (Good, Fair, Poor)			
Quality Rating (Good, Fair, or Poor)			
Rater #1 initials: LL,			
Rater #2 initials:			
Additional Comments (If POOR, please state why):			

*CD, cannot determine; NA, not applicable; NR, not reported

Appendix 2.3

Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

- Study Quality Assessment Tools

Criteria:	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?			
2. Was the study population clearly specified and defined?			
3. Was the participation rate of eligible persons at least 50%?			
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?			
5. Was a sample size justification, power description, or variance and effect estimates provided?			
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?			
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			

Criteria:	Yes	No	Other (CD, NR, NA)*
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
10. Was the exposure(s) assessed more than once over time?			
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
12. Were the outcome assessors blinded to the exposure status of participants?			
13. Was loss to follow-up after baseline 20% or less?			
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?			

Quality Rating (Good, Fair, or Poor)
Rater #1 initials:
Rater #2 initials:

Quality Rating (Good, Fair, or Poor)

Additional Comments (If POOR, please state why):

*CD, cannot determine; NA, not applicable; NR, not reported

Guidance for Assessing the Quality of Observational Cohort and Cross-Sectional Studies

The guidance document below is organized by question number from the tool for quality assessment of observational cohort and cross-sectional studies.

Question 1. Research question

Did the authors describe their goal in conducting this research? Is it easy to understand what they were looking to find? This issue is important for any scientific paper of any type. Higher quality scientific research explicitly defines a research question.

Questions 2 and 3. Study population

Did the authors describe the group of people from which the study participants were selected or recruited, using demographics, location, and time period? If you were to conduct this study again, would you know who to recruit, from where, and from what time period? Is the cohort population free of the outcomes of interest at the time they were recruited?

An example would be men over 40 years old with type 2 diabetes who began seeking medical care at Phoenix Good Samaritan Hospital between January 1, 1990 and December 31, 1994. In this example, the population is clearly described as: (1) who (men over 40 years old with type 2 diabetes); (2) where (Phoenix Good Samaritan Hospital); and (3) when (between January 1, 1990 and December 31, 1994). Another example is women ages 34 to 59 years of age in 1980 who were in the nursing profession and had no known coronary disease, stroke, cancer, hypercholesterolemia, or diabetes, and were recruited from the 11 most populous States, with contact information obtained from State nursing boards.

In cohort studies, it is crucial that the population at baseline is free of the outcome of interest. For example, the nurses' population above would be an appropriate group in which to study incident coronary disease. This information is usually found either in descriptions of population recruitment, definitions of variables, or inclusion/exclusion criteria.

You may need to look at prior papers on methods in order to make the assessment for this question. Those papers are usually in the reference list.

If fewer than 50% of eligible persons participated in the study, then there is concern that the study population does not adequately represent the target population. This increases the risk of bias.

Question 4. Groups recruited from the same population and uniform eligibility criteria

Were the inclusion and exclusion criteria developed prior to recruitment or selection of the study population? Were the same underlying criteria used for all of the subjects involved? This issue is related to the description of the study population, above, and you may find the information for both of these questions in the same section of the paper.

Most cohort studies begin with the selection of the cohort; participants in this cohort are then measured or evaluated to determine their exposure status. However, some cohort studies may recruit or select exposed participants in a different time or place than unexposed participants, especially retrospective cohort studies—which is when data are obtained from the past (retrospectively), but the analysis examines exposures prior to outcomes. For example, one research question could be whether diabetic men with clinical depression are at higher risk for cardiovascular disease than those without clinical depression. So, diabetic men with depression might be selected from a mental health clinic, while diabetic men without depression might be selected from an internal medicine or endocrinology clinic. This study recruits groups from different clinic populations, so this example would get a "no."

However, the women nurses described in the question above were selected based on the same inclusion/exclusion criteria, so that example would get a "yes."

Question 5. Sample size justification

Did the authors present their reasons for selecting or recruiting the number of people included or analyzed? Do they note or discuss the statistical power of the study? This question is about whether or not the study had enough participants to detect an association if one truly existed.

A paragraph in the methods section of the article may explain the sample size needed to detect a hypothesized difference in outcomes. You may also find a discussion of power in the discussion section (such as the study had 85 percent power to detect a 20 percent increase in the rate of an outcome of interest, with a 2-sided alpha of 0.05). Sometimes estimates of variance and/or estimates of effect size are given, instead of sample size calculations. In any of these cases, the answer would be "yes."

However, observational cohort studies often do not report anything about power or sample sizes because the analyses are exploratory in nature. In this case, the answer would be "no." This is not a "fatal flaw." It just may indicate that attention was not paid to whether the study was sufficiently sized to answer a prespecified question—i.e., it may have been an exploratory, hypothesis-generating study.

Question 6. Exposure assessed prior to outcome measurement

This question is important because, in order to determine whether an exposure causes an outcome, the exposure must come before the outcome.

For some prospective cohort studies, the investigator enrolls the cohort and then determines the exposure status of various members of the cohort (large epidemiological studies like Framingham used this approach). However, for other cohort studies, the cohort is selected based on its exposure status, as in the example above of depressed diabetic men (the exposure being depression). Other examples include a cohort identified by its exposure to fluoridated drinking water and then compared to a cohort living in an area without fluoridated water, or a cohort of military personnel exposed to combat in the Gulf War compared to a cohort of military personnel not deployed in a combat zone.

With either of these types of cohort studies, the cohort is followed forward in time (i.e., prospectively) to assess the outcomes that occurred in the exposed members compared to nonexposed members of the cohort. Therefore, you begin the study in the present by looking at groups that were exposed (or not) to some biological or behavioral factor, intervention, etc., and then you follow them forward in time to examine outcomes. If a cohort study is conducted properly, the answer to this question should be "yes," since the exposure status of members of the cohort was determined at the beginning of the study before the outcomes occurred.

For retrospective cohort studies, the same principal applies. The difference is that, rather than identifying a cohort in the present and following them forward in time, the investigators go back in time (i.e., retrospectively) and select a cohort based on their exposure status in the past and then follow them forward to assess the outcomes that occurred in the exposed and nonexposed cohort members. Because in retrospective cohort studies the exposure and outcomes may have already occurred (it depends on how long they follow the cohort), it is important to make sure that the exposure preceded the outcome.

Sometimes cross-sectional studies are conducted (or cross-sectional analyses of cohort-study data), where the exposures and outcomes are measured during the same timeframe. As a result, cross-sectional analyses provide weaker evidence than regular cohort studies regarding a potential causal relationship between exposures and outcomes. For cross-sectional analyses, the answer to Question 6 should be "no."

Question 7. Sufficient timeframe to see an effect

Did the study allow enough time for a sufficient number of outcomes to occur or be observed, or enough time for an exposure to have a biological effect on an outcome? In the examples given above, if clinical depression has a biological effect on increasing risk for CVD, such an effect may take years. In the other example, if higher dietary sodium increases BP, a short timeframe may be sufficient to assess its association with BP, but a longer timeframe would be needed to examine its association with heart attacks.

The issue of timeframe is important to enable meaningful analysis of the relationships between exposures and outcomes to be conducted. This often requires at least several years, especially when looking at health outcomes, but it depends on the research question and outcomes being examined.

Cross-sectional analyses allow no time to see an effect, since the exposures and outcomes are assessed at the same time, so those would get a "no" response.

Question 8. Different levels of the exposure of interest

If the exposure can be defined as a range (examples: drug dosage, amount of physical activity, amount of sodium consumed), were multiple categories of that exposure assessed? (for example, for drugs: not on the medication, on a low dose, medium dose, high dose; for dietary sodium, higher than average U.S. consumption, lower than recommended consumption, between the two). Sometimes discrete categories of exposure are not used, but instead exposures are measured as continuous variables (for example, mg/day of dietary sodium or BP values).

In any case, studying different levels of exposure (where possible) enables investigators to assess trends or dose-response relationships between exposures and outcomes—e.g., the higher the exposure, the greater the rate of the health outcome. The presence of trends or dose-response relationships lends credibility to the hypothesis of causality between exposure and outcome.

For some exposures, however, this question may not be applicable (e.g., the exposure may be a dichotomous variable like living in a rural setting versus an urban setting, or vaccinated/not vaccinated with a one-time vaccine). If there are only two possible exposures (yes/no), then this question should be given an "NA," and it should not count negatively towards the quality rating.

Question 9. Exposure measures and assessment

Were the exposure measures defined in detail? Were the tools or methods used to measure exposure accurate and reliable—for example, have they been validated or are they objective? This issue is important as it influences confidence in the reported exposures. When exposures are measured with less accuracy or validity, it is harder to see an association between exposure and outcome even if one exists. Also as important is whether the exposures were assessed in the same manner within groups and between groups; if not, bias may result.

For example, retrospective self-report of dietary salt intake is not as valid and reliable as prospectively using a standardized dietary log plus testing participants' urine for sodium content. Another example is measurement of BP, where there may be quite a difference between usual care, where clinicians measure BP however it is done in their practice setting (which can vary considerably), and use of trained BP assessors using standardized equipment (e.g., the same BP device which has been tested and calibrated) and a standardized protocol (e.g., patient is seated for 5 minutes with feet flat on the floor, BP is taken twice in each arm, and all four measurements are averaged). In each of these cases, the former would get a "no" and the latter a "yes."

Here is a final example that illustrates the point about why it is important to assess exposures consistently across all groups: If people with higher BP (exposed cohort) are seen by their providers more frequently than those without elevated BP (nonexposed group), it also increases the chances of detecting and documenting changes in health outcomes, including CVD-related events. Therefore, it may lead to the conclusion that higher BP leads to more CVD events. This may be true, but it could also be due to the fact that the subjects with higher BP were seen more often; thus, more CVD-related events were detected and documented simply because they had more encounters with the health care system. Thus, it could bias the results and lead to an erroneous conclusion.

Question 10. Repeated exposure assessment

Was the exposure for each person measured more than once during the course of the study period? Multiple measurements with the same result increase our confidence that the exposure status was correctly classified. Also, multiple measurements enable investigators to look at changes in exposure over time, for example, people who ate high dietary sodium throughout the followup period, compared to those who started out high then reduced their intake, compared to those who ate low sodium throughout. Once again, this may not be applicable in all cases. In many older studies, exposure was measured only at baseline. However, multiple exposure measurements do result in a stronger study design.

Question 11. Outcome measures

Were the outcomes defined in detail? Were the tools or methods for measuring outcomes accurate and reliable—for example, have they been validated or are they objective? This issue is important because it influences confidence in the validity of study results. Also important is whether the outcomes were assessed in the same manner within groups and between groups.

An example of an outcome measure that is objective, accurate, and reliable is death—the outcome measured with more accuracy than any other. But even with a measure as objective as death, there can be differences in the accuracy and reliability of how death was assessed by the investigators. Did they base it on an autopsy report, death certificate, death registry, or report from a family member? Another example is a study of whether dietary fat intake is related to blood cholesterol level (cholesterol level being the outcome), and the

cholesterol level is measured from fasting blood samples that are all sent to the same laboratory. These examples would get a "yes." An example of a "no" would be self-report by subjects that they had a heart attack, or self-report of how much they weigh (if body weight is the outcome of interest). Similar to the example in Question 9, results may be biased if one group (e.g., people with high BP) is seen more frequently than another group (people with normal BP) because more frequent encounters with the health care system increases the chances of outcomes being detected and documented.

Question 12. Blinding of outcome assessors

Blinding means that outcome assessors did not know whether the participant was exposed or unexposed. It is also sometimes called "masking." The objective is to look for evidence in the article that the person(s) assessing the outcome(s) for the study (for example, examining medical records to determine the outcomes that occurred in the exposed and comparison groups) is masked to the exposure status of the participant. Sometimes the person measuring the exposure is the same person conducting the outcome assessment. In this case, the outcome assessor would most likely not be blinded to exposure status because they also took measurements of exposures. If so, make a note of that in the comments section.

As you assess this criterion, think about whether it is likely that the person(s) doing the outcome assessment would know (or be able to figure out) the exposure status of the study participants. If the answer is no, then blinding is adequate. An example of adequate blinding of the outcome assessors is to create a separate committee, whose members were not involved in the care of the patient and had no information about the study participants' exposure status. The committee would then be provided with copies of participants' medical records, which had been stripped of any potential exposure information or personally identifiable information. The committee would then review the records for prespecified outcomes according to the study protocol. If blinding was not possible, which is sometimes the case, mark "NA" and explain the potential for bias.

Question 13. Followup rate

Higher overall followup rates are always better than lower followup rates, even though higher rates are expected in shorter studies, whereas lower overall followup rates are often seen in studies of longer duration. Usually, an acceptable overall followup rate is considered 80 percent or more of participants whose exposures were measured at baseline. However, this is just a general guideline. For example, a 6-month cohort study examining the relationship between dietary sodium intake and BP level may have over 90 percent followup, but a 20-year cohort study examining effects of sodium intake on stroke may have only a 65 percent followup rate.

Question 14. Statistical analyses

Were key potential confounding variables measured and adjusted for, such as by statistical adjustment for baseline differences? Logistic regression or other regression methods are often used to account for the influence of variables not of interest.

This is a key issue in cohort studies, because statistical analyses need to control for potential confounders, in contrast to an RCT, where the randomization process controls for potential confounders. All key factors that may be associated both with the exposure of interest and the outcome—that are not of interest to the research question—should be controlled for in the analyses.

For example, in a study of the relationship between cardiorespiratory fitness and CVD events (heart attacks and strokes), the study should control for age, BP, blood cholesterol, and body weight, because all of these factors are associated both with low fitness and with CVD events. Well-done cohort studies control for multiple potential confounders.

Some general guidance for determining the overall quality rating of observational cohort and cross-sectional studies

The questions on the form are designed to help you focus on the key concepts for evaluating the internal validity of a study. They are not intended to create a list that you simply tally up to arrive at a summary judgment of quality.

Internal validity for cohort studies is the extent to which the results reported in the study can truly be attributed to the exposure being evaluated and not to flaws in the design or conduct of the study—in other words, the ability of the study to draw associative conclusions about the effects of the exposures being studied on outcomes. Any such flaws can increase the risk of bias.

Critical appraisal involves considering the risk of potential for selection bias, information bias, measurement bias, or confounding (the mixture of exposures that one cannot tease out from each other). Examples of

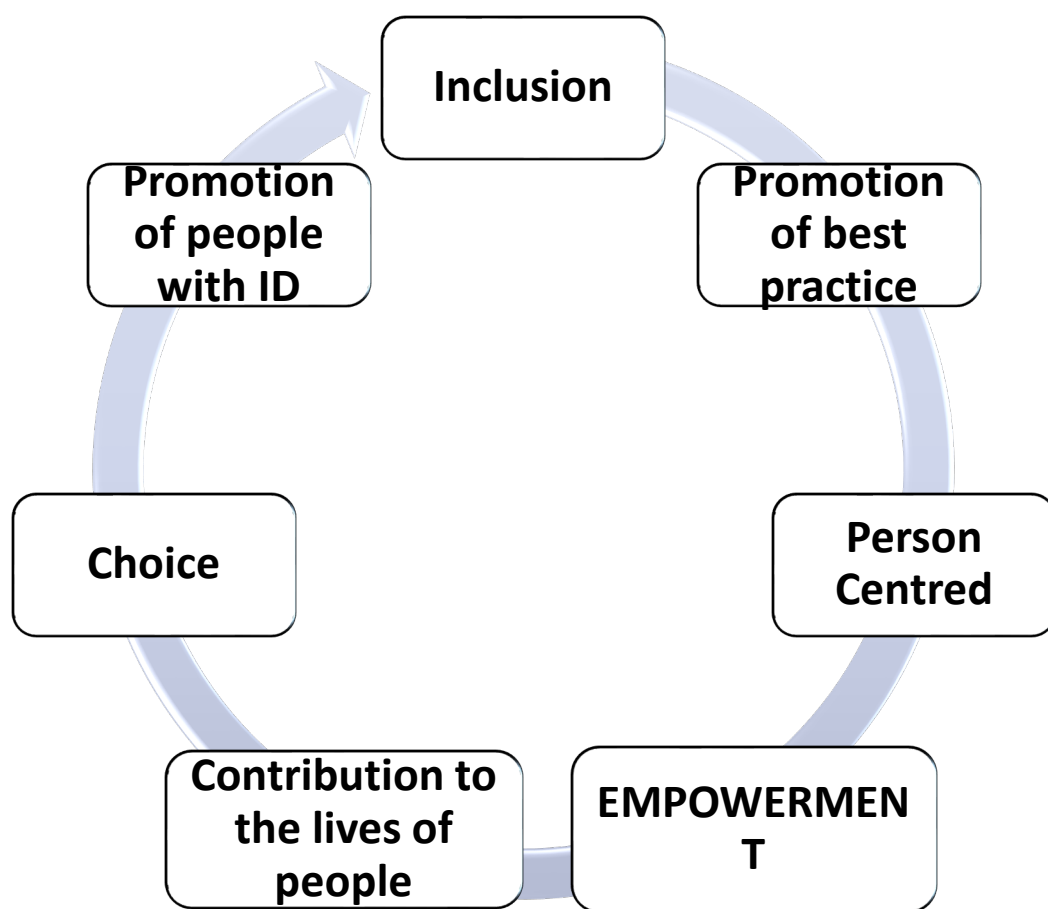
confounding include co-interventions, differences at baseline in patient characteristics, and other issues throughout the questions above. High risk of bias translates to a rating of poor quality. Low risk of bias translates to a rating of good quality. (Thus, the greater the risk of bias, the lower the quality rating of the study.)

In addition, the more attention in the study design to issues that can help determine whether there is a causal relationship between the exposure and outcome, the higher quality the study. These include exposures occurring prior to outcomes, evaluation of a dose-response gradient, accuracy of measurement of both exposure and outcome, sufficient timeframe to see an effect, and appropriate control for confounding—all concepts reflected in the tool.

Generally, when you evaluate a study, you will not see a "fatal flaw," but you will find some risk of bias. By focusing on the concepts underlying the questions in the quality assessment tool, you should ask yourself about the potential for bias in the study you are critically appraising. For any box where you check "no" you should ask, "What is the potential risk of bias resulting from this flaw in study design or execution?" That is, does this factor cause you to doubt the results that are reported in the study or doubt the ability of the study to accurately assess an association between exposure and outcome?

The best approach is to think about the questions in the tool and how each one tells you something about the potential for bias in a study. The more you familiarize yourself with the key concepts, the more comfortable you will be with critical appraisal. Examples of studies rated good, fair, and poor are useful, but each study must be assessed on its own based on the details that are reported and consideration of the concepts for minimizing bias.

Appendix 4.1: IDS-TILDA values frame



Appendix 4.2: Wave 1 ethical approval



THE UNIVERSITY OF DUBLIN

TRINITY COLLEGE

SCHOOL OF MEDICINE

FACULTY OF HEALTH SCIENCES

Professor Dermot Kelleher, MD, FRCPI, FRCP, F Med Sci
Head of School of Medicine
Vice Provost for Medical Affairs

Ms. Fedelma McNamara
School Administrator

Trinity College, Dublin 2, Ireland

Tel: +353 1 896 1476

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Email: medicine@tcd.ie

Email: fmcnamar@tcd.ie

Prof. Mary McCarron
School of Nursing and Midwifery,
Trinity College Dublin,
24 D'Olier Street, Dublin 2

10th July, 2008

**Study Title: An Intellectual Disability Supplement to the Irish Longitudinal Study
on Ageing (TILDA)**

Dear Prof. McCarron,

Further to the meeting of the Faculty of Health Sciences Research Ethics Committee on 27th May 2008, I am pleased to inform you that the above project has been approved without further audit.

Yours sincerely,

Dr. Orla Sheils
Chairperson
Faculty of Health Sciences Ethics Committee

Appendix 4.3: Wave 2 ethical approval



TRINITY COLLEGE DUBLIN
The University of Dublin
Research Ethics Committee
Faculty of Health Sciences,
Chemistry Building,
Trinity College,
Dublin 2, Ireland.
T: +353 (0)1 8964255

Professor Mary McCarron
Dean of the Faculty of Health Sciences and Principal Investigator of IDS-TILDA,
Chemistry Building,
Trinity College Dublin,
Dublin 2.

28 January 2013

Study: Intellectual Disability to the Irish Longitudinal Study on Ageing (IDS-TILDA) – Wave 2

Dear Professor McCarron,

Further to the review of the modifications submitted for the IDS-TILDA Study Wave 2, I am pleased to inform you that ethical approval has been granted by the Faculty of Health Sciences Research Ethics Committee.

Wishing you the best of luck with your study

Yours sincerely,

Dr. Ruth Pilkington
Chairperson
Faculty Research Ethics Committee

Appendix 4.4: Wave 3 ethical approval



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin

Ollscoil Átha Cliath | The University of Dublin

Prof. Mary McCarron,
Intellectual Disability Supplement to TILDA
School of Nursing and Midwifery
2 Clare Street
Trinity College
Dublin Dublin 2.

Ref: 151208

**Title of Study: WAVE 3 - AN INTELLECTUAL DISABILITY SUPPLEMENT TO THE
IRISH LONGITUDINAL STUDY ON AGEING (herein referred to as
IDS-TILDA)**

Dear Prof. McCarron,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in
January 2016, we are pleased to inform you that the above project has been
approved without further audit.

Yours sincerely,

PP Brian Brown

Prof. Brian O'Connell
Chairperson
Faculty Research Ethics Committee

Appendix 4.5: Wave 4 ethical approval



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin

Ollscoil Átha Cliath | The University of Dublin

School of Nursing & Midwifery,
Trinity College,
2 Clare Street,
Dublin 2

23rd January 2019

Ref: 181210

Title of Study: An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (hereafter IDS-TILDA)

Dear Prof McCarron,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in December 2018. We are pleased to inform you that the above project has ethical approval to proceed.

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'pp Brian O'Connell'.

Prof. Brian O'Connell Chairperson
Faculty Research Ethics Committee

Appendix 4.6

Data protection Training certificate



Appendix 4.7

Epigeum data integrity training certificate



Appendix 4.8

IDS-TILDA Data statement

IDS-TILDA is hosted by the Trinity Centre for Ageing and Intellectual Disability (TCAID). The aim of TCAID is to address the inequalities and health disparities that occur for people with intellectual disability as they age. We do this by conducting rigorous engaged research on the physical and social determinants of health and wellbeing and translation of findings to inform models of policy and practice. To do this work, we gather, store and use 'personal data' such as names, email addresses, photographs and telephone numbers. All data are important to us and we always aim to treat them in a clear, secure manner as a way of respecting the people who gave us the data about themselves.

IDS-TILDA Data

While we already provide information in our cover letter, our information leaflets and on our consent forms, we want to ensure that we can keep everyone informed on all aspects of how we work. In December 2018, the Department of Health issued a document called 'Guidance on Information Principles for informed consent for the processing of personal data for health research'. Prompted by this guidance, we are happy to share the following information:

1. General

Title and Purpose of the Research

IDS-TILDA is the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.

It is a longitudinal study researching ageing in Ireland among people with an intellectual disability aged 40 and over. The aim of the study is to identify the principal influences on successful ageing in persons with an intellectual disability, and then determine if they are the same or different from the influences for the general population.

Personal Data Collected and Used

Name; address; phone number; age; date of birth; living arrangements; friendship and family; quality of relationships; social activities; physical, mental and cognitive health; health care utilisation; medication, occupation and functional limitations. In addition, personal physical health measures and biological samples will be collected to include -

Activity patterns; Blood drop sample; Blood pressure; Bone density; Breath; Calf circumference; Cognitive functioning; Foot health; Grip strength; Hair sample; Height; Mobility and falls risk; Nutritional health; Oral health; Waist and hip measurement; Weight.

Using Pseudonymised Data

IDS-TILDA removes information like name, address, contact details, etc. from the collected data. This information is kept apart from the other data so that the person cannot be identified. This process is called pseudonymisation. Pseudonymised data is used in IDS-TILDA because the researchers need to go back to the same people during the next wave of data collection and must have a way of keeping in touch with them.

Benefits of IDS-TILDA

The purpose of IDS-TILDA is to understand the ageing process for people with an intellectual disability, what health conditions they have and how this relates to the wider determinants of health and wellbeing such as social contact, living arrangements, etc. This research endeavours to inform policy and practice in the area of intellectual disability so that both the State and services can be better equipped to support healthy ageing among this population.

Finding Out about Health

Anyone who takes part in the IDS-TILDA Health Fair is provided with a report card on data gathered. This information may lead them to take action about any of these results. People also have a choice about whether they give samples of blood, hair or breath. If they agree, they can request the results. If, after analysis, the sample shows something unexpected, the person will be informed.

Giving Consent

IDS-TILDA seeks consent on an ongoing basis throughout the data gathering process – we call this ‘process consent’. We check that consent is given freely and voluntarily. If someone decides not to consent, it will have no adverse consequences. People can also withdraw their consent by contacting the Project Manager, Margaret Haigh at the contact details below – by letter, by email or by phone. Personal information will be deleted from the dataset, apart from any data that has already been analysed or in the process of being published.

Complaints

If someone involved in IDS-TILDA would like to make a complaint, they can do so by contacting the Project Manager, Margaret Haigh at the contact details below – by letter, by email or by phone.

2. Details on who is conducting the research

Data Controller

The data controller for this research is Trinity College Dublin and the Data Protection Officer:

Data Protection Officer

Secretary's Office, Trinity College Dublin

Dublin 2, Ireland.

Principal Investigators

IDS-TILDA has two Principal Investigators for the study. Prof Mary McCarron is Professor of Ageing & Intellectual Disability in the School of Nursing and Midwifery and is the Director of the Trinity Centre for Ageing and Intellectual Disability. Prof Philip McCallion is Director of the School of Social Work in Temple University, Philadelphia. He is a visiting Professor at Trinity College Dublin.

Prof Mary McCarron

Trinity Centre for Ageing and Intellectual Disability

2 Clare Street

Dublin 2

D02 CK80

Tel: + 353 1 896 3186

Prof Philip McCallion

c/o Office of Admissions

College of Public Health

1101 W. Montgomery Avenue

Suite 370

Philadelphia

PA 19122

Tel: + 215 204 5806

Data Processors

A data processor is used to hold and process data which has been gathered by researchers in the field. One of the data processors is engaged to design the CAPI (Computer Assisted Personal Interviewing) data collection tool which will be used in face-to-face interviews. It holds the data securely until such time as it is transferred to the appropriate secure servers within Trinity College Dublin.

This data processor for Wave 4 is Behaviour & Attitudes, Milltown House, Mount St Annes, Milltown, Dublin 6, D06 Y822. This company acted as data processor in Wave 3 of the study and has the skills and expertise needed to fulfil this role. Behaviour & Attitudes subcontract work to two data management companies: IT Force, 27 Fitzwilliam Street Upper, Dublin 2, D02 TP23; and Kefron, 53 Park W Rd, Cherry Orchard, Dublin, D12 F8RK.

A number of other data processors are used in order to hold and process data which has been collected during the Health Fair. This is due to the fact that the study itself does not have the capacity to analyse the samples provided.

The data processors for Health Fair data in Wave 4 are: for blood samples, MedLab Pathology, Unit 3, Sandyford Business Centre, Sandyford Business Park, Dublin 18; for breath samples, Biochemistry Department, Laboratory Medicine Directorate, St. James's Hospital, James's Street, Dublin 8; for dietary information Open Lab, Floor 1, Urban Sciences Building, 1 Science Square, Science Central, Newcastle Upon Tyne, NE4 5TG, United Kingdom; for hair follicle samples, Dresden LabService GmbH, Tatzberg 47-49, D-01307 Dresden, Germany.

Physical activity / sedentary behaviour information will also be gathered using devices and software created by PAL Technologies Ltd (50 Richmond Street, Glasgow G1 1XP, Scotland, UK) but they will not have any access to the data gathered using their devices or software.

In addition, interviews carried out as part of the End-of-Life part of IDS-TILDA research will be transcribed by Audiotrans, 25 Pinelawn, Oldbawn, Tallaght, Co. Dublin, D24 KX4P, a company specialising in transcription of research material.

IDS-TILDA also uses couriers to ensure that secure information is delivered straight to the IDS-TILDA offices. For international packages, IDS-TILDA will use FDS Worldwide and for Ireland-wide deliveries, IDS-TILDA will use Cyclone.

Confidentiality

All researchers involved in the gathering or analysis of IDS-TILDA are bound by the rules and regulations that protect the identity of anyone involved in the research.

Funding

IDS-TILDA is funded by the Health Research Board and the Department of Health. These funders do not have access to any of the data provided for the study.

Data Protection Training

All staff in the Trinity Centre for Ageing and Intellectual Disability and researchers using IDS-TILDA data must complete the online module on GDPR provided by Trinity College Dublin. All field workers are also provided with a half-day workshop on the influence of GDPR and research integrity on IDS-TILDA as part of their comprehensive training to participate in IDS-TILDA.

3. Obtaining, use, storage and disclosure of personal data

Data from Healthcare Providers

Principal data will be collected, with consent, from those involved in the study, i.e. people with an intellectual disability, their family members or carers. In certain cases, key workers employed by disability support services may support the person to participate in IDS-TILDA.

Processing Promise

Personal data will be processed only as is necessary to achieve the objectives of IDS-TILDA and will not be processed in a way that damage or distress will be caused to the data subject.

Duration of Data Retention

As this is a longitudinal study, all data will be retained for the duration of the study plus a further five years, in a pseudonymised format. By its nature, this study compares data over different waves of the study and the data from early waves must remain available to researchers in order to compare with data from later waves.

At the End of the Study

While IDS-TILDA is in progress, the data will remain pseudonymised and available to TCAID / IDS-TILDA researchers for analysis. Any personal contact information will be available to core IDS-TILDA staff only for the purposes of the logistics of the study. On completion of the study, the data will be fully anonymised and a review will take place of what data could be archived in a public repository which would not identify any living participants of the study.

Disclosure of Data

Any relevant contact data is disclosed to a data processor (currently Behaviour & Attitudes) for supply to an IDS-TILDA field researcher in order to identify interviewees for the study. All data collected by the IDS-TILDA field researchers is also handled by that data processor for the sole purpose of supply to IDS-TILDA.

Once the data is gathered, it is no longer retained by the data processor or any field researcher. The data is then only disclosed to researchers working with the IDS-TILDA team and is not disclosed to anyone external to that group.

For the health fair information, pseudonymised samples are created. These are then supplied to data processors for analysis, without any other personal data. Once analysis by the processor is complete, samples are destroyed and results are returned to IDS-TILDA. In any case where a data processor wishes to retain data, it will be done with the explicit consent of the person who supplied the sample.

Non-Commercial Purposes

No data will be used or disclosed for commercial purposes. In the event of any commercial use being proposed, re-consent would be sought.

Data Security

All paper copies of data are held in locked filing cabinets in secure, alarmed offices in the Trinity Centre for Ageing and Intellectual Disability.

All electronic copies of data are held in secure folders on the TCAID server only accessible by a small number of TCAID staff.

Risk Assessment

A Data Protection Impact Assessment, which identifies whether there are any risks involved in research such as IDS-TILDA, is being carried out.

Data Leaving the State

None of the data from the main study is intended to leave the State. Data gathered from the Health Fair will be sent to data processors in the UK and in Germany for analysis. This data will be pseudonymised prior to sending.

4. Research Ethics Committee

Ethical Approval was granted in December 2018 by:

Health Sciences Ethics Committee

Health Sciences' Faculty Office

Ground Floor, Chemistry Building

Trinity College Dublin, Dublin 2

Email ethicscommittee@tcd.ie

The Principal Investigator was the Dean of the Faculty of Health Sciences at the time of the application. All TCAID staff who work on IDS-TILDA are employees of Trinity College Dublin.

All approved research requires six-monthly Monitoring reports and an End of Project report. No conditions were attached to the research by the Research Ethics Committee

5. Lawful basis for the research

Under Article 6 and Article 9 of the General Data Protection Regulation, the legal basis for the processing of data is that the person has given their explicit consent for the use of their data in pursuit of the aim of IDS-TILDA.

6. Follow-up contact

As this is a longitudinal study, all participants will be followed up during future waves of the research. IDS-TILDA also has a 'keep in touch' strategy where it distributes a newsletter to participants and greeting cards at Easter and Christmas.

7. Project Manager

For further information about these or any other aspect of the IDS-TILDA study, please contact:

Margaret Haigh

Project Manager

IDS-TILDA

Trinity Centre for Ageing and Intellectual Disability

2 Clare Street

Dublin 2 D02 CK80

Tel: +353 1 896 3187

Consent Form for Health Fair

PLEASE TICK TO AGREE WITH THE STATEMENT



This form is about getting your permission to do the health measures.

YES

NO



I have read the information booklet or had it read for me.

☐
☐

I understand the information about the health measures.

☐
☐


The researcher has explained the measures to me.

☐
☐


I understand why these measures are being taken. I have been told the risks and the values of the health measures.

☐
☐


I understand what is involved in taking the health measures.

☐
☐


I know that it is my choice to take part.

☐
☐



	YES	NO
		
	☐	☐
	☐	☐
	☐	☐
	☐	☐
	☐	☐
	☐	☐
5 years	☐	☐



YOUR CONSENT TO DO THE MEASURES

YES

NO



I give consent for my
information to be used in the
study

☐☐

I give consent for my health
measures to be used in the
study

☐☐

I wish to take part

☐☐

Please sign your name:

Name: _____

Signature: _____

Date: _____

Support Person:

Name _____

Signature: _____



Appendix 4.10

Easy read booklet for weight measurement



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Weight


The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-ILISA)

1.		Now we will measure your weight
2.		Take off your shoes
3.		Step on the scales carefully
4.		Stand still for a few seconds

4.11 ActivPAL protocol

The ActivPAL device is a miniature electronic logger designed to quantify free-living daily activities. The ActivPAL measures any form of movement. For example, it measures the amount of time spent lying, sitting, standing and stepping. It does this by inclinations and postural positions. The ActivPAL helps in the measurement of the physical activity of people. As a result, patterns of sedentary behaviours may be identified. It can also give researchers insight into the amount of time people spend in bed and their movement patterns while in bed. The device takes measurements every second of the day. The ActivPAL is most comfortable worn on the midline of the right thigh and located halfway down between the hip and the knee. This is to ensure valid and accurate results. The ActivPAL is attached to a person for a total of one week, seven days continuously. This will help gain a clear understanding of a person's daily activities through a second-by-second breakdown. The device can also provide a measure for the rate of steps completed daily (i.e. cadence) of upright activities. This will accurately record the intensity and quantity of a person's physical activity and the type and quantity of sedentary behaviour. It is very important the device is applied correctly in the field as this will help us get the most accurate results.



Equipment

Flexible Nitrile sleeve

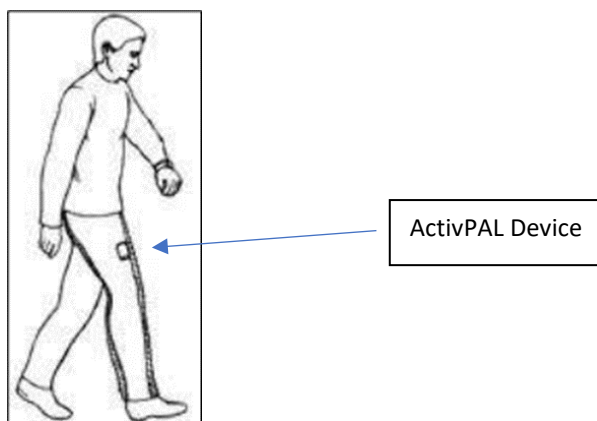
Hydrocolloid Tegaderm

Tegaderm waterproof dressing 10 X 10 cm

ActivPAL4 micro accelerometer

Preparing the participant

- Show the participant the ActivPAL device “ *This is what we call an ActivPAL*”.
- Tell the participant what the device does “*This device measure how physically active you are by measuring the number of steps.*”
- Show the participant where the device will be placed. “*The device will be placed on your thigh*” (Show where on the leg).
- Ensure the participant that the device is comfortable to wear. “ *You don’t feel it when you’re wearing it*”.
- Give a demonstration of how you will attach the device.
- Ask for verbal consent off the participant, “ Do you think you’d like to wear this for a week? The choice is up to you”.
- If the participant agrees to wearing the device tell them “ the device is not to be taken off during the week. It is important to mind this device.



- If the participant insists on the getting it changed at one point in the week, you'll provide dressing to the support worker.
- Inform the participant that the device will continuously be recording for the week and will never stop recording. **The participant can check the little light in the front panel. If the light flashes green every six seconds the device is working perfectly. If the device is not flashing green, the participant should contact the field researcher as soon as possible.**
- Ask the participant if they have any additional questions regarding the device or the procedure.
- Remind the participant that the field researcher will be back in seven to eight days to remove the device

Procedure for applying the ActivPAL

1. Before applying the ActivPAL device, using an alcohol wipe clean the participants skin at the midline point of the right thigh, where the device will be attached.
2. Next the device will need to be covered with the nitrile sleeve. Using the flexible nitrile sleeve, start at the rounded edge of the device and roll the sleeve down the ActivPAL (See Step 1 in Figure A below)
3. Once the sleeve is rolled all the way down (See Step 2 in Figure A below), fold over the sleeve and trim off the end of the sleeve. Please note that this is only the bottom of the sleeve and not all of it (see step 3 in figure A below).
4. Draw a stick man on the nitrile sleeve, facing the same direction as the man on the device itself. This is to guide you for the direction you need to have the device facing and upright (the stick man will always be standing up).



5. Gently fold the sleeve up towards the back of the device (See Step 4 in Figure A below and pic below).



6. Ensure the sleeve is folded level with the device edge (See Step 5 in Figure A below).

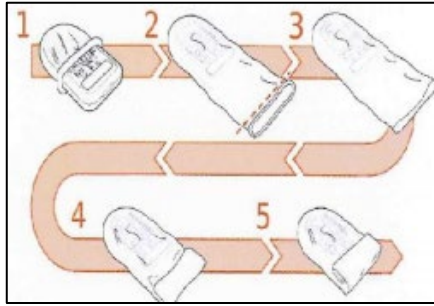


Figure A- Process for covering the ActivPAL

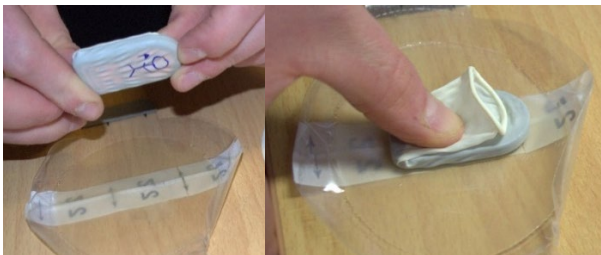
7. Apply the Hydrocolloid thin tegaderm layer to midline on the right thigh. This layer is to prevent skin irritations.



8. Before applying the waterproof dressing (i.e. Tegaderm), cut to the size of 10cm X 10cm. It is best to have these pre-cut before the health fair begins.



9. Using the waterproof dressing, peel back the backing sheet (i.e. paper side). See Step 1 in Figure B below.
10. Place the device (wrapped in sleeve) along the centre line of the waterproof dressing. Ensure the folded end is facing in (See Steps 2-3 in Figure 29).



11. Attach the device to the midline right thigh. The rounded side of the device is facing toward the top of the thigh and the stick man on the device is facing out. Press the device on the leg (See Step 4 in Figure B).
12. Attach the dressing carefully to the leg and minimise air pockets.
13. Peel the outer layer of the dressing off and again flatten the dressing against the skin.



14. Ensure there are no air pockets or gaps between the device, skin and dressing (See Step 6, Figure B).



15. Remind the participant of the ActivPAL guidelines.

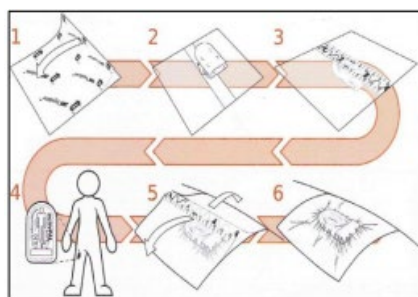


Figure B- Applying the ActivPAL to the leg

ActivPAL guidelines for participants

- The device must be worn for a minimum of 7 days.
- The device should be worn at all times, even when sleeping, and playing sports.
- The activPAL4 micro can be worn when showering. However, the device must be removed for swimming, bathing or for any other water-based activities when the device is immersed in water for prolonged periods.
- The only other time the device should be removed is if it is necessary to change the dressings which attach it to the individual.
- If the device is obstructive during a sporting activity (e.g. Judo, Taekwondo), it can be removed, but efforts should be made to wear the device at all times.
- If the device is removed please record in the diary provided in the pack the time and day that you took the ActivPAL off and when it was put back on. Please also state why you took off the ActivPAL.
- The device must be returned following the completion of the seven-day assessment. Ensure the participant does not leave the Health Fair without the field researcher giving a time that they will be picking up the device the following week.
- The device should be worn on the anterior aspect of the midline of the right thigh, halfway between the knee and the hip as shown in the pictures above.
- Notify the participant and the participant support worker that if the device is misplaced, they should retrace their steps to find it. It is very important to contact the researcher if a device is misplaced.

Appendix 4.12

Field researcher training content

Structure of Training Programme Day One



- Overview of IDS-TILDA
- Field Researcher roles and responsibilities
 - Managing caseload and setting up interviews
 - Obtaining consent, interviewing procedures and techniques
 - Data protection
- CAPI (Computer Assisted Programme for Interviewing) overview

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Structure of Training Programme Day Two



- CAPI overview - continued
- Pre-Interview Questionnaire (PIQ)
- CAPI training
- Practical CAPI sessions

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Structure of Training Programme Day Three



- Completing and submitting cases
- Fieldwork administration
- Practical session
- Final recap

Opportunity to ask questions throughout the programme

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Appendix 4.13

Other comorbidity indexes evaluated

- Charlson Comorbidity Index

The Charlston Comorbidity Index (CCI) quantifies the burden of disease and the ten-year survival rate, using the International Classification of Diseases (ICD) system (Charlston *et al*, 1987). The CCI used a weighted index system (based on hazard ratios) to score the more critical comorbidities for predicting mortality. The scoring system incorporated both age and comorbidities. Higher indexes were predictive of a lower chance of survival (Charlston *et al*, 1987). A 2003 systematic review found the CCI was the most commonly used index for mortality prediction (De Groot *et al*, 2003). The CCI was updated in 2011 to reflect medical advances and further validated to predict mortality more accurately in patients with *Staphylococcus aureus* bacteraemia in 2018 (Quan *et al*, 2011; Ternavasio-De La Vega *et al*, 2018). The updated CCI contained 12 comorbid conditions versus the 19 in the original and consequently the maximum score reduced from 33 to 24.

- Elixhauser Comorbidity Measure

The Elixhauser Comorbidity Measure (ECM) was developed to decipher large amounts of hospital administrative data with respect to comorbidities and the length, cost and mortality of hospital stays and later modified to a single index which reflected disease burden (Elixhauser *et al*, 1998; Van Walraven *et al*, 2009). The ECM consisted of 30 and later 31 comorbidities, easily identifiable from ICD codes. ECM was a better predictor of hospital resource utilisation and adverse effects after shoulder and hip replacement surgery than the CCI (Kim *et al*, 2018; Ondeck *et al*, 2018).

- Whitney Comorbidity Index

A new index was established for use with a group with Cerebral Palsy who may have had an intellectual disability and/or epilepsy. The Whitney Comorbidity Index (WCI) consisted of 27 items. Scores were divided into categories i.e. 13+, 23+ but even a score of one was indicative of poor health (Whitney and Basu, 2021). The WCI was found to predict 1- and 2- year mortality better than either the CCI or the ECM (Whitney and Kamdar, 2021).

Appendix 4.14

Modified CUMULATIVE ILLNESS RATING SCALE (CIRS-G)

Each system should be rated as follows:

0 - None

1 - Mild

2 - Moderate

3 - Severe

4 - Extremely Severe

Body system	Score				
1. Cardiac (heart only)	0	1	2	3	4
2. Hypertension (rating is based on severity; organ damage is rated separately)	0	1	2	3	4
3. Vascular (blood, blood vessels and cells, bone marrow, spleen, lymphatics)	0	1	2	3	4
4. Respiratory (lungs, bronchi, trachea below the larynx)	0	1	2	3	4
5. EENT (eye, ear, nose, throat, larynx)	0	1	2	3	4
6. Upper GI (esophagus, stomach, and duodenum; pancreas; do not include diabetes)	0	1	2	3	4
7. Lower GI (intestines, hernias)	0	1	2	3	4
8. Hepatic (liver and biliary tree)	0	1	2	3	4
9. Renal (kidneys only)	0	1	2	3	4
10. Other GU (ureters, bladder, urethra, prostate, genitals)	0	1	2	3	4
11. Musculo-skeletal-integumentary (muscle, bone, skin)	0	1	2	3	4
12. Neurological (brain, spinal cord, nerves, do not include dementia)	0	1	2	3	4
13. Endocrine-Metabolic (includes diabetes, thyroid; breast; systemic infections; toxicity)	0	1	2	3	4
14. Psychiatric/Behavioral (includes dementia, depression, anxiety, agitation/delirium, psychosis)	0	1	2	3	4

0 = None-no impairment to that organ/system.

1 = Mild impairment does not interfere with normal activity; treatment may or may not be required; prognosis is excellent. (Examples could be skin lesions, hernias, or haemorrhoids.)

2 = Moderate impairment interferes with normal activity ; treatment is needed; prognosis is good. (Examples could be gall stones, diabetes, or fractures.)

3 = Severe impairment is disabling; treatment is urgently needed; prognosis is guarded. (Examples could be resectable carcinoma, pulmonary emphysema, or congestive heart failure.)

4 = Extremely severe impairment is life-threatening ; treatment is emergent or of no avail ; prognosis is grave. (Examples could be myocardial infraction, cerebrovascular accident, gastrointestinal bleeding, or embolus.)

Source: Salvi *et al*, 2008.

Appendix 4.15

IDS-TILDA Question	IDS-TILDA Codes	Modified to	Modified Barthel Index Codes
Mobility Please indicate the level of difficulty, if any, you have with walking 100 yards	1=No difficulty 2=Some difficulty 3=A lot of difficulty 4=Cannot do at all	→ → → →	3=Independent 2=Walks with help 1=Wheelchair independent 0=Immobile
Stairs Please indicate the level of difficulty, if any, you have with climbing one flight of stairs without resting.	1=No difficulty 2=Some difficulty 3=A lot of difficulty 4=Cannot do at all	→ → → →	2=Independent 1=Needs help 0=Unable
Dressing Please indicate the level of difficulty, if any, you have with dressing, including putting on shoe and socks.	1=No difficulty 2=Some difficulty 3=A lot of difficulty 4=Cannot do at all	→ → → →	2= Independent 1= Needs help 0=Unable
Bathing Please indicate the level of difficulty, if any, you have with bathing or showering.	1=No difficulty 2=Some difficulty 3=A lot of difficulty 4=Cannot do at all	→ → → →	1= Independent 0= Dependent
Grooming Please indicate the level of difficulty, if any, you have with cleaning your teeth/taking care of your dentures.	1=No difficulty 2=Some difficulty 3=A lot of difficulty 4=Cannot do at all	→ → → →	1= Independent 0= Needs help
Feeding Please indicate the level of difficulty, if any, you have with eating such as cutting up your food, use of utensils, drinking from a cup/glass etc?	1=No difficulty 2=Some difficulty 3=A lot of difficulty 4=Cannot do at all	→ → → →	2=Independent 1=Needs help 0= Dependent
Transfer Please indicate the level of difficulty, if any, you have with getting in or out of bed.	1=No difficulty 2=Some difficulty 3=A lot of difficulty 4=Cannot do at all	→ → → →	3= Independent 2=Minor Help 1 =Major help 0=Unable
Toileting Please indicate the level of difficulty, if any, you have with using the toilet, including getting up or down.	1=No difficulty 2=Some difficulty 3=A lot of difficulty 4=Cannot do at all	→ → → →	2=Independent 1=Needs help 0= Dependent
Bladder Continence During the last 12 months, have you lost any amount of urine beyond your control?	Yes	→	0=Incontinent
Did this happen more than once during a 1 month period?	No	→	1=Occasional (In last month)
Bowel Continence During the last 12 months, have you lost any amount of faeces beyond your control?	Yes	→	0=Incontinent
During the last 12 months, have you lost any amount of urine beyond your control?	No	→	1=Occasional (In last month)
During the last 12 months, have you lost any amount of faeces beyond your control?	No	→	Continent

Appendix 6.1

Missing data for all 30 investigated risk factors and TV category

	N	Missing	
		Count	Percent
Residence	609	0	0.0
Sex	609	0	0.0
Age	609	0	0.0
Educ. & train	607	2	0.3
Day service	607	2	0.3
Occupation	607	2	0.3
Self-rated health	604	5	0.8
Epilepsy	603	6	1.0
Marital Status	603	6	1.0
Wheelchair user	602	7	1.1
Employed	601	8	1.3
Diff walk 100yds	601	8	1.3
TV 5Cat	601	8	1.3
Alcohol	600	9	1.5
Smoker	600	9	1.5
DS	598	11	1.8
hearing	598	11	1.8
Difficulty community*	596	13	2.1
Born Dublin	592	17	2.8
Up in morning	591	18	3.0
Part of community	582	27	4.4
Bedtime	576	33	5.4
Level ID	561	48	7.9
Fizzy_4cat	554	55	9.0
Psychotropic	549	60	9.9
Educ. Level	522	87	14.3
BMI	418	191	31.4
Diff footpaths	192	417	68.5
Diff street crossings**	192	417	68.5
Diff signage**	192	417	68.5
Diff recreat. areas**	192	417	68.5
Diff unsafe**	192	417	68.5

*Does not travel around community (N=163) was classed as missing in original dataset.

** These are filter questions from difficulty getting around community. Only 192 had problems getting around the community so that is all who answered these questions. Hence 0% missing values actually existed here.

APPENDIX 6.2

Wave 1 multinomial logistic regression for intellectual disability versus 5 categories TV

W1 5 categories TV hours ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hour	Intercept	1.386	0.423	10.762	1	0.001						
	Severe/profound	-2.410	0.488	24.431	1	0.000	0.090	0.035	0.234	11.130	28.939	4.281
	Moderate	-0.675	0.484	1.948	1	0.163	0.509	0.197	1.314			
	Mild	0 ^b			0							
1-3 hours	Intercept	2.331	0.396	34.657	1	0.000						
	Severe/profound	-2.728	0.442	38.054	1	0.000	0.065	0.027	0.155	15.309	36.428	6.434
	Moderate	-0.963	0.451	4.565	1	0.033	0.382	0.158	0.923	2.620	6.339	1.083
	Mild	0 ^b			0							
3-5 hours	Intercept	0.944	0.445	4.496	1	0.034						
	Severe/profound	-2.012	0.509	15.605	1	0.000	0.134	0.049	0.363	7.481	20.302	2.756
	Moderate	-0.215	0.503	0.182	1	0.669	0.807	0.301	2.163			
	Mild	0 ^b			0							
>5 hours	Intercept	0.539	0.476	1.284	1	0.257						
	Severe/profound	-2.501	0.594	17.718	1	0.000	0.082	0.026	0.263	12.190	39.057	3.805
	Moderate	-1.196	0.578	4.273	1	0.039	0.302	0.097	0.940	3.306	10.274	1.064
	Mild	0 ^b			0							

a. The reference category is: None/don't watch TV or videos.

b. This parameter is set to zero because it is redundant.

Appendix 6.3

Wave 2 multinomial regression for ID level and 5 categories TV

W2 5 categories TV hours ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hour	Intercept	1.135	0.383	8.774	1	0.003						
	Severe/profound	-2.010	0.451	19.863	1	0.000	0.134	0.055	0.324	7.467	18.076	3.084
	Moderate	-0.808	0.450	3.225	1	0.073	0.446	0.185	1.077			
	Mild	0 ^b			0							
1-3 hours	Intercept	2.051	0.354	33.555	1	0.000						
	Severe/profound	-2.175	0.401	29.404	1	0.000	0.114	0.052	0.249	8.805	19.329	4.011
	Moderate	-0.749	0.408	3.371	1	0.066	0.473	0.213	1.052			
	Mild	0 ^b			0							
3-5 hours	Intercept	0.575	0.417	1.907	1	0.167						
	Severe/profound	-2.367	0.539	19.303	1	0.000	0.094	0.033	0.270	10.667	30.664	3.710
	Moderate	-0.372	0.482	0.595	1	0.440	0.690	0.268	1.773			
	Mild	0 ^b			0							
>5 hours	Intercept	0.105	0.459	0.053	1	0.819						
	Severe/profound	-2.254	0.609	13.705	1	0.000	0.105	0.032	0.346	9.524	31.407	2.888
	Moderate	-0.767	0.553	1.922	1	0.166	0.465	0.157	1.373			
	Mild	0 ^b			0							

a. The reference category is: None/don't watch TV or videos.

b. This parameter is set to zero because it is redundant.

Appendix 6.4

Wave 3 Multinomial regression for level of ID and 5 categories TV

W3 5 categories TV hrs ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hour	Intercept	0.154	0.393	0.154	1	0.695						
	Severe/profound	-0.708	0.462	2.356	1	0.125	0.492	0.199	1.217			
	Moderate	1.193	0.502	5.654	1	0.017	3.297	1.233	8.813	na	na	na
	Mild	0 ^b			0							
1-3 hours	Intercept	1.833	0.311	34.742	1	0.000						
	Severe/profound	-1.751	0.371	22.287	1	0.000	0.174	0.084	0.359	5.760	11.915	2.784
	Moderate	0.373	0.427	0.765	1	0.382	1.452	0.629	3.352			
	Mild	0 ^b			0							
3-5 hours	Intercept	0.734	0.351	4.368	1	0.037						
	Severe/profound	-1.326	0.428	9.605	1	0.002	0.266	0.115	0.614	3.766	8.711	1.628
	Moderate	0.812	0.465	3.043	1	0.081	2.252	0.905	5.608			
	Mild	0 ^b			0							
>5 hours	Intercept	-0.087	0.417	0.043	1	0.835						
	Severe/profound	-1.461	0.544	7.219	1	0.007	0.232	0.080	0.674	4.308	12.504	1.485
	Moderate	0.161	0.568	0.080	1	0.777	1.175	0.386	3.576			
	Mild	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.5

Wave 2 level of ID versus 2 categories TV

W2 >3hrs=sed ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
>3hrs TV	Intercept	-1.415	0.219	41.865	1	0.000						
	Severe/profound	-0.679	0.337	4.052	1	0.044	0.507	0.262	0.982	1.973	3.822	1.018
	Moderate	0.167	0.268	0.391	1	0.532	1.182	0.700	1.997			
	Mild	0 ^b			0							

a. The reference category is: <3 hrs (not sed)

b. This parameter is set to zero because it is redundant.

Appendix 6.6

Imputed Wave 3 Level of ID and 5 categories TV data

Hours TV/DVD's/day ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hour	Intercept	0.208	0.373	0.309	1	0.578						
	Severe/profound	-0.772	0.440	3.081	1	0.079	0.462	0.195	1.094			
	Moderate	1.110	0.473	5.498	1	0.019	3.033	1.200	7.669			
	Mild	0 ^b			0							
1-3 hours	Intercept	1.817	0.299	36.923	1	0.000						
	Severe/profound	-1.779	0.358	24.734	1	0.000	0.169	0.084	0.340	5.922	11.936	2.938
	Moderate	0.388	0.404	0.919	1	0.338	1.473	0.667	3.254			
	Mild	0 ^b			0							
3-5 hours	Intercept	0.869	0.330	6.917	1	0.009						
	Severe/profound	-1.543	0.409	14.231	1	0.000	0.214	0.096	0.477	4.678	10.426	2.098
	Moderate	0.613	0.437	1.965	1	0.161	1.845	0.783	4.345			
	Mild	0 ^b			0							
>5 hours	Intercept	-0.167	0.410	0.166	1	0.683						
	Severe/profound	-1.462	0.536	7.438	1	0.006	0.232	0.081	0.663	4.315	12.342	1.509
	Moderate	0.232	0.545	0.181	1	0.671	1.261	0.433	3.668			
	Mild	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.7

Wave1 multinomial regression for residence type versus 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
W1 5 categories TV hours ^a								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hour	Intercept	1.705	0.544	9.836	1	0.002						
	Residential	-2.058	0.573	12.899	1	0.000	0.128	0.042	0.393	7.827	24.057	2.547
	Community Group Home	-1.162	0.599	3.767	1	0.052	0.313	0.097	1.012	3.198	10.343	1.012
	Independent/family	0 ^b			0							
1-3 hours	Intercept	2.526	0.520	23.627	1	0.000						
	Residential	-2.387	0.543	19.299	1	0.000	0.092	0.032	0.267	10.882	31.569	3.751
	Community Group Home	-1.091	0.565	3.723	1	0.054	0.336	0.111	1.017	2.976	9.012	0.983
	Independent/family	0 ^b			0							
3-5 hours	Intercept	1.658	0.546	9.239	1	0.002						
	Residential	-2.156	0.577	13.939	1	0.000	0.116	0.037	0.359	8.633	26.769	2.784
	Community Group Home	-1.240	0.603	4.222	1	0.040	0.290	0.089	0.944	3.454	11.267	1.059
	Independent/family	0 ^b			0							
>5 hours	Intercept	0.693	0.612	1.281	1	0.258						
	Residential	-2.289	0.675	11.513	1	0.001	0.101	0.027	0.380	9.867	37.021	2.630
	Community Group Home	-1.139	0.691	2.719	1	0.099	0.320	0.083	1.240			
	Independent/family	0 ^b			0							

a. The reference category is: None/don't watch TV or videos.

b. This parameter is set to zero because it is redundant.

Appendix 6.8

Wave 2 multinomial for residence type versus 5 categories TV

W2 5 categories TV hours ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hour	Intercept	1.253	0.567	4.883	1	0.027						
	Residential	-1.759	0.600	8.579	1	0.003	0.172	0.053	0.559	5.805	18.832	1.789
	Community Group Home	-0.899	0.611	2.167	1	0.141	0.407	0.123	1.347			
	Independent/family	0 ^b			0							
1-3 hours	Intercept	2.464	0.521	22.378	1	0.000						
	Residential	-2.340	0.547	18.308	1	0.000	0.096	0.033	0.281	10.377	30.302	3.553
	Community Group Home	-1.048	0.556	3.553	1	0.059	0.351	0.118	1.043	2.851	8.475	0.959
	Independent/family	0 ^b			0							
3-5 hours	Intercept	1.099	0.577	3.621	1	0.057						
	Residential	-1.986	0.619	10.277	1	0.001	0.137	0.041	0.462	7.286	24.534	2.164
	Community Group Home	-1.161	0.629	3.406	1	0.065	0.313	0.091	1.075	3.194	10.961	0.930
	Independent/family	0 ^b			0							
>5 hours	Intercept	1.558	0.550	8.022	1	0.005						
	Residential	-3.213	0.628	26.179	1	0.000	0.040	0.012	0.138	24.846	85.061	7.258
	Community Group Home	-3.263	0.707	21.310	1	0.000	0.038	0.010	0.153	26.125	104.401	6.537
	Independent/family	0 ^b			0							

a. The reference category is: None/don't watch TV or videos.

b. This parameter is set to zero because it is redundant.

Appendix 6.9

Wave 3 Multinomial for residence type versus 5 categories TV

W3 5 categories TV hrs ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hour	Intercept	0.606	0.508	1.426	1	0.232						
	Residential	-0.849	0.550	2.386	1	0.122	0.428	0.146	1.257			
	Community Group Home	0.182	0.575	0.101	1	0.751	1.200	0.389	3.702			
	Independent/family	0 ^b			0							
1-3 hours	Intercept	2.120	0.432	24.083	1	0.000						
	Residential	-1.467	0.465	9.943	1	0.002	0.231	0.093	0.574	4.337	10.795	1.742
	Community Group Home	-0.320	0.495	0.419	1	0.518	0.726	0.275	1.915	0.726	0.275	1.915
	Independent/family	0 ^b			0							
3-5 hours	Intercept	1.099	0.471	5.431	1	0.020						
	Residential	-1.041	0.510	4.166	1	0.041	0.353	0.130	0.959	2.833	7.702	1.042
	Community Group Home	-0.163	0.540	0.091	1	0.764	0.850	0.295	2.450	0.850	0.295	2.450
	Independent/family	0 ^b			0							
>5 hours	Intercept	0.405	0.527	0.592	1	0.442						
	Residential	-1.342	0.589	5.181	1	0.023	0.261	0.082	0.830	3.825	12.143	1.205
	Community Group Home	-1.322	0.673	3.858	1	0.049	0.267	0.071	0.997	3.750	14.021	1.003
	Independent/family	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.10

Wave2 Multinomial for residence and 2 categories TV

W2 <3hrs=not sed, >3hrs=sed ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
>3hrs	Intercept	-0.740	0.218	11.506	1	0.001						
	Residential	-0.772	0.278	7.695	1	0.006	0.462	0.268	0.797	2.164	3.733	1.254
	Community Group Home	-1.024	0.282	13.222	1	0.000	0.359	0.207	0.624	2.784	4.835	1.603
	Independent/family	0 ^b			0							

a. The reference category is: <3hrs (not sed)

b. This parameter is set to zero because it is redundant.

Appendix 6.11

Wave2 BMI versus 5 categories TV

W2 5 categories TV ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)	
								Lower Bound	Upper Bound
<1 hour	Intercept	-0.715	0.254	7.887	1	0.005			
	Overweight	1.194	0.326	13.420	1	0.000	3.301	1.742	6.254
	Underweight	-1.231	1.099	1.255	1	0.263	0.292	0.034	2.516
	Normal	0 ^b			0				
1-3 hours	Intercept	0.120	0.200	0.360	1	0.549			
	Overweight	1.328	0.268	24.570	1	0.000	3.775	2.232	6.382
	Underweight	-0.967	0.719	1.813	1	0.178	0.380	0.093	1.554
	Normal	0 ^b			0				
3-5 hours	Intercept	-1.142	0.297	14.832	1	0.000			
	Overweight	1.285	0.369	12.162	1	0.000	3.615	1.756	7.445
	Underweight	-19.282	0.000		1		0.000	0.000	0.000
	Normal	0 ^b			0				
>5 hours	Intercept	-1.653	0.364	20.638	1	0.000			
	Overweight	1.125	0.449	6.279	1	0.012	3.080	1.278	7.424
	Underweight	-0.293	1.129	0.067	1	0.795	0.746	0.082	6.823
	Normal	0 ^b			0				

a. The reference category is: None/don't watch TV or videos.

b. This parameter is set to zero because it is redundant.

Appendix 6.12

TV viewing correlates Pearson chi-square p-values (2 & 5 cat TV & 5cat imputed dataset)

Correlate	p-value (2cat TV)	p-value (5cat TV)	p-value (5cat imputed data)
Marital status*	0.658	0.293	0.224*
Fizzy drinks (4cat)*	0.31	0.008	0.007*
Sense of community	0.434	<0.001	<0.001*
Employment	0.597	<0.001	<0.001*
Education/training*	0.388	0.079	0.001*
Attend day service	0.287	0.028	<0.001*
Highest level of education (3cat)	0.261	0.007*	0.061*
Occupation	0.453	<0.001	0.433*
Difficulty getting around community: main question	0.669	0.036	<0.001*
Difficulty getting around community: unsafe**	0.935	0.277	n/a
Difficulty getting around community: footpaths**	0.726	0.445	n/a
Difficulty getting around community: no street crossings**	0.709	0.554*	n/a
Difficulty getting around community: signage issues**	0.392	0.564	n/a
Difficulty getting around community: access recreational areas**	0.520*	0.699*	n/a
Mobility: wheelchair user	0.606	0.075	0.001*
Mobility: difficulty walking 100 yards (4 cat)	0.076	0.009	n/a
Mobility: difficulty walking 100 yards (2 cat)	0.014	0.001	<0.001*
Epilepsy	0.236	0.012	0.002*
Smoker	0.257	0.581	0.794*
Drink alcohol	0.685	0.001	0.266*
Hearing	0.231	0.443	0.036*
3 cat SR health	0.82	0.008	0.003*
Time to bed*	0.115	0.385	0.03*
Time up in morning*	0.005	0.016	0.05*
Psychotropic medication	0.841	0.431	0.127*

*Pearson chi-square assumptions of minimum cell frequency of 80% >5 violated so Monte-Carlo exact run

** Filter question for those who experience difficulty getting around community

Appendix 6.13

Multinomial regression for Wave 3 4-category fizzy drink and 5-categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)	
								Lower Bound	Upper Bound
<1hr	Intercept	-0.141	0.238	0.352	1	0.553			
	4+/day	0.141	1.434	0.010	1	0.922	1.152	0.069	19.141
	5/week- 3/day	0.930	0.590	2.486	1	0.115	2.533	0.798	8.044
	1/month- 4/week	0.453	0.338	1.798	1	0.180	1.574	0.811	3.053
	Never	0 ^b			0				
1-3 hrs	Intercept	0.937	0.191	23.978	1	0.000			
	4+/day	-17.961	4974.466	0.000	1	0.997	0.000	0.000	. ^c
	5/week- 3/day	0.672	0.526	1.634	1	0.201	1.959	0.699	5.491
	1/month- 4/week	0.482	0.279	2.977	1	0.084	1.619	0.937	2.799
	Never	0 ^b			0				
3-5 hrs	Intercept	0.124	0.223	0.308	1	0.579			
	4+/day	0.570	1.245	0.209	1	0.647	1.767	0.154	20.274
	5/week- 3/day	0.346	0.612	0.320	1	0.571	1.414	0.426	4.692
	1/month- 4/week	0.536	0.316	2.865	1	0.091	1.709	0.919	3.177
	Never	0 ^b			0				
>5 hrs	Intercept	-1.558	0.389	16.045	1	0.000			
	4+/day	-17.506	0.000		1		0.000	0.000	0.000
	5/week- 3/day	2.347	0.665	12.452	1	0.000	10.450	2.838	38.474
	1/month- 4/week	0.722	0.511	1.992	1	0.158	2.058	0.755	5.609
	Never	0 ^b			0				

Appendix 6.14

Multinomial for sense of community and 5 TV categories

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 1 hr	Intercept	0.647	0.263	6.037	1	0.014						
	Not at all	-1.136	0.393	8.374	1	0.004	0.321	0.149	0.693	3.115	6.724	1.443
	A little	-0.125	0.391	0.103	1	0.749	0.882	0.410	1.900			
	A lot	0 ^b			0							
1-3 hrs	Intercept	1.721	0.231	55.283	1	0.000						
	Not at all	-1.572	0.337	21.739	1	0.000	0.208	0.107	0.402	4.814	9.321	2.487
	A little	-0.070	0.341	0.043	1	0.836	0.932	0.478	1.818			
	A lot	0 ^b			0							
3-5 hrs	Intercept	0.693	0.261	7.047	1	0.008						
	Not at all	-0.908	0.375	5.874	1	0.015	0.403	0.193	0.841	2.480	5.169	1.190
	A little	0.254	0.376	0.458	1	0.499	1.289	0.617	2.693			
	A lot	0 ^b			0							
>5 hrs	Intercept	-0.383	0.335	1.308	1	0.253						
	Not at all	-0.653	0.485	1.813	1	0.178	0.520	0.201	1.347			
	A little	-0.259	0.515	0.253	1	0.615	0.772	0.282	2.116			
	A lot	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.15

Multinomial for employment and 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		Exp(B)	95% CII for Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hr	Intercept	0.245	0.315	0.607	1	0.436						
	Unemployed	-0.029	0.361	0.006	1	0.936	0.972	0.479	1.970			
	Employed	0 ^b			0							
1-3 hrs	Intercept	1.905	0.253	56.888	1	0.000						
	Unemployed	-0.982	0.296	10.975	1	0.001	0.374	0.209	0.670	2.670	4.775	1.494
	Employed	0 ^b			0							
3-5 hrs	Intercept	0.938	0.278	11.390	1	0.001						
	Unemployed	-0.695	0.329	4.466	1	0.035	0.499	0.262	0.951	2.003	3.815	1.052
	Employed	0 ^b			0							
>5 hrs	Intercept	-1.099	0.471	5.431	1	0.020						
	Unemployed	0.472	0.521	0.820	1	0.365	1.603	0.577	4.454			
	Employed	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.16

Multinomial for day service and 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hr	Intercept	0.424	0.214	3.908	1	0.048						
	No day service	-0.449	0.309	2.110	1	0.146	0.639	0.349	1.170			
	Yes Day service	0 ^b			0							
1-3 hrs	Intercept	1.522	0.184	68.496	1	0.000						
	No day service	-0.592	0.260	5.159	1	0.023	0.553	0.332	0.922	1.807	3.011	1.084
	Yes Day service	0 ^b			0							
3-5 hrs	Intercept	0.665	0.205	10.513	1	0.001						
	No day service	-0.408	0.292	1.953	1	0.162	0.665	0.375	1.179			
	Yes Day service	0 ^b			0							
>5 hrs	Intercept	-0.944	0.315	8.991	1	0.003						
	No day service	0.366	0.409	0.803	1	0.370	1.443	0.647	3.214			
	Yes Day service	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.17

Multinomial for occupation and 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hr	Intercept	0.435	0.193	5.062	1	0.024						
	No occupation	-0.636	0.324	3.861	1	0.049	0.529	0.281	0.998	1.889	3.562	1.002
	Occupation	0 ^b			0							
1-3 hrs	Intercept	1.614	0.165	95.585	1	0.000						
	No occupation	-1.239	0.280	19.592	1	0.000	0.290	0.167	0.501	3.453	5.978	1.995
	Occupation	0 ^b			0							
3-5 hrs	Intercept	0.748	0.183	16.730	1	0.000						
	No occupation	-0.844	0.312	7.330	1	0.007	0.430	0.234	0.792	2.325	4.282	1.262
	Occupation	0 ^b			0							
>5 hrs	Intercept	-0.649	0.257	6.356	1	0.012						
	No occupation	-0.209	0.410	0.259	1	0.610	0.812	0.364	1.812			
	Occupation	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.18

Experience difficulty getting around community and 5 categories TV

Hours TV/DVD's/day ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hr	Intercept	1.073	0.321	11.145	1	0.001						
	Does not travel	-1.227	0.406	9.113	1	0.003	0.293	0.132	0.650	3.410	7.563	1.538
	Yes difficulty	-1.150	0.425	7.331	1	0.007	0.317	0.138	0.728	3.157	7.256	1.374
	No difficulty	0 ^b			0							
1-3 hrs	Intercept	2.239	0.292	58.899	1	0.000						
	Does not travel	-1.769	0.363	23.791	1	0.000	0.170	0.084	0.347	5.865	11.941	2.881
	Yes difficulty	-1.069	0.366	8.550	1	0.003	0.343	0.168	0.703	2.912	10.168	1.423
	No difficulty	0 ^b			0							
3-5 hrs	Intercept	1.367	0.311	19.355	1	0.000						
	Does not travel	-1.488	0.397	14.075	1	0.000	0.226	0.104	0.491	4.429	9.638	2.036
	Yes difficulty	-0.999	0.399	6.270	1	0.012	0.368	0.168	0.805	2.716	5.937	1.242
	No difficulty	0 ^b			0							
>5 hrs	Intercept	0.208	0.373	0.309	1	0.578						
	Does not travel	-1.365	0.509	7.198	1	0.007	0.255	0.094	0.692	3.916	10.616	1.445
	Yes difficulty	-1.201	0.526	5.216	1	0.022	0.301	0.107	0.843	3.323	9.313	1.186
	No difficulty	0 ^b			0							

Appendix 6.19

Wheelchair and 5 TV categories multinomial

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hr	Intercept	0.296	0.169	3.062	1	0.080						
	wheelchair	-0.503	0.410	1.509	1	0.219	0.604	0.271	1.350			
	No wheelchair	0 ^b			0							
1-3 hrs	Intercept	1.374	0.143	91.889	1	0.000						
	wheelchair	-0.928	0.351	6.994	1	0.008	0.395	0.199	0.787	2.529	5.029	1.271
	No wheelchair	0 ^b			0							
3-5 hrs	Intercept	0.553	0.161	11.822	1	0.001						
	wheelchair	-0.617	0.394	2.457	1	0.117	0.540	0.249				
	No wheelchair	0 ^b			0							
>5 hrs	Intercept	-0.710	0.223	10.128	1	0.001						
	wheelchair	-0.117	0.505	0.054	1	0.817	0.890	0.331				
	No wheelchair	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.20

Difficulty walking 100yard (2 categories) and 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hr	Intercept	0.480	0.204	5.540	1	0.019						
	Difficulty walking	-0.651	0.315	4.283	1	0.038	0.521	0.281	0.966	1.918	3.555	1.035
	No difficulty walking	0 ^b			0							
1-3 hrs	Intercept	1.551	0.176	77.448	1	0.000						
	Difficulty walking	-0.782	0.264	8.793	1	0.003	0.457	0.273	0.767	2.186	3.667	1.304
	No difficulty walking	0 ^b			0							
3-5 hrs	Intercept	0.613	0.199	9.509	1	0.002						
	Difficulty walking	-0.379	0.294	1.661	1	0.197	0.684	0.384	1.218			
	No difficulty walking	0 ^b			0							
>5 hrs	Intercept	-0.956	0.304	9.891	1	0.002						
	Difficulty walking	0.409	0.405	1.019	1	0.313	1.505	0.680	3.330			
	No difficulty walking	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.21

Multinomial for epilepsy and 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hr	Intercept	0.414	0.206	4.024	1	0.045						
	Epilepsy	-0.468	0.311	2.266	1	0.132	0.626	0.340	1.152			
	No epilepsy	0 ^b			0							
1-3 hrs	Intercept	1.518	0.177	73.739	1	0.000						
	Epilepsy	-0.667	0.262	6.469	1	0.011	0.513	0.307	0.858	1.949	3.259	1.165
	No epilepsy	0 ^b			0							
3-5 hrs	Intercept	0.814	0.192	17.896	1	0.000						
	Epilepsy	-0.955	0.306	9.738	1	0.002	0.385	0.211	0.701	2.598	4.733	1.426
	No epilepsy	0 ^b			0							
>5 hrs	Intercept	-0.719	0.280	6.607	1	0.010						
	Epilepsy	-0.085	0.404	0.044	1	0.833	0.918	0.416	2.028			
	No epilepsy	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.22

Multinomial for those who drank alcohol and 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)	
								Lower Bound	Upper Bound
<1 hr	Intercept	-0.193	0.197	0.959	1	0.328			
	Yes drink	1.047	0.332	9.963	1	0.002	2.850	1.487	5.461
	Do not drink	0 ^b			0				
1-3 hrs	Intercept	0.994	0.155	41.096	1	0.000			
	Yes drink	0.702	0.288	5.917	1	0.015	2.017	1.146	3.551
	Do not drink	0 ^b			0				
3-5 hrs	Intercept	0.220	0.178	1.525	1	0.217			
	Yes drink	0.716	0.318	5.071	1	0.024	2.047	1.097	3.819
	Do not drink	0 ^b			0				
>5 hrs	Intercept	-1.047	0.260	16.239	1	0.000			
	Yes drink	0.824	0.424	3.773	1	0.052	2.280	0.993	5.237
	Do not drink	0 ^b			0				

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.23

Multinomial for 3 categories self-rated health and 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)		1/Exp(B)	95% CI for 1/Exp(B)	
								Lower Bound	Upper Bound		Lower Bound	Upper Bound
<1 hr	Intercept	0.322	0.244	1.739	1	0.187						
	Poor/fair	-0.968	0.445	4.734	1	0.030	0.380	0.159	0.908	2.633	6.299	1.101
	Good	0.167	0.345	0.233	1	0.629	1.181	0.600	2.325			
	V.good/excellent	0 ^b			0							
1-3 hrs	Intercept	1.493	0.206	52.744	1	0.000						
	Poor/fair	-1.136	0.351	10.473	1	0.001	0.321	0.161	0.639	3.114	6.195	1.565
	Good	-0.106	0.298	0.127	1	0.721	0.899	0.502	1.611			
	V.good/excellent	0 ^b			0							
3-5 hrs	Intercept	0.710	0.227	9.808	1	0.002						
	Poor/fair	-1.116	0.413	7.302	1	0.007	0.328	0.146	0.736	3.052	6.855	1.359
	Good	-0.114	0.330	0.120	1	0.729	0.892	0.467	1.703			
	V.good/excellent	0 ^b			0							
>5 hrs	Intercept	-0.659	0.318	4.297	1	0.038						
	Poor/fair	-0.083	0.499	0.027	1	0.868	0.921	0.346	2.447			
	Good	-0.239	0.479	0.249	1	0.618	0.788	0.308	2.013			
	V.good/excellent	0 ^b			0							

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.24

Time up in morning (2 categories) and 5 categories TV

		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)	
								Lower Bound	Upper Bound
<1 hr	Intercept	- 0.080	0.400	0.040	1	0.842			
	After 7am	0.344	0.434	0.627	1	0.428	1.410	0.602	3.301
	Before 7am	0 ^b			0				
1-3 hrs	Intercept	0.961	0.326	8.692	1	0.003			
	After 7am	0.320	0.356	0.811	1	0.368	1.378	0.686	2.767
	Before 7am	0 ^b			0				
3-5 hrs	Intercept	- 0.619	0.469	1.744	1	0.187			
	After 7am	1.185	0.495	5.744	1	0.017	3.272	1.241	8.627
	Before 7am	0 ^b			0				
>5 hrs	Intercept	- 1.179	0.572	4.249	1	0.039			
	After 7am	0.470	0.612	0.588	1	0.443	1.599	0.482	5.311
	Before 7am	0 ^b			0				

a. The reference category is: None/don't watch TV or DVD's.

b. This parameter is set to zero because it is redundant.

Appendix 6.25

Multicollinearity table for Wave 3 TV significant variables

		Collinearity Statistics	
		Tolerance	VIF
1	level ID	0.756	1.323
	residence	0.680	1.471
	BMI	0.849	1.177
	fizzy drinks	0.944	1.060
	alcohol	0.900	1.111
	Part community	0.810	1.234
	Employed or not	0.779	1.284
	Day service	0.895	1.118
	Education level	0.866	1.155
	Occupation	0.936	1.068
	Diff in community	0.689	1.452
	Wheelchair	0.804	1.244
	Diff walking 100yds	0.736	1.359
	epilepsy	0.872	1.147
	Self-rated health	0.915	1.093
	Time up in morning	0.966	1.035

a. Dependent Variable: Hours TV/DVD's/day

Appendix 6.26

Imputed multinomial for significant bivariate variables & standard covariates forced back in by 5-category TV dependent variable

Hours TV/DVD's/day ^a		B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)	
								Lower Bound	Upper Bound
< 1 hour	moderate	1.394	0.529	6.950	1	0.008	4.029	1.430	11.356
	Part comm: not at all	-0.881	0.440	4.009	1	0.045	0.415	0.175	0.982
	Deaf/fair/poor hearing	-1.052	0.506	4.316	1	0.038	0.349	0.129	0.942
1-3 hours	Severe/profound	-1.011	0.440	5.288	1	0.021	0.364	0.154	0.861
	Moderate	0.932	0.460	4.112	1	0.043	2.540	1.032	6.255
	Not at all part comm.	-0.756	0.385	3.851	1	0.050	0.469	0.221	0.999
	SR health fair/poor	-0.897	0.428	4.401	1	0.036	0.408	0.176	0.943
3-5 hours	Moderate	1.067	0.493	4.690	1	0.030	2.908	1.107	7.641
	Does not travel in comm.	-1.251	0.476	6.899	1	0.009	0.286	0.113	0.728
	SR health fair/poor	-0.986	0.481	4.202	1	0.040	0.373	0.145	0.958
	>7am	1.398	0.546	6.548	1	0.011	4.048	1.387	11.811
>5 hours	Severe/profound	-1.389	0.662	4.409	1	0.036	0.249	0.068	0.912
	Does not travel comm.	-1.400	0.623	5.045	1	0.025	0.247	0.073	0.837
	yes Diff walking 100yds	1.124	0.504	4.969	1	0.026	3.077	1.145	8.267

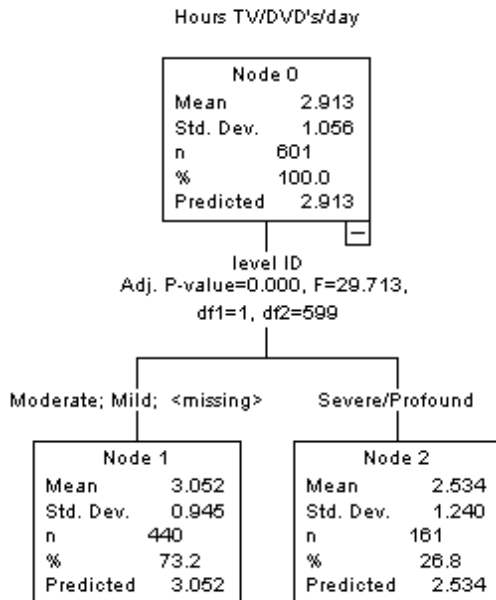
Appendix 6.27

Imputed model significant factors for decreased TV viewing

TV time	Variable	B	Std. Error	Wald	df	Sig.	Exp(B)	95% CI for Exp(B)	
								Lower Bound	Upper Bound
< 1 hour	Part comm: not at all	-0.881	0.440	4.009	1	0.045	0.415	0.175	0.982
	Deaf/fair/poor hearing	-1.052	0.506	4.316	1	0.038	0.349	0.129	0.942
1-3 hours	Not at all part comm.	-0.756	0.385	3.851	1	0.050	0.469	0.221	0.999
	SR health fair/poor	-0.897	0.428	4.401	1	0.036	0.408	0.176	0.943
	Severe/profound	-1.011	0.440	5.288	1	0.021	0.364	0.154	0.861
3-5 hours	Does not travel in comm.	-1.251	0.476	6.899	1	0.009	0.286	0.113	0.728
	SR health fair/poor	-0.986	0.481	4.202	1	0.040	0.373	0.145	0.958
>5 hours	Severe/profound	-1.389	0.662	4.409	1	0.036	0.249	0.068	0.912
	Does not travel comm.	-1.400	0.623	5.045	1	0.025	0.247	0.073	0.837

Appendix 6.28

CHAID for original dataset 14-variable model & 5-categories TV



The CHAID algorithm for the original dataset determined three terminal nodes indicating the prevalence of TV watching. The root node (Node 0) contained the dependent variable (TV watching) and showed that participants watched approximately 2.9-hours TV/day. The next and final level of nodes (1 and 2) were based on level of intellectual disability, the only predictive indicators of TV watching determined by the CHAID algorithm [$p < 0.001$]. Over 73% with a mild/moderate intellectual disability watched an average of 3.05-hours TV/day while over 26% with a severe/profound intellectual disability watched an average of 2.5-hours/day.

Appendix 7.1

Multicollinearity analysis for individual health variables

Model	Collinearity Statistics	
	Tolerance	VIF
(Constant)		
Age	0.580	1.725
Sex	0.454	2.201
Level ID	0.611	1.638
Aetiology	0.651	1.536
2 cat BMI	0.450	2.220
Residence type	0.490	2.039
Cardiac	0.638	1.567
Hypertension	0.560	1.784
vascular	0.338	2.954
Respiratory	0.593	1.687
ENT	0.608	1.644
Upper GI	0.410	2.440
lower GI	0.429	2.329
Cirrhosis	0.077	12.988
Renal	0.076	13.111
Cancer	0.804	1.244
Musculoskeletal	0.620	1.613
Neurological	0.481	2.079
Endocrine	0.650	1.539
Behavioural/psychiatric	0.646	1.548

Appendix 7.2

Missing value analysis for the sedentary variables & Barthel & CIRS-G indexes

	N	Univariate Statistics	
		Missing	
		Count	Percent
Total Sedentary Time m	72	0	0.0
Sitting Time m	72	0	0.0
Primary Lying Time m	72	0	0.0
Activity Score MET/h	72	0	0.0
Num. Sit To Stands	72	0	0.0
Modified BI Score	69	3	4.2
CIRS-G Total Score	72	0	0.0
PAL mean	72	0	0.0
Modified BI Category	69	3	4.2
Barthel_2cat	69	3	4.2
CIRS_SI_2cat	72	0	0.0

Appendix 7.3

ANOVA bivariate p-value results between activPal sedentary dependent variables and standard covariates

Covariate*	Sitting time (mins) p-value	Primary Lying (mins) p-value	Tot sedentary time (mins) p-value	PAL p-value
Age	0.619	0.379	0.671	0.163
Sex	0.980	0.520	0.559	0.429
Level of ID	0.782	0.252	0.626	0.059
Aetiology	0.208	0.515	0.032	0.676
Living circumstance	0.797	0.593	0.679	0.167
BMI	0.796	0.572	0.837	0.882

*ANOVA Used for correlations

Appendix 7.4

Bivariate associations for covariates & sedentary bout length and number of bouts >30 & >60minutes

Covariate	No of bouts						
	<30m*	>30m & <60m*	>60m & <120m ⁺	>120m & <240m ⁺	>240m ⁺	>30mins ⁺⁺	>60mins ⁺⁺
Age	0.009	0.37	0.534	0.151	0.18	0.66	0.195
Sex	0.915	0.857	0.293	0.479	0.423	0.811	0.644
Level of ID	0.894	0.54	0.721	0.603	0.917	0.887	0.75
Aetiology	0.627	0.196	0.039	0.908	0.395	0.739	0.893
Living circumstance	0.108	0.064	0.21	0.27	0.526	0.02	0.165
BMI	0.169	0.134	0.718	0.176	0.607	0.803	0.851

*ANOVA, ⁺Kruskal-Wallis, ⁺⁺Chi-square

Appendix 7.5

Bivariate Kruskal-Wallis p-values for activPal participants for CIRS-G by standard covariates

Covariate	CIRS-G score*
Age	0.005
Sex	0.154
Level of ID	0.386
Aetiology	0.799
Living circumstance	0.003
BMI	0.319

*Kruskal-Wallis