OVERWEIGHT AND OBESITY IN OLDER ADULTS WITH AN INTELLECTUAL DISABILITY

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

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DECLARATION

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and it is entirely my own work.

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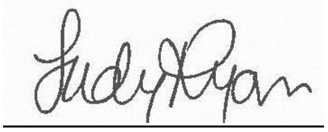

Judy Ryan

SUMMARY

Methods

This research is situated within the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) a nationally representative study involving 753 participants with an intellectual disability (ID) over the age of 40 years. Ethical approval for the study was granted by the University of Dublin, Faculty of Health Sciences, Trinity College, and all involved service providers. Face-to-face interviews were conducted with question topics ranging from demographics to behavioural health and social characteristics of participants lives. A Computer Assisted Personal Interview (CAPI) system supporting data collection and a Pre Interview Questionnaire (PIQ) formed part of the data collection. The PIQ included health related questions and doctors diagnosed Chronic Health Conditions (CHC). Objective measures of weight, height and waist circumference were collated during a health fair. Analysis of the prevalence of overweight and obesity and doctors diagnosed CHC was conducted using the Statistical Package for Social Science (SPSS) version 22 (IBM 2011). Pearson's chi-square test to determine whether significant bivariate associations (*p*-value <0.05) existed between being overweight/obese, the demographic characteristics and the various chronic health conditions (95% confidence interval). Logistic regression was used to model CHC on BMI while controlling for demographic differences and assessed based on the p-value of a likelihood ratio test (0.05 level of significance) and Nagelkerke R^2. Wald test p-values (0.05 level of significance). Odds ratios and associated 95% confidence intervals were also included.

Additionally, in Wave 3 of the IDS-TILDA study, a food frequency questionnaire (FFQ), framed on the full SLÁN instrument (Survey of Lifestyle Attitudes and Nutrition) was completed by participants which included questions on food consumption across all food groups. A system for analysis used for the original SLÁN survey was not publicly available, however the researcher obtained codes from the original authors of the SLÁN survey. Based on codes, each of the 192 items on the FFQ were re-coded into portions per day/week/month to determine consumption levels. Each shelf of the food pyramid were allocated a measurement as a portion per day (PPD) in terms of greater than (>) daily recommendations, recommendations per day and less than (<) recommended per day. Portions were further categorised into shelf count based on PPD. Analyses based on demographics was correlated with weight status against national recommendations based on the food pyramid. Pearson's chi-square test determined significant bivariate associations (p-value <0.05) between being overweight/obese, the demographic characteristics and the shelves on the food pyramid. Logistic regressions were assessed based on the p-value likelihood ratio test (0.05 level of significance). Demographics were examined relative to weight status (overweight or obese) and food intake based on Recommended Daily Amount (RDA) as PPD with data presented on the number of portions per food item per day, week or month based on the food pyramid.

Results

In this study, women were overweight or obese (72.2%, n=239/331) as were men (64.7%, n=156/241) as were participants at midlife (aged between 50-64 years) (70.1%, n=204/291). Across the study population, significant associations were identified between BMI (overweight and obese) and level of intellectual disability and living arrangements ($p<0.001$). Chronic health conditions were reported in overweight or obese participants with statistically significant associations found for; gastrointestinal (GIT) disorder (59.2%, n=148/250) ($p<0.001$); respiratory disease (89.2%, n=33/37) (p-0.006); musculoskeletal disease (56.7%, n=80/141) ($p<0.001$).

Women at menopause reported CHC, with the majority of who were overweight/obese aged between 50-64 years (65.8%, n=106/161). A significant association was found between CHC, menopause and level of ID (p *value*= <0.001) and residents type (p *value*= <0.043). Significant associations were reported in overweight and obese women at menopause with GIT conditions 36% (n=58/161) ($p=0.001$); neurological conditions 33.5% (n=54/161) ($p=0.002$) and muscular skeletal disorders (30.4%, n=49/161) ($p=0.001$). In terms of objectively measured waist circumference, 65.9% (n=116/176) of women age between 50-64 years had a waist circumference putting them at metabolic disease risk ($p=0.010$). In terms of CHC, both GIT disorder ($p=0.007$) and neurological conditions ($p=0.013$) were also statistically significant.

Analysis of dietary intake and compliance with recommendations of the food pyramid across all food groups was poor. Overweight and obese participants consumed less that recommended for shelves of the food pyramid containing important foods providing essential nutrients for balance such as fruit and vegetables or protein for growth and repair with 45.4% (n=129/284) of overweight or obese participants consuming less fruit and vegetables than the recommended 5-7 PPD and 46.3% (n=74/160) of women consuming < RDA for shelf 1 as was the case for 44.4% (n=55/124) of men. In contrast almost all overweight or obese women exceeded the RDA for high sugar, salt and fat foods (97.5%, n=155/159) as did 96% (n=119/124) of men.

Overall, this study found overweight and obesity omnipresent among those with intellectual disability. Consequently the possibility of negative effects on the health and wellbeing of people with intellectual disability is prominent, particularly so for women at midlife.

DEDICATION

For my husband Harry with all my love

09 April 1961~13 September 2021

There are some who bring a light so great to the world
that even after they have gone, the light remains.

ACKNOWLEDGEMENT

Firstly to all the people with an Intellectual Disability I have had the privilege to meet in my life, thank you for teaching me so much.

"A leader takes people where they want to go. A great leader takes people where they don't necessarily want to go, but ought to be." (Rosalynn Carter). To my distinguished leaders and supervisors Dr Éilish Burke, Prof Mary McCarron and Prof Philip McCallion, who did all they could and more to support and inspire me on this journey. Thank you for your time, guidance and expertise, I have learned so much from each of you. Thank you for introducing me into this wonderful area of research which will have had a lasting positive impact on me.

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CONFERENCE ORAL PRESENTATIONS

HSE National policy launch 2021

Title: Ryan, J. (2021) Food, nutrition and hydration and disability services. On line symposium.

Title: Ryan, J., McCallion, P., McCarron, M. and Burke, E. (2020) Overweight and Obesity and obesity in older adults with an Intellectual Disability, Results from Wave 2 Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA).

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5th IASSIDD Europe Congress, Athens Greece; 18-20th July 2018. Diversity & Belonging: Celebrating Differences. 5th IASSIDD Europe Congress.

Title: Ryan, J., McCarron, M., McCallion, P., Byrne, D. and Burke, EA (2018), Exploring the relationship between obesity and interrelated chronic health conditions in older adults with an intellectual disability (ID) Results from Wave 2 IDS-TILDA.

5th IASSIDD Europe Congress, Athens Greece; 18-20th July 2018. Diversity & Belonging: Celebrating Differences. 5th IASSIDD Europe Congress.

Ryan, J., McCarron, M., McCallion, P., Byrne, D. and Burke, EA (2018), Overweight & Obesity, Health and Wellbeing among Menopausal Women with an Intellectual Disability (ID) through the Wellness Model Lens Results from Wave 2 IDS-TILDA.

School of Nursing and Midwifery's 21st Anniversary Symposium on December 2017

Ryan, J., McCarron, M., McCallion, P., Byrne, D. and Burke, EA (2017) Perceptions of Overweight and Obesity amongst people with an Intellectual Disability Results from Wave 2 and 3 IDS TILDA Study.

POSTER PRESENTATION

Ryan, J., McCarron, M., McCallion, P., Byrne, D. and Burke, E. (2017) Overweight & Obesity, Health and Wellbeing among Menopausal Women with an Intellectual Disability through the Wellness Model Lens: Results from Wave 2 IDS-TILDA.

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REPORTS

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HSE National Policy Membership of the Technical Working Group

Food, Nutrition and Hydration Policy for Adults Accessing Disability Services (2020).

HSE National Policy Membership of the Technical Working Group

Implementation Toolkit Food, Nutrition and Hydration Policy for Adults Accessing Disability Services (2020).

ABBREVIATIONS

ADL	Activities of Daily Living
ANP	Advanced Nurse Practitioner
BAPEN	British Association for Parenteral and Enteral Nutrition
BMI	Body Mass Index
CAPI	Computer Assisted Program For Interviewing
CHCs	Chronic Health Conditions
CP	Cerebral Palsy
CT	Control Group
CVD	Cardiovascular Disease
DoH	Department of Health
Dr	Doctor
DS	Down syndrome
F	Female
FFQ	Food Frequency Questionnaire
GERD	Gastroesophageal Reflux Disease
GIT	Gastrointestinal
GP	General Population
HIPE	Hospital In-Patient Enquiry Scheme
HSE	Health Service Executive
ID	Intellectual Disability
IDS-TILDA	The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
IPAQ	International Physical Activity Questionnaire
M	Male
MetS	Metabolic Syndrome
MUAC	Mid Upper Arm Circumference
MUST	Malnutrition Universal Screening Tool
NIDD	National Intellectual Disability Database
NS	Not specified
NQAIS	National Quality Assurance and Improvement System (NQAIS) Clinical
OB	Obese

OM	Objective Measurement
OR	Odds Ratio
OW	Overweight
PA	Physical Activity
PBF	Percentage of body fat
PIQ	Pre Interview Questionnaire
PKU	Phenylketonuria
PPD	Portions Per Day
RNID	Registered Nurse Intellectual Disability
SD	Standard Deviation

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POSITIONING MYSELF IN THE RESEARCH

Having trained as a nurse in Intellectual Disability (ID) and worked across a number of different areas during my career including end of life care, the poor health outcomes experienced by people with an ID has always concerned me. Equally, engagement in further professional development opportunities over time has resulted in a deeper understanding of my knowledge deficits. Prior to embarking on my PhD I had completed a research masters using a qualitative research methodological approach involving face to face interviews with people with an ID. This experience was inspiring and unwrapped an appreciable awareness of the importance and value of research. It instilled a drive within me to continue on a research progression pathway. It also revealed the need for flexibility in my approach to research as the participants often wanted to speak about life experiences they had encountered rather than the topic I had presented. During this time, I developed interview skills and techniques that subsequently served me well. At this juncture I was in a regional nurse practice development role within which I was continually refreshing my understanding of a range of subject matters relevant to ID. I found this aspect of my role enjoyable and it had a bearing on my pursuit of PhD opportunities. I also had an appreciation that within my professional role I would have opportunities to share my learning and influence change at a service and policy level.

With a particular interest in diet and nutrition, when I went seeking research openings, the chance to position my study within a longitudinal study (IDS-TILDA) afforded me an opportunity I could not contest. I was aware of the study, its principle investigators and with a conceptual framework inclusive of both physical and behavioural health, this presented the prospect of examining a range of potential contributory factors for overweight and obesity. Notwithstanding the merits of conducting this study, initially I was apprehensive. I was concerned that as a part-time student I would struggle to manage my workload while maintaining the integrity and quality of the study. I worried that I that I would not be good enough and my shortfalls would negatively impact a successful outcome. Nevertheless, I quickly realised I was embarking on a journey within a community of supportive researchers. Despite challenges over time and the ebbs and flows of the study, I set out on what was to become one of the most rewarding journeys I have taken. As I evolved through this study, I changed work roles and encountered great personal change. With all of its challenges, I persisted and developed a greater sense of my personal resolve and understanding of the strength of commitment to my study.

As a nurse with a number of years' experience working in ID, when I began exploring overweight and obesity, despite an appreciation of the context of people's lives and potential lifestyle influences contributing to this disease, I had not anticipated the breath of dynamics involved. Furthermore, my expectation that the presentation of overweight and obesity within ID populations would somewhat mirror that of the general population quickly dissipated. At an early stage in this research, I was challenged by assumptions on the direction of my study quickly realising that I needed to let the evidence tell the story. This tested my resolve and although it took time and consideration to develop the research question. Nevertheless, on reflection it was worthy of this attention. My learning and development through this early stage of the research process endured and evolved throughout the study.

CHAPTER 1: INTRODUCTION AND CONTEXTUALISING THE THESIS

The way to get started is to quit talking and begin doing

Walt Disney

1.0. Introduction

This chapter offers the reader an introduction to this study. In setting the scene, overweight and obesity situated within intellectual disability (ID) is described. Introducing the thesis, the researcher guides the reader through the rationale for examining this topic and its importance to the health and wellbeing of people with an ID. This chapter provides the study context and its structure and definitions used throughout the study. This is followed by the overall study aims and objectives, which are mapped to subsequent chapters.

1.1. Thesis Structure and Outline

Chapter 1: Introduction and contextualising the thesis

In this chapter, the reader is introduced to the study topic together with the background information and rationale for the study. The chapter concludes with an outline of the study aims and objectives, which are linked to subsequent chapters which are proceeded with a systematic examination of the literature.

CHAPTER 2: Systematic Literature Review and Meta-analysis Exploring Overweight and Obesity within the Literature

A systematic literature review guided by PRISMA establishes the prevalence of overweight and obesity in this chapter. Following a thorough search of MEDLINE, EMBASE, PubMed, PsycInfo and CINAL Complete databases and grey literature, 349 articles are identified with 36 initially quality assessed and a final 9 studies put forward for data extraction. Findings indicate that overweight and obesity is omnipresent in adults with an ID. Moreover, women with an ID are more obese than men although the inverse is the case for overweight. The effects of excess weight particularly on health was apparent across the literature as are some of the unique challenges experienced by people with an ID. A number of measures for weight status were used across the studies. Following an initial systematic review of the literature to establish the prevalence of overweight and obesity, the author revisited the systematic results and these are presented in chapter 2.

CHAPTER 3: An Exploration of the Risk Factors for Overweight and Obesity in Older adults with an Intellectual Disability

Within this chapter, the reader is guided through an exploration of the literature describing risk factors exposing older people with an ID to overweight and obesity. Additionally, the barriers and challenges to maintaining normal weight status which is correlated with positive overall health in older adults with an ID is described.

CHAPTER 4: Research Methods and Design

This chapter introduces the reader to the IDS-TILDA study. The sampling strategy, the conceptual underpinning and values framework contributing to this thesis and the IDS-TILDA study participants are described. In conclusion, this chapter presents the ethical principles underpinning the study, which provided guidance and direction for the researcher throughout this study.

CHAPTER 5: Overweight, Obesity and Chronic Health Conditions in Older adults with an Intellectual Disability

This chapter explores Chronic Health Conditions (CHCs) and overweight and obesity. Reported Doctors diagnosed CHC were examined in terms of its association with overweight and obesity. These negative health outcome for older people with an ID who are overweight or obese are also identified in this chapter.

CHAPTER 6: Women, Menopause, Overweight and Obesity

Evidence presented in both the systematic literature review and the CHCs highlighted in the previous chapter directed towards higher prevalence and impact of overweight and obesity on women than men with an ID. Therefore, within this chapter, overweight and obesity in women with an ID is examined with the results shining a particular light on women at menopause and the associated risk that overweight, obesity and central adiposity poses to their overall health and wellbeing.

CHAPTER 7: Diet and Nutrition: A Descriptive Examination of Dietary Patterns of Older Adults with an Intellectual Disability

In this chapter the reader is guided through diet and the critical role it plays in maintaining positive health status in ID. Additionally, this chapter presents an analysis of the habitual dietary intake of the older adults with an ID who participated in Wave 3 of IDS TILDA. The IDS-TILDA Food Frequency Questionnaire (FFQ) is described and offers a first time overview of the dietary patterns of participants who were also overweight or obese.

CHAPTER 8: Converging Insights: Synthesising Key Findings and Shaping Future Directions in Addressing Overweight and Obesity among Individuals with Intellectual Disabilities

This concluding chapter provides the reader with an executive summary of the findings and presents recommendations for clinical practice, research, education and policy.

Figure 1.1 presents the chapters diagrammatically.

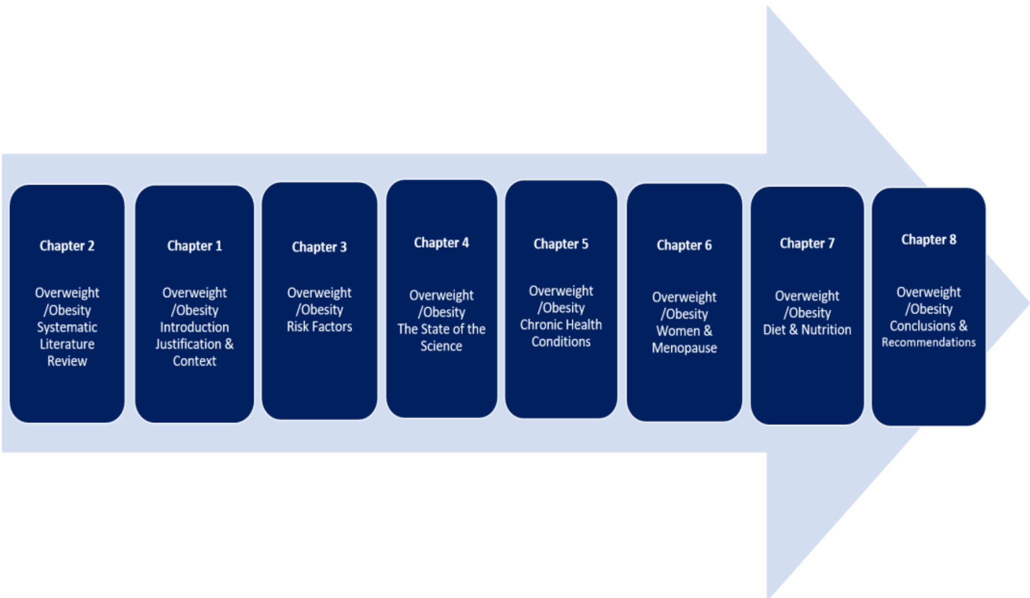


Figure 1.1. Flow Chart Thesis Chapter Outline

1.2. Intellectual Disability as an Ageing Population

The World Health Organisation (WHO) expects the world population of those over the age of 60 years to increase to more than 22% within the general population by the year 2050 (WHO, 2015). Consequently, life expectancy in some developed countries has increased by as much as 30 years (Christensen *et al.* 2009). The ageing population trajectory of those with an ID is similar to that reported in the general population. The proportional increase of people with an intellectual disability (ID) over the age of fifty five was expected to grow over a twenty year period (McCarron and Lawlor, 2003). This change is perceptible within the National Intellectual Disability Database (NIDD). Of the 28,388 people registered on the NIDD during 2017, 49.1% were over the age of 35 years, compared to 28.5% in 1974, and with a greater number of males registered over the age of 35 years (Hourigan *et al.* 2017). However, despite this addition in life years, people with an ID continue to experience a greater predilection to poor health outcomes (Sadowsky *et al.* 2020; Bowness, 2014; Mencap 2004) and a shorter life expectancy (Doyle *et al.* 2021; McCarron *et al.* 2015, Heslop *et al.* 2014; Gibbs and Priest 2010). Premature mortality continues to affect people with an ID and in particular women with an ID (Doyle *et al.* 2021).

Correlated with health inequality (Melville *et al.* 2005), obesity is a life limiting condition associated with secondary disability compounding poor health and further disability as people age (Perry *et al.* 2012; Ells *et al.* 2006). As one of the world's greatest challenges contributing to poorer health outcomes, the international narrative indicates that 1.9 billion adults are overweight and over 650 million are obese (WHO 2018). Now a greater proportion of the world's population reside in countries where obesity related mortality outweighs that caused by under nutrition (WHO 2017). A quarter of children (aged 3-9 years) are overweight or obese and will transition into adulthood (Smyth *et al.* 2017). As countless countries now face the challenges of overweight and obesity, many healthcare policies are placing the onus on individuals to actively age well and be responsible for their own health (Government of Ireland 2017; Government of Ireland 2015a). However, obesity in itself hinders this aspiration.

A number of interconnected factors influence positive ageing. These include lifestyle behaviours and environmental and socioeconomic dynamics, which if not balanced, impact health and give rise to disease presentation in older people (Department of Health (DoH), 2013). In addition, age progression leads to physiological age-related changes to the body, thus exposing older people and indeed older people with an ID to poorer health outcomes and increased disease occurrence as they age (DoH 2013). In Ireland, people with an ID present to hospitals with different disease patterns and experience longer average lengths of stay in hospitals than the population as a whole (Doody *et al.* 2021). The expressive language required to describe symptoms or a feeling of being unwell may allude some people with an ID where communication challenges exist. Furthermore, diagnostic overshadowing although described across mental health service areas (Mason and Scior 2004), also relates to the physical health in ID populations where expressive behaviour is not investigated as a potential response to an underlying health or pain condition. These specific aspects culminate to a poorer health experience for individuals with ID.

While human longevity is a success story, as populations age so too does the projected number of older adults who are overweight and obese. Obesity in the adult population requires scrutiny due to its universal life limiting effect on society and consequent increase in health costs (Danata *et al.* 2019; Neumeire *et al.* 2017; Tyrovolas *et al.* 2015). This is especially true for those with an ID who experience additional disability, which is further compounded by other challenges such as communication, access to health and existing health disparities. Consequently, an increasingly older population who are overweight or obese challenges government policy, health resource provision and utilisation (Fakhouri *et al.* 2012) requiring planning at both a societal and illness prevention level.

1.3. Contextualising Overweight and Obesity

International evidence suggests that increased body weight presents the most prominent contemporary global health care challenge (Grondhuis and Aman 2014) and is the fifth principal cause of death globally (WHO 2010). Disturbing the body's physiological equilibrium, obesity contributes to CHCs such as hypertension, diabetes, heart disease, osteoporosis, depression (Sari *et al.* 2016; Phillips *et al.* 2014) some cancers (Patterson *et al.* 2013; Ogunbode *et al.* 2009) and where central adiposity features, is a predominant risk factor for metabolic syndrome (Gaston *et al.* 2019; Adult Treatment Panel III 2001). For those with an ID the emerging risk is also apparent (Oppewal, and Hilgenkamp 2020; Tyrer *et al.* 2019).

1.4. Overweight and Obesity

Energy expenditure relative to energy intake is an important contributor in maintaining the body's balance. Energy in food and drink is measured in calories. Nutrients from food required by the body go through a process of digestion where they are absorbed into the blood stream and transported through the body for use or excretion. Overweight and obesity occurs when there is a surplus between energy intake and the body requirements (WHO 2015). Described as a chronic disease, obesity occurs where superfluous body fat poses health risk (WHO 2022) and where the body hosts greater than 20% of its recommended weight (DeAngelo *et al.* 2017). Exerting negative effects on the body (Elia *et al.* 2005), a superfluous calorie intake of free sugars relative to the body's energy requirements (WHO 2015), coupled with habitual consumption of excess processed food, contributes not only excessive weight gain, but to hypertension, cardiovascular disease (WHO 2019) and diabetes. This in turn can lead to physical dependency and supplementary disability (WHO 2011; Baeyens *et al.* 2006).

1.5. Contributory Factors for Overweight and Obesity

In addition to dietary imbalance, environmental dynamics, lifestyle and genetics contribute to overweight and obesity (Serra-Majem and Bautista-Castaño 2013). A genetic predisposition to obesity is noted as a contributory factor for a limited number of people (Ranadive and Vaisse 2008). Sex and certain aetiology, which are not amenable to change, present as unique risks for obesity for people with an ID. For example, obesity presents as a common and complex feature in syndromes such as Prader-Willi-Syndrome (Holsen *et al.* 2009).

Modifiable health risks include lifestyle factors which affect the weight status of people with an ID. Furthermore, lower socioeconomic status and level of educational attainment, (Lee *et al.* 2019; Cohn 2013) together with obesogenic environments with freely available processed food exerts a negative impact on this contemporary international health challenge. Medical conditions including hypothyroidism are acknowledged as instrumental factors for overweight and obesity (Sanyal and Raychaudhuri 2016) and present frequently in the aetiology of people with Down syndrome (Cebeci *et al.* 2013). Commonly used prescribed medications among this cohort, such as anticonvulsants, antidepressants, antipsychotics and antihyperglycemics can lead to weight gain (Wharton *et al.* 2018).

Consequently, these pre-existing factors among people with an ID increase risk and exposure to overweight or obesity. Therefore, in the absence of an evidence base, narrating weight status in an older population of people with an ID in Ireland, this research study is timely. Establishing a baseline understanding of the extent of this contemporary societal challenge, in people with an ID is judicious.

1.6. Measurement of Overweight and Obesity

As a complex phenomenon, overweight and obesity is influenced by a number of interconnected factors, including lifestyle (Frood *et al.* 2013; Novak 2009). The establishment of the person's weight status through measurement provides a constructive baseline for nutritional screening using an internationally recognised standardised measurement. Body Mass Index (BMI) which is an internationally accepted measure of body fat and weight status and is calculated as body weight in kilograms divided by height in meters squared (kg/height m^2) (Rolland-Cachera *et al.* 2015). The World Health Organisation (WHO) cut-offs for BMI include underweight BMI ≤18.50; Normal Weight ≥18.50-24.99; Overweight ≥25.00-29.99 and Obese ≥ to 30 (WHO 1995) (table 1.1). In addition to BMI, waist circumference is used to measure central adiposity and is an indicator of increased risk for metabolic disease (Carroll *et al.* 2014) (table 1.2). The WHO (2011) describe a waist circumference of >94cm (male) and >80cm (female) as that which increases the risk of metabolic complications (table 1.1). Substantial risk for metabolic complications arises where waist measurements are >102cm (M) and >88cm (F). Additionally measures such Percentage of Body Fat and Waist to Hip Ratio, also considered more accurate, can also be used in the overall assessment of weight status. Nevertheless, BMI and waist circumference are easy to use indicators for clinical practice. Having a standardised measurement not only supports clinical practice but also provides researchers with a standard method of measurement to compare and establish prevalence, incidence and risks among research populations.

Table 1.1 WHO (2002) Body Mass Index (BMI)

BMI (kg/m2)	Indicator
<18.50	Under weight
18.50-24.99	Normal weight
25.00-29.99	Overweight (pre-obese)
>30- 34.99	Moderately Obese (Class I)
35.00-39.9	Severely Obese (Class II)
≥40	Morbidly Obese (Class III)

Table 1.2 World Health Organisation cut-off waist circumference points and risk of metabolic complications

Indicator	Cut-off points	Risk of metabolic complications
Waist circumference	>94 cm (M); >80 cm (W)	Increased
Waist circumference	>102 cm (M); >88 cm (W)	Substantially increased
Waist–hip ratio	≥0.90 cm (M); ≥0.85 cm (W)	Substantially increased

1.7. Prevalence of Overweight and Obesity

Monitoring overweight and obesity through prevalence ensures the availability of robust scientific data. This, in turn enables the description of change in population health over time and can therefore influence policy and health spend. Obesity in adulthood is now a global challenge and described by the WHO as an epidemic (WHO 2015). Flegal and colleagues identified rates of obesity of over 40% among women and 35% among men in a US study involving over five and half thousand people. Alarmingly in this study over 9.9% of women and 5.5% of men were morbidly obese, that is a BMI of >40 (Flegal *et al.* 2016). Obesity in Denmark is also increasing with prevalence rates (2010-2020) expected to reach to 27% for men and 26% for women and where patterns across the decades are resulting in an examination of early life and pre-natal influences (Due *et al.* 2007). Similarly 61.9% of Canadians present as overweight or obese (Statistics Canada 2019), with increases across age ranges doubling over a 28 year period (Public Health Agency of Canada 2011). In Latin

America, Polynesia and Micronesia similar rates of obesity are being recognised particularly associated with lower socio-economic status (Abarca-Gómez *et al.* 2017). Ireland has, over the last two decades seen the level of overweight and obesity in the general population double (Dee *et al.* 2015; WHO 2011). A study in the Republic of Ireland using cross-sectional data analysis on over 10,000 adults found 59% males and 42% of females to be overweight or obese (Kearns *et al.* 2014). Furthermore, the Irish Longitudinal Study on Ageing (TILDA) described 50% of older Irish adults over the age of 50 as obese with 43% presenting as overweight using BMI as the indicator (Leahy *et al.* 2014). Within the eight year period 2007-2015, obesity in Irish women increased by 70% with a 56% increase in males (Smyth *et al.* 2017). Moreover, the Republic of Ireland was placed at the top of the European rankings for future levels of obesity in 2010 (WHO 2010) and in 2019 was ranked in the top four countries for obesity for both women (26%) and men (25.7%) (Eurostat statistics explained 2019). The concerning consistent increased trajectory for obesity poses a threat to the overall health and wellbeing of future adult aging populations including those with an ID.

1.8 Overweight and Obesity in Intellectual Disability

The pervasive nature and dynamics of overweight/obesity also threaten the health and wellbeing of people with an ID (Bowness 2014; Willis *et al.* 2007; Mencap 2004). Down syndrome (Melville *et al.* 2005), low activity levels (Burke *et al.* 2014; Grundi 2006; Emmerson 2005), conditions such as epilepsy (Daniels *et al.* 2009; Kobau 2008) and environmental influences (Hsieh *et al.* 2014) contribute to increased risk exposure. In the context of advancing age in ID, the prospect of developing age-related health conditions is recognised (Petrenko *et al.* 2014) and augmented when coexisting with overweight and obesity. A further risk for people with an ID lies within diminished understanding or appreciation of the risk to life that overweight and obesity brings. Evidence suggests that whilst people with an ID express awareness of what constitutes a healthy lifestyle (Caton *et al.* 2012), they require ongoing support to maintain a positive lifestyle (Lorentzen and Wikström 2012). Understanding the extent of this global contemporary challenge in ID provides a bases for policy change.

Consistently higher levels of obesity are reported in people with an ID (Neumeier *et al.* 2017; deWinter *et al.* 2012; Bradely 2005) with women with an ID most at risk. Burke *et al.* (2017) In a longitudinal study on ageing and ID, using objective measures, reported 79.7% of older adults to be overweight or obese. In Wave 2 of IDS-TILDA researchers noted that, despite high levels of overweight and obesity, six in ten participants who fell within this category perceived themselves to be the correct weight (60%) and consuming fast food weekly (Burke *et al.* 2014). A further Irish study by McGuire *et al.* (2007) reported 68% of people with an ID to be overweight or obese. Foley *et al.* (2013) examined BMI and waist circumference records from 4,174 (2683 males and 1491 females) Latin American Special Olympic athletes demonstrating a significant difference in prevalence, with overweight/obesity (BMI ≥25) and where males had lower levels of overweight or obesity (40.8%) than females (49%). This was also the case for waist circumference measures where the waist measurement increasing exposure to metabolic disease risk (≥90cm M and ≥94 F) was again lower in males (19.6%) and appreciably higher in females (24.4%) (Foley *et al.* 2013).

It is not surprising to find such prevalence figures bearing in mind that individuals with an ID do not engage in lifestyle behaviours to the point of accruing benefit. This is evident in research by McCarron *et al.* (2014) where reported levels of activity were well below those of the general population (2.5% versus 33% respectively). Furthermore, people with an ID maybe genetically predisposed to overweight or obesity. Conditions such Prader-Willi (Khan *et al.* 2018) bear specific risk with overweight and obesity is also problematic for people with Down syndrome (Kinnear *et al.* 2018; Nixon *et al.* 2018; Krause *et al.* 2016; Hsieh *et al.* 2014) in examining the prevalence of multi-morbidity in people with an ID involving over 1,000 participants aged 16 years and older, cited obesity as the second most prevalent of 20 dominant conditions (40.6%) but the most dominant condition for people with Down syndrome (56.5%).

Overweight and obesity is a complex persistent individual and societal challenge with its causes and consequences in older people with an ID poorly understood (Royal College of Physicians Ireland 2015). Although associated with poor health outcomes (Brown and Kuk, 2015), chronic diseases and increased healthcare costs (Kearns *et al.* 2014), there is a dearth of available evidence addressing overweight and obesity in the context of the lives of people with an ID. Longevity and the quality of those extended life years requires an appreciation of the impact overweight and obesity has in people with an ID.

Therefore, this research, framed in terms of weight status (overweight and obesity) and sex, age, living circumstances and level of ID will explore related areas of health including chronic health conditions and dietary intake patterns. Objective measures for BMI including height, weight and waist circumference underpin this study, leading to an examination of behavioural health involving a comprehensive examination of diet in the context of overweight and obesity as presented in figure 1.0 below.

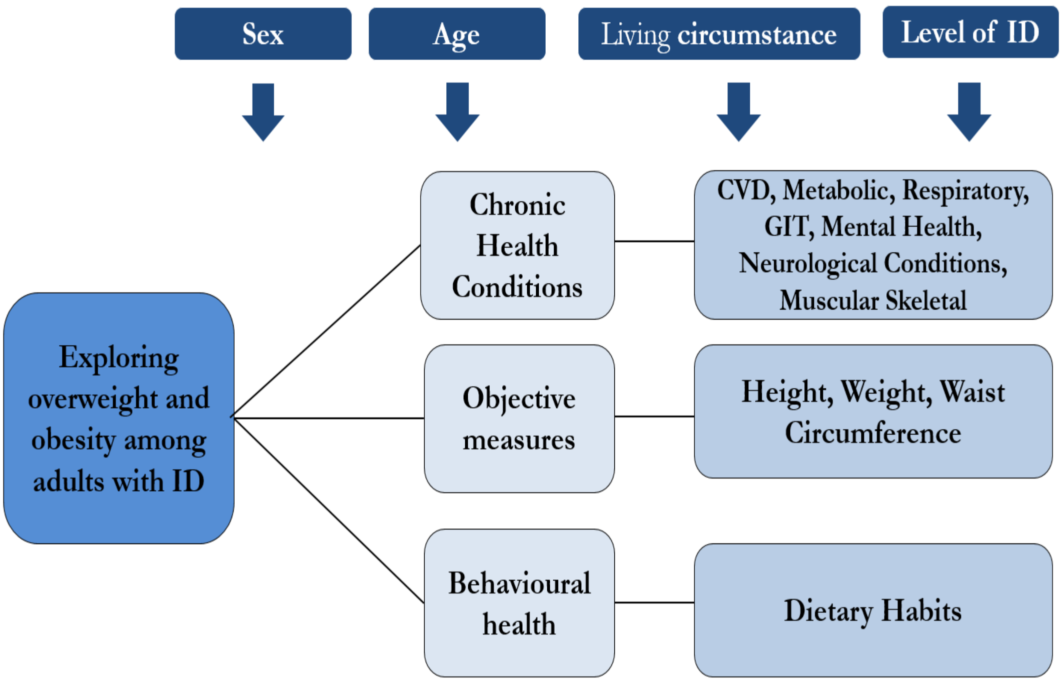


Figure 1.0. Framework Guiding the Study

1.9. Positioning the Study

Positioning the research in IDS-TILDA offers a unique opportunity to examine overweight and obesity in the context of lifestyle dynamics which influence overweight and obesity. To appreciate the contemporary challenge that is overweight and obesity in older Irish adults with an ID, the reseracher examined data pertaining to health and diet.

1.10. The Research Question

To establish the state of the science of overweight and obesity among older adults with ID in Ireland, its health consequences and diet as contributory factors for obesity the researcher will ask the following questions:

1) What is the prevalence of overweight and obesity among older adults with ID in Ireland?
2) What are the consequences of overweight and obesity on individual's physical health?

3) What are the physical health implications for women with an ID who are overweight or obese?

4) What are the dietary habits of an older population of people with an ID who are overweight or obese?

5) Are there specific dietary factors that contribute to overweight and obesity among individuals with ID in Ireland?

1.11. Aims

The aim of this study is to describe overweight and obesity among older adults with ID in Ireland, its unique contributory factors, health consequence and the contribution diet plays to identify the consequences of overweight or obesity on the health and wellbeing of older adults with intellectual disability.

1.12. Objectives

1) To examine the prevalence and incidence of overweight and obesity among older people with an ID using objective measurement.

2) To investigate the implications of overweight and obesity on the physical health of older people with an intellectual disability.

3) To examine dietary consumption patterns in an older population of people with an ID across all food groups, including known contributory dietary factors to overweight and obesity in the context of national recommendations based on the food pyramid (Department of Health 2016a).

4) To provide data to inform the development of overweight and obesity guidelines for people with an ID and inform the development of interventions to address such obesity.

In order to achieve these objectives, the researcher has mapped the thesis with this chapter presenting an overview of the overall study and will be followed with a systematic literature review and a review of the risk factors (modifiable and non-modifiable). This then leads to a descriptive chapter describing the methodological approach to the overall study. The impact on health for people with an ID who are also overweight or obese is charted, leading into an examination in the context of women's health. The age profile in this study for women relates to menopause as a life stage occurring within the participant's age profile. A comprehensive examination of diet will ensue and the overall thesis will conclude with a chapter presenting recommendations.

1.13. Conclusion

This chapter began by signposting the reader to the thesis. The reader was introduced to the topic under investigation subsequently guided through an outline of the research chapters. The context of ageing within ID was presented leading on to discussion on health implications influenced by lifestyle behaviours. One such outcome is overweight and obesity.

The factors, which influence this problematic chronic disease, were presented. Moreover, risk factors specific to people with an ID, identified into two distinct categories of non-modifiable and modifiable factors were examined. These included non-modifiable risks such as sex and aetiology, both of which are not amenable to change. Modifiable risks included living circumstances, diet, physical activity, CHC, prescription medications, socioeconomic status and education and are areas where if addressed could contribute to weight loss and health improvements.

This was followed with a description of the measurement for overweight and obesity with internationally recommended parameters for both BMI and waist circumference used in line with WHO guidance. The magnitude of overweight and obesity in general populations was outlined proceeding with ID. Obesity was indicated as a particular risk for women with an ID which was concerning considering this research studies participant's profile.

Positioning this research study in IDS-TILDA was described including the unique opportunity to examine overweight and obesity not only in the lives of an older population of people with an ID but also enabled an examination of the context of their lives. To this end, data was addresses in terms of sex, age, living circumstances and level of ID. This chapter concluded with the research question which guided this research study and the overall study aims and objectives.

The first step in establishing a picture of the prevalence of obesity among those with ID is to examine the literature systematically. The ensuing chapter examines the state of the science as it pertains to overweight and obesity through a systematic examination of the literature on overweight and obesity, moreover overweight and obesity in ID.

CHAPTER 2: SYSTEMATIC LITERATURE REVIEW EXPLORING OVERWEIGHT AND OBESITY WITHIN THE LITERATURE

"*All things hang like a drop of dew upon a blade of grass*".

WB Yeats

2.0. Chapter Summary

The following chapter examines the prevalence of overweight and obesity amongst older adults with intellectual disability through a systematic literature search and subsequent review process. A robust protocol was developed to guide the systematic review with predetermined terms named and the search concept developed diagrammatically. The following databases were chosen for the search; MEDLINE, EMBASE, PubMed, PsycInfo and CINAHL Complete. Additional searches were conducted by scrutinising reference lists and national and international policy documents. The PRISMA guide was applied to refine the search. In total n=36 full articles were extracted and following further scrunity n=9 papers went forward for quality assessment. Studies were considerd eligible for inclusion if they met the following criteria: studies on adults (≥18 years) who had an Intelectaul Disability (ID) and where anthropemetric measurements were taken to determine levels of overweight and obesity (BMI ≥ 25.00-29.99 (overweight) and BMI ≥ 30.00 (obese)) as an outcome measure for overweight or obesity (WHO 2009). Studies involving children with an intellectual disabity were excluded as were non English language and non human studies.

Robust appraisal of the data was conducted seperately by two independent investigators utilising the National Institute of Health (NIH) guidelines for assessing the literature quality. Concensus on emerging uncertainty was resolved through discussion reaching consensus with the independent investigator. Where divergence of opinion occured a third investigator arbitrated. Following quality appraisal 9 articles were chosen for further data extraction.

Consistency in the literature materialised with overweight and obesity occuring more frequently in women with an intellectual disability. Additionally, some inquiries concluded that men with an intellectual disability present with higher rates of overweight but lower levels of obesity than their female counterparts and higher levles of obesity than the general population. However, stringent comparative analysis was challenged by inconsistenceis with methods of data collection and anthropemetric measures for overweight and obesity used with disparity with the type of measures chosen. Percentage of Body Fat (PBF); Waist to Hip Ratio (WHR); Waist Circumgference (WC) and Skinfold Thickness featured as measurements within the studies reviewed. Nonetheless all of the studies used BMI as a measure, with only two studies not identifying supplementary measures for overweight and obesity. However, where BMI was used it was considered differently across studies. This data measurement ranged from overweight to obesity to overweight and obesity. In addition some studies compared data with general population studies and others isolated Down syndrome as a comparator.

Participants level of intellectual disability in the main was representative across the range of mild, moderate, severe/profound ID, with a small number of studies reporting higher numbers of participants with a mild ID. In terms of prevelance of overweight and obesity in ID, this was charted across all of the studies. Where comparators with a general population sample were used, overweight and obesity was more prevelant in ID. Overall what was of particular concern was the apparent risk to women with an ID. Whilst in some studies men were more overweight that women, the inverse was the noted for obesity. This was also the case for women with Down syndrome. Waist circumference measures, where used also indicated high risk eposure to metabolic disease risk and as with BMI were more problematic for women with an ID.

In the context of an ageing population in ID, the addition of health complications imposed as an affect of overweight and obesity or central adiposity is deeply concerning. Therefore, further exploration is warranted in addressing the true extent of overweight and obesity in people with an intellectual disability with predictors, health and lifestyle risk factors being examined.

2.1. Introduction

Peer-reviewed literature was examined analytically to ascertain the prevalence of overweight and obesity in adults with an intellectual disability. This chapter provides justification for this study as being overweight and obese is problematic among those with an ID. Nonetheless, there is little available evidence presenting this chronic disease in the context of an ageing population of adults with an ID. Therefore, this chapter sought to methodically examine the state of the science as it pertains to overweight and obesity and people with an ID. The ensuing chapter presents the search strategy and methods applied to identify the most relevant literature. The researcher delineates a detailed description of the search strategy applied and how the PRISMA provided the frame for identification of the literature. The critical appraisal process is also outlined.

2.2. Background to Overweight, Obesity Prevalence

Obesity is rooted in an energy imbalance (DeAngelo *et al.* 2017). Global overweight and obesity is described as a dominant modern-day health care challenge worldwide (Grondhuis and Aman, 2014) and is one of the top five principal cause of death globally (WHO 2009). A pressing 21st century challenge, but a modifiable health condition, obesity affects systems of the body resulting in preventable, unnecessary conditions inclusive of hypertension, diabetes, heart disease, stroke, depression (Sari *et al.* 2016; Phillips *et al.* 2014) and ultimately premature death (Ludwing 2016; U.S. Department of Health and Human Services 2010). In 2017, WHO reported that more people now face higher mortality due to obesity than undernutrition, with nearly a quarter of the world's population being either overweight or obese (WHO 2017). Ireland has seen exponential increases in levels over the last two decades contributing to poorer health outcomes, particularly observed among women (Smith *et al.* 2017; Dee *at al.* 2012; WHO 2011).

2.3. Prevalence of Obesity in the ID Population

Consistently higher levels of obesity are reported in people with an intellectual disability (Neumeier *et al.* 2017; Bradley 2005) with women with an intellectual disability most at risk (McCarron *et al.* 2011). McGuire *et al.* (2007) in an Irish study involving people with an ID found 68% of those surveyed to be overweight or obese, signifying a higher prevalence rate than found within the general population (Kearns *et al.* 2014) which is similar to research by Melville *et al.* (2007). Furthermore, obesity is a dominant multi-morbid disease affecting young people with an ID (Kinnear *et al.* 2018) and these high levels of overweight and obesity in adults with an ID is disquieting; particularly in the context of an ageing population in and ID at stage in life where the likelihood of declining health can intensify.

2.4. Overweight and Obesity and Health

Correlated with health inequality (Melvill *et al.* 2005), obesity in itself as a life limiting condition is associated with secondary disability increased health burden and further disability as people age (Perry *et al.* 2012; Ellis *et al.* 2005). Co-morbidities relative to obesity are presenting at an increasingly younger age and sustaining into adulthood (Lau *et al.* 2007). Equally, obesity exerts influence on chronic ill health as people advance in years (Smyth *et al.* 2017) thus intensifying health risk. Similarly, central adiposity, correlated with metabolic syndrome contributes to the chronic disease profile (NCEP 2001). This is especially problematic for people with an ID who already experience higher levels of poor health (Doody *et al.* 2021; Bowness 2014; Mencap 2004) and shorter life expectancy (Doyle *et al.* 2021; McCarron *et al.* 2015; Heslop and Glover 2015; Heslop *et al.* 2014; Gibbs and Priest 2010). As a chronic disease, obesity is nonetheless influenced by a myriad of factors

(Pankhurst *et al.* 2015). Diet plays a significant role with overweight and obesity resulting particularly when there is an imbalance between food intake and the body's energy use or requirements (World Health Organisation 2015). This resulting nutritional imbalance among those with an ID leads to overweight and obesity imposing negative effects on the body, dependency and further disability (Palstow *et al.* 2014; WHO 2011; Baeyens *et al.* 2006; Elia *et al.* 2005).

2.5. Obesity, Nutrition and People with ID – Implications

Overweight and obesity is a complex global challenge. This is evidenced in strategies and public policy targeted on diet, exercise, and modification of commercial food behaviours, which have not produced any enduring results (Ramos 2015). In addition, the absence of effective international obesity management in sustained overweight and obesity levels internationally is again an indication of this complexity of this disease. Moreover, the absence of standardised systematic treatment outcome measures (Flodgren *et al.* 2010) relative to intellectual disability, supports the need for investigation.

Given the problematic nature of overweight and obesity, there is currently no systematic methodology applied nationally to collect this data in Ireland. The Expert Report on the Clinical Management of Obesity in Ireland (Royal College of Physicians Ireland Policy Group on Obesity 2015) acknowledges the need to systematically collate information on overweight and obesity in people with an ID, recommending that this could be achieved through the National Intellectual Disability Database, however this is not yet in place.

Although overweight and obesity appears to be a prevalent and persistent challenge in ID, the paucity of data collection and investigation, hampers a real understanding of full extent of the problem in adults with an ID in Ireland. Therefore, identifying the prevalence of overweight and obesity in adults with an intellectual disability provides valuable information for clinical practice, policy makers and strategists. Furthermore, data collection and analysis would identify areas for supplementary research would authenticate the interconnected complex nature of the condition (Frood *et al.* 2013; Novak, 2012). The purpose of this systematic literature review is to determine the prevalence of overweight and obesity among older adults with an intellectual disability. As previously described the WHO criteria for BMI and Waist Circumference will be applied to this systematic review.

2.6. Measuring Overweight and Obesity using International Parameters

Associated with excess body fat, obesity is identified using Body Mass Index (BMI) as a measure with waist circumference measures used to indicate central adiposity. Detailed descriptions of these measures re available in Chapter 1 of this thesis.

2.7. Search Strategy

The initial steps involved in identifying the concepts that applied to the study, developing MeSH and free text terms. The application of boolean operators is presented in figure 2.0 below.

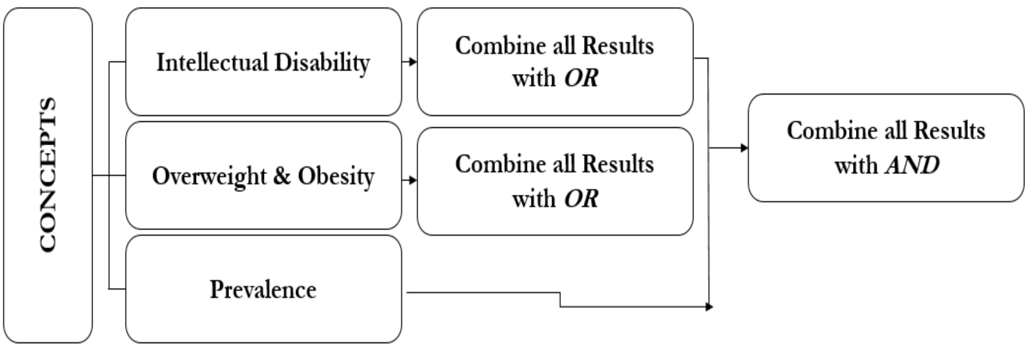


Figure 2.0 Concept Flow Plan

The review question was then developed with the application of the PIOS (see table 2.1). Applying key concepts, the population of interest was identified as adults of all levels of intellectual disability, the intervention was determined as adults who were overweight or obese, the outcome would be the prevalence of that weight measure and the study designs involved would include both quantitative and qualitative studies. Incorporating the: who, what, how and where enabled a focused question to be developed. This would ensure that the search strategy to answer that question was also focused and clear.

Table 2.1 PIOS

P	**Population**	Adults with an ID who are overweight or obese Adults with an ID who had a mild/moderate/severe/profound ID	**Who**	Adults with an ID
I	**Intervention**	Adults with an ID who presented as overweight or obese	**What**	Prevalence of Overweight and Obesity
O	**Outcome**	Prevalence of overweight and obesity in	**How**	Systematic Literature Review
S	**Study Design**	General population prevalence studies of Overweight and Obesity in adults with an intellectual disability studies	**Where**	National and Internationally

2.7.1. Inclusion Criteria

When considering the studies for inclusion, the following criteria were applied: published studies addressing overweight or obesity and ID, prevalence of overweight and obesity, which were specifically pertinent to adults ≥ 18 years, people with an ID across all levels, peer reviewed publications, English language publications and human subjects only. No time restriction was applied to the studies and grey literature would also be included in the search. Table 2.2 provides an outline of the key concepts included in the search strategy. These encompassed ID, prevalence of overweight and obesity.

Table 2.2 Main Concepts for the Search Strategy

1) Date	**November 2017 refreshed September 2022**	
Research Topic	**Overweight and obesity and people with an intellectual disability**	
Search Strategy	**Key concepts**	**Synonyms/alternative terminology (consider regional variations here also) – combine using OR**
	Intellectual* disab* or "learning disability" or "learning disabilities" or Mentally Disabled Perso* or Developmental Disabilit* or mental* disab* or retard* "mental retard* or "cognitive impairment" or "cognitively impaired" or intellectual impair* or handicap* or subnormal* or sub-normal* or feeble-mind* or "learning disorder" or "learning disorders" or angelman* or bardet-biedl* or brachmann-de lange* or cri-du-chat* or coffin-lowry* or crying cat* or de lange* or down's syndrome or downs syndrome or "fragile x syndrome" or labhart-willi* or laurence-moon* or laurence-moon-biedl* or martin-bell or prader-labhart-willi* or prader-willi or "retts syndrome" or rubinstein* or rubinstein-taybi* or willi-prader* or william* or beuren*	
AND		
	Obesit* or weight gain or "body mass index" or BMI or " Morbid Obesity " or overweight or "fat overload syndrome" or adipos* or "Metabolic disease" or "Metabolically benign" or "Central obesity" or "Abdominal fat" or "Skinfold thickness" or fat prevalen* or occurrence or incidence or frequency or epidemic	
AND		
	Prevalen* or occurrence or incidence or frequency or epidemic	

2.7.2. Roles and responsibilities

These were decided prior to the commencement of the search. The principal investigator (JR) developed the protocol inclusive of background, definitions, search strategy, methods and quality assessment criteria, data extraction plan and analysis and discussion flow. Overall, there were three investigators involved in this systematic review of the literature and this strengthened the search through extensive consultation between the principal investigator and the other researchers. The first and second investigators conducted the search, refinement and reviewed independent of each other with the third consulted where arbitration was required. The principal investigator developed an initial question to guide the strategy as specified below.

2.8. Conducting the search

A systematic review is a structured approach to identify quality evidence from a variety of available evidence (Boland *et al.* 2017). The databases chosen for the search included MEDLINE, EMBASE, PubMed, PsycInfo and CINAHL Complete. Additional searches were conducted by scrutinising refference lists and national and international policy documents and using recognised grey literature repositories (table 2.3). Keywords and search strings were developed for the three main concepts of this study namely 'Intellectual Disability', 'Overweight or Obesity' and 'Prevalence'. Each of the concepts had predefined terms and were initally searched individually then combined to complete the search. Searches were conducted during November 2017 and the search refreshed in September 2022 to ensure any updated material was considered. The results were imported to End Note and Duplications removed in advance of the next stage where the results were refined through title, abstract and finally full text screening of the remaining manuscripts. A review of Policies and Strategies was also conducted as indicated in table 2.3 to identify any further relevant grey literature.

Table 2.3. Review of Policies and Strategies

GREY LITERATURE REVIEW SEARCHED			
Site	***Terms Used***	***Results***	***Relevance to search strategy***
RIAN.ie	*Overweight and obesity* *Prevalence* *Intellectual Disability*	*1 MSc* *1 PhD*	*MSc examined prevalence*
British Library	*Overweight and obesity* *Prevalence* *Learning Disability*	*2 Reports*	*None of the findings relevant to the search strategy*
CADTH	*Overweight and obesity* *Prevalence* *Intellectual Disability*	*5 Reviews*	*None of the findings relevant to the search strategy*
Kings Fund	*Overweight and obesity* *Prevalence* *Learning Disability*	*1 Article*	*Not relevant to the search strategy*
NDLTD- Thesis Resources	*Overweight and obesity* *Prevalence* *Intellectual Disability* *Learning Disability*	*0*	

2.9. Results

The identification, screening and eligibility of articles was guided by the PRISMA flow, see figure see figure 2.1 below. In total 9 articles were deemed appropriate to all of the inclusion criteria and sent forward for full review and quality appraisal (appendix 1) out of a preliminary search yielding 349 papers. Duplicate articles were eliminated (n=4). Articles were screened by title with n=222 removed as they did not meet the inclusion criteria, where for example, there were studies involving children or studies with obesity as a subject matter but not prevalent studies. This left a total of 36 articles which were then reviewed by title and abstract (appendix 2). Following this appraisal, 9 articles were selected to be included in this study, full determination of included articles can be seen in the PRISMA figure 2.1. These 9 articles were further scrutinised and a data extraction form was prepared which would enable the identification of the evidence base relative to the prevalence of overweight and obesity in adults with an intellectual disability.

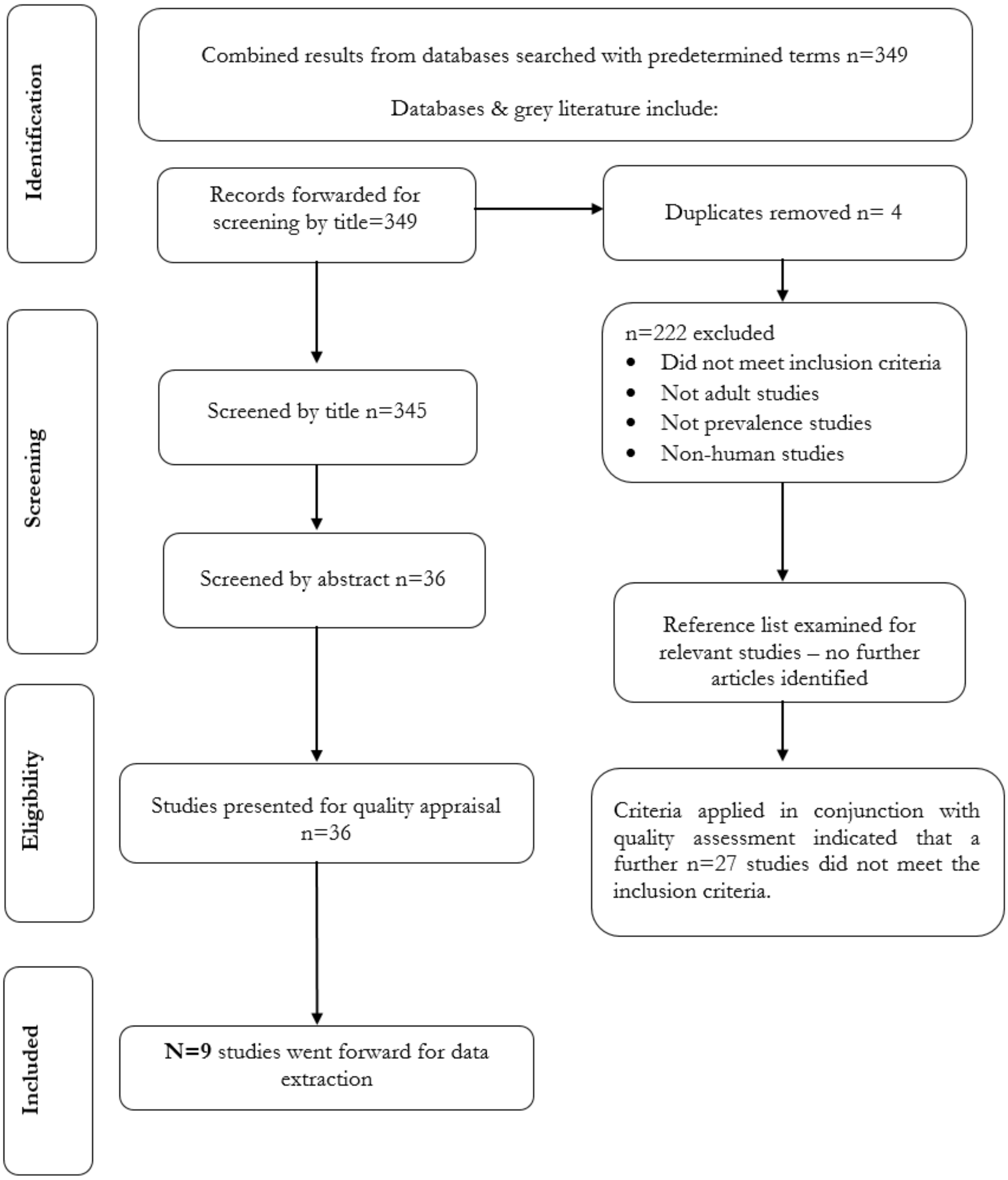


Figure 2.1. PRISMA Flow

Quality Appraisal:

This appraisal was conducted in conjunction with the National Institute of Health (NIH) guidelines for assessing the quality of case-control, cohort and cross-sectional studies. The 14 question assessment tool for cohort studies and cross-sectional studies were employed (see appendix 1). Two investigators (JR and MD) independently assessed the quality of the studies relative to the research question. The appliance of a quality rating guide facilitated a standardised approach to evaluation. Ratings relative to the study type were considered 9-12/10-14 (Good) 6-8/7-9 (Fair) <5/<6 (Poor) (see table 2.4). Furthermore, it was agreed that rating disparity between reviewers would be moderated by a third independent investigator and differences in coding resolved through discussion and consensus.

Table 2.4. Quality Rating Guide

Rating	Case control Studies	Observational Cohort & Cross Sectional Studies	Action	Rate 1	Rate 2	Agreed
Good	9-12	10-14	Proceed to data extraction			
Fair	6-8	7-9	Seek expertise from a third adjudicator			
Poor	≤ 5	≤ 6	Reject the paper			
***Other**	C/D, N/R, N/A		Determine with principal investigator (JR) if particular area has implications on the overall study			

* C/D Cannot determine N/R = not reported N/A = not applicable

2.10. Summary of the Studies Included in the Review

The 9 studies included in this review involved cohort and case series studies with research ranging in country of origin. Three studies examined populations in the USA whilst a further three studies originated in the UK (one Scottish study). Two of the studies from the UK identified their population from one region however one looked at prevalence rates for people with Down syndrome whilst the second study was non-specific relative to the cause of ID. Of the remaining two studies one was based in Latin America and the other in Norway. The 9 studies chosen span a 26 year time frame with the date of publication for the majority in the early to late 2000s. In 3 out of the 9 studies the participants, all people with an ID, had their data compared with general population data. In the remaining studies the population was adults with an ID over the age of 16 years (Kinner *et al.* 2018), over 50 years (De Winter *et al.* 2012) and over 18 years respectively.

Overall study samples sizes were large. Stancliffe *et al.* (2011) collated data from people with an ID who were participants in a National Core Indicator survey (NCIN=8,911) whilst Foley *et al.* (2017) examined Body Mass Index (BMI) and Waist Circumference (WC) from 4,174 Special Olympians. Three further studies had sample sizes in excess of 1,000 participants; Hsieh *et al.* (2014) N=1,450, Bhaumik *et al.* (2008) N=1,110 and Kinnear *et al.* (2018) N=1,023. de Winter *et al.* (2012) examined 945 people with an ID over the age of 50. The remaining 3 studies had participant numbers of N=247, N=183, and N =93, (Melville *et al.* 2005; Belle & Bhate 1992; Moore *et al.* 2004). Out of the 9 studies, Melville *et al.* (2005) was the only study to focus their investigation on people with Down syndrome, although Kinnear *et al.* (2018) and Belle & Bhate (1992) specifically isolated prevalence rates for people with Down syndrome as well as those with other causes of ID. Descriptive data on each of the studies is outlined in table 2.5.

2.11. Data Extraction

The data extraction included, study design, population sample size, demographics including sex, age, level of ID, aetiology measurement of weight reported and BMI measures. Prevalence rates for overweight and obesity were identified, extracted and recorded within the predetermined fields in the data extraction form. Weight measures included BMI, waist circumference, Percentage of Body Fat (males only) were extracted from the studies.

Table 2.5 Description of the 9 Studies included in the Systematic Review

Study	Design	Participants (ID) General Population (GP)		Sex M/F		Age Mean (SD)		Level of ID	Aetiology	Measures reported	BMI measure
		ID N=	GP N=	ID	GP	ID	GP				
Moore *et al.* 2004	Case control	93	-	43 F 52 M	-	*M*=37.1 Males *M*=31.46 *SD*=96.2 Females *M*=33.57 *SD*=9.26	-	Mild/Severe	Not specified [NS]	BMI Percentage of body fat (PBF) Males only	OW 35.5% (n=33) Obese 33.3% (n=31)
Foley *et al.* 2017	Cohort Study	4174	-	149 1 F 268 3 M	-	Males *M*=26.49 *SD*=8.14 Females *M=26.50* *SD*=8.46	-	[NS]	[NS]	BMI (Height &Weight) Waist Circumferen ce [WC]	
Melville *et al.* 2005	Case control study	247	247	117 F 130 M	117 F 130 M	DS *M*=37.24 *SD*=10.46 ID *37.23*	CG *M*=37.23 *SD*=10.5 1	[NS]	DS	BMI	DS OW 37.7% (n=49) Ctls OW 22.3% (n=29) DS OB 20.0% (n=26)

Study	Design	Participants (ID) General Population (GP)		Sex M/F		Age Mean (SD)		Level of ID	Aetiology	Measures reported	BMI measure
		ID N=	GP N=	ID	GP	ID	GP				
											Ctls OB 18.40% (n=24)
Kinnear *et al.* 2018	Population based cross sectional study	1023	-	461 F 562 M	-	*M*=43.9 *M/DS=41.1*	-	Mild/Profound	DS-186 (18.2%) Other ID	BMI WC	(N=415) 40.6
de Winter *et al.* 2012	Cross sectional study	945	3663	463 F 482 M	1790 F 1873 M	*M*=61.5	[NS]	Borderline severe/ profound	DS Autism	BMI WC Waist to hip ratio (WHR) Skin fold thickness	(N=893) ID OW 38.2% ID OB 25.6% (N=3663) GP OW 41.2% GP OB 9.6%
Bhaumik *et al.* 2008	Population based prevalence study	1119	-	458 F 661 M	-	Age 20-≥50	-	Level of understanding *Fairly good* *Poor/ Moderate* *Very poor*	DS CP Autism	BMI	(N=1119) OW 28.0% OB 20.7%

Study	Design	Participants (ID) General Population (GP)		Sex M/F		Age Mean (SD)		Level of ID	Aetiology	Measures reported	BMI measure
		ID N=	GP N=	ID	GP	ID	GP				
Heist *et al.* 2014	Population Based study	1,450	-	800	650	Age 18-68 Mean age 37.1		Borderline to severe/ profound or unknown	ID Autism/PDD CP DS Other	BMI	
Belle & Bhate 1992	Survey	183	-	78 F 105 M	-	F- 20-53 M-20-68	-	[NS]	DS 58	BMI	
Hsieh *et al.* 2014	Cross sectional study	1450	NS	650 F 800 M	NS	*M*=37 *SD*=14.1	*M*=47.8 *SD*=8.14	Mild/ profound	DS CP Autism	BMI	N=1450 ID 38.3% GP 28%
Stancliffe *et al.* 2011	Cohort study	8,911	-	3,906 F 5,005 M	-	*M= 43.48*	*NS*	[NS]	Autism spectrum disorder DS CP Prader-Willi (12 other disabilities and diagnosis not named in the article)	BMI	N=8,101 OW 33% OB 61.8%

ID=Intellectual Disability; GP=General Population; NS=not specified; CT-= Control Group; SD=Standard Deviation; F=Female M=Male; *BMI=Body Mass Index; DS=Down syndrome; CP=Cerebral Palsy PBF*=Percentage of body fat; OW=Overweight; OB=Obese.

2.12. Findings: Prevalence of Overweight and Obesity

Foley *et al.* (2007) studied BMI and waist circumference for a large population of Latin American athletes who were participants in the Special Olympics with 4,174 records examined (2683 males and 1491 females). The results of this examination demonstrated a significant difference in prevalence with overweight and obesity (BMI ≥25) (p<0.001), appreciably higher in females than males with 42% prevalence in males compared with 49.1% in females. Additionally Foley *et al.* reported waist circumference measures indicating a prevalence rate of 24.5% females and 19.6% in males in athletes where the waist circumference measure was above parameter for abdominal obesity (≥ 94 cm for men and ≥ 80 cm for women). Considering the correlation between increased waist circumference and associated risk of metabolic disease this was a worrying finding (Foley *et al.* 2017).

de Winter *et al.* (2012) used both BMI and waist circumference as a measure for overweight and obesity. BMI yielded a 13.7% prevalence of obesity in males and 39.8% females. A comparative analysis with general population-based BMI indicates prevalence rates for males of 47.7% overweight and 13.2% obese and 35.3% and 14.8% for female participants. However, using waist circumference as a measure for obesity generated prevalence rates of 26.7% males and 66.4% females. Contrasting evidence from Moore *et al.* (2004) emerged where no significant difference in BMI between males and females ($t_{(91)}$=*1.14, p>.001)* was reported and similarly when measuring BMI and Percentage of Body Fat in Males (PBF) (*r =.897 p>.001).* What was revealed in this study was a disparity with obesity levels in males relative to the measurement (BMI 30.8% PBF 73%). Moreover, there was evidence to suggest double the prevalence of morbid obesity in the ID population when compared to general population figures (Heish *et al.* 2004).

The overall number of participants for each study, their sex and living circumstances are presented in table 2.6 below. Of note across all of the studies is the risk to women with an intellectual disability, with some evidence showing double the prevalence of obesity across almost all of the studies. Bhaumik *et al.* (2008) reported a standard morbidity ratio (SMR) relative to obesity for male study participants at 0.80 (95% CI 0.64-1.00), evidently much higher at 1.48 (95% CI 1.23-1.77) in females. Of the total study population with an ID (N=1119), 30% (n=661) males and 25.1% (n=458) females were overweight. Obesity was more frequently observed in women at 29.5% than men at 14.7% ($P<0.001$). Interestingly however, there was some evidence to indicate that although women with an ID presented with lower percentages of overweight than their male counterparts, this trend is reversed for obesity. Furthermore, females with an ID were found to be exposed to double the risk of morbid obesity (Stancliffe *et al.* 2011; Heish *et al.* 2014). Bhaumik *et al.* (2008) also found obesity to be more pervasive in females with an ID than the matched cohort (SMR 1.48; 95% CI 1.23-1.77), 32% and 23% respectively.

A further aspect to emerge across the studies was those with Down syndrome when considering prevalence of overweight and obese was phenotype. Melville *et al.* (2005) examined levels of overweight and obesity in people with Down syndrome using matched height and weight measurements (247 pairs with a comparison group with an ID of another aetiology) concluding that both overweight and obesity are omnipresent in women with Down syndrome when compared to their matched sample (r=2.17). Overall 37.6% of women with Down syndrome were overweight compared to 29.5% of those without Down syndrome; 33.3% and 29.9% respectively were found to be obese and 6.8% and 2.6% morbidly obese. Interestingly however, men with Down syndrome only showed a statistical difference with overweight but not obesity (r=0.85). Similarly in an earlier study conducted by Bell and Bhate (1992) involving 183 people with both Down syndrome (58) and other forms ID (71) report greater levels of overweight and obesity in all those with an ID when compared to general population figures and even greater prevalence for those with Down syndrome. Results indicated that 37.14% of males were overweight; reducing to 19.04% (total overweight and obese 56.91%) compared to 34%; 6% and 40% respectively in the general population participants. For the female population however, greater prevalence rates were recorded with 38.46% overweight and 34.61% obese contrasted with general population figures at 24%. 8% and 32%. Similar to Melville's study both males and females with Down syndrome presented with greater levels of overweight and obesity than those with and ID but not Down syndrome (DS M(n=34) F(n=24) prevalence rates for overweight at 38.23% and 54.16% and obesity at 32.35% and 41.66% respectively). Kinner *et al.* (2018) explored multi-morbidity in people with an ID in a study involving 1023 adults (186 participants had Down syndrome). Using the international Statistical Classification of Disease and health related problems (ICT-10) the prevalence of obesity was second only to visual impairment in order of frequency. With a participant mean age of 41.1yrs and level of intellectual disability ranging from mild to profound, 40.6% of the total study population (n=1023) were found to be obese. Further analysis indicates that more than half of those with Down syndrome were obese (56.5% n=105). Alarmingly this study determined that of the total population involved in the study almost all of the participants were living with multi morbidity (98.7%) including obesity related conditions such as muscular skeletal and gastrointestinal disorders.

Table 2.6 and 2.7 below provide an overview of the 9 studies, the population sample size, sex and living circumstances to determine prevalence of overweight and obesity.

Table 2.6. Demographics of Participants in Studies included in the Reviewed

Study Authors	Participant No	Sex F (n)	Sex M (n)	Living Circumstances
Moore ***et al.*** **2004**	93	41	52	8% lived independently 44% with parents 21% in community residential units
Foley ***et al.*** **2017**	4,174	1491	2683	Not reported
Melville ***et al.*** **2005**	247 (matched pairs)	117	130	2% living in 'in patient' facilities
Kinnear ***et al.*** **2018**	1,023	461	562	Living with family carer 390 Lives independently 102 Lives with paid support 467 Lives in congregate setting 64
De Winter ***et al.*** **2012**	945	463	482	Participants were in receipt of formal care and support or who lived independently
Bhaumik ***et al.*** **2008**	1,119	458	661	With family/alone M=37.4 F=46.3 Residential care M=62.6 F=53.7
Belle & Bhate 1992	183 58 DS	78	105	Majority resided at home (with parents or relatives) and attended adult training centre Some in social service hostel or supervised flatlets
Hsieh ***et al.*** **2014**	1,450	650	800	Total population (n=1450) Males (n=650) Females (n=800) Least supported 28.3% Moderately supported 57.4% Most supported 14.3%
Stancliffe ***et al.*** **2011**	8,8911	3,906	5,005	Living arrangements for the *Obese* population Total population (n=8,233) Institution 18.6% Group home 31.6% Agency apartment 41.1%

Study Authors	Participant No	Sex F (n)	Sex M (n)	Living Circumstances
				Own home 42.8% Family home 37.7% Host/foster home 27% Living arrangements for the *Overweight or Obese* population (n=8,233) Institution 47.6% Group home 63.5% Agency apartment 70.5% Own home 69.3% Family home 62.0% Host/foster home 61.2%

Table 2.7. Weight Status and Sex across the Studies

Study	Design	Sex Overweight		Sex Obese		Sex Overweight/obese		Sex Morbid Obesity		Other
Moore *et al.* 2004		Male ID OW		Male General Population OW		Male ID OB		Male General Population OB		Male ID OW & OB
		30.8%	42.5%	30.8%	18.5%	-	-	-	-	73%
	BMI Percentage of body fat (PBF) Obesity Males only	Female ID OW	Female General Population OW	Female ID OB	Female General Population OB	Female ID OW & OB	Female General Population OW & OB	Female ID Morbid obesity	Female General Population Morbid Obesity	Percentage Body Fat Female ID only
		41.4%	28.8%	36.6%	18.2%	-	-	-	-	-
Foley *et al.* 2017	BMI	Male ID OW	Male General Population OW	Male ID OB	Male General Population OB	Male ID OW & OB	Male General Population OW & OB	Male ID Morbid obesity	Male General Population Morbid obesity	Male Waist Circumference
		32.1%		8.68%	-	-	-	-	-	19.63%
		Female ID OW	Female General Population OW	Female ID OB	Female General Population OB	Female ID OW & OB	Female General Population OW & OB	Female ID Morbid obesity	Female General Population Morbid obesity	Female Waist Circumference
		33.87%		15.22%						24.49%
Melville *et al.* 2005	BMI	Male DS OW Male ID OW	Male DS OW Male ID OW	Male DS OB	Male ID OB	Male DS OW & OB	Male ID OW & OB	Male DS Morbid obesity	Male ID Morbid obesity	
		37.7%	22.3%	20.0%	18.4%	-	-	1.5%	-	
		Female DS OW	Female ID OW	Female DS OB	Female ID OB	Female DS	Female ID OW & OB	Female DS	Female ID Morbid obesity	

Study	Design	Sex Overweight		Sex Obese		Sex Overweight/obese		Sex Morbid Obesity		Other
						OW & OB		Morbid obesity		
		37.6%	29.5%	33.3%	29.9%	-	-	6.8%	2.6%	
Kinnear *et al.* 2018	BMI	Male ID OW	Male DS OW	Male ID OB	Male DS OB	Male ID OW & OB	Male DS OW & OB	Male ID Morbid obesity	Male DS Morbid obesity	ID OB
		-	-	-	-	-	-	-	-	37%
		Female ID OW	Female DS OW	Female ID OB	Female DS OB	Female ID OW & OB	Female DS OW & OB	Female ID Morbid obesity	Female DS Morbid obesity	DS OB
		-	-	-	-	-	-	-	-	56.5%
de Winter *et al.* 2012	BMI Waist/hip ratio Waist Circumference	Male ID OW	Male General Population OW	Male ID OB	Male General Population OB	Male ID Waist/ hip ratio OW	Male General Population Waist/hip ratio OW/ OB	Male ID Waist circumfere nce OW	Male General Population Waist circumference OW	
		39.2%	47.7%	13.7%	13.2%	50.1%	33.3%	23.9%	26.7%	
		Female ID OW	Female General Population OW	Female ID OB	Female General Population OB	Female ID Waist/ hip ratio OW	Female General Population Waist/hip ratio OW/ OB	Female ID Waist circumfere nce OW	Female General Population Waist circumference OW	
		37.1%	35.3%	38.0%	14.8%	22.4%	63.0%	19%	66.4%	
Bhaumik *et al.* 2008	BMI	Male ID OW	Male General Population OW	Male ID OB	Male General Population OB	Male ID OW & OB	Male General Population OW & OB	Male ID Morbid obesity	Male General Population Morbid obesity	
		30.0%		14.7%	-	-	-	-	-	
		Female ID OW	Female General Population OW	Female ID OB	Female General Population OB	Female ID OW & OB	Female General Population OW & OB	Female ID Morbid obesity	Female General Population Morbid obesity	

Study	Design	Sex Overweight		Sex Obese		Sex Overweight/obese		Sex Morbid Obesity		Other
		25.1%		29.5%	-	-	-	-	-	
Belle & Bhate 1992	BMI	Male ID OW	Male General Population OW	Male ID OB	Male General Population OB	Male ID OW & OB	Male General Population OW & OB	Male ID Morbid obesity	Male General Population Morbid obesity	
		37.14%	34.0%	19.04%	6.0%	56.19%	40%		-	
		Female ID OW	Female General Population OW	Female ID OB	Female General Population OB	Female ID OW & OB	Female General Population OW & OB	Female ID Morbid obesity	Female General Population Morbid obesity	
		38.46%	24%	34.61%	8.0%	37.07%	32.0%	-	-	
Hsieh *et al.* 2014	BMI	Male ID OW	Male General Population OW	Male ID OB	Male General Population OB	Male ID OW & OB	Male General Population OW & OB	Male ID Morbid obesity	Male General Population Morbid obesity	Male DS OB
		31.6%	-	34.3%	-	-	-	4.5%	3.0%	53.4%
		Female ID OW	Female General Population OW	Female ID OB	Female General Population OB	Female ID OW & OB	Female General Population OW & OB	Female ID Morbid obesity	Female General Population Morbid obesity	Female DS Morbid obesity
		25.5%	-	43.2%	-	-	-	10.9%	5.4%	10.4%
Stancliffe *et al.* 2011	BMI	Male ID OW	Male General Population OW	Male ID OB	Male General Population OB	Male ID OW & OB	Male General Population OW & OB	Male ID Morbid obesity	Male General Population Morbid obesity	
			-	33.6%	33.8%	60.5%	72.3%	5.1%	4.2%	
		Female ID OW	Female General Population OW	Female ID OB	Female General Population OB	Female ID OW & OB	Female General Population OW & OB	Female ID Morbid obesity	Female General Population Morbid obesity	
		-	-	38.9%	35.5%	64.5%	64.1%	10.8%	7.2%	
		Male DS OW	Male General Population OW	Male DS OB	Male General Population OB	Male DS OW & OB	Male General Population OW or OB	Male DS Morbid obesity		
		-	-	-	-	72.5%	-	30.7%	-	
		Female DS OW	Female General Population OW	Female DS OB	Female General Population	Female DS	Female General Population	Female DS Morbid obesity		

Study	Design	Sex Overweight	Sex Obese	Sex Overweight/obese	Sex Morbid Obesity	Other
			OB	OW & OB OW or OB		
				27.8%	40.4%	

BMI=Body Mass Index Control group =(general population) ID=Intellectual Disability OW=Overweight OB=Obese DS=Down syndrome

2.13. Discussion

The systematic review demonstrated a pervasiveness for overweight and obesity among people with an ID, particularly among women. Using BMI as a measure of weight status, both Foley *et al.* (2017) and deWinter *et al.* (2012) show marked difference in prevalence across sexes. This contrasts with findings by Moore *et al.* (2004) who reported no statistically significant sex difference. Where comparisons with general population data, overweight was reported with greater frequency in males but the inverse was the case for obesity (Moore *et al.* 2004; deWinter *et al.* 2012; Bhaumik *et al* 2008; Belle and Bhate *et al.* 1992). Where examined, (Kinnear *et al.* 2018; Melville *et al.* 2005; Belle and Bhate 1992) having Down syndrome was also linked with greater levels of overweight or obesity, although Down syndrome was not isolated across all studies. Nevertheless, relatively high levels of overweight and obesity were reported in people with an ID of any aetiology. The findings in this review demonstrate a disquieting portrait of the weight status of adults with an ID.

Overweight and obesity is understood to be a chronic disease determined by a range of interconnected physical, psychological and environmental factors (World Health Organisation 2022) requiring an understanding and approach to addresses its influences. Recognition of the negative consequences of excess weight dates back to Hippocrates (Haslam and James 2005) where it was noted that carrying too much weight was detrimental to health. The distinctive yet inconsistent prevalence evident from this review presents a challenge. Furthermore, despite examining international evidence, no Irish study addressing prevalence for overweight and obesity in adults with an ID met the criteria for inclusion in this review. Only in understanding the nature and extent of overweight and obesity in this population, in Ireland can we begin to address the challenge with meaningful national strategic approaches reflective of the myriad of contributory factors.

2.14. Limitations of this systematic literature review

This review aimed to establish the extent of overweight and obesity in adults with an ID. However with a miscellany of mechanisms used to report overweight and obesity in people with an intellectual disability and heterogeneity within the reported samples, the extent of overweight and obesity is not immediately apparent. Measures used within the studies vary from BMI to waist circumference and in limited studies Percentage of Body Fat (PBF). Consequently, the prevalence of overweight and obesity can differ in the midst of sub groupings within a population (Moore *et al.* 2004). Therefore general prevalence rate for overweight and obesity was difficult to establish because of the disparity in reporting weight measurements across the studies. Nonetheless, BMI was a measure that was common across the studies.

2.15. Conclusion

Foundations for change begin with a presentation of the case for action. This review sought to establish overweight and obesity prevalence in adults with an ID. Considering the negative impact being overweight or obese exerts on the body this is important for individuals with ID to enjoy a healthy lifespan. The quality of those extended life years and an appreciation of the extent of overweight and obesity in people with an ID within an Irish context provides an insight into the extent of this international challenge which is ultimately detrimental in people with ID. The collated information in this study has the potential to inform policy and future planning, knowing the extent of the problem is a call to pay attention. This initial step within this thesis confirms and provides evidence of the extent of the problem and therefore, the focus of this study will be to examine overweight and obesity in adults with an ID. The evidence presented in this review forms the basis for further exploration in the ensuing chapters of this research.

CHAPTER 3: AN EXPLORATION OF THE RISK FACTORS FOR OVERWEIGHT AND OBESITY IN OLDER ADULTS WITH AN INTELLECUTAL DISABILITY

It is wiser to find out than suppose

Mark Twain

3.0 Chapter Summary

The extent of the problem in terms of prevalence has been established, however what risks expose people with ID to being overweight and obese? To address this question the researcher conducted a broad literature review which is presented in the following chapter. Examining risk factors for overweight and obesity across the literature using a systematic approach to data searching within the databases, the following chapter presents risks experienced by people with an ID. Presented as modifiable or non-modifiable risks, with evidence grounded on national and international literature and policy documents pertaining to overweight and obesity, people with an ID are exposed to unique challenges. As a societal problem, excess weight centred on interrelated adjustable and nonadjustable risks is amenable to change (Frood *et al.* 2013; Novak 2012). Sex, moreover being female and cause of ID are non-adjustable risk factors for overweight and obesity in ID. Nonetheless, there are a number of adjustable risks including some risks with unique presentations in the ID population, such as diet, living circumstances and educational attainment. The subsequent implications for overall health as a known risk factor is examined as is engagement in physical activity, health and use of prescription medications. To conclude, although there are a number of risk factors amenable to change, being female, risks to health and type of diet are examined further in ensuing chapters. The following chapter presents these risks as they pertain to the lives of people with an ID.

3.1. Introduction

Considered a chronic condition, overweight and obesity is a public health concern for whole populations and one which plays a significant role in overall health, with its effect contributing to harmful health outcomes and diminished longevity (Olshansky *et al.* 2005). These effects are levied as early as in utero when coexisting with maternal obesity. Attention is directed towards maternal health both in the antenatal and postnatal period (Yu *et al.* 2006;

Galtier-Dereure *et al.* 2000). In addition, neurodevelopmental delay is correlated with maternal obesity (Denzli *et al.* 2022). In early childhood inadequate sleep, access to poor food choices and sedentary lifestyle patterns (Lynch *et al.* 2022; Reilly *et al.* 2005) can set concerning parameters for obesity in later life. This is borne out in research emerging from the recent COVID-19 pandemic, where the risk of increased weight as a result of amplified patterns of sedentary behaviours and food consumption in children was reported (Burkart *et al.* 2021). Acknowledging the need to address this chalenge in early childhood, Irelands Healthy Weight for Children HSE Action Plan 2021 – 2023, specifically action area 2, outlines a series of undertakings to address obesity pre-conception education for health care workers so they can effect change (Health Service Executive 2019). Targeted actions such as highlighted above form a basis for early intervention progressing into preschool and primary education. Evidence suggests that overweight and obesity in childhood results in co-morbidities allied to obesity emerging at a younger age which then evolve into adulthood (Lau *et al.* 2007).

Analysis of overweight and obesity in people with an ID suggests that sustained overweight transgresses into obesity in adulthood (Melville *et al.* 2007). Therefore these early intervention measures are critical in preventative strategies considering the perpetuation of childhood obesity to adulthood and on into later life.

The anticipated global increase in longevity is apparent for the ID population with the numbers of people with an ID aged 60 years and over expected to double over the next 35 years (WHO 2015). Despite evidence of longevity for those with an ID, this increase nonetheless appears to have teetered out at or around 60-65years. Data from an Irish national disability database indicated a 24.7% frequency in those aged between 40-59 years at but 12.3% for those aged 60+ for that same year (Casey *et al.* 2020). Additionally, there is evidence of continued earlier mortality by as much as 20 years than those in the general population (Doyle *et al.* 2021; McCarron *et al.* 2015).

Disease presentations in older people poses a risk to positive healthy ageing (Department of Health 2013). The age profile and increased life expectancy for people with an ID brings with it the prospect of developing age related health conditions (Petrenko *et al.* 2014). Overweight and obesity, evident in the ID population poses additional and unique modifiable and non-modifiable mitigating risks for this population. These include sex (being female), aetiology such as Down syndrome (Melville *et al.* 2005) and environmental influences (Hsieh *et al.* 2014) including living circumstances and for some, negligible activity levels (Burke *et al.* 2014; Grundi 2006; Emmerson 2005). These mitigating factors contribute to increased risk exposure to poorer health for people with an ID. Additionally, lifestyle decision making for those with an ID, bound in complexity are dependent on external factors such as autonomous decision-making and understanding of overweight and obesity (Smyth and Belle 2006). In the context of advancing age in the ID population, the risk of developing age-related health conditions is greater when coexisting with overweight or obesity (Petrenko *et al.* 2014). These collective challenges predispose people with an ID towards further risk of overweight and obesity, the foundation for which begins in early life and transcends the life stages.

Considered a societal challenge, overweight and obesity is encased within a complex array of interconnected modifiable and non-modifiable risk factors (Novak 2009; Frood *et al.* 2013). Non-modifiable risk factors include intrauterine factors, ethnicity, sex, genetics and environmental interactions. As previously indicated, obesity is pervasive presenting as a chronic condition occurring when weight extends beyond the recommended norms. Positive weight status and healthy ageing requires interconnected contributory factors such as environmental and socioeconomic dynamics to coexist harmoniously. With consideration to these issues, this chapter will explore the risk factors that contribute to overweight and obesity among ID populations through the lens of non-modifiable and modifiable risks.

3.2. Identifying and Categorising Risk Factors for Obesity

For the purposes of this chapter overweight and obesity will be defined in accordance with the WHO indicators for BMI and in the cases where BMI is not used, waist circumference (WHO 2011). The question posed is:

What are the risk factors for overweight and obesity among adults with intellectual disability?

The following concepts and key terms were identified and a broad literature search using CINHAL complete, PubMed, PsycInfo and PsycArticles was conducted. A plethora of literature was identified among the general population, however less so for those with intellectual disaiblity demonstrating the paucity of investigation within this cohort. Following extensive searches and including the WHO, health policy and strategy, a number of risk factors both modiafiable and non-modifiable for overweight and obeisty were identified, grouped and classified into categories presented in figure 3.0.

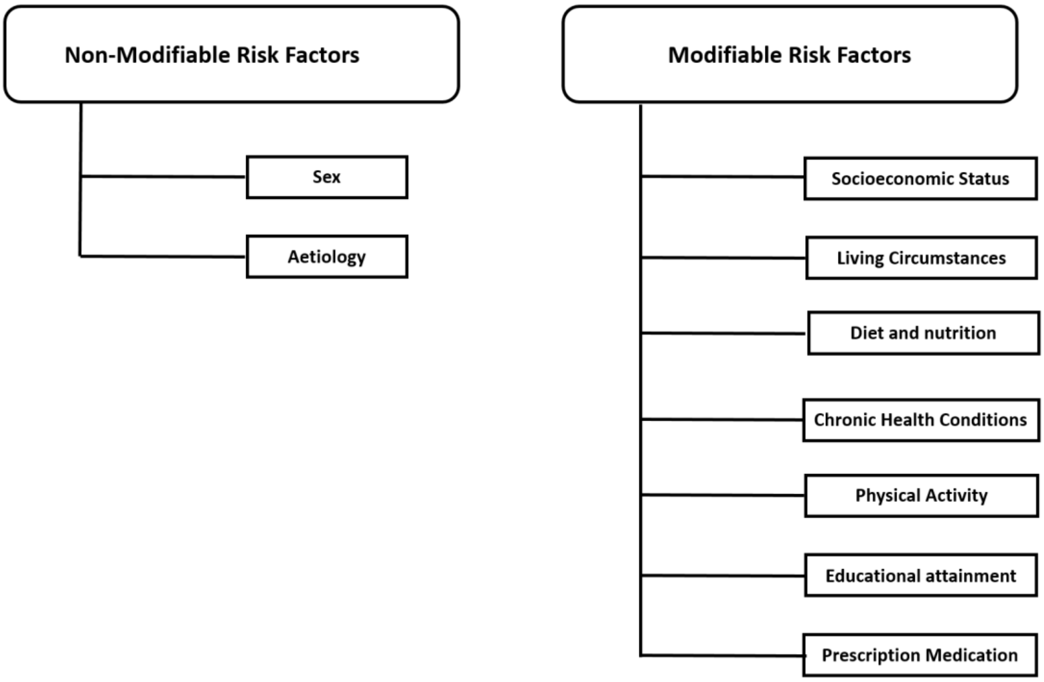


Figure 3.0 Classification of Risk Factors for Obesity

3.3. Risk Factors for Overweight and Obesity - Non-Modifiable

Given the consequences of sustained elevated weight status described in previous chapters coupled with unique mitigating factors, understanding the overweight and obesity risk for older adults with an ID is opportune. Associated health effects, some of which lead to chronic disease exert effects with subsequent implications not only on quality of life but on years lived. In ID, the risk of overweight or obesity is amplified, where the support structures in place primarily focus on the intellectual disability as opposed to secondary chronic conditions such as overweight and obesity (Health Service Executive 2021). Interrogating the literature resulted in the identification of a range of potential non-modifiable risk factors listed in figure 3.0. However, there are non-modifiable risks relating to overweight and obesity in ID which include sex and aetiology. The following writing describes these non-modifiable risks leading to those risks which are subjected to change.

3.3.1. Overweight Obesity and Sex

Although increased weight is observed across both sexes, it is more prevalent in females and more specifically adult women. Bhaumik *et al.* (2008) noted that women were more likely to present with obesity (29.5%) compared with men involved in the study (14.7%) ($P<0.001$). What was interesting in this study however, was that the opposite was true for overweight where 30% (n=661) of males and 25.1% (n=458) of females had a BMI indicative of overweight. Nevertheless, the trend towards obesity pose greater risk to women. Similarly, Melville *et al.* (2005) concluded that both overweight and obesity are pervasive in women specifically those with Down syndrome. Overall, 37.6% of women with Down syndrome were overweight compared to 29.5% of those without Down syndrome. In terms of obesity again, Melville *et al.* (2005) identified women with the higher prevalence and particularly those with Down syndrome (women 33.3%, women with Down syndrome 29.9%). Similarly, morbid obesity was more prevalent among women with Down syndrome compared to a matched group of women without Down syndrome (6.8% versus 2.6%). Foley *et al.* (2007) in their examination of athletes with ID concurred, identifying a greater prevalence among females than males (49.1%, females versus 42% males). Another factor which again points to being female was identified by Kearns *et al.* (2012) and Chang *et al.* (2000) who noted that women with an ID at midlife experiencing menopause, an acknowledged risk factor for overweight and obesity (Banco *et al.* 2012), are exposed to altered visceral fat distribution and subsequently increased risk of metabolic disease. Similarly, deWinter *et al.* (2012), using both BMI and waist circumference as a measure for overweight and obesity identified women at greater risk of being overweight or obese than men (39.8% versus 13.7%).These findings are further substantiated by, Heish *et al.* (2014), McCarron *et al.* (2011) and Stancliffe *et al.* (2011) all noting that females with an ID are at greater risk of obesity.

3.3.2. Overweight, Obesity and Aetiology

Aetiology is a further unique and non-modifiable risk associated with being overweight and obesity to emerge from the literature. Down syndrome bears specific risk as does Prader-Willi syndrome (Khan *et al.* 2018). Both overweight and obesity (Nixon *et al.* 2018; Krause *et al.* 2016; Hsieh *et al.* 2014) is omnipresent in women with Down syndrome (Melville *et al.* 2005; Bell and Bhate 1992). Early resesearch by Bell and Bhate (1992) involving people with both Down syndrome and other aetiologies described higher prevalence of overweight and obesity in participants with Down syndrome. More recently, Kinnear *et al.* (2018) when examining the prevalence of multi-morbidity in people with an ID (1,023 participants) aged 16 years and older, cited obesity as the most dominant condition for people with Down syndrome at 56.5%. A further but concerning finding in this study related to the level of multi-morbidity across almost all of the study population inclusive of obesity related conditions such as muscular skeletal and gastrointestinal disorders. Research by Burke *et al.* (2014) described 70.6% prevalence for overweight or obesity in an older population of people with Down syndrome, however this study reports the overall prevalence rate across the study was also high (69%). While there is limited evidence indicating the reasons overweight and obesity is more prolific in both adults and children with Downs syndrome, a number of factors have been insolated. These include hypothyroidism, decreased resting metabolic rate, amplified leptin levels and food preferences (Artioli 2017). Hypothyroidism, a prevalent conditions identified among those with Down syndrome (Amr 2018) in turn contributes to overweight status (Bertapelli *et al.* 2016).

Prader-Willi Syndrome is a predominant genetic indication for morbid obesity in children transgressing with problematic food behaviors into adulthood (Butler *et al.* 2017). This syndrome presents a different emergent picture of overweight and obesity with weight gain occuring in cycles from birth extending from failure to thrive to hyperphagia and subsequent obesity (Khan *et al.* 2018). The absence of saiety regulation and hormonal inbalance coupled with behavioural manfestations (Muscogiuri *et al.* 2021) render obesity as a highly risky disease pathway indicated in Prader-Willi Syndrome. Moreover, research by Butler *et al.* (2017) which examined mortality in this cohort over a 40 year period reported obesity as a direct cause in 7% of deaths.

3.4. Risk Factors for Overweight and Obesity - Modifiable

Overweight and obesity is also shrouded within a complex array of impelling but modifiable risk factors (Pankhurst *et al.* 2015). These risks encompass socioeconomic status, living circumstance, diet, chronic health conditions and physical activity, education and prescription medications. With targeted solutions, modifiable risks for overweight and obesity are nonetheless amenable to change.

3.4.1. Overweight, Obesity and Socioeconomic Status

In some societies, trends towards overweight and obesity are linked to socioeconomic status (Abarca-Gómez *et al.* 2017), but this is dependent on and fluctuates in accordance with the countries Human Development Index (Dinsa *et al.* 2012). Evidence of the effect of socioeconomic status and the risk of overweight and obesity in ID is not well defined; nonetheless, the socioeconomic status of parents and subsequent lifestyle influences on children in the general population are acknowledged (McGillivray *et al.* 2013). Emmerson *et al.* (2016) in a cohort study of British children reported both sustained maternal obesity and level of educational attainment of the mother as significantly associated with childhood obesity for children aged 11years. Furthermore, the Healthy Ireland Survey reported correlations between healthy food consumption and income level (Government of Ireland 2015a).

Adults with an ID in Ireland, reside across a variety of home settings ranging from family home to supported accommodation and may be provided within an array of community support models or residential settings and as citizens of the state can be in employment or in receipt of state funded financial support. However, the number of adults with an ID in employment is diminutive with reduced working hours further affecting earning potential (McGlinchey *et al.* 2013). The burden of living expenses including health care costs affect the financial means of people with an ID (Ervin and Merrick 2014) as do transport and other related costs. Inadequate nutrition in early childhood is implicated, not only in obesity, but also in child development. This in turn affects educational attainment and sustains the cycle of poor socioeconomic positioning of the family which affects their ability to maintain adequate diet (Okoli *et al.* 2022).

3.4.2. Living Circumstances

As life expectancy increases and weight trends rise within the general population, it is inevitable that this increase would emerge for those with ID. Longevity, as previously stated, is also evident in ID (McCarron and Lawlor, 2003) but is grounded on sustained higher mortality than reported across the general population with a number of extenuating contributory factors in ID (Hosking *et al.* 2016; Bowness 2014; Heslop *et al.* 2013; Gibbs and Priest 2010). One factor worthy of exploration is living arrangements. Where and how people live provide an important insight into influences on weight status in ID with unique circumstances for consideration. In Ireland, national health policies place emphasis on illness prevention and population health initiatives in order to support people live independently in their own community for as long as possible (Government of Ireland 2021). Moreover considering the substantial but welcome changes and developments in service supports for people with an ID over the last 20 years, including the shift from traditional institutionalised approaches to care to one based on social inclusion and holistic supports, the inadvertent consequences of lifestyle changes is evident. People with an ID now reside predominately within domestic style living arrangements within their community. This change in direction from institutional support systems to community living (Health Service Executive, 2011) provides opportunity for people with an ID to exercise greater choice over their lives (Government of Ireland, 2015b). However, these environments have also changed. In western society, the abundance of a foods, many of which are highly processed, has resulted in the emergence of obesogenic environments. The unintended but subsequent health consequences for people with an ID are many.

Given that people with an ID experience more frequent and poorer health outcomes, diagnostic overshadowing, multi-morbidity and premature mortality than reported within the general population living arrangements merit attention. With national policy advocating change in the direction of support models, from one of congregation to more independent living arrangements, an understanding of the historic context of people's lives and its influence on decision-making warrants reflection (Carey 2021). Legislative frameworks are now in place to support autonomous decision-making (Government of Ireland 2015b). This includes decisions relating to living arrangements and lifestyle choices. Nonetheless, decision-making involves choice from a range of options influenced by past and present experiences and can be complex and result in negative consequences for the individual. Balancing the right to choice with supportive informed decision-making in ID is an important consideration in overall health promotion strategies that address overweight and obesity prevention and management. Research by Smyth and Belle (2006) in examining challenges experienced by people with an ID making seemingly modest dietary decisions, endorsed the importance of access to knowledgeable decision making support. The home provides a natural learning environment for people with and ID to absorb these positive lifestyle choices and in particular dietary decision.

3.4.3. Overweight, Obesity, Diet and Nutrition

Diet plays a critical role in health. This is principally true in ageing with nutrient deficiencies linked to cognitive decline and depression (Moore *et al.* 2018). Furthermore diminished muscle mass and ineffective nutrient absorption increases frailty risk (Thillainadesan *et al.* 2020) and risk of protracted diseases such as osteoporosis, a condition that is highly prevalent among those with ID (Burke *et al.* 2017). In additional consumable diet risk involves the disproportionate consumption of sugar-sweetened drinks (Te Morenga *et al.* 2013). Such consumables contain sugar and caffeine as key ingredients (Safe food 2019).

Progressive energy intake with unmatched energy output is one contributory factor for consideration with overweight and obesity which implicated in older populations with an ID (Burke *et al.* 2014; De Winter *et al.* 2012). Suboptimal nutrition and consequential overweight and obesity is framed within a range of diverse factors such as choice and control, access to food and understanding the diet disease relationship (Shoneye 2012; Smyth and Belle 2006). In identifying the impact obesity has on non-communicable disease, the World Health Organisation recognises positive nutrition as pivotal and in doing so, set the global targets for the creation of positive food environments for action by 2025 (WHO 2019). Unfortunately these positive food environments are slow to emerge with the proliferation of fast foods and quick easy processed foods contributing to obesogenic environments. Availability of such a range of fast and processed foods also expose people with an ID to long-term harmful health outcomes (Cohn 2010; Smyth 2006).

Given the complex but prolific dietary messaging and the rise in commercialisation of the food industry (Zylke *et al.* 2016), the influence of living arrangements on dietary intake for people with an ID is ostensive. Additionally progressive nutritional health in ID is reliant on the knowledge and skills of circles of support (Cartwright *et al.* 2015; Shoneye, 2012). However, as a critical support pillar the disparity between the knowledgebase of care workers and their understanding of diet and nutritional requirements reveals risk (Hamzaid *et al.* 2018). Historically in residential settings, food was prepared in bulk in central kitchens. This excluded direct involvement of people with an ID and their carer's in food preparation and cooking. The lack of opportunity to engage in these aspects of dietary preparation within the home undoubtedly negated a developed understanding of food and its nutritional value. Nonetheless for these now older adults, the situation can be improved by targeting education programmes focusing on diet and nutrition with progressive measurable outcomes (Yilmaz *et al.* 2014). However, research indicates that less than half its participants with an ID had access to such information or structured regular education programmes on nutrition including accessible information (Burke *et al.* 2014). In line with research by Hsieh *et al.* (2014), IDS TILDA described how people with an ID who lived within a community setting had a greater pattern of risk factors for overweight or obesity such as poorer nutritional health, paltry levels of physical activity and food choice (Burke *et al.* 2014). A further Irish study by McGuire *et al.* (2007) collated data on the dietary habits of people with an ID from their carer's using the food pyramid as a comparator, reporting deficits in fruit and vegetable intake as well as inadequate consumption of protein and carbohydrates. Therefore as adjustable risks, diet plays a pivotal role in the maintenance of overall health and wellbeing and is particularly important in ID.

3.4.4. Overweight and Obesity and Chronic Health Conditions

The persistent prevalence and trends toward overweight and obesity poses not only a serious international societal challenge, but threatens the health and wellbeing of people with an ID (Bowness 2014; Mencap 2004). With its effects transcending all life ages, ovweweight and obesity increases disease burden and is problematic in ID (Bray *et al.* 2017; National Institute for Health and Care Excellence 2014). However, measuring weight alone does not offer an appreciation of the impact excess weight has on the body or its physiological impact on the body's alignment (Thibault *et al.* 2012). This is linked with multiple morbidity including muscular skeletal and gastrointestinal disorders (Kinner *et al.* 2018, Plastow *et al.* 2014) and is a contemporary challenge in ID (Hussain *et al.* 2020; Tyrer *et al.* 2019; McCarron *et al.* 2013). Additional factors such as genetic predisposition and aeitology coupled with palrty activity leveles increase risk exposure to consequential chronic diseases including hypertension, diabetes, heart disease, osteoporosis and depression (Sari *et al.* 2016; Phillips *et al.* 2014) and some cancers (Patterson *et al.* 2013; Ogunbode *et al.* 2009).

Kinner *et al.* (2018) explored multiple-morbidities in people with an ID in a study involving 1023 adults (186 participants had Down syndrome) using the international Statistical Classification of Disease and health related problems (ICT-10), noting the prevalence of obesity was second only to visual impairment in order of frequency. With a participant mean age of 41.1yrs and level of intellectual disability ranging from mild to profound, 40.6% of the total study sample (N=1023) were found to be obese. Further analysis indicated that more than half with Down syndrome were obese (56.5%, n=105). Alarmingly this study determined that of the total sample almost all of the participants were living with multi morbidity (98.7%) including obesity related conditions such as muscular skeletal and gastrointestinal disorders. Holmgren *et al.* (2014), reporting on a Swedish adult population over an eight year period (2002-2010), concluded that being overweight and obese with a mobility disability exerted a greater negative impact on health related quality of life indicators than being overweight or obese and without a physical disability (Holmgren *et al.* 2014). Despite the negative implications overweight and obesity impose on aging people with an ID, excess weight is a modifiable and amendable to change with expected corresponding improvements in health outcomes (Dee *et al.* 2014; Ellis *et al.* 2006).

3.4.5. Overweight, Obesity and Physical Activity

Just as diet is central to positive overall health, so too is physical activity. Physical activity plays a key role in not only maintaining positive body composition and better health outcomes, but contributes to psychological health and wellbeing and is an important consideration in healthy ageing (WHO 2021). Despite this, inactivity is reported across the older population of Irish adults (McNicholas and Laird 2018). This is also the case for individuals with ID where deficiencies in physical activity evident across time reported (McCarron *et al.* 2011; Burke *et al.* 2014). Of particular note, paltry levels of engagement in vigorous activity described as lasting between ten to twenty minutes where the heart rate increases and sweating occurs were reported for only 3.2% of participants in 2011and even less in 2014 (2.5%) negating health benefits.

The correlation between activity levels, obesity and physically debilitating conditions is evident in older people of all populations (Leahy *et al.* 2014). Inadequate physical activity coupled with age related physiological inclinations towards conditions such as dysphagia, neurological conditions and dementia cause additional risk for older people with an ID (Burke *et al.* 2014; Grundi 2006). Despite this, inadequate activity levels widely reported among older people with an ID increases the risk of poorer health outcomes and increased disease risk as they age (Lynch *et al.* 2021; García-Domínguez *et al.* 2020). This threat is particularly acute for women with evidence indicating that women with an ID engage in less activity and are more exposed to overweight and obesity than their male counterparts (Emmerson 2006).

Limited activity is known to intensify conditions such as sarcopenia (Karlsson *et al.* 2020). Merrick *et al.* (2013) in a study involving older women with an ID who were overweight or obese and who engaged in an aerobic exercise programme, described positive and significant outcome for weight loss although this was not the case for muscle strength. Lack of muscle strength expose older people with an ID who are overweight or obese to additional risks including frailty where the body's reserves are compromised thus increasing the possibility of fragility and fractures (Afonso *et al.* 2021; Xu *et al.* 2020; Burke *et al.* 2019).

There are however everyday modifiable barriers to engagement in physical activity for people with an ID which need to be acknowledge such as physical obstacles or poorly maintained walking areas or footpaths (Centres for Disease Control and Prevention 2011). Despite this, the benefits of a structured walking programme for people with an ID with no requirement for a specialised equipment is reported to have positive outcomes in tackling overall health and contribute to addressing weight status (Son *et al.* 2016). Therefore any solution focused approaches addressing overweight and obesity should consider environmental barriers to physical activity.

3.4.6. Overweight, Obesity and Educational Attainment

Educational attainment has been identified within the literature as a risk factor for overweight and obesity in the general population (Department of Health 2016c; Devaux and Sassi 2013; Public Health Agency of Canada, 2011; Hajian-Tilaki and Heidari 2010). A large population based US study by Ogden *et al.* (2018) for example, reported comparatively higher prevalence rates of childhood obesity (2-19 years) where both household income and education level were lower. Within their study, children of college graduates had lower levels of obesity (9.6%) when compared with high school or children who attained a lower level of educational attainment (21.6%). Similarly, an Irish longitudinal study reported higher prevalence of overweight (21.3%) and obesity (9.4%) in children of parents who attained a lower secondary education level or less compared with those of parents who attended university, where a 16.6% rate for overweight and 2.8% obese was conveyed (Keane *et al.* 2012).

However, this picture differs for those with an ID. Education provision for people with an ID ranges from Special Education to mainstream education settings (Kauffman *et al.* 2009). For the adult population with an ID in Ireland, research by McCausland *et al.* (2016) described limited completion of primary education with very few participants finishing formal secondary level education. Constricted access to education and by implication lifelong learning, inevitably affects the dietary knowledge of people with an ID and their understanding of the potential health implications lifestyle behaviours impose. Additionally, poor skills towards independence and employment are also allied with overweight or obesity. In further research by McCausland *et al.* (2014) difficulties understanding and engaging with purchasing transactions, understanding monetary change following a purchase and financial banking was described across almost 90% of their study participants. Literacy and numeracy skills are central to awareness of the nutritional components of food and their often-complex metrics. Consequently, without these skills required to make informed healthy choices people with ID are more vulnerable to poor dietary intake and are dependent on their carers to support decision-making. Nonetheless, carer's too may lack the skills require to navigate this often complex minefield (NHS England 2019). Furthermore, the application of autonomous decision-making within environments with an abundance of products providing little or no nutritional value and strategic, marketing strategies is a challenge for people with an ID.

3.4.7. Overweight, Obesity and Prescription Mediations

Some medications are associated with weight gain. These include but are not limited to atypical psychotropic medication used in the management of disordered behaviour (McLennan 2019) and mental health conditions (Correll 2007). In addition, a number of anticonvulsant therapies for neurological disorders such as epilepsy, are allied with increased weight (Janousek *et al.* 2013) as are medications used to treat conditions such as depression, mental health disorders (Ranjan *et al.* 2018). In examining risk factors for obesity in ID Hsieh *et al.* (2013) noted a significant association with obesity and certain medications with the potential to cause weight gain (AOR = 1.80, 95% CI = 1.38–2.37). Research by O'Dwyer *et al.* (2016) described polypharmacy (5-9 medicines) in 25.7% of a population of older Irish adults with an ID, hyper polypharmacy (10+ medicines) in 20.1%. Most frequently prescribed medication were associated with neurological conditions and depression (O'Dwyer *et al.* 2016). Therefore, the potential side effects of weight gain secondary to prescription medication should be considered in the collective assessment of weight status across populations with an ID. This is a particular concern in an already overweight and obese population when alternative medication options could be considered.

3.5. Conclusion

This chapter offers the reader an overview of risk factors connected with overweight and obesity and people with an ID. When examining the associated literature, particular attention was given to the known risks pertaining to the lives of people with an ID. Whilst sex and aetiology presented as factors not amenable to preventative interventions, the particular risk obesity poses in the lives of women with an ID is of note. There were a number of modifiable risks identified bearing overweight or obesity risk. Some of these factors differ to what is expected within the general population. For example, where and how people with an ID live; moreover the level of residential care experienced by people with an ID with exposure to a natural home kitchen environment and where the purchasing and preparing food is limited. Additionally, the move away from congregated settings with subsequent availability of an array of food products within obesogenic environments was highlighted. The need for education not only for the person with an ID but their support network was a risk factor which is not expected within the general population and which was discussed. Aetiology and ID as a non-modifiable risk factor for overweight and obesity when compared to the background population was examined. Similarly the high polypharmacy rate within the ID population in comparison to the general population and the weight challenges people with an ID face as a result was discussed. Education attainment and socioeconomic status, both allied with overweight or obesity in the general population, again have a unique presentation in ID and are described in this chapter. Given the unique risk factors for overweight or obesity in ID, researcher has investigated overweight and obesity amongst an older population of adults with an ID. The ensuing chapter present an overview of the study design, data collection and methodology used.

CHAPTER 4: RESEARCH METHODS AND DESIGN

Don't judge each day by the harvest you reap but by the seeds that you plant
Robert Louis Stevenson

4.0. Chapter Summary

This chapter presents *The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing* (IDS-TILDA). This longitudinal study provides the opportunity to extensively explore the issues of overweight and obesity in older people with an ID. In Wave 2 and of IDS TILDA, in order to determine weight status, recognised standardised measures including objectively measured Body Mass Index (BMI) and waist circumference were objectively measured and collated. Furthermore, in Wave 3, a Food Frequency Questionnaire formed part of the data collection process providing an opportunity to understand food consumption patterns and review them in line with the national recommendations for dietary balance. The researcher completed over 70 interviews with participants involved in the study and the data described above forms the basis for this research thesis.

IDS-TILDA is the first longitudinal study involving older people with an ID taking place in parallel with a general population study '*The Irish Longitudinal Study on Ageing*' (TILDA) (Kenny *et al.* 2010). Having originated in 2008 following a preliminary pilot study, data captured within IDS TILDA provides an important and unique insight into the participant's distinctive, health and social determinants. Data is collected across waves, a wave being every 3 years. The University of Dublin, Trinity College provided ethical approval through the Faculty of Health Sciences ethics committee for each distinct wave of data collection. In addition, the 138 separate service providers supporting participants of the study granted ethical approval.

This study is supported within a framework addressing domains of health and wellbeing, and a values frame that provides procedures for inclusive research. These procedures guide those involved in the study, from developers to researchers, through a values frame, thus endorsing inclusive participation from commencement of the study, to information sharing, developing guidance material and the participant interview process. This thesis is situated within IDS TILDA Wave 2 and 3 and the encompassing guidance frameworks. The following chapter will outline the study methodology. As part of the research team and as a contribution to her PhD study, the researcher engaged in 70 interviews with participants each lasting between 90 – 150 minutes, following comprehensive field research training. The researcher was also involved in data cleaning, dataset creation and analysis. Data protection is imperative in a study of this magnitude and the IDS-TILDA study provides all involved researchers training, along with the training from Trinity College Dublin. At all times ethical principles are adhered to and this chapter presents an overview on how all these elements pertain to this thesis.

4.1. Introduction

The IDS-TILDA study is a national longitudinal study on ageing and intellectual disability in Ireland. This unique study examining ageing and ID across socioeconomic and health determinants is part of an international collection of longitudinal studies. Data is collected over periods referred to as study Waves which occur every three years. In 2006 a study titled The Irish Longitudinal Study on Ageing (TILDA) commenced which examined the health and socioeconomic data of a population of Irish adults aged 50years and over longitudinally. This study was guided towards contributions to strategic policy and planning for a growing population of people in Ireland who were ageing. A large sample of Irish adults over the age of 50 years in Ireland, selected to participate from the GeoDirectory (Kearney *et al.* 2011) were engaged in TILDA. However, inclusion of specific criteria for participation such as the need for participants to be living independently at home and to self-consent to participate in the study (Kenny *et al.* 2010), had a bearing on the representation of older people with an ID in the study. Following on in 2008 an intellectual disability supplement to TILDA commenced with the first Wave of the study published in 2011 (McCarron *et al.* 2011). This was followed by subsequent waves, Wave 2 (2011-2014) and Wave 3 (2014-2017), which will be reported on for this study.

4.2. Recruiting for IDS-TILDA

In Ireland, the National Intellectual Disability Data (NIDD) base was established in 1995 to capture data on intellectual disability and the services people with an ID accessed. Evolving over time, the repository hosted data on over 28,000 people with an ID in the Republic of Ireland in 2017 (Hourigan *et al.* 2017). This data provides valuable information to inform specialist service planning for people with an ID through emerging trends, the collation of current service usage and anticipated future needs. Random selection of participants for IDS-TILDA from the NIDD followed a pilot feasibility study by McCarron *et al.* (2009). This feasibility study examined approaches to recruitment and the applicability of the TILDA research methods to respondents with an ID, including approaches to inclusive research involving accessible materials (McCarron *et al.* 2009). Following on from this early pilot, participants for IDS-TILDA were recruited from the NIDD which has now been replaced by the National Ability Support System (NASS) resulting from an amalgamation of the NIDD and the National Physical and Sensory Database.

IDS-TILDA initiated the first series of data collection in 2009. In order to deem eligibility to engage with the study, participants were required to be aged 40 years or older and were randomly recruited from the NIDD. Pin numbers were arbitrarily selected from 1800 people as potential study participants. These numbers were sequentially released to database managers for trained database administrators supporting the study from regions across the country. This facilitated the staged release of pin numbers following requests from the IDS-TILDA team with 1600 actually released. Following on from the release of pin numbers, invitation packs prepared by the IDS-TILDA team and sent them to potential participants at increments determined by the IDS-TILDA team. Anonymity was strengthened through the establishment of a gatekeeper within each region nationally and within each service provider. To ensure the ongoing integrity of the study, a Scientific Advisory Steering Committee was established. In addition, advocacy groups involving people with an intellectual disability were co-opted to act as independent advisors for the study. The groups were critical to support the development of the overall recruitment of participants onto the study. Once the consent form was returned to the IDS-TILDA team, the participant's details were anonymised with a unique IDS-TILDA study PIN assigned to the participant. Only when confirmation from the participant was received endorsing their consent to engage with the study, was this PIN shared with an assigned trained field researcher with each assigned a case load of interviews to complete. Data protection procedures were initiated to maintain participants privacy with personal information stored securely in a locked area separate from the data identified by the PIN. Following on from Wave 1, participants were invited to participate in subsequent study waves. Flowchart 4.0 below outlines participation, attrition and retention across the study waves (1, 2 and 3). As indicted in this chart, from the original sample in Wave 1 (N=753), the response rate for Wave 2 was 94% (N=708) and subsequently 86% (N=609) in Wave 3. This current study is situated within Wave 2 and 3 of IDS TILDA.

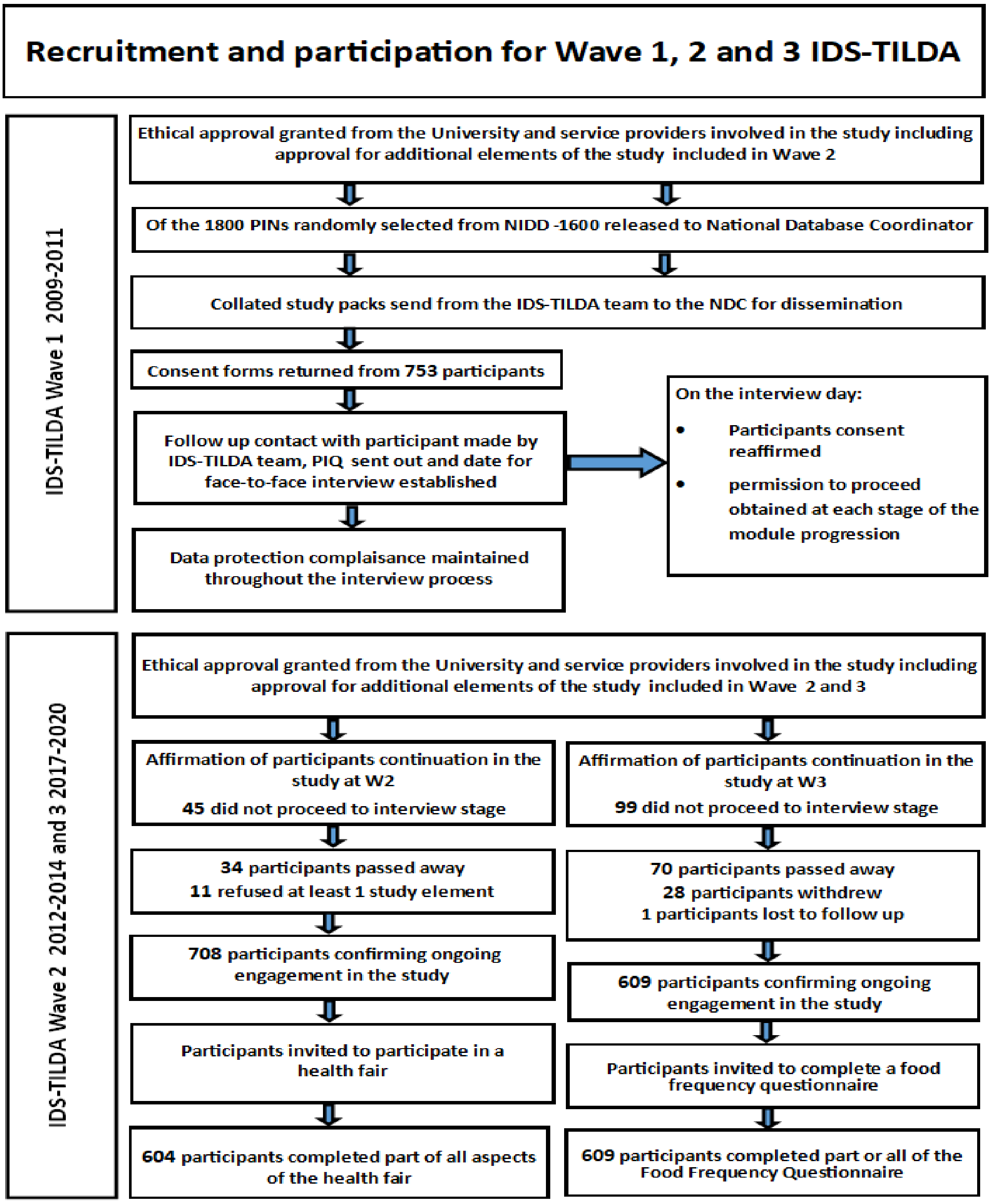


Figure 4.0. Flowchart Recruitment and Participation in Wave 1, 2 and 3 of IDS TILDA

4.3. Ethical Principles and Consent

Research purposes to develop new information using a strategic developmental approach with the aim of enhancing understanding of a topic. Ethical principles guide the research process with rights and integrity of its participants at its core (Pilot and Beck 2004). Ethical approval for this study was granted by the Faculty of Health Sciences, Trinity College Dublin and by all participating Service Providers (n=138). The researcher at all times underpinned her approach to this current study with the ethical principles of beneficence, non-malfeasance, fidelity and veracity, justice confidentiality and respect for human dignity (Parahoo 1997). Adherence to ethical principles at all times for all aspects of this study included the acquisition of consent, participants interviews (seventy in total) and data management and storage.

The ability and right to independent decision making is enshrined in Human Rights Legislation (Government of Ireland 2014). Consent is a process and involves the giving of permission to another or entering into an agreement for a range of services treatment or research (HSE 2022); the right of an individual to make a decision and have that decision respected. Consent in itself needs to be informed and obtained in a manner that is transparent and framed within legislative requirements (HSE 2022). A system of process consent is integral to this study. To this end, the researched participated in a comprehensive three day training programme prior to commencement of the interview process. This training involved an examination of the ethical principles of research and the consent process reaffirmed the researcher's moral obligation to act at all times for the benefit of the participant. The researcher was instructed on the consent process for IDS-TILDA whereby consent was obtained at the time of the face-to-face interview and then reaffirmed throughout the interview process. This research design and interview method supported the principle of beneficence. Non-maleficence was averted through assurances that the researcher was trained and experienced. Additionally, the presentation of information using a range of accessible materials and supporting documentation including visual ques within descriptive materials developed in an accessible formats supported participation and understanding. The affirmation of consent at all stages of the interview process including the day of interview and at intervals throughout the interview process, reinforced informed decision-making. Participants were also offered alternative dates to complete interviews where completion may have been tiring or possibly burdensome for the participant. A flexible interview approach was adapted with interviews conducted over a number of meetings if required by the participant. Where communication challenges presented, support was sought from family members or carers in order to obtain the most effective outcome with the participant. Nonetheless, proxy interviews were limited and active participation by people with an intellectual disability encouraged.

In addition, the approach to co-production involving people with an intellectual disability, an overarching scientific committee and steering committee provided further oversite. The voluntary nature of participation and the use of interview questionnaires for all participants facilitated a just approach to the study. Respect for participants human dignity and their individual autonomy was enabled through their direct involvement in the study. Fidelity and veracity or trustworthiness was maintained through consistency again within the research approach. Data was stored on an encrypted computer securely located with no identifiable indicators used in the analysis or presentation of data.

4.4. Data Protection and Data Management

Participants were assigned a unique identifier or PIN number. During the data collection phase, the researcher had access to a double encrypted secured laptop securely stored when not in use. Data collected from participants for the study was pseudonymised using this unique identifier and subsequently transferred onto a double encrypted secured data drive hosted by the university with access limited to the researcher and core IDS-TILDA team members only. This data was accessible only on site and with permission to access data granted only following training and with the researcher returning a signed data access protocol (see appendix 4). Information collated in hard copy was securely stored in locked facilities. This data was then held on file in accordance with the Data Protection Act (Government of Ireland 2003) and subsequently Government of Ireland (2018) and stored for 5 years post completion of the core IDS-TILDA study as specified. Participants were assured at the time of their interview that their personal identifying information was not shared with others or identifiable from the reporting of study findings. Hard copies of material were returned to the IDS-TILDA office to be managed in accordance with the agreed data protection protocol. Further information on the IDS-TILDA methodology applied is available (Carroll *et al.* 2017; Carroll *et al.* 2014; McCarron *et al.* 2011).

4.5. Values Framework

A values framework with principles underpinning the overall study (Figure 4.1) was developed to ensure respect, inclusion and appropriate involvement of participants. These principles have person centeredness at its core, with people with an intellectual disability playing a central role in all aspects of the study. In addition, since commencement of IDS-TILDA, dissemination of study findings has remained a central pillar of the overall foundation of this longitudinal study contributing to sustained change at a national policy level, as well as translating the research findings into practice (McCarron *et al.* 2022).

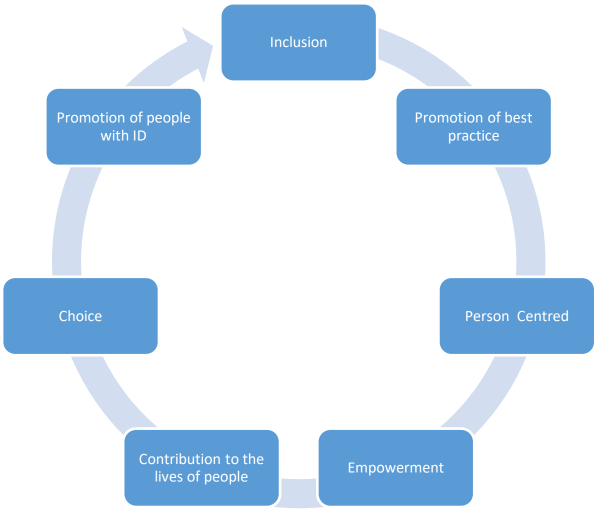


Figure 4.1. Values Framework for the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (McCarron et al. 2022)

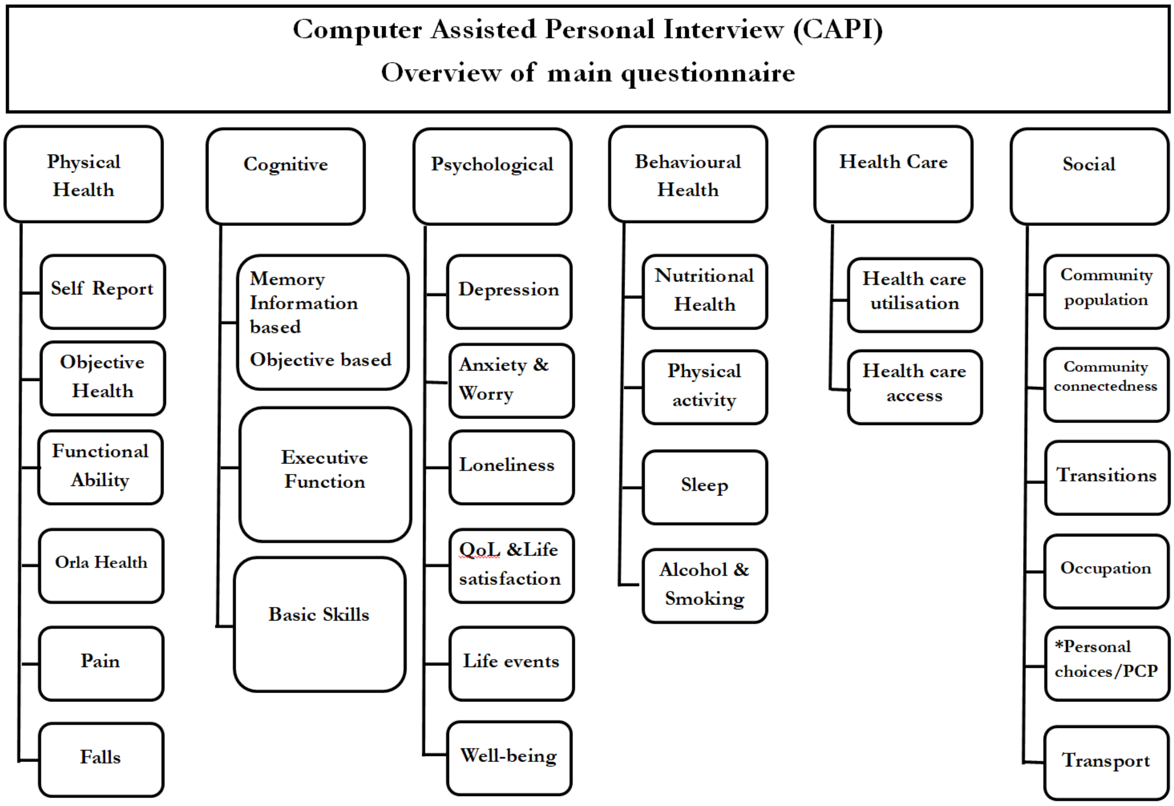
Inclusion and meaningful participant engagement is core to the IDS-TILDA study. To enable this happen, accessible materials were designed to support an active engaged recruitment process with advice sought from a representation of self-advocacy groups in the Republic of Ireland. This material incorporated the use of plain English and picture imagery to enable individual's active participation. The use of accessible materials guided participants in their understanding of the study and provided a basis from which those supporting participants could facilitate informed decision-making relating to participation. This material was organised into a participant packs which included; an accessible explanatory letter, information brochure, an accessible consent form and stamped self-addressed envelope to return the consent form and sent to the identified participant. In addition, a family information pack outlining the study was included to inform family members who may be supporting their family member contemplate engagement in the study (see appendix 5 for sample of an overall accessible pack).

4.6. Methodology

This research is situated within the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). A nationally representative study, IDS-TILDA involved 753 participants with an ID over the age of 40 years. Addressing ageing health and wellbeing among those with ID, this study is comparable to the general population based study (The Irish Longitudinal Study on Ageing-TILDA). Participants were recruited from the National Intellectual Disability Database (Kelly *et al.* 2007), a database comprising of eligible participants with an ID in the Republic of Ireland. The data is collected every three year which represents a wave. Wave 1 concluded in 2009, Wave 2 in 2014 and Wave 3 in 2017.

4.7. Data Collection and the Interview Process

During the training, the researcher received intensive training on the full interview process and included involvement on the completion of a face-to-face interview aided by the Computer Assisted Personal Interview (CAPI) system. This CAPI system, is used to support the data collection process and comprised the overall IDS-TILDA protocol. This involves a suit of questions examining the following components; demographics; cognitive health; social participation; social connectedness; personal choice; happiness; ageing perceptions; employment situation; voluntary work; lifelong learning; day services; planning for retirement; sources of income; physical health; mental health; and behavioural health (figure 4.2).



*Person centred Planning

Figure 4.2. Conceptual Framework for the Computer Assisted Personal Interview (CAPI) Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

Sourced from: McCarron *et al.* (2022)

4.7.1. The Pre Interview Questionnaire (PIQ)

In addition to the CAPI and in support of data collection, a Pre Interview Questionnaire (PIQ) was included as a part of the data collection process. The PIQ included a range of questions addressing areas such as leisure time, dietary patterns, exercise, health related questions, cognition and behaviours of concern as well as medications, income sources and transport. This PIQ was sent to the participants a minimum of one week prior to their face-to-face interview. This afforded participant opportunity to gather the information required to complete the questionnaire and seek assistance in completing it where necessary (figure

4.3). The data captured on the PIQ was retrieved on the day of the interview and response gaps addressed with the participant.

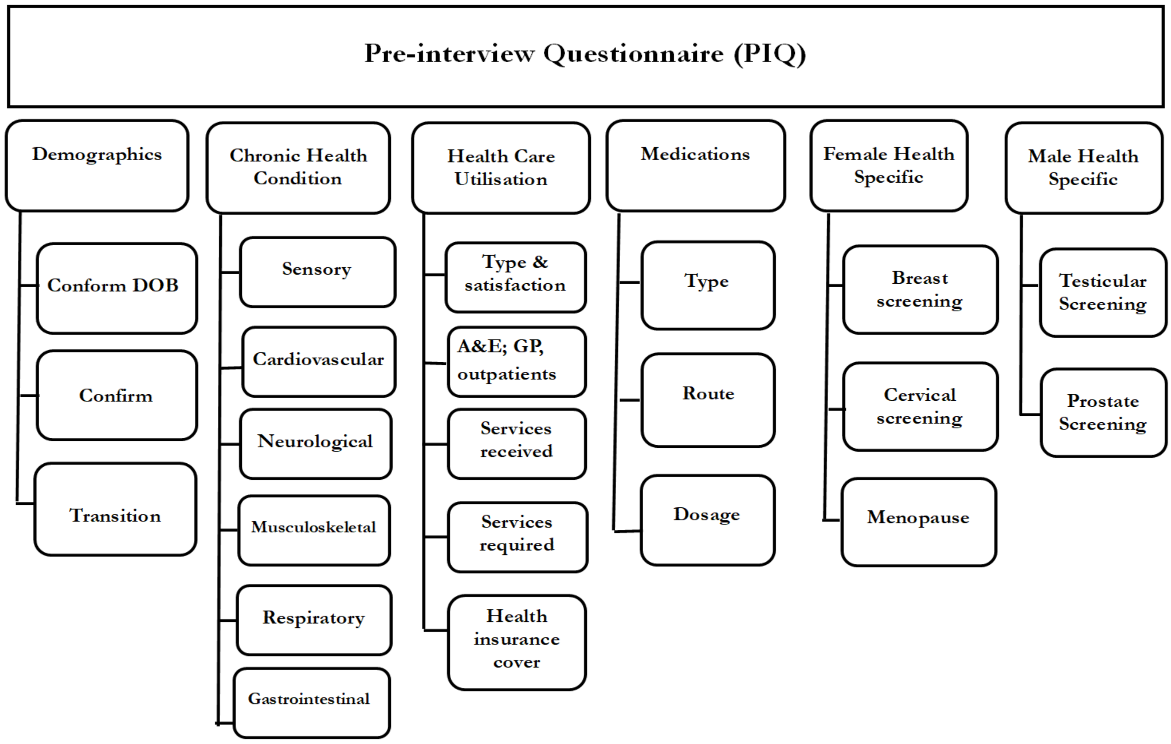


Figure 4.3. Pre-interview Questionnaire for the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

4.7.2. The Interview Process

The approach to the interview process for this study offered participants three interview options as follows to provide all participation the opportunity to participate:

1. A self-report interview only where the participant was interviewed independent of support.
2. An interview where the participant actively engaged in the interview process but were supported by a proxy. This proxy support was a person known to the participant for at least six months and provided support ranging from facilitating comprehension of the interview process and questions asked, supporting the participant to answer some

of the questions asked, to assisting in accessing the information on the documents shared.

3. A proxy interview, whereby the full interview was conducted with a proxy on behalf of the person. This interview process resulted in sections of the questionnaire being omitted where there was a requirement for the person's personal perception of a topic that is, those questions that were subjective in nature.

Interviews were conducted in a place of the individual choosing including their own home facilitating a more comfortable interview environment and at a time of their choosing including evenings and weekends. This questionnaire was completed with the participant or where indicated, their proxy on the day of the interview and if requested interviews were conducted over more than one scheduled date.

4.8. The Health Fair Wave 2

In IDS TILDA across Waves, health and health conditions were examined through a series of questions based on a *Doctors diagnosed health conditions*. Following a review of this first study wave, objective measures of health indicators to assess dimensions of physical health were introduced in the form of a Health Fair in Wave 2. This enabled the inclusion of objective measurement of BMI in this current study when Wave 2 was examined. This health fair incorporated a full suite of non-evasive objective health measures collected by a trained nurse. This comprised of anthropometric measures of height, weight and waist circumference, waist to hip ratio, blood pressure (both sitting and standing), Timed Up and Go, grip strength and bone density (measured using calcaneus quantitative ultrasound (QUS) (Burke *et al.* 2019). In total 604 participants completed all or part of the health fair (figure 4.4).

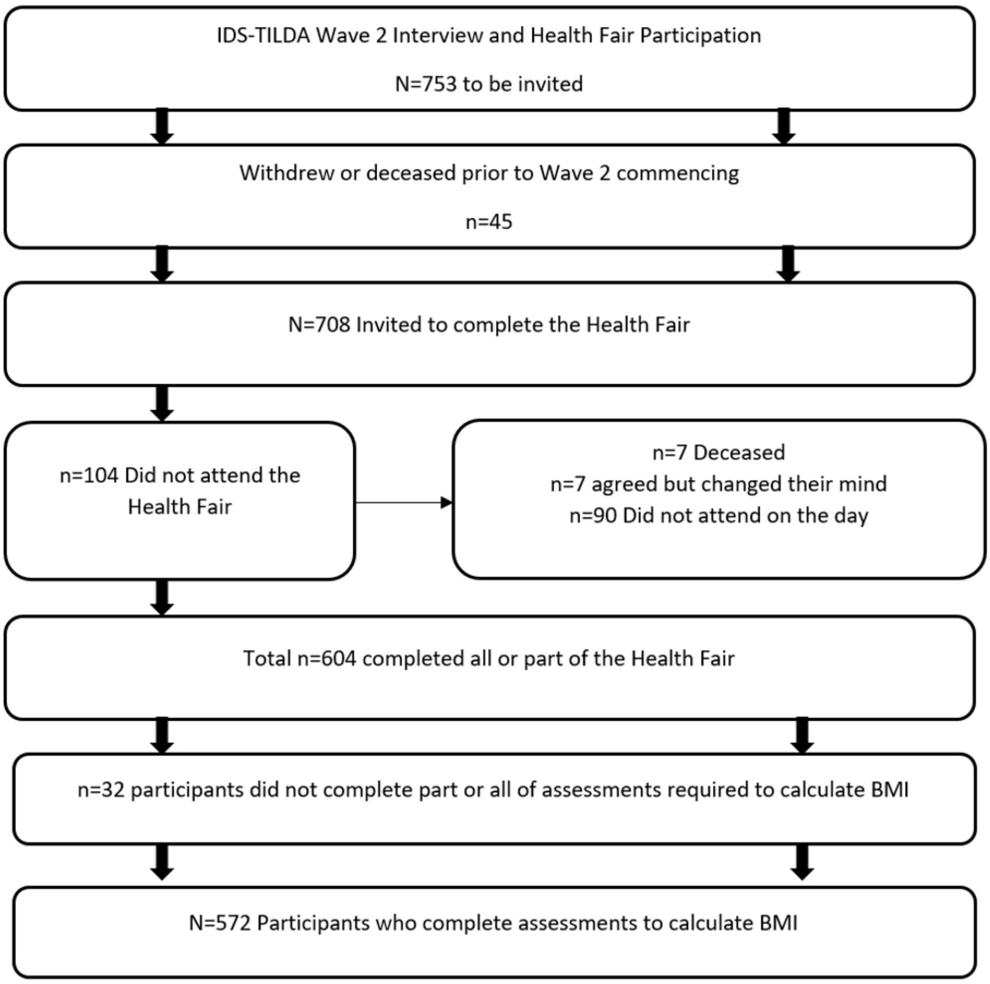


Figure 4.4 Health Fair Attendance flow

BMI is fundamental to this current study and in total 572 participants engaged with measures to calculate BMI. Within the health fair in order to objectively measure weight status, overweight and obesity was considered using BMI (calculated as body weight in kilograms divided by height in meters squared (kg/m2)) (Rolland *et al.* 2015). The World Health Organisation (WHO) classification of body mass index identifies, Underweight BMI <18.50; Normal Weight 18.50-24.99; Overweight 25.00-29.99 and Obese ≥ to 30 as outlined in table 4.1 below. In addition to weight, waist circumference (WHO 2011), waist to hip ratios were logged.

Table 4.1 World Health Organization Cut-off Points and Risk of Metabolic Complications

Indicator	Cut-off points		Risk of metabolic complications
	Male	Female	
Waist circumference	>94 cm	>80 cm	Increased
Waist circumference	>102 cm	>88 cm	Substantially increased
Waist–hip ratio	≥0.90 cm	≥85 cm	Substantially increased

Adapted from the WHO, 2011

The Malnutrition Universal Screening Tool (MUST) protocol provided an alternative measurement for Body Mass Index (BMI). Mid-Upper Arm Circumference (MUAC), was used as a surrogate measure of BMI where mobility was a challenge (Das *et al.* 2020; Nowak-Szczepanska *et al.* 2019; BAPEN 2012). Ulna length was used (measuring length between olecranon process and the styloid process) as a surrogate height measure for participants who were unable to have their height measured (BUAPEN 2012). Appendix 4 provides the parameters for estimating height from ulna length.

4.9. Demographics and BMI

Figure 4.5 below provides an overview of the participants who engaged in the health fair (Wave 2) and who had anthropometric measurements reported.

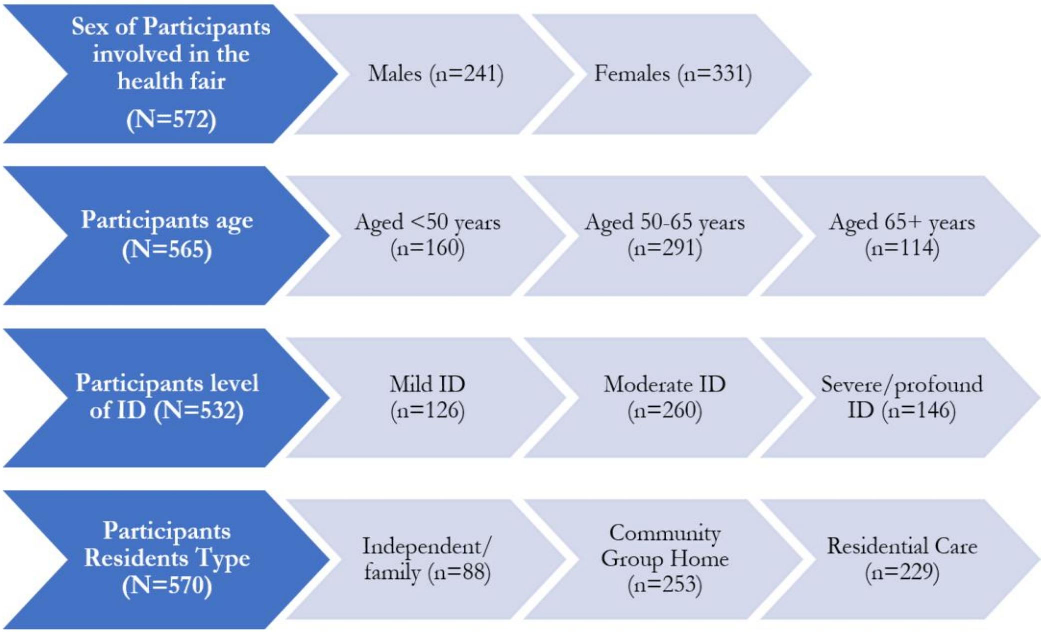


Figure 4.5. Health fair attendance flow chart

4.10. The Food Frequency Questionnaire Wave 3

As well as analysis of anthropometric measures for overweight and obesity, Wave 3 of the study involved the administration of a food frequency questionnaire, with this food data central to the study. Questionnaire which was essential for this thesis. The researcher collated the data following completion of Wave 3, completed the quality checks on the FFQ data and engaged with all follow up. The following segment provides a descriptive overview of the process used for analysing the food frequency questionnaire in this thesis. Additional detail including quality checks, manipulation of data and recoding and are described later.

Following each wave of the study, a review of the study protocol was conducted and some questions were not repeated such as date of birth and aetiology which would not be subject to change. However, following a structured consultative process with the Scientific Advisory Committee, some other areas of questioning were modified to include additional questions or hold questions (Carroll *et al.* 2014). In Wave 3 of the IDS TILDA, an additional module on dietary patterns in the form of a Food Frequency Questionnaire (FFQ) was introduced in the PIQ. Modelled on the full SLÁN instrument (Survey of Lifestyle Attitudes and Nutrition) (Morgan *et al.* 2008), questions within this module include inquiry into dietary intake across all food groups in accordance with the food pyramid (Department of Health 2016a). These included vegetables, salads and fruit; wholemeal cereals, breads, potatoes, pasta and rice; dairy products including milk, yoghurt and cheese; meat, poultry, fish and egg; beans and nuts, fats, oils and spreads and finally foods and drinks high in fat, sugar and salt.

Participants were asked to identify their daily, weekly and monthly servings. Using estimated measures to indicate "medium serving" these were identified based on recommended recognisable household measurements e.g., slice, 200 mls=disposable cup, 5ml teaspoon and measure of cheese=matchbox and pictures were provided to participant for clarity.

Inquiries addressing '*what you like to eat and drink'* aimed to assemble information to provide an understanding of the frequency of consumption per portion of food types. Consumption frequency patterns were indicated as daily to never/less than once per month by marking each line in each section (table 4.2). These were based on average consumption over the previous year. Of the total sample for Wave 3 (n=609), 594 (97.5%) completed the PIQ.

Questions were then grouped for analysis in line with the Food Pyramid recommendations in the 2007 Survey for Lifestyle, Attitudes and Nutrition (SLAN) in Ireland (Department of Health 2016a) as the percentage of respondents consuming the recommended number of daily servings from each shelf of the Food Pyramid. This grouping supported comparison of this study's results with the food pyramid and national daily recommended number of servings per food shelf. These included the following food groups - Vegetable shelf count; Carbohydrate shelf count; Dairy shelf count; Protein shelf count; Fats shelf count; Sweets shelf count. The data analysis process will be described in greater detail in subsequent chapters.

Table 4.2. Questions on Dietary Patterns (200ml cup/pint measures)

Variable name (Average daily)

Options for amount of food or fluid consumption	**Conversion of amounts to daily intake for analysis purposes**	
	Code	**Conversion to daily**
Never/less than once a month	0	
1-3 per month	0.067	(2/30days)
Once a week	0.143	(1/7days)
2-4 per week	0.429	(3/7days)
5-6 per week	0.786	(5.5/7days)
Once a day	1	(7/7days)
2-3 per day	2.5	
4-5 per day	4.5	
6+ per day	6	

4.11. Rigour of Data Collection

The researcher was assigned a case load of 70 participants to advance to interview. A number of measures were taken to promote rigour throughout the interview process. With a phased schedule of contact details released by the gatekeeper, the researcher contacted each participant or their proxy by telephone to arrange a mutually agreed date, time and location for interview. Once established, the study gatekeeper was notified and the interview pack including the PIQ sent to the participant in advance of the interview. The researcher contacted the participant the day before the scheduled interview to reaffirm their availability. Participants were asked to complete the PIQ in advance of the interview. On the day of the scheduled interview, this questionnaire was checked for missing data and where evident, verified with the participant or their proxy. Throughout the interview process, the researcher sought the participant's agreement to proceed to the next topic area. The accuracy of the anthropometric measures recorded as part of the process were facilitated through measurements in accordance with the study protocol and recorded on the CAPI. The use of the CAPI facilitated swift recording reducing interviewer subjectivity and the need for recall post interview. The questionnaire was rechecked and uploaded onto a secure site. This collective process facilitated data quality and integrity.

4.12. Conclusion

This chapter presented the study design which frames this research study, the population sample and recruitment of participants. Positioning this study within IDS-TILDA with the analytical plan for the subsequent chapters was described. The conceptual framework for IDS-TILDA and demographic data are included within this chapter based on participants enrolment into the study from a national Intellectual Disability database, moreover Wave 2 and 3. Recruitment of participants onto the study and the ethical considerations were charted and the values framework underpinning this research is presented. Structures applied to protect the anonymity of the study contributors were included. Following on the interview process was outlined, proceeding with an explanation of the methodological approach adapted for this study and researcher training programme incorporating CAPI training, consent processes and data collection. In addition, the objective measures collated as part of the health fair in the second study Wave and food frequency questionnaire from Wave 3 are described.

The focus of this research is overweight and obesity. As an international challenge, overweight and obesity needs to be understood in the context of the lives of people with an ID. This will not only contribute to our understanding of this complex issue with contributory factors but consequential health outcomes. An important aspect of this study, the health fair where objective measurement for BMI were collated were charted. These objective measurements enabled BMI to be examined with chronic health conditions, identifying disease patterns in older adults with an ID. The food frequency data, when combined with BMI used in this study, provides a unique examination of dietary patterns in ID. Methods used to translate portion size into measurements for analysis also formed part of this descriptive process but will be described with a greater level of detail in Chapter 7. This studies empirical evidence augments awareness of diet, as one but nonetheless an important consideration in the drive to address levels of overweight and obesity in ID. Focusing on the magnitude of overweight and obesity, the researcher will provide a unique insight into this chronic illness using the lens of ID in the ensuing chapter.

CHAPTER 5: OVERWEIGHT, OBESITY AND CHRONIC HEALTH CONDITIONS IN OLDER ADULTS WITH AN INTELLECTUAL DISABILITY

He who has health has hope; and he who has hope has everything

Arabian Proverb

Ryan, J., McCallion, P., McCarron, M., Luus, R. & Burke, E.A. (2021) Overweight/obesity and chronic health conditions in older people with intellectual disability in Ireland. Journal of Intellectual Disability Research, 65 (12), pp.1097–1109.

5.0. Chapter Summary

This cross-sectional observational study examines overweight obesity and chronic health conditions (CHC) in older people with an intellectual disability (ID) aged ≥40 years across all levels of ID. Participation involved an interview process and collation of objective health measures. Using BMI as a measure, weight status was calculated according to the WHO cut-offs and examined with clustered doctor's diagnosed Chronic Health Conditions (CHC). Descriptive analysis was conducted where counts (n) and proportions (%) were used for univariate summation of the variables, while cross-tabulations were used for bivariate summary into counts and proportions. With overweight and obesity prevalence established and patterns described using logistical regression, Pearson's chi-square test was used to test for significant associations. Overweight and obesity was identified in 69% (395/572) of participants. When examined in terms of gender, 72% (n=239/331) of women were overweight or obese as opposed to 27.8% (n=92/331) within the normal weight range. A higher percentage of participants aged <50 years (72.5%, n=116/160) were overweight or obese as were those aged 50-64 (70%, n=204/291) and 65+ (61.4%, n=70/114). Level of ID was significantly associated with weight status ($p<0.001$), with overweight or obesity prevalence high in participants with a mild (85.7%, n=108/126), moderate (72.3%, n=188/260) or severe/profound ID (51.4%, n=75/146). This was also the case for residents type where of those who lived independently/family, 78.4% (n=69/88) were overweight or obese, as were 74.3% (n=188/253) living in a community group home or residential care (59.8, n=137/229) ($p<0.001$). Waist circumference was significantly associated with BMI ($p<0.001$). Almost all participants with a waist measurements in the substantially increased risk of metabolic disease waist measurement category were overweight or obese (91.6%, n=304/332). Additionally, in terms of CHC, of all the participants with GIT, 59.2% (n=148/250) were overweight or obese and this association was statistically significant ($p<0.001$). This was also the case for muscular skeletal disorders were reported in participants and where over half with the condition were also overweight or obese (56.7%, n=80/141) (p<0.001).

5.1. Introduction

Obesity is a chronic disease where body fat exceeds the recommended measurable norms negatively affecting health (Bray *et al.* 2017; National Institute for Health and Care Excellence 2014). As a life limiting but modifiable condition, overweight and obesity is also associated with secondary disability, increased health burden and further disability as people age (Dee *et al.* 2014; Ellis *et al.* 2006). It contributes to chronic health conditions (CHC) such as hypertension, diabetes, heart disease, osteoporosis and depression (Sari *et al.* 2016; Phillips *et al.* 2014) and some cancers (Patterson *et al.* 2013; Ogunbode *et al.* 2009). Denney-Wilson *et al.* (2020) in a study involving adolescent males and females, reported a significant association between obesity, irregular insulin levels, cholesterol and hypertension. Although the focus of their study was on adolescents, the foundations for poor health outcomes in later life is evident in the study findings. Obesity is also a predominant risk factor for metabolic syndrome where increased waist circumference features (Gaston*,* *et al.* 2019; Carroll *et al.* 2014; Adult Treatment Panel III 2001). Andreyeva *et al.* (2006) examined data from a large scale European study examining ageing and retirement across Europe, demonstrating differences in obesity prevalence across countries where both sexes with a high BMI had a significantly higher risk of chronic disease with this risk growing in line with increased weight gradient.

Similarly, the pervasive nature and dynamics of overweight and obesity threaten the health and wellbeing of people with an ID (Bowness 2014; Willis *et al.* 2007; Mencap 2004). Down syndrome (Melville *et al.* 2005), low activity levels (Burke *et al.* 2014; Grundi 2006; Emmerson 2005) and environmental influences (Hsieh *et al.* 2014) contribute to increased risk exposure.

In the context of advancing age in ID, the prospect of developing age-related health conditions is recognised (Petrenko *et al.* 2014) and augmented when coexisting with overweight/obesity.

Overweight and obesity is prevalent among people with an ID (Ryan *et al.* 2021; Burke *et al.* 2017; Foley *et al.* 2017; Neumeier *et al.* 2017; de Winter *et al.* 2012; Bradley 2005). Despite available research describing its prevalence in adults with ID, little research addressing weight status and CHC exists. Flygare Wallén *et al.* (2018), in a comparative analysis of data over a 17-year period on the prevalence of diabetes, hypertension and obesity in people with ID, Autism Spectrum Disorder (ASD) and Down syndrome compared with general population data, reported more than double the risk for both obesity and diabetes in those with ID or ASD. Haveman *et al.* (2010) studied the health risk experienced by people with an ID as they age. This examination not only described obesity as a risk to positive ageing but also as a contributory factor for other health related conditions. Further research by Rimmer *et al.* (2010) and Yamaki *et al.* (2011) considered health conditions associated with obesity in adolescents. Although these studies focused on adolescents with an ID, in both studies, obese participants had higher levels of CHC including hypertension and diabetes.

With limited available evidence describing overweight and obesity (Folch *et al.* 2019) and CHC in an older people with an ID, the purpose of this study therefore was to determine if older adults with ID in Ireland who are overweight or obese experience CHC.

5.2. Methods

In total 572 participants, had their Body Mass Index (BMI) calculated based on objective measures, with BMI as body weight in kilograms divided by height in meters squared (Rolland-Cachera *et al.* 2015).

5.3. Sample

Data for this study was obtained from N=572 participants of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) Wave 2 study. Participants had their Body Mass Index (BMI) calculated based on objective measures as body weight in kilograms divided by height in meters squared (Rolland-Cachera *et al.* 2015) and reported on doctor's diagnosed CHC (see flow chart 5.0 below).

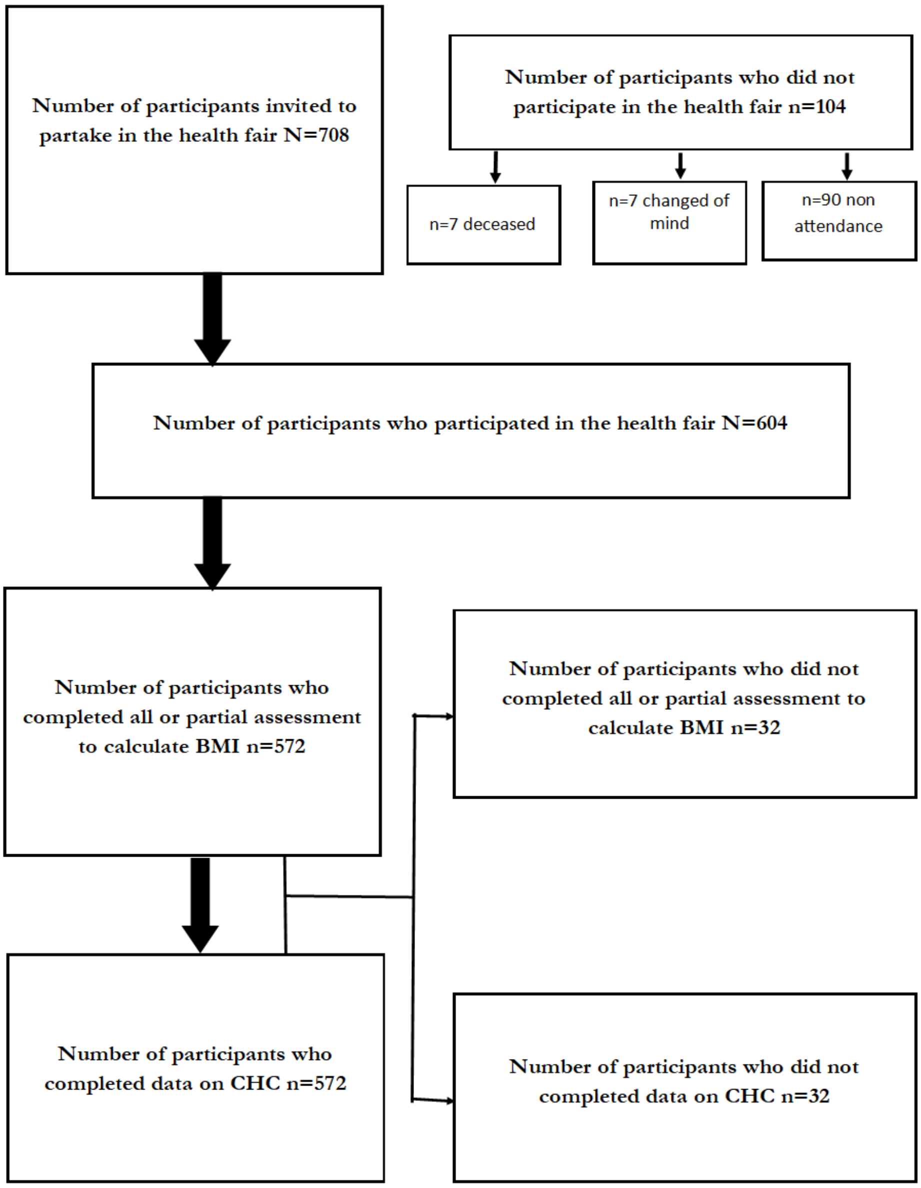


Figure 5.0. Health Fair Attendance Flow Chart

5.4. Measurement

The Health Fair included the anthropometric measures of height weight and waist circumference (Burke *et al.* 2020). In total 572 participants, had their Body Mass Index (BMI) calculated based on objective measures, with BMI as body weight in kilograms divided by height in meters squared (Rolland-Cachera *et al.* 2015). The World Health Organisation cut-offs for BMI were adopted; underweight BMI ≤18.50; Normal Weight ≥18.50-24.99; Overweight ≥25.00-29.99 and Obese ≥ to 30 (WHO 1995). Ulna length (measuring length between olecranon process and the styloid process) as a surrogate height measure was used for participants who were unable to have their height measured (n=155). Additionally, Mid-Upper Arm Circumference (MUAC) (n=79) was used as an alternative for participants with mobility issues (Das *et al.* 2020; Nowak-Szczepanska *et al.* 2019; BAPEN 2012). Involving measures of the left upper arm circumference at the midpoint between the olecranon and acromion process', a MUAC <23.5cm indicated a BMI less than 20kg/m^2 (underweight) and >32.0cm a BMI greater than 30kg/m^2 (obese). Therefore, for the purpose of analysis in this study, overweight and obesity were analysed as a single category. With BMI considered the predictor variable, CHC the response variable, data was stratified by sex, age, level of intellectual disability, living circumstances and waist circumference.

5.5. Chronic Health Conditions

Chronic health conditions (table 5.1) were clustered into broad disease categories representing associated systems of the body. Grouping CHC based on the biological interactions enables examination of disease patterns (Chudasama *et al.* 2021), and for this study included Cardiovascular disease (CVD), Metabolic disease, Gastrointestinal disorders (GIT), Respiratory disease, Neurological disease, Musculoskeletal disorders and Mental Health.

Table 5.1.Chronic Health Conditions

*Description of conditions included in clusters	Clustered condition
High Cholesterol, Heart Murmur, Abnormal Heart Rhythm, High Blood Pressure, Angina, Heart Attack, Congestive Heart Failure, Stroke, Mini stroke, TIA, Varicose ulcer	**Cardio Vascular Disease (CVD)**
Diabetes, Hyperthyroid and Hypothyroid Disease	**Metabolic Disease**
Coeliac, Stomach ulcers, PKU, Gastrointestinal Reflux, Constipation	**Gastro Intestinal Tract (GIT)**
Asthma, Lung Disease	**Respiratory Disease**
Cerebral palsy, Alzheimer disease, Dementia, Epilepsy, Parkinson's Disease, Multiple Sclerosis, Muscular dystrophy	**Neurological Disease**
Osteoporosis, Arthritis, Scoliosis	**Musculoskeletal Disorders**
Emotional, Nervous or Psychiatric Disorder	**Mental Health**

**Variables mapped and combined from literature and IDS-TILDA for the purpose of analysis*

5.6. Data Analysis

The Statistical Package for Social Science (SPSS) version 22 (IBM 2011) was used to conduct analysis for this study. Pearson's chi-square test was used to determine whether significant bivariate associations (*p*-value <0.05) existed between being overweight or obese, the demographic characteristics and the various chronic health conditions. Alpha was set at 0.05 (95% confidence interval). All classes had expected frequencies sufficiently large enough not to use Fisher's exact test. Since all the CHCs were binary targets, logistic regression was used to model CHC on BMI while controlling for demographic differences. Logistic regressions were assessed based on the p-value of a likelihood ratio test (0.05 level of significance) and Nagelkerke's R^2. For each CHC, the reference category was "not having the CHC". Predictors were assessed for significance based on their associated Wald test p-values (0.05 level of significance). Odds ratios and associated 95% confidence intervals were also included. Waist classification was not included in the model because its' confounding association with BMI. With consideration to missing data, only valid percentages are presented throughout this chapter. Underweight, as a distinct weight category, was not considered in this analysis, as the overall level for underweight was low (2.7%). Therefore for the purpose of this this research weight status measures were focused on two BMI groupings, normal and overweight or obese.

5.7. Results

As indicated in participants profile (table 5.2), the majority of the 572 participants were female (57.8%, n=331/572), with 28% (n=160/565) of participants aged <50 years, over half (51.5%, n=291/565) aged 50-64 years, a further 20.1% (n=114/565) aged 65 years and older. The most frequently reported level of ID was moderate (48.8%, n=260/532), severe/profound (27%, n=146) followed by mild ID (23.6%, n=126/532). Participants lived in a community group home (44.3%, n=253), residential care (40%, n=229/570) or independent/with family (15.4%, n=88/570).

Table 5.2. Demographic Profile of Study Participants

		Frequency	%	Total (n)
Sex				572
	Male	241	42.13	
	Female	331	57.87	
Age				565
	40-50	160	28.32	
	50-64	291	51.50	
	≥65	114	20.18	
Level of ID				532
	Mild ID	126	23.68	
	Moderate ID	260	48.87	
	Severe/Profound ID	146	27.44	
Residence type				570
	Independent/with family	88	15.44	
	Community Group Home	253	44.39	
	Residential Centre	229	40.18	

Table 5.3 depicts BMI stratified by demographics and CHC. Of the total number of participants (N=572), over two thirds (69%, n=395/572) were overweight or obese

compared with the normal weight range (30.9 %, n=177/572). Females were more overweight/obese than males (72.2%, n=239/331) versus 64.7%, (n=156/241) respectively. All age categories presented with high levels of overweight and obesity. Of those aged <50 years, 72.5% (n=116/160) were overweight or obese as were 70% (n=204/291) of participants aged 50-64 years and 61.4% (n=70/114) aged 65 years and over.

Individual association tests revealed that level of ID, residence type, waist classification and chronic health conditions [GIT, and musculoskeletal disorders] were significantly related to overweight or obesity as indicated in table 5.3. Similarly, a significant association was found between level of ID and BMI (p<0.001). Participants with a mild (85.7%, n=108/126) or moderate ID (72.3%, n=188/260) were more overweight or obese than those with a normal BMI. This was also the case for participants with a severe/profound ID (51.4%, n=75/76) although the difference between both weight groupings was less that for the other levels of ID and where 48.6% (n=71/146) had a normal BMI. Living arrangements were statistically significantly associated with BMI (p<0.001). Over there quarters of participants who lived independently/family (78.4%, n=69/88), were overweight or obese, as were 74.3% (n=188/253) who lived in a community group home or in residential care (59.8%, =137/229). Furthermore waist circumference measures (n=499), indicated risk of metabolic complications (WHO 2008). Almost all overweight/obese participants had a waist measurement which put them at substantially increased risk of metabolic disease (91.6%, n=304/332). This was also the case for over half of all participants with an increased risk waist measurement (51.8%, n=44/85) and the association was significant (p<0.001).

In terms of CHC, there were significant associations with GIT (p<0.001), and musculoskeletal disorders (p<0.001). Over half who had GIT disorder were overweight or obese (59.2%, n=148/250), as were 56.7% (n=80/141) with musculoskeletal disorders.

Although the overall number with respiratory disease was low (n=37/572), almost all who had the disease were overweight or obese (89.2%, n=33/37) (p<0.006). Interestingly, CVD, an acknowledged risk factor associated with excess weight, was not found to be significant in this study population (71%, n=201/283) (p–value=0.321).

Table 5.3. BMI Stratified by Demographics and CHC

Characteristic		Normal		Overweight/Obese		*p*-value	***Total***
		n	%	n	%		
Sex						0.056	572
	Male	85	35.3	156	64.7		
	Female	92	27.8	239	72.2		
Age*						0.125	565
	<50	44	27.5	116	72.5		
	50-64	87	29.9	204	70.1		
	65+	44	38.6	70	61.4		
ID level*						**<0.001**	532
	Mild	18	14.3	108	85.7		
	Moderate	72	27.7	188	72.3		
	Severe/Profound	71	48.6	75	51.4		
Residence type*						**<0.001**	570
	Independent/family	19	21.6	69	78.4		
	Community group home	65	25.7	188	74.3		
	Residential care	92	40.2	137	59.8		
Waist Classification*						**<0.001**	499
	Normal	69	84.1	13	15.9		
	Increased risk	41	48.2	44	51.8		
	Substantially increased risk	28	8.4	304	91.6		
Chronic Health Conditions							
	CVD					0.321	572
		82	29.0	201	71.0		
	Metabolic					0.74	572
		41	32.5	85	67.5		
	GIT					**<0.001**	572

Characteristic	**Normal**		**Overweight/Obese**		***p*-value**	***Total***
	102	40.8	148	59.2		
Respiratory					**0.006**	572
	4	10.8	33	89.2		
Neurological					0.059	572
	76	35.7	137	64.3		
Musculoskeletal Disorders					**<0.001**	572
	61	43.3	80	56.7		
Mental Health					0.175	572
	81	28.3	205	71.7		

*Alpha set at 0.05; All significant factors in bold *denotes missing values – participants did not answer all questions asked*

**Obs missing (not all participants answered all items)

5.8. Odds Ratio

Logistical regression used to model Chronic Health Conditions (CHC) on BMI showed significant association between BMI and gastrointestinal tract disease (GIT) (*predictive)* (OR = 1.222, p-value <0.001, 95% CI = [1.110; 1.345]). BMI was also predictive of musculoskeletal condition (OR = 1.210, p-value <0.001, 95% CI = [1.087; 1.348]) (table 5.4).

Table 5.4. Logistical Regression of the Risk factors for CHC in Participants who were Overweight/obese (BMI)

CHC in participants who are overweight/obese with the condition or not			
	BMI		
	p-value	**Adjusted Odds Ratio (OR)**	**95% confidence interval (CI)**
GIT (no GIT)	<0.001	1.222	1.110-1.345
Muscular Skeletal (no MSK)	<0.001	1.210	1.087-1.348

~Cox and Snell R^2*= 0.081, Nagelkerke* R^2*= 0.115*
~Percentage correct predicted overall 70.6%
~Normal weight correct predicted 16.9%
~Overweight and obesity correct predicted 94.7%
**Reference category in parenthesis with all statistically significant risks in bold (p<0.05)*

5.9. Discussion

Obesity's contribution to chronic ill health among people with ID is not fully established. This study reports novel information on the association between overweight/obesity (BMI) and doctor's diagnosed CHC, in older people with an ID. Most participants in this study, with measured BMI were overweight or obese (69%, n=395/572), which was more prevalent in females (72.2%, n=239/572). Over 60% of participants in each age category were overweight/obese, with the highest prevalence in those aged <50 years (72.5%, n=116/160) and participants in middle age (70.1%, n=204/219). These findings are similar to other studies involving people with an ID (Hsieh *et al.* 2014; Stancliffe *et al.* 2011; Bhaumik *et al.* 2008) but differ to some general population studies. A longitudinal general population study on the ageing in Ireland (TILDA) reported higher levels of obesity in males than females although the variance was low (38% versus 33%) (Leahy *et al.* 2014). A further Irish study using self-reported weight status described fewer women than men as overweight (33% versus 45%); however, the inverse was true for obesity (26% versus 24%) (Morgan *et al.* 2008). In contrast, systematic examination of prevalence rates for obesity across Europe signify slightly higher overall frequency for women (Berghöfer *et al.* 2008). Women in this current study were at midlife and experienced menopause, a life stage linked with weight gain (Kozakowski *et al.* 2017), central adiposity and subsequent metabolic disease risk (Lizcano and Guzmán 2014). Considering the risk excess weight poses to women's health at menopause (Davis *et al.* 2012), coupled with the age profile in this study, the potential risk to their health is noteworthy (Branco *et al.* 2012).

Lifestyle factors are implicated in overweight and obesity. Participants of this study who were overweight or obese lived independently/family (78.4%, n=69/88) or in a community group home (74.3%, n=188/253). Moreover, level of ID was significantly associated with a BMI ≥25.00, (p value <0.001) with mild (85.7%, n=108/126) or moderate ID posing the greatest risk (72.3%, n=188/260). Policy changes in service supports, coupled with increased personal decision-making autonomy (Government of Ireland 2015a; Department of Health 2005), may contribute to this finding. Factors including personal awareness, limited individual, carer or family understanding of positive nutrition (Hamzaid *et al.* 2018; Cartwright *et al.* 2015) or associated health risks (Bowers *et al.* 2014) influence decision making. Further challenges equating feelings of hunger and satiety to food consumption may also act as contributory factors (Rubbert 2012) signifying support to maintain a healthy lifestyle (Lorentzen and Wikström 2012).

Associational findings between BMI ≥25 and GI disorders are illustrated in studies where both stomach ulcers, PKU, gastro reflux and constipation are problematic in ID (Curtis *et al.* 2021; Galli-Carminati *et al.* 2006; Bohmer *et al.* 2000). Coeliac disease is also more frequently described in obesity (Valletta *et al.* 2010) and a particular risk for people with Down syndrome (Harper 2018). Overall 43.7% (n=250/572) of all participants in this study with a BMI ≥25 had a GIT (*predictive*) which was also shown to be significant across the model (OR = 1.222, p-value <0.001, 95% CI = [1.110; 1.345]). Despite this, there is a paucity of evidence examining correlations between GIT and obesity in ID with general population studies indicate divergent findings (Emerenziani *et al.* 2020). Ringhofer *et al.* (2017) reported significant association between overweight/obesity and gastroesophageal reflux disease when using Waist to Hip Ratio as a measure. Talley *et al.* (2004) and Eslick (2012) reported associations between BMI and GIT symptoms including heartburn, gastroesophageal reflux, abdominal pain (upper), increased stool frequency and incomplete bowel evacuation, although significant associations with symptoms such as constipation, problematic in ID were not found. This issue requires further examination in the context of ID, including alternative measures for GIT disorder with consideration given to diagnostic overshadowing acknowledged as problematic in ID (Javaid *et al.* 2019; Merrick and Merrick 2007).

Similarly, musculoskeletal disorders were prevalent in the overweight or obese population (56.7%, n=80/141). In the regression analyses BMI was also predictive of musculoskeletal condition (OR = 1.210, p-value <0.001, 95% CI = [1.087; 1.348]). Available data suggest that limited activity intensifies conditions such as sarcopenia (Karlsson *et al.* 2020) with frailty compromising the body's reserves increasing exposure to fragility and fractures (Burke *et al.* 2019). Furthermore, inadequate activity levels widely reported among people with ID (Lynch *et al.* 2021; Burke *et al.* 2014; Grundi 2006), has been identified as exposing older people with an ID to morbidity and risk of additional disability (García-Domínguez *et al.* 2020). The significance of these physiological changes expressed in the literature are supported in this study analyses.

Findings linked to respiratory disease warrant attention. A condition recognised by the WHO as a predominant risk factor contributing to mortality (WHO 2014), respiratory disease is also a leading cause of death in ID (NHS 2019; Trollor *et al.* 2017). Although the overall level of reported respiratory disease in this study was relatively low (n=37/572), almost all who had respiratory disease were overweight or obese (89.2%, n=33/37). Compromising the mechanism of breathing, obesity imposes both physiological and biological alternations in lung capacity (Parameswaran *et al.* 2006) and can substantially affect respiratory effectiveness, interfering with respiratory system compliance, risk exposure and the development of respiratory conditions (Dixon and Peters 2018).

Mental health also arose in this study with over seven in ten also presenting as overweight or obese (71.7%, n=205/286), although the association was not found to be significant (p=0.175). The high prevalence rate found in this study population correlates with other literature indicating that people who experience mental ill health are often also overweight or obese (Avila *et al.* 2015; National Collaborating Centre for Mental Health 2014; Preiss *et al.* 2013; Cohn 2010). A number of factors such as medications (not examined as part of this study) or lifestyle habits may contribute to this high level. Whatever the cause, the impact on health translates to all of the systems of the body including the cardiovascular system.

CVD risk factors vary across countries and communities (Chow *et al.* 2009) with excess weight an acknowledged risk factor. However, what is of interest in this study, was the associated risk between CVD and BMI which was neither indicated nor significant when examined across the model (p value= 0.321). It is unclear why this may be the case when risks are seeming and overall prevalence rates for CVD in participants who were also overweight or obese were high (71%, n=201/283). Interestingly, IDS TILDA reported low rates of hypertension (17.5%) despite 69% being overweight or obese and activity levels low with almost 70% not meeting normal daily activity levels (Burke *et al.* 2014). Nevertheless, other risk factors such as smoking, and alcohol consumption were low which may be a contributing factor to reducing overall risk (Burke *et al.* 2014). Moreover, the possibility of underreporting in ID is noted, (Jansen *et al.* 2013) coupled with the absence of objective medical tests which may imply hidden disease. Consequently, further investigation to establish greater understanding of absent associated risks is warranted. Nonetheless, the range of data collated in this study, coupled with objective measures resulted in the presentation of distinctive information, particularly relating to women and is to the researcher's knowledge the first study presenting data on the health conditions experienced by people with an ID who are overweight or obese. Providing such discourse appraises health and social care professionals of the need to effect change and is a basis for focused education and research. Targeted health and wellbeing guidance available for parents at pre-school level, when problematic eating habits and food taste are developing is required. School and community programmes including nutritional health and wellbeing, with cookery classes ensuring reasonable adjustment should be readily available to people with an ID. Moreover, considering participants living arrangements, mandating health and wellbeing education programmes for support workers with regulators monitoring service support against contributing metrics should be regularised. Enabling people with an ID to lead this change through enhanced policy development is ostensible.

Policy targets recommend daily activity levels (Department of Health 2016b). However, active lifestyles require enabling physical environments, surfaced off road walkways, public lighting and accessible public toilet facilities to sustain meaningful engagement by people with an ID. Understanding the lived experience as a prerequisite to inclusive ambitious policy targets is apparent as is cross-departmental government work practice addressing lifestyle factors, including health housing, transport and food safety. Open access to active community groups and sports organisations, with reasonable adjustments made for people with an ID should be contingent on the provision of government funding supports with longitudinal data collation providing an evidence base effecting change.

5.10. Limitations

Although this research provides a scientific foundation in understand overweight/obesity and CHC, there are limitations when interpreting the results. Deeper analysis across causes of ID, risk factors and complexity of the chronic disease, would inform emergent risks across groups. BMI is not an optimal measure of body fat but a globally accepted instrument for weight categories recommended by the WHO (1995). Lifestyle influences, psychosocial dynamics, biological and environment factors all exert influence on weight status and consequential health outcomes (Abarca-Gómez *et al.* 2017; Sharma and Kushner 2009) although should not be inferred from these findings as they were not the focus of this study. Reporting respiratory disease, as a single category is somewhat restrictive compared to previous studies (Zammit *et al.* 2010; Murugan and Sharma 2008), but significant considering evidence linking mortality to respiratory disease (Blair *et al.* 2019) and Obstructive Sleep Apnoea, principally associated with Downs syndrome (Simpson *et al.* 2018).

5.11. Conclusion

Although evidence citing the prevalence of overweight and obesity in ID exists, this nationally representative study uniquely contributes to understanding overweight, obesity and the health of an older population of people with an ID. The burden excess weight poses on health and wellbeing across the life course, from early pregnancy (Denzli *et al.* 2022) to advanced age in ID highlights the need for early intervention within primary care.

This study highlights concerning adverse health effects associated with overweight and obesity in older people with an ID including, GIT, respiratory disease and musculoskeletal disorders. Level of ID, living arrangements and waist circumference were all found to be significantly associated with overweight and obesity. Identifying disease risk in adults with an ID is justified. Considering the presentation of participant's age profile at mid-life, coupled with the level of overweight and obesity in women involved in this study, further investigation into this patent risk is warranted. Moreover where women are exposed to bodily changes including increased risk of weight gain and central adiposity during menopause. Therefore, the following chapter will explore the nature of overweight and obesity in women with an ID.

CHAPTER 6: WOMEN, MENOPAUSE, OVERWEIGHT AND OBESITY

I may not have gone where I intended to go but I think I have ended up where I need to be
Douglas Adams

6.0. Chapter Summary

This chapter explores menopause, overweight, obesity and the risk posed to the health of women with an ID. Menopause as an expected life stage can present unique challenges to the health of women with an ID as they progress through life. When coexisting with overweight and obesity, the risk to women's health is augmented. This study provides a distinctive opportunity to understand overweight and obesity in women with an ID at menopause. In addition to reporting menopause status, objective measurements including BMI and waist circumference obtained at Wave 2 of IDS-TILDA are used in this study.. Acknowledging exposure to metabolic syndrome (MetS) associated with increased waist circumference, the findings presented within this chapter contribute important data to support future planning and policy direction. Descriptive analysis was conducted with counts (n=) and percent's (%).

In total, N=350 women indicated their menopause status with 75.1% (n=263/350) experiencing menopause. Overweight and obesity prevalence and waist circumference measures were established for women reporting menopause status with patterns described using logistical regression. Of the women who reported menopause 74.9% (n=161/215) were overweight or obese (BMI). Waist circumference measures, as an indication of visceral adiposity were also objectively measured in women at menopause (N=248). Results revealed that 75.9% (n=176/232) of women who had reported menopause had a waist circumference which exposed them to increased risk of metabolic disease. More women at menopause with a moderate ID were overweight or obese (53.5%, n=83/176) and this was also apparent where waist circumference was the measure used (52.1%, n=88/169). Of all the women who were overweight or obese, more lived in in a community group home (46.6%, n=75/94) than in residential care (37.9%, n=61/94). A similar pattern emerged for women with a waist circumference measure exposing them to the risk of MetS where 47.7% (n=84/176) of participants at risk resided in a community group home or residential care (36.4%, n=176).

Significant associations were tested using Pearson's chi-square test for overweight and obesity (BMI) and demographic data. Age was significantly associated with waist circumference measures (*p* value=0.010) as was level of ID (*p*<0.001) and residence type (*p*<0.043) when BMI was the measure used. Logistical regression indicated that women who were overweight or obese (BMI) at menopause had 1.241 times the greater likelihood of the presence of GIT disorders 95% CI [1.060-1.770] and this risk increased to 1.516 (95% CI [1.007-2.284] when waist circumference was the measurement used. This risk was 1.218 times greater (95% CI [1.037-1.431] for neurological conditions, as was the case with waist circumference measures 1.405 (95% CI [l 0.986-2.004] although this risk was not found to be statistically significant (*p*-value=0.060). Muscular skeletal conditions indicated that women at menopause who were overweight or obese (BMI) were exposed to 1.232 times the risk of this disorder (95% CI [1.048-1.449] (*p*-value =0.012) and this risk was 1.801 (95% CI [0.753-1.485], times greater when waist circumference was the measure.

6.1. Introduction

Obesity, a chronic condition (National Institute for Health & Care Excellence 2014) arises when body weight reaches and persists at a level where the prospect of developing related chronic disease materialises. The overweight or obesity risk is endemic (Dietz, 2015) exposing older populations to further disease load as they age. Extended life years increases the risk of people with an ID developing age associated secondary but interconnected health conditions (Petrenko *et al.* 2014). Furthermore, comparative mortality remains higher in ID (Hosking *et al.* 2016; Bowness 2014; Heslop *et al.* 2014; Gibbs and Priest 2010; Mencap 2004) with the propensity to reduced life expectancy reported. Women with an ID experience high prevalence rates for overweight or obesity (Hsieh *et al.* 2014; Burke *et al.* 2014; Stancliffe *et al.* 2011; Bradley 2005). This combined with diminished health in older women with an ID is particularly problematic in menopause (Atapattu 2015). Greater prevalence of multiple morbidity coupled with poor health outcomes are reported among women with intellectual disability as opposed to women within general populations (Carey *et al.* 2016). This is particularly concerning for women with an ID, evidenced with a median mortality age gap by as much as 20 years (Heslop *et al.* 2014). Menopause can be a challenging time for all women and a time when many women struggle with weight gain as oestrogen drops increasing the risk of poorer health outcomes.

6.2. Menopause

Menopause is a period of a woman's life cycle during which menstruation ceases followed by amenorrhea for one year marking the end of the reproductive cycle (WHO 1981). Perimenopause, the precursor phase of menopause, is a period in women's reproductive cycle where alterations in the menstrual cycle begin and symptoms synonymous with menopause occur. Menopause is diagnosed in healthy women aged 45 years and older who present with synonymous symptoms (NICE 2015). Although the average age of onset for menopause, lies between the ages of 44-55 years, research indicates that 1% of women experience early menopause (Okeke *et al.* 2013). Additionally, early menopause is reported in women with Down syndrome increasing their dementia and worryingly mortality risk (Coppus *et al.* 2010).

Resulting from a number of interconnected physiological factors including reduced hormone secretion and oestrogen, required to maintain the reproductive system, women at menopause experience both physical and psychological difficulties (Makara-Studzińśka *et al.* 2014) including weight gain (Al-Safi and Polotsky 2015). Oestrogens and oestrogen receptors involved in mechanics of fat and glucose metabolism, are reduced during menopause elevating risk exposure to metabolic disease (Lizcano and Guzmán 2014). These subsequent changes in the body's metabolic response also lead to weight gain (Kozakowski *et al.* 2017). In addition to higher BMI, increased waist circumference augments health risk (Stachowiak *et al.* 2015; Chang *et al.* 2000) and is associated with metabolic disorders (Stachowiak *et al.* 2015). Altered visceral fat distribution is a threat across menopause as it amplifies exposure to breast and other cancers (Patterson *et al.* 2013), osteoporosis and cardiac conditions (Willis 2007).

Further to physiological symptoms, menopause carries a variety of physical symptoms. These symptoms vary and include changed and fluctuating body temperature in the form of hot flashes and night sweats. Additional psychosocial changes include altered mood state, depression and anxiety (Hunter and Rendall 2007). A recent study by Lillis *et al.* (2021) involving women in Ireland (N=855), found that 78.5% of the respondents self-reported that their daily lives were affected by symptoms of menopause. Notwithstanding this expected life stage with physical and psychiological symptons described across menopause, it is poorly understood for and by women with an ID (Willis *et al.* 2011; McCarthy and Millard 2003; Carr and Hollins 1995) and noted as a neglected area of research (Yueh-Ching *et al.* 2013, Willis *et al.* 2011; Martin *et al.* 2003). Limited understanding of bodily changes and derisory support for peri and postmenopausal women with an ID (Willis 2011) compounded with low activity levels (McCarron *et al.* 2014) and environmental influences exposing women with an ID to weight gain. This in turn is harmful to women's overall health and wellbeing (Willis *et al.* 2011). Furthermore the reliance on carers and family to support an appreciative understanding of menopause in women with an ID is also restrictive (McCarthy and Millard 2003; Martin *et al.* 2003).

Interrelated ill health, chronic disease and increased weight status is accepted. Co-morbidities relative to obesity are presenting at an increasingly younger age and sustaining into adulthood (Lau *et al.* 2007). Furthermore, for women with an ID, amplified risk of breast cancers (Lorincz and Sukumar 2006) osteoporosis and cardiac conditions (Willis 2007) present when coexisting with overweight or obesity. This intensifies the health burden for older women with an ID who are shown in this and other studies to be more overweight and obese that men with an ID (Ryan *et al.* 2021). As indicated in previous chapters, research evidence directs greater risk to women with an ID who are overweight or obese (de Winter *et al.* 2012; Bhaumik *et al.* 2008).

6.3. Menopause, waist circumference measures and, overweight and obesity

Age associated increased waist circumference and subsequent abdominal fat pose health risks and is a primary phase in advancement to metabolic disease (Carroll *et al.* 2014; Alberti *et al.* 2006). Moreover, deposition of visceral fat, as a health risk exposes women at midlife to increased risk of metabolic syndrome (MetS) and consequently, metabolic complications (Kearns *et al.* 2014), increasing disease burden as they advance through their lifecycle. Causative factors for MetS in women at and post menopause include central adiposity, alterations in lipid profile, increased insulin levels and hormonal changes (Ward *et al.* 2019; Stachowiak *et al.* 2015). This is borne out in in a study by Donato *et al.* (2006) using waist circumference as a measure, where the risk MetS was indicated in postmenopausal women where waist circumference was increased. Similarly Arthur *et al.* (2013) described significantly larger waist circumferences for post-menopausal women compared to younger participants. Hoey *et al.* (2017) determined that, women over the age of 40 years experienced greater prevalence of waist circumference measures putting them at substantially increased risk of metabolic complications (45%) compared with males (32%). Foley *et al.* (2017), studied BMI and waist circumference for a large population of Latin American athletes (2683 males and 1491 females), participants in the Special Olympics. Findings indicated half of all female athletes were overweight or obese (49%), with prevalence rates appreciably higher than for male athletes (40.8%) and more women also had a waist circumference indicative of central adiposity. Considering athletes were at the optimal competitive level in their respective sports, these findings are disquieting.

In addition, women with elevated BMI (overweight or obese) and increased waist circumference are at risk of developing chronic health conditions including type 2 diabetes and coronary heart disease (Li *et al.* 2006; Mosca *et al.* 2004). Despite this, the cardiovascular disease profile in older populations of women with an ID is perhaps not reflective of the risk at or post menopause. Burke *et al.* (2014) reported comparatively low prevalence of doctor's diagnosed hypertension (17.8%) and diabetic profile (11.1%) for women. Nevertheless, what was of interest in these study findings was the higher prevalence with age for both diseases with 50.4% of women with high BP over the age 50 years and a quarter of women with diabetes over 50 years. (Burke *et al.* 2014). When considered in the context of overall worrying trends for overweight and obesity and at risk waist circumference measures women with an ID at midlife, exposure to suboptimal health outcomes prevails. Moreover, premature death, particularly documented in women with an ID (O'Leary *et al.* 2018; Heslop *et al.* 2014) must act as a driver for targeted improvements to the health of women with an ID.

Contributory factors for overweight and obesity and subsequent health consequences for women include lifestyle influences such as physical activity. Dynamic lifestyles reduce the risk of developing metabolic syndrome in mid-life women (Ward *et al.* 2019). Nonetheless, studies report paltry physical activity and high levels of sedentary behaviour in older populations with an ID (Lynch *et al* 2021; Burke *et al.* 2014). This profile of older women with an ID presenting as overweight or obese, coupled with at risk waist circumference measures highlights considerable risks to the overall health of this population at midlife. Nonetheless, there is a dearth of available evidence to indicate the association if any, between weight status (overweight obese or central adiposity) and chronic health conditions (CHC) in women with an ID at midlife. Therefore, this ensuing chapter explores overweight obesity (BMI) waist circumference and associated CHC in an older population of women with an ID who have experienced menopause.

6.4 Sample Selection

As previously explored, IDS-TILDA enabled the selection of the sample for this study namely, women of all levels of intellectual disability age 40 years and above residing in a variety of living circumstances participated (N=393). See figure 6.0 for sample selection.

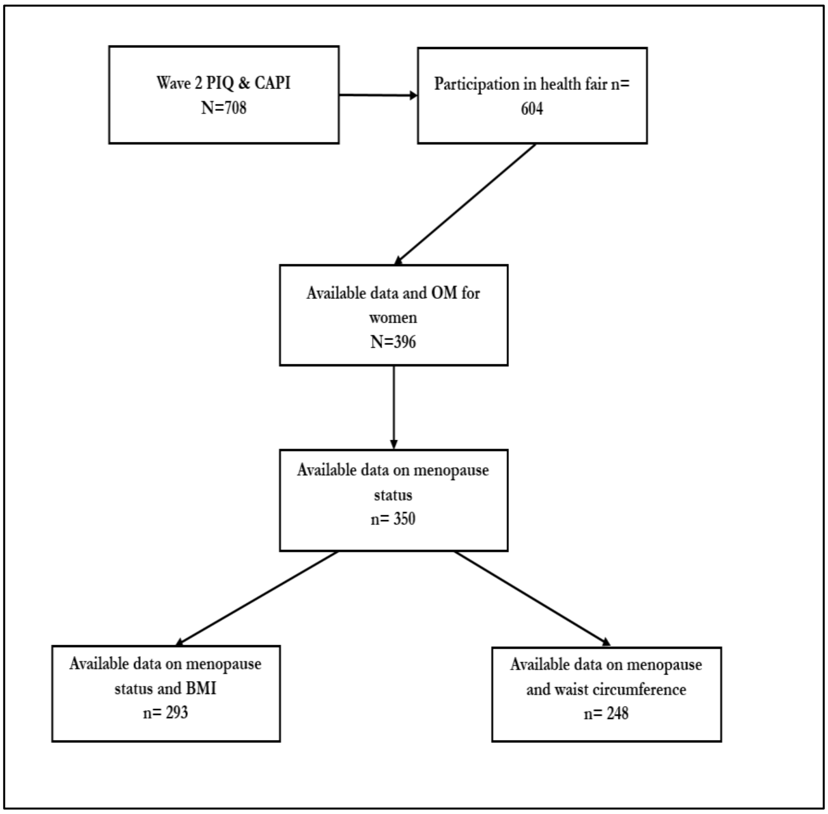


Figure 6.0. Sample Selection

6.5. Design and Data Collection

A cross-sectional quantitative design was used in this study. In view of the overweight or obese risk, exposure for women with an ID reported on in previous chapters, this particular study focuses on women at menopause. Menopause status was categorised as pre (reporting continuation of menses) and post (self-reported 12 months amenorrhea). Participants of this study provided health and wellbeing information via the pre-interview questionnaire and CAPI interview across all life domains. Participants were also invited to partake in a health fair, consisting of objective health measures including height, weight and waist circumference (Burke *et al.* 2020). Surrogate measures were also included to capture those with mobility challenges. These included mid-upper arm circumference (MUAC) and ulna length, a measurement between the olecranon process and styloid process as per the Malnutrition Universal Screening Tool (MUST), (HSE, 2020). Mid-upper arm circumference (MUAC) was calculated as follows: MUAC <23.5cm indicated a BMI less than 20kg/m^2 (underweight) and >32.0cm a BMI greater than 30kg/m^2 (overweight/obese) (Das *et al.* 2020; Nowak-Szczepanska *et al.* 2019). Body Mass Index (BMI) was calculated according to the WHO, see table 6.1 (Rolland *et al.* 2015; WHO 1995). Therefore, for the purpose of analysis in this study, overweight and obesity is presented as one category.

Table 6.1. Parameters for BMI and Waist Circumference Measures

WHO cut-off for BMI		**WHO (2008) cut-off points & risk of metabolic complications**		
BMI		**Waist circumference**		
Indicator	**BMI (kg/m^2)**	**Indicator**	**Cut-off points**	**Risk of metabolic complications**
Underweight	<18.50			
Normal Weight	18.50-24.99	**Waist circ**	**Waist circ**	
Overweight	25.00-29.99	Male	Female	Increased risk
Obese	>30	>94 cm	>80 cm	Substantially increased risk
		>102 cm	>88 cm	Substantially increased risk
		≥0.90 cm	≥85 cm	

**Waist circumference = waist circ*

Chronic health conditions (CHC) (table 6.2) were clustered into broad disease categories representing associated systems of the body. Grouping CHC based on biological interactions enables examination of disease patterns (Chudasama *et al.* 2021), and for this study included CVD, Metabolic disease, GIT, Respiratory disease, Neurological disease, Musculoskeletal disorders and Mental Health. .

Table 6.2. Chronic Health Conditions

*Description of conditions included in clusters	Clustered condition
High Cholesterol, Heart Murmur, Abnormal Heart Rhythm, High Blood Pressure, Angina, Heart Attack, Congestive Heart Failure, Stroke, Mini stroke, TIA, Varicose ulcer	**Cardio Vascular Disease (CVD)**
Diabetes, Hyperthyroid and Hypothyroid Disease	**Metabolic Disease**
Coeliac, Stomach Ulcers, PKU, Gastrointestinal Reflux, Constipation	**Gastro Intestinal Tract (GIT)**
Asthma, Lung Disease	**Respiratory Disease**
Cerebral palsy, Alzheimer disease, Dementia, Epilepsy, Parkinson's Disease, Multiple Sclerosis, Muscular dystrophy	**Neurological Disease**
Osteoporosis, Arthritis, Scoliosis	**Musculoskeletal Disorders**
Emotional, Nervous or Psychiatric Disorder	**Mental Health**

**Variables mapped and combined from literature and IDS-TILDA for the purpose of analysis*

6.6. Data Analysis

The following chapter presents results as BMI measures and associated CHC followed by waist circumference metabolic disease risk. Data for this existing study was conducted using SPSS v22. Descriptive analysis was conducted where counts (n) and proportions (%) were used for univariate summation of the variables, while cross-tabulations were used for bivariate summary into counts and proportions. Pearson's chi-squared test was used to detect for significant bivariate associations (P-value <0.05) between overweight/obesity, demographic characteristic and the CHC listed above. In addition, this analysis process was also administered for waist circumference measures associated risk of metabolic disease, demographics and CHC. Alpha was fixed at 0.05 [95% confidence interval (CI)]. In terms of missing data, only valid percentages are presented throughout this chapter. Underweight, as a distinct weight category was not considered in this analysis as the overall level for underweight was low (1.8%). In preparation for logistic regression multicollinearity was examined to ensure there were no inter-variable dependency which would affect results. Tolerance (1-R^2) and Variance Inflation Factor (VIF) were used whereby 1-R2 having a larger number was more favorable and the opposite to tolerance for VIF (<10). A tolerance of <0.1 meaning the correlation with other variable was high suggesting multicollinearity. In this study VIF values were less than two with a minimum tolerance of 0.76 indicating minimal inter-variable correlation.

6.7. Profile of Study Participants

The profile of all females involved in the study is presented in table 6.3 below. Over half of all women (52.9%, 208/393) were aged between 50-64 years and lived in either residential care (42.6%, n=167/392) or a community group (41.8%, 164/392). Additionally, more women had a moderate level of ID (47.8%, n=175/336) than severe/profound (n=28.1%, n=103/366) or mild ID (24%, n=88/366). Of the women who responded to questions relating to their menopause status, 75.2% (n=263/350) experienced menopause.

Table 6.3. Profile of Study Participants (N=393)

	Frequency	%	Total (n)
Age			393
<50	101	25.7	
50-64	208	52.9	
65+	84	21.4	
Level of ID			366
Mild ID	88	24.0	
Moderate ID	175	47.8	
Severe/Profound ID	103	28.1	
Residence type			392
Independent/with family	61	15.6	
Community Group Home	164	41.8	
Residential Centre	167	42.6	
Menopause			350
Yes	263	75.1	
No	87	24.9	
Age at menopause			263
<50	30	11.4	
50-64	164	62.4	
65+	69	26.2	
BMI			331
Normal	92	27.8	
Overweight/obese	239	72.2	

**Not all questions were answered by participants*

6.8. Menopause and BMI stratified by Demographics and Chronic Health Conditions

In terms of each individual CHC, when examined in relation to women at menopause who were overweight or obese or within the normal weight range, more women were overweight or obese. Moreover, individual associated tests revealed that broad disease category of GIT disorders, neurological and muscular skeletal disorders were significantly associated with being overweight or obese.

Overall n=396 women engaged in this study comprising of 55.9% of the collective study populace (N=708). Table 6.4 presents a profile of weight status, menopause with CHC listed above. Of the women involved, 41.4%, (n=293) answered questions relating to their menopause status. Cross tabs were used to examine the relationship between categorical data of women at menopause who were overweight or obese (BMI) relative to broad disease categories including, CVD, Metabolic disease, GIT, Respiratory disease, Neurological disease, Musculoskeletal disorders and Mental Health. Additionally demographic data is presented relative to menopausal women who are overweight or obesity. Only valid percentages presented in this table. Of all the women who reported menopause status, 74.9% (n=161/215) had experienced menopause and were overweight or obese.

6.8.1 Menopause and BMI stratified by Demographics

When BMI was considered for the women in this study at menopause, 74.9% (n=161/215) were overweight or obese with a quarter of women with a BMI in the overweight/obese grouping not reporting menopause (25.1%, n=54/215). Menopause status and BMI and was also examined in terms of level of ID (N=208). Of all the overweight or obese women, over half had a moderate level of ID (53.5%, n=83/155) followed by 31.6% (n=49/155) with a mild ID. Women reported on their living arrangements (N=219). More women who were overweight or obese at menopause lived in a community group home (46.6%, n=75/161) or residential care (37.9%, n=161) followed by women who lived independently/with family (15.5%, n=161). In examining the overall demographic profile of the women, level of ID (*p*<0.001) and residents type (*p*<0.043) were the two most statistically significant associations allied to menopause and overweight or obesity noted in this study.

6.8.2 Chronic Health Conditions, overweight and obesity

Chronic disease is described in overweight and obesity. In this current study women reported on doctors diagnosed CHC. Conditions such as constipation and gastric reflex present challenges in ID and are described in overweight and obesity. For this current study, of all the women at menopause with a doctors diagnosed GIT disorder, 36% (n=58/161) were overweight or obese. Similar to GIT disorders, women who were overweight or obese women had neurological disease 33.5% (n=54/161). Nonetheless, women who did not report neurological disease at menopause were also overweight or obese (66.5%, n=107/161). As with all other disease categories, overweight or obese women at menopause had musculoskeletal disorders with three in ten women with the condition also overweight or obese (30.4%, n=49/161). Individual associated tests revealed that broad disease category of GIT disorder (p<0.001), neurological disease (p<0.002) and musculoskeletal disorders (p<0.001) were significantly associated with overweight or obesity.

Similarly cardiovascular disease risk is elevated where there are high levels of adiposity. This is borne out for the women at menopause in this current study where of all the women with CVD 57.8% (n=93/161) were overweight or obese compared with 42.2% (n=68/161) of women who did not have the disease but who were overweight or obese. Interestingly of all the women at menopause who did not have CVD six in ten were also overweight or obese (60.3%, n=35/58).

Metabolic disease, synonymous with overweight and obesity as expected was evident in women in this study, but was only reported in three in ten women at menopause who were also overweight or obese (30.4%, n=49/161) as opposed to 69.6% (n=112/161) with a normal BMI.

The results pertaining to respiratory disease in this study were interesting in that for the overall number of respondents (women at menopause) reports of respiratory illness were low (N=16), although most women with the disease were also overweight or obese (8.1%, n=13/161).

Similarly, mental health is described in both obesity and menopause. What was of interest in this study was the absence of a significant relationship (p=0.192). Nevertheless, of all the women who reported mental ill health over half were also overweight or obese (56.5%, n=91/161) as opposed to 43.5% (n=70/161) without the disease but in the same weight range.

Table 6.4. Menopause and BMI Stratified by Demographics and Chronic Health Conditions (N=350)

Characteristic		Normal BMI		Overweight/ Obese		P-value	Total n=
		n	%	n	%		
Menopause						0.927	293
	Yes	58	74.4	161	74.9		
	No	20	25.6	54	25.1		
Age						0.098	219
	<50	8	13.8	17	10.6		
	50-64	29	50.0	106	65.8		
	65+	21	36.2	38	23.6		
ID level and menopause						**<0.001**	208
	Mild	2	3.8	49	31.6		
	Moderate	24	45.3	83	53.5		
	Severe/Profound	27	50.9	23	14.8		
Residents type						**0.043**	219
	Independent/family	6	10.3	25	15.5		
	Community group home	19	32.8	75	46.6		
	Residential care	33	56.9	61	37.9		
CHC and menopause							
CVD						0.732	219
	Yes	35	60.3	93	57.8		
	No	23	39.7	68	42.2		
Metabolic						0.569	219
	Yes	20	34.5	49	30.4		
	No	38	65.5	112	69.6		
GIT Conditions						**<0.001**	219

Characteristic		Normal BMI		Overweight/ Obese		P-value	Total n=
	Yes	37	63.8	58	36.0		
	No	21	36.2	103	64.0		
Respiratory						0.466	219
	Yes	3	5.2	13	8.1		
	No	55	94.8	148	91.9		
Neurological						**0.002**	219
	Yes	33	56.9	54	33.5		
	No	25	43.1	107	66.5		
Musculoskeletal						**<0.001**	219
	Yes	32	55.2	49	30.4		
	No	26	44.8	112	69.6		
Mental Health						0.192	219
	Yes	27	46.4	91	56.5		
	No	31	53.4	70	43.5		

6.9. Menopause and Waist Circumference Stratified by Demographics and CHC

Abdominal obesity, considered a risk factor and primary phase in the development and progression of metabolic syndrome (Alberti *et al.* 2006; NCEP 2001) is embellished in altered visceral fat distribution, exposing women to metabolic disease and poorer health consequences (Chang *et al.* 2000). As well as BMI, this study logged objectively measured anthropometric measures of waist circumference (Morgan *et al.* 2008). Based on World Health Organisation (WHO) cut-off points for the risk of metabolic complications (WHO 2008), central adiposity is represented using waist circumference measures based on the previously presented data in table 4.1. Data was analysed using cross tabs and logistic regression was applied to determine the scale of the relationships between menopause and waist circumference controlling for all other variables in the model.

6.9.1 Menopause and Waist Circumference stratified by Demographics

Of the 350 women involved in the study, n=248 who had their waist circumference objectively measured. Table 6.5 below presents a profile of participant's demographic data stratified by waist classification. In addition, three quarters of these women had experienced menopause (75.9%, n=176/232). Menopause status was indicated where women either had no risk or were at risk of metabolic complications associated with waist circumference measures. Statistical significance was indicated for age (*p*-value= 0.010) and doctors diagnosed medical condition GIT disorders (*p*-value = 0.007) and neurological disorders (*p*-value= 0.013). Across age categories, more women at menopause had a waist circumference, which exposed them to the risk of metabolic disease than did women with a waist circumference within the normal measurement parameters. Specifically, of all the women at menopause with a waist circumference measurement concomitant with MetS, more were aged between 50-64 years (65.9%, n=116/n=176) than aged 65+ (23.9%, n=42/176) or in the younger age group with this level of risk (10.2%, n=18/186) with statistical significance found (*p*=value =0.010).

Similarly level of ID was considered in relation to menopause status and waist circumference measures. Of all the women who had a waist circumference measure which exposed them to metabolic disease risk, over half had a moderate ID (52.1%, n=88/169) as opposed to 29.6% (n=50/169) with a mild ID. By comparison, the overall number of women at menopause with a normal waist measurement was paltry (n=10) but no statistically significant association between level of ID and waist circumference measures were found (*p*-value = 0.254).

Community group home was the most frequently cited living arrangement for the women in this study at menopause with a waist circumference measure which exposed them to metabolic disease risk (47.7%, n=84/176). This was followed by 36.4% (n=64/176) women who lived in residential care and lastly women who lived independently/with family (15.9%, n=28/176).

6.9.2 Menopause and Waist Circumference stratified by Demographics

Further to BMI, waist circumference was also reported as is linked to the risk of developing MetS and this is also presented in table 6.5. Firstly, the level of GI disorders and the at risk waist measurement level was evident irrespective of the presence of the disorder and was statistically significant (*p*-value =0.007). Nonetheless, of all the women at menopause with this at risk waist circumference measure, 36.9% (n=65/176) also had GIT. As with GIT disorders, there was also a statistically significant association between neurological conditions and waist circumference measures in women at menopause (*p*-value =0.013). Overall 31.8% (n=56/176) of the women with a waist circumference exposing them to the risk of MetS also a doctors diagnosed neurological condition.

Overall in terms of cardiovascular disease, there were very few women with a waist circumference measure within the parameters of the recognised normal waist measurement (n=10/176) and CVD was reported in 40%, (n=4/176) of women. Moreover, more than half of the women with a waist circumference with MetS risk exposure, also had doctors diagnosed CVD (58%, n=102/176) although not statistically significant (*p*-value 0.265).

Additional CHCs reported by women at menopause in this study included metabolic disease such as diabetes, hypo and hyperthyroid disease. Over three in every ten woman in this study at menopause who had a waist circumference exposing them to metabolic disease risk already had a doctors diagnosed metabolic condition (33%, n=58/176). However, similar to CVD, patent risk was evident irrespective of the presence of the condition where 67% (n=118/176) of women at menopause did not report metabolic disease but were exposed to the risk of developing this disease by virtue of their waist measurement reported.

As was the case with BMI measures reported earlier in this chapter, the overall number of recorded respiratory disease in women with objectively measured waist circumference an reported menopause was relatively low (n=13). Of this cohort, 6.3% (n=11/186) had the disease which was also not statistically significant (*p* value =0.097). Finally over half of all the women at menopause with a waist measurement exposing them to the risk of metabolic disease had doctors diagnosed mental health illness (56.3%, n=99/176) although this was also the case for 43.8% (n=77/176) of women at menopause without the disease. And again no statistical significance was reported (*p*- value =0.105).

Table 6.5. Reported Menopause and Waist Circumference Stratified by Demographics and Chronic Health Conditions (N=263)

Waist Circumference						P-value	n=
		Not at risk		At risk			
		n=	%	n=	%		
Menopause						0.233	248
	Yes	10	62.5	176	75.9		
	No	6	37.5	56	24.1		
Age						**0.010**	186
	<50	4	40	18	10.2		
	50-64	3	30	116	65.9		
	65+	3	30	42	23.9		
Level of ID						0.254	176
	Mild	1	14.3	50	28.6		
	Moderate	3	42.9	88	52.1		
	Severe/profound	3	42.9	31	18.3		
Current Residents						0.407	186
	Independent/with family	3	30	28	15.9		
	Community group home	3	30	84	47.7		
	Residential care	4	40	64	36.4		
CVD						0.265	186
	Yes	4	40.0	102	58.0		
	No	6	60.0	74	42.0		
Metabolic						0.268	186
	Yes	5	50.0	58	33.0		
	No	5	50.0	118	67.0		
GIT							186

Table 6.5. Reported Menopause and Waist Circumference Stratified by Demographics and Chronic Health Conditions (N=263)

	Yes	8	80.0	65	36.9	**0.007**	
	No	2	20.0	111	63.1		
Respiratory						0.097	186
	Yes	2	20.0	11	6.3		
	No	8	80.0	165	93.8		
Neurological						**0.013**	186
	Yes	7	70.0	56	31.8		
	No	3	30.0	120	68.2		
Musculoskeletal						0.286	186
	Yes	5	50.0	59	33.5		
	No	5	50.0	117	66.5		
Respiratory						0.097	186
	Yes	2	20.0	11	6.3		
	No	8	80.0	165	93.8		
Mental Health						0.105	186
	Yes	3	30.0	99	56.3		
	No	7	70.0	77	43.8		

**Not all participants answered all questions in the PIQ*

6.10. Logistical Regression of the Risk Factors for CHC in Women who were Overweight/obese or with a Waist Circumference in the at Risk of MetS Category

Using logistical regression, this study presents an indication of the exposure to CHC for women with an ID at menopause using BMI and Waist Circumference as parameters with results presented in table 6.6. The model included 3 significant independent variables (metabolic disorders, neurological and musculoskeletal disorders). With BMI as a measure, the model as a whole explained between 11.3% (Cox and Snell R square) and 16.5% (Nagelkerke R squared) of the variance in CHC, and correctly classified 77.2% of cases. As shown in table 6.6 below, only three of the independent variables made a unique statistically significant contribution to the model (GIT disorders, neurological conditions and muscular skeletal conditions). When waist circumference was the metric used to examine risk exposure, the model indicated between 06.0% (Cox and Snell R square) and 17.4% (Nagelkerke R squared) with 94.6% correctly classified and GIT the only CHC indicating statistical significance. These results indicate a consistent risk for women at menopause who are overweight or obese.

When holding other predictor variables constant, women who were overweight or obese (BMI) at menopause were 1.248 times more likely to have GIT disorder (95% CI [1.060-1.470]) which was statistically significant (*p*-value= 0.008). Risk was also evident when waist circumference was the measure of central adiposity used in the model. In this case women were 1.516 (95% CI [1.007-2.284]) times more likely to have a GIT disorder (*p*-value= 0.046).

Women who were overweight or obese at menopause had neurological disease with results signifying the risk to be 1.218 times greater (95% CI [1.037-1.431]) for women in this weight category which again was statistically significant (*p*-value=0.016). This risk pertaining to waist circumference and neurological conditions was at 1.405 (95% CI [l 0.986-2.004]) although this risk was not statistically significant (*p*-value=0.060). Finally muscular skeletal conditions indicated that women at menopause who were overweight or obese (BMI) were exposed to 1.232 times the risk of this disorder (95% CI [1.048-1.449]), *p*-value =0.012 and this risk was 1.801 (95% CI [0.753-1.485]), times greater when waist circumference was the measure although no statistical significance was reported (*p*-value = 0.746).

Table 6.6. Logistical Regression of the Risk Factors for CHC in Women who were Overweight/obese or with a Waist Circumference in the at Risk of MetS Category

CHC in women at menopause who are overweight/obese or with a waist circumference in the at risk of MetS reference category with the condition or not						
	BMI			**Waist Circumference**		
	p-value	**Adjusted Odds Ratio (OR)**	**95% confidence interval (CI)**	**p-value**	**Adjusted Odds Ratio (OR)**	**95% confidence interval (CI)**
GIT (no GIT)	**0.008**	1.248	1.060 – 1.470	**0.046**	1.516	1.007 – 2.284
Neurological (no neuro)	**0.016**	1.218	1.037 – 1.431	0.060	1.405	0.986 – 2.004
Muscular Skeletal (no MSK)	**0.012**	1.232	1.048 – 1.449	0.746	1.058	0.753 – 1.485
	˜Cox and Snell R^2=0.113, Nagelkerke R^2= 0.165 *˜Percentage correct predicted overall 77.2%* *˜Normal weight correct predicted 29.3% - Overweight or obese predicted 94.4%* **Reference category in parenthesis with all statistically significant risks in bold (p<0.05)*			*˜Cox and Snell R^2= 0.060, Nagelkerke R^2= 0.174* *˜Percentage correct predicted overall 94.6%* **Reference category in parenthesis with all statistically significant risks in bold (p<0.05)*		

6.11. Discussion

Excess adiposity, a known contributor to poor health outcomes threatens the health of women with an ID at midlife exposing them to diseases such as cancer (Willis *et al.* 2008) and CVD. Women with an ID have higher mortality with indicators including overweight and obesity, compromising health (National Health Service 2019; Coppus *et al.* 2010). Furthermore, menopause as an expected phase in the life cycle of women brings with it additional health risks (Stachowiak *et al.* 2015; Patterson *et al.* 2013; Willis 2007). In this present study, data was examined in the context of recognised associated disease risk in a population of older women with an ID. Two succinct measures were used, namely BMI and waist circumference to establish weight and health risk status.

Results indicate that weight parameters were high in women who reported menopause with almost three quarters of all women who were overweight or obese also reporting menopause 74.9% (n=161/215). Menopause can result in compromised health (El Khoudary *et al.* 2019) as can overweight and obesity. Given the age profile of women in this study, particularly at midlife, consideration to menopause and weight status emerged in this study as an important factor in addressing overweight and obesity in women with an ID. Perimenopause, the precursor phase of menopause, is a time where alterations in the menstrual cycle begins and symptoms synonymous with menopause occur prior to the onset of menopause. The average age of menopause for women in the general population lies between the ages of 44-55 years with symptoms presenting in healthy women anytime from aged 45 years (NICE 2015). In this study, 65.8% (n=106/161) of women aged between 50-65 years who reported menopause were also overweight or obese. This was also the case for 23.6% (n=38/161) women aged 65+ years. Earlier research by Schupf *et al.* (1997) reported that women with Down syndrome experienced menopause up to two years earlier than other forms of ID. Likewise, Seltzer *et al.* (2001) described the average age of menopause in women with Down syndrome at 46 years. In this study, although Down syndrome was not isolated, of all the women who were overweight or obese and had experienced menopause, one in ten were aged <50 years (10.6%, n=17/161). This was also the case for 13.8% (n=8/58) of women within the normal weight grouping who had reported menopause.

Menopause results in bodily alterations specifically relating to fat deposition associated with declining oestrogen, leading to increased exposure to weight gain and problematic visceral adiposity (Numao *et al* . 2020). This is a risk for women with an ID. Ensuing loss of muscle tissue coupled with lifestyle factors such as diet and lack of exercise also contribute to increased waistlines. Evidence does suggest nonetheless, that irrespective of existing risk factors, significant increases in MetS has been found in women during both perimenopause and early postmenopausal years (Janssen *et al.* 2008). Considering all of the women in this study at menopause, 75.9% (n=176/248) had waist circumference measures exposing them to MetS risk exposure.

Women with an ID present with unique lifestyle variances compared with women within the general population, namely where and how they live. In examining factors such as level of ID and place of residents, this study revealed that over half of all the women at menopause who were overweight or obese had a moderate 53.5%, (n=83/155), or mild ID 31.6% (n=49/155) (p=<0.001). Although no inference can be taken from these findings, they are worth noting and may be influenced in some way by other factors including living arrangements. People with an ID now predominately reside within domestic style living arrangements within their community. Women in this study who were overweight or obese and reported menopause lived either in a community group home (46.6%, n=75/161) or in residential care (37.9%, n=61/161) with only 15.5% (n=25/161) in this weight category residing independently or with family. Altered lifestyles, emergent with developments in service supports for with people with an ID in particular over the past two decades, including the drive for equity and social inclusion potentially expose people with an ID to inadvertent lifestyle risks including overweight or obesity. Food environments have also changed with the exposure to an abundance of foods, many of which are highly processed.

In terms of waist circumference measures, a similar pattern emerged. Examined in terms of no risk or an at risk waist measurement (MetS), considering all the women with an at risk waist circumference measure, the majority were as with BMI in the 55-64 year age group (65.9%, n=116/186). Just under half of women with a waist measurement at risk of MetS also lived in a community group home (47.7%, n=84/186) as opposed to residential care (36.4%, n=64/176), independently or with family (15.9%, n=28/176). In contrast, only n=7 women irrespective of level of ID had a waist circumference with no associated risk. In the context of women with an ID in Ireland, these findings shed an important spotlight on current and future challenges to the health of women with an ID.

Changed models of service provision with seamless exposure to foods containing little or no nutritional value, coupled with the dominance of overweight and obesity in older women with an ID, poses a patent risk to their health and subsequent longevity. This is particularly acute at midlife. A further but not surprising finding of this present study were the high level of CHC in the women involved in this study using both BMI and waist circumference as measures. GIT disorders (*p*-value =<0.001), neurological (*p*-value =0.002) and musculoskeletal conditions (*p*-value =<0.001) were found to be statistically significantly associated with women at menopause and BMI weight measures. This was also the case for GIT disorders (*p*-value =0.007) and neurological conditions (*p*-value =0.013) when waist circumference was the measure used. Chronic health conditions are reported at menopause (Lambrinoudaki *et al.* 2022; van Dijk *et al.* 2015). Respondents in this study reported GIT disease, including coeliac disease, stomach ulcers, gastrointestinal reflux and constipation, ubiquitous in ID (Galli-Carminati *et al.* 2006). This disorders grouping is shown to be higher among ID when compared with general population figures (Perera *et al.* 2020). Although the direction of cause and effect between GIT disease and obesity is not clear (Acosta and Camilleri 2011), it is reported in obesity; the effects of which extend to the severity of the disease and impact on treatment responses (Emerenziani *et al.* 2019). Constipation is one GIT disorder commonly reported in older populations of people with an ID. Burke *et al.* (2017), in describing levels of constipation in an older population of people with an ID longitudinally, reported notable elevated constipation levels between the first and third study waves ranging from 17% (2010-2011) to 44% (2016-2017) with higher prevalence in women than men particularly across the third wave. In this present study, GIT disorders where found to be statistically significant with both BMI (p =<0.001) and waist circumference as the measures used (p =<0.007). Of all the women at menopause with a doctors diagnosed GIT disorder, 36% (n=58/116) of women were also overweight or obese (BMI). Likewise, using waist circumference as a measure, of the women at menopause with measures in the at risk grouping, 36.9% (n=65/176) also reported GIT disorders. The discomfort of symptoms associated with GIT disorder are important considerations for women with an ID who are overweight or obese. Constipation and gastrointestinal reflux disease cause pain and discomfort, including symptoms such as gastroesophageal reflux, debilitating cramps or incomplete bowel evacuation (Eslick 2012). However, descriptive language required to convey these symptoms to elicit diagnostics, treatments and supports pose a challenge to women with ID who may have language limitations. This, at a time when symptoms of menopause also prevail, render the possibility of suffering for women with an ID at midlife. Additionally, acknowledging the likelihood of diagnostic overshadowing (Javaid *et al.* 2019), where women are overweight or obese with central adiposity, symptoms of GIT disorders need to be considered.

Similarly, doctor diagnosed neurological condition such as cerebral palsy Alzheimer's disease, dementia and epilepsy were examined in women across this study and found to be statistically significant across both measures. In total, considering all the women with a doctors diagnosed neurological condition, 33.5% (n=54/161) with this condition were also overweight or obese (*p* value=0.002). In addition, of the women at menopause with a waist circumference indicative of significant risk association with metabolic disease 31.8%, (n=56/176) also had a neurological condition with a significant association noted (*p*=0.013). Alzheimer's disease and dementia is recognised in ID, moreover in people with Down syndrome (Lott and Head 2019). A UK study examining mental and physical health conditions using national data collated through general practice, reported double the rate of dementia in ID compared with general population data (Perera *et al.* 2020). In an earlier study by Tyrrell *et al.* (2001), 13.3% prevalence rate for dementia in a population of Irish adults with Down syndrome was reported. Similarly McCarron *et al.* (2017) indicated increases in dementia diagnosis in people with Down syndrome over time, with as much as a 14% rate increase between Wave 1 of the IDS-TILDA study reported in 2011 and figures reported in Wave 2 in 2014 (Burke *et al.* 2014). Given the higher rates of obesity and increased waist circumference identified in this study population, coupled with the aforementioned dementia prevalence in ID attention on this area is defensible. Moreover, in light of the 2017 Lancet Commission on dementia prevention indicating obesity to be a contributor factor but nonetheless one that can contribute to a reduction in the probability of dementia if addressed (Livingston *et al.* 2020). In this context, findings from this current study present valuable outcomes. However compounding the issue is the impact of neurological conditions on capacity to manage changes required to bring about positive lifestyle changes which are inevitably challenging for those women with ID and indicates the need for support, education and guidance.

As with the other CHC, musculoskeletal disease was prolific across this study with a *p*-value=<0.001 when BMI was the measure used. Three in ten women with the disorder and menopause were overweight or obese (30.4%, n=49/161). When waist circumference was the measure used, a similar level was indicated for harmful central adiposity (33.5%, n=59/176) although this was not statistically significant (*p*-value=0.286). Increased risk to bone health is described not only in the older ID populations but also more frequently for women with an ID. Burke *et al.* (2019) using objective measurement, conducted quantitative examination of the bone health status of older adults with ID, noting greater frequency of osteoporosis in women at 44.5% than men 36.3%. Li (2022) reported an association between obesity and low bone mineral density in participants between the ages of 40-59 years (2022). A small scale study involving people with an ID who engaged with a heel scanning clinic by Walsh *et al.* (2022) reported 10.3% rate for normal bone mineral density and as with other studies, women also presented with greater frequency for both osteopenia and osteoporosis. However, as weight or menopause status did not form part of either of the above studies, no inference is intended from these results. Lifestyle factors, moreover diet affects not only bone health but also is an important consideration for women at menopause. Furthermore, dietary deficits, implicated in bone metabolism (Heaney and Layman 2008) are described in menopause (Harper, 2017). This is an important consideration in the overall drive towards positive health for women with an ID and should be included in strategies to improve women's musculoskeletal health. While developments in living standards and health care have undoubtedly contributed to increased longevity in ID, as previously reported mortality remains higher that within the general population with chronic disease omnipresent (Ryan *et al.* 2021; Doyle *et al.* 2020). In addition the link between high BMI, musculoskeletal conditions, loss of productivity and economic cost is acknowledged in the literature (Chen *et al.* 2023). The societal and personal cost of debilitating musculoskeletal disorders for women with an ID with resulting pain and loss of productivity exposes these women to not only increased disability and higher risk of fragility, fractures and frailty but affects longevity and quality in years lived.

This is also the case for other CHC such as CVD as a leading cause of hospital admission (Doody *et al.* 2021) and mortality in ID (Cooper *et al.* 2004). Although contemporary research on cardiac health and ID is limited, earlier research by Young *et al.* (2004) described the need for an inclusive but multifaceted approach to heart health for people with an ID. Holly and Sharp (2014) in recognising the impact of poor cardiac health on the lives of people with an ID reported positive changes in approaches to cardiac health following a targeted education program for support personnel. In this present study and notwithstanding the high levels of overweight and obesity reported across the women, neither BMI (p value= 0.732) nor waist circumference (p value= 0.265) were statistical significant for CVD disease, both synonymous with overweight and obesity. Nonetheless, using BMI as a metric, women in this study presented with CVD. Of all the women who reported CVD, over half had this chronic disease (57.8%, n=93/116). Again a similar level of the disorder was reported when waist circumference measures were the metric use with 58% (n=102/176) of women who reported doctors diagnosed CVD having an at risk measurement. This contrasts with a low overall number of women with a normal waist measurement either with or without the disease (n=10) and is reflective of the overall prevalence of large waist circumferences in the at risk category for women across this study.

As was the case with CVD, metabolic disease although not statistically significant in terms of weight and menopause status (p value= 0.569), was present in women who were overweight or obese. In view of all the women with metabolic disease, three in ten (30.4%, n=49/161) were overweight or obese although this contrasted with 69.6% (n=112/161) of women who were overweight or obese without the disease. As with BMI, in this study metabolic disease was not statistically significant when waist circumference was the objective measure used (*p* value= 0.268). Interestingly, of all the women who had waist circumference measures recorded in the at risk grouping, fewer reported metabolic disease (33%, n=58/176) compared to those without the disease but with this waist measurement (67%, n=118/176). This is surprising considering the association between overweight, obesity and metabolic conditions such as diabetes (Kirkman *et al.* 2012). However, the possibility of underreporting requires consideration (Gatimu *et al.* 2016). IDS-TILDA for example reported 1.3% prevalence rate for diabetes across the study population who were also overweight or obese with higher prevalence in women (11.1%) (McCarron *et al.* 2014). It should be noted nonetheless, that data collection for this study was reliant on a single metric, namely doctor's diagnosed conditions. Testing using biomedical disease markers in conjunction factors such as family history and weight status may have yielded higher result. Nevertheless, these findings are however line with research by Dunkley *et al.* (2017) who, following a diabetes screening program involving almost 700 adults with an ID reported relatively low rates of 6.5% (95% CI 4.7-8.4) of undiagnosed abnormal glycaemia with ethnicity and family history isolated as additional risk features.

Mental health was also examined in terms of weight status. Although omnipresent in ID and occurring more frequently in older women with an ID (Mulryan *et al.* 2014), no statistically significance was found for the women in this study when wither BMI (*p* value= 0.192) or waist circumference was the measure used (*p* value=0.105). Nevertheless, of all the women with a mental health illness, 56.6% (n=91/161) were overweight or obese as were 56.33% (n=99/171) of women with mental health condition who had a waist circumference measure which exposed them to MetS risk. Central adiposity in women at mid-life, is problematic. Min *et al.* (2022) for example described greater prevalence and intensity of reported depressive symptoms in women at menopause with metabolic syndrome than those without.

Although this current study did not examine symptoms and their intensity or effect on the participant's mental health, it is reasonable to expect that the effects noted above would reflect the experience of women with an ID.

Finally, respiratory disease is a dominant cause of death among those with ID (O'Leary *et al.* 2018; Glover *et al.* 2017; Glover and Ayub 2010). Furthermore, Doody *et al.* (2021), in examining admissions across hospitals in Ireland from 2016-2020, described respiratory related illness as the principle reason for admission to Irish hospitals for both adults and children with an ID. Respiratory disease is recognized in overweight or obese populations. Despite this, in this current study the overall number of women at menopause reporting a doctor's diagnosed respiratory disease with BMI measure in the overweight or obese category was low (8.1%, n=13/161). Interestingly, in terms of waist circumference, when all the women who had an at risk waist circumference were considered, only 6.3% (n=11/176) also reported doctors diagnosed respiratory disease. Why this was the case is unclear as lifestyle factors contribute to this disease. Cronin *et al.* (2011) for example in a longitudinal study on ageing within the general population in Ireland, reported respiratory disease progressing with age and dominant in men with cigarette smoking and socioeconomic factors acknowledged. Comparatively low smoking levels are reported in older populations of people with an ID (McCarron *et al.* 2011). Although this current study did not include specific questions relating to the contributory factors or nature of the respiratory illness, Doody *et al.* (2021) report cited acute lower respiratory lung infection and pneumonia as two of the top causes resulting in hospital admission. Therefore, in acknowledging the link between respiratory conditions, obesity and central adiposity (Zammit *et al.* 2010), overweight and obesity coupled with high risk central adiposity reported in this study has the potential to expose women at menopause with an ID to respiratory disease.

6.12. Conclusion

Despite this acknowledged risk to the health of women with an ID who are overweight or obese (Kinner *et al.* 2018; Burke *et al.* 2014; Merriman *et al.* 2005), there is very limited available evidence examining BMI and waist circumference in women with an ID who experience menopause. Therefore, reflecting on the potential risks overweight, obesity (BMI) and central adiposity (waist circumference) pose to the health of women with an ID who experience menopause, this study provides a valuable insights. Findings provide the reader with an inimitable opportunity to understand menopause in a population of older women at midlife.

Increased life expectancy among women with ID brings with it life events such as menopause not extensively seen or greatly understood. Menopause places women with ID at increased risk of obesity a factor evident in this study. However as no causal relationship was investigated, more longitudinal analysis is recommended to address this. Nonetheless, overweight and obesity feature in these women's lives along with the presence of chronic health conditions.

This study does show a tentative link between CHC menopause and being overweight or obese. Although the findings are concerning for women with an ID they do offer a distinct and unique opportunity to understand menopause and chronic health conditions in women with an ID. This is a time in life for women when health is compromised but is a life stage where the spotlight on health ought to be focused. As a critique, the findings of this research provide a foundation to anchor improvements, in not only understanding the challenge but pathways to improved service supports and futures planning for women with an ID who are overweight or obese with central adiposity. The benefit of targeted health approaches is evidently necessary. This research asserts the narrative necessary for policy planning and service development into the future. Nonetheless, further longitudinal analysis is necessary to affirm the relationships and causation of CHC among women with ID experiencing the menopause.

CHAPTER 7: DIET AND NUTRITION: A DESCRIPTIVE EXAMINATION OF DIETARY PATTERNS OF OLDER ADULTS WITH AN INTELLECTUAL DISABILITY

"The voyage of discovery is not in seeking new landscapes but in having new eyes".

Marcel Proust

7.0. Chapter Summary

The ensuing chapter presents analysis of the habitual dietary intake of adults with an ID who are overweight or obese using data from a Food Frequency Questionnaire (FFQ). In IDS TILDA Wave 3, participants were invited to complete a Food Frequency Questionnaire (FFQ) (N=609). This questionnaire comprised of questions on dietary intake across all food groups, including known contributory dietary factors to overweight and obesity, such as foods high in sugar and fat content, sugary drinks and fast-food consumption. The data presented in this study presents important information on dietary patterns based on gender, age, level of ID and living circumstances. This type of analysis offers an understanding of food intake patterns correlated with weight status against national recommendations based on the food pyramid (Government of Ireland 2019) and the implications therein.

Diet plays a critical role in maintaining positive nutritional and health status. Additionally, food and eating provides one of the greatest pleasures in life with its tastes and smells and textures. Food not only affords opportunity for experimentation with ingredients, it also provides opportunities for social engagement. Furthermore, enjoying and savouring food supports digestion and helps maintain homeostasis for the body. Moreover, food is associated with nutritional health and is an important consideration in overweight and obesity. The precarious role of food as a contributory factor in overweight and obesity is recognised and can be problematic when consumed at levels in excess of what the body requires. This is particularly the case for foods high in sugar, salt and fat or highly processed foods which, when taken in excess over an extended period can lead to overweight or obesity. Nonetheless, dietary patterns are modifiable with poor dietary choices contributing to not only increased weight status but possible vitamin and mineral imbalance. Despite this, the dietary intake in older populations of adults with an ID is an area that is not well researched.

This analysis found that overall compliance with government recommendations (DOH 2016a) was poor across all food groups. Participants consumed less than is recommended for shelves 1, 2, and 3 of the food pyramid containing important foods which provide essential nutrients for balance such as fruit and vegetables or protein for growth and repair. In contrast, however, above recommended intake levels of foods from shelf 5 and 6 comprising of foods high in fats sugar and salt of the food pyramid were reported. These foods have little or no nutritional value and are implicated as contributory factors in overweight and obesity and negative health outcomes. Excess intake of these food types was reported for participants in this study who were overweight or obese. When weight status was examined in terms of dietary intake patterns, overweight or obese participants, moreover women at mid-life who were overweight or obese consumed higher concentrations that recommended of foods from the top shelfs of the food pyramid associated with higher risk of weight gain.

Data presented across this chapter provides a unique opportunity to understand the dietary intake of an older population of people with an ID in Ireland who are overweight or obese and offering information to underpin strategic planning and policy development.

7.1. Introduction

It is estimated that 13% of the global population is affected by overweight and obesity, with prevalence rates in adults doubling over the past 30 years (WHO 2019). Nutritional status is interconnected with health and progressive healthy ageing, extending benefit across society as a whole. Understating this link between ageing well and diet is imperative particularly as population's age.

International evidence suggests that as a form of mal nourishment, obesity contributes to less than optimal health and increased health burden (International Food Policy Research

Institute 2016). Superfluous calorie intake of free sugars contributes not only to excessive weight gain, but also to hypertension, subsequent cardiovascular disease and diabetes (Gillespie *et al.* 2023; WHO 2019). Acknowledging diet as a major risk factor in the development of non-communicable diseases, the World Health Assembly endorsed international nutrition targets including government led strategies, policies and action plans focused on reducing the prevalence of overweight and obesity (WHO 2004). While global nutrition and non-communicable disease targets are on course in some countries, adult overweight and obesity continues to rise internationally (International Food Policy Research Institute 2016). Moreover, age progression leads to physiological age-related changes to the body and given the associated health risks and ageing populations of people with an ID, contributory factors such as diet need to be considered.

7.2. Age Progression, Diet and Nutrition

Older people with an ID in particular are predisposed to poorer health outcomes and increased disease presentation as they age (DoH 2013). As the body ages, changes befall muscle mass, nutrient absorption diminishes exposing older people to increased levels of associated disorders and frailty (Thillainadesan *et al.* 2020). Additionally, overweight and obesity is problematic in older populations. The Irish Longitudinal Study on Ageing (TILDA) for example, a longitudinal study conducted over waves examining ageing within the general population in Ireland reported levels of overweight and obesity increasing with age (Leahy *et al.* 2014). In a matched longitudinal study on intellectual disability, a similar pattern emerged (McCarron *et al.* 2017). In view of reported levels of overweight and obesity and the acknowledged role diet plays in this chronic condition in older adults in Ireland, examining the contributory role of diet in an older population of people with an ID is beneficial.

Over consumption of food, with habitual consumption of excess processed food diminishes health outcomes, imposes dependency and further disability (Morgan *et al.* 2008; Baeyens *et al.* 2006). Nonetheless, food is considered essential for life and the influence diet has on overall health is widely accepted. Nutrients provide sustenance for the body and when lacking or consumed in amounts contrary to acceptable limits, contribute to disease processes such as coronary heart disease, reproductive challenges, some cancers and insulin resistance (Kishore *et al.* 2017; Department of Health 2016c). Furthermore, appetite or moreover a change in appetite can act as an indicator of an underlying health condition or an emotional challenge for the person and is a useful gauge where communication challenges exist (Preiser *et al.* 2014).

National dietary recommendations guide optimal nutritional intake and are represented to the public in Ireland in the form of a food pyramid or optimal food plate (Department of Health 2019a). In Ireland, the Healthy Ireland Survey (2016) highlighted disparities between the national recommendations for nutritional intake and the portion of the population surveyed (DoH 2016). Within this survey, 60% of participants consumed snacks daily, with 42% having 6 or more snacks daily. The 2018 survey found 34% of participants consumed at least one of the five types of unhealthy foods on a daily basis (DoH 2018). This rate of consumption remained steady in the 2021 survey findings with 36% of the survey population consuming 2 or more unhealthy snacks daily. This valuable insight into dietary choices based on a full SLÁN survey within the general population is not to the author's knowledge available for people with an ID across the island of Ireland.

7.3. Sugar Sweetened Beverages

In addition to food intake, body weight is affected by consumption of sugar-sweetened beverages (Harrington *et al.* 2020). A commissioned study by the WHO examined the influence so-called free sugars and supplementary sugar in sweetened drinks on populations (Te Morenga, *et al.* 2012). This research studied dietary sugars and body weight through systematic review and meta-analyses of randomised controlled trials and cohort studies; concluding that the consumption of sugary sweetened beverages influences body weight, in particular in children and adolescents. It is widely acknowledged that childhood obesity exerts itself in adulthood with related poor health outcomes affecting critical life stages (Rundle *et al.* 2020; Kuh *et al.* 2003).

Energy dense drinks are alcohol free products with sugar and caffeine among its main ingredients (Government of Ireland 2019). These sugar-sweetened beverages (SSB) also include drinks containing additional calories such as sucrose or fruit juice concentrates (WHO 2015). Disproportionate consumption of high-sugary energy drinks is an acknowledged barrier in the global race against overweight and obesity (Malik and Hu 2022; Davis *et al.* 2017). The past twenty years has seen a discernible growth in the energy drinks market both globally and in Ireland. Reported sales of energy drinks were appraised in 2012 to be over 12.5 billion US dollars demonstrating a 60% increase over a 4 year period from 2008 (Breda *et al.* 2014). In Ireland, the number of energy drink products available increased from 10 products in 2000 to 39 products by 2015 (Government of Ireland 2017). In the UK there was a 155% increase in overall consumption of high sugary drinks reported from 2006-2014 (Visram *et al.* 2015).

The World Health Organisation (2015) noted the potential positive benefits of fiscal policies on patterns of dietary consumption recommending the application of Sugar Sweetened Tax as part of an overall measure in addressing health. The Irish Government, in an effort to tackle rising levels of overweight and obesity, introduced a specific tax on these readily available high sugary dense drinks. Since 2018, this Sugar Sweetened Drinks Tax (SSDT) is applied to manufacturers of these products in accordance with the volume of sugar-sweetened beverages they produce or import. Duties are set at a rate of 5g of sugar and below 8g per 100ml where products were taxed at a rate of 16.26c per litre and a second higher rate provided for those above 8g per 100ml taxed at 24.39c per litre (Government of Ireland 2017). A similar tax is in place in the UK and many other countries (WHO 2015). In a further effort to address this contemporary challenge, in 2019, the government of Ireland extended the Sugar Sweetened Drinks Task (SSDT) to protein drinks and those containing milk fats (Revenue Commissioners 2022). However, it is yet to be determined if this tax had led to changes in consumer purchase patterns within the general population let alone people with an ID.

Although there are a number of interrelated lifestyle, environmental and genetic factors which contribute to overweight and obesity, the protracted correlation between nutrition and positive health status in older people has long since been recognised as evident in seminal paper by Rhuden (1995). Notwithstanding the recognised link between diet and weight status, dietary patterns within ID is an area which has not received a lot of attention.

7.4. Diet, Nutrition and People with an Intellectual Disability

There are unique risk factors affecting the weight status of people with an ID. Diverse dynamics including choice and control, access to food, understanding health information associated with obesity (Zylke *et al.* 2016; Shoneye 2012) contribute to the challenge in ID. In addition, informed decision-making is subject to available information accessible to the individual. The welcome change in direction from institutional support systems for people with an ID (Health Service Executive 2011) now affords greater opportunity for people with an ID to exercise personal choice and control. Nevertheless, poorly informed decision making within wider societal obesogenic environments can lead to less than optimal food choices (Cohn 2010), ultimately increasing the risk of long-term harmful health outcome in ID (Smyth 2006). There is some available evidence to suggest that targeted education programmes for people with an ID focusing on diet and nutrition results in positive measurable outcomes (Yilmaz *et al*, 2014). Nevertheless, IDS-TILDA found that less than half the participants had access to such information or structured regular education programmes on nutrition including accessible information (Burke *et al.* 2014). Furthermore, Burke *et al.* (2014), described how those who lived within a community setting had high prevalence (66%) and greater patterns of risk factors for overweight or obesity. These risk factors included suboptimal nutritional health, poor food choice and paltry levels of physical activity, with high levels of inactivity noted (Burke *et al.* 2014). Despite the overweight and obesity risk there are limited validated nutritional assessment tools available to people with an ID (Humphries *et al.* 2009).

Overweight and obesity is present amongst people with ID with prevalence rates noted between 38% and 69% (Ryan *et al.* 2021 Hsieh *et al.* 2013). Contributory factors include consumption of foods of less than optimal nutritional quality, coupled with impelling factors ranging from poor underlying dietary knowledge, access to a range of food options, to dependency on others for informed support (Zwack *et al.* 2022). Evidence indicates that people with an intellectual disability present with limited knowledge of their nutritional needs, in particular the choice of healthy food and the diet disease relationship (Hamzaid *et al.* 2018). Rubbert *et al.* (2012) reported that people with an ID experience difficulty equating feelings of hunger and satiety and a rational for food consumption. Furthermore, food literacy and approaches by support teams either family or paid support influence food consumption patterns in those with ID. Therefore, a facilitative approach to assistance with mealtimes is a factor for consideration in the provision of adequate and safe nutrition for people with an ID and highlights the need for evidence on dietary consumption intake.

Although research on overall nutritional health based on dietary patterns was conducted within the general population in Ireland using a SLAN food frequency questionnaire, to this researcher's knowledge the use of the full FFQ in ID has not being previously explored.

7.5. Assessment of Food Patterns

Nutritional assessment in intellectual disability is limited. The Mini Nutritional Assessment tool for example, is recommended in older persons (Tsai *et al.* 2008) and has been shown to be effective in ID. Nevertheless, successful application is contingent on carer involvement where cognition is compromised (Bastiaanse *et al.* 2012). As previously indicated however, progressive nutritional status plays a vital role in maintaining health and wellbeing. Despite this, there is a dearth of studies examining overweight and obesity in people with an ID using dietary patterns as an evidence base with limited published targeted policy and guidelines for people with an ID (Royal College of Physicians Ireland 2015). These factors, together with the drive to improve outcomes for people with an ID addressing lifestyle factors amenable to change such as diet, merit attention in the effort to address levels of overweight and obesity across ID.

Food is essential for life and comprises of energy in the form of protein, fats and carbohydrates measured in the form of kilocalories (kcal) or kilojules (kj). When energy intake exceeds that required by the body to manitain homeostasis, body weight increases. In the context of illness prevention, the critical role diet and subsequently nutritional health has on determinants of health for populations is universally accepted (DoH 2016). Food consumption patterns provide an important insight into the diet disease relationship (Gila-Díaz *et al.* 2020). Depicting patterns of dietary consumption contributes information on the influence diet, as a modifiable factor has on overweight and obesity in an older populations with an ID and is evidentially beneficial.

This is particularly the case in the older populations of people with an ID and extends value when data collection directly from individuals is problematic (Dias Medici Saldiva *et al.* 2017).

Valid food frequency questionnaires (FFQ) are one method used to collate such data. FFQ questions range from food types, consumption patterns to lifestyle behaviours (Gila-Díaz *et al.* 2020; Hite 2013; Tseng *et al.* 2008). Examining patterned intake through food frequency questionnaires has proven beneficial in some studies (Mulligan *et al.* 2015; Liu *et al.* 2013) although its limitations must be acknowledged, and its use is censured (Affret *et al.* 2018; Hite 2013). The need for recall and accurate representation of portion sizes is recognised. Nevertheless, the imposition of health risks associated with overweight and obesity in ID justifies an examination of dietary patterns using a valid food frequency questionnaire to enhance understanding of intake patterns particularly in overweight or obese adults with an ID.

7.6. Methods

The data for this study was drawn from Wave 3 of the IDS-TILDA study, which included a food frequency questionnaire administered to participants. The questionnaire was based on the SLÁN food frequency questionnaire (Morgan *et al.* 2008). The collection of this type of data presented an opportunity to examine dietary patters from a large-scale sample of older people with an ID in Ireland from a population health perspective.

7.6.1. Sample

In total 609 participants engaged in this study wave. Of that number, n=594 participants returned the PIQ which included questions relating to food consumption patterns based on the full SLÁN food frequency questionnaire (FFQ) with n=584 participants completing the FFQ (see flow chart 7.0 below).

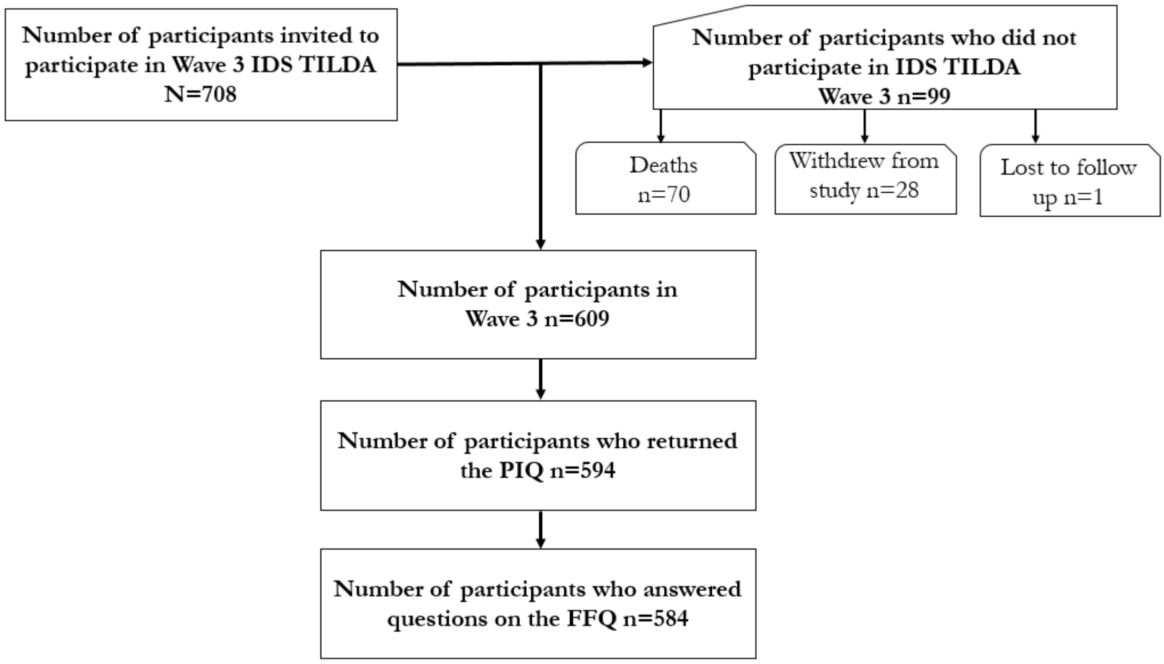


Figure 7.0 Flow Chart Participation across Wave 3 IDS TILDA

7.6.2. Ethics Review

Full ethical approval for this study was granted by the University of Dublin, Trinity College through the Faculty of Health Sciences ethics committee and by the 138 separate service providers supporting participants to engage in the study. Participation was voluntary and materials were presented to participants in accessible formats in support of an informed consent process. In addition, the affirmation of consent at all stages of the interview process including the day of interview and at intervals throughout the interview process, reinforced informed engagement in the study.

7.6.3. Data Collection

Food consumption is directly associated with health outcomes and is an important consideration in overweight and obesity. Dietary patterns are modifiable with poor dietary choices contributing to increased weight status and possible vitamin and mineral imbalance. People with an ID can present as overweight or obese and historically have limited exposure to nutritional information (Russell *et al.* 2018). Combining measures of weight with dietary data measured against national recommended food group intake levels (Department of Health 2016a) offers a distinctive insight into dynamics contributing to the overall health of older people who present with overweight or obesity.

7.7. The Food Pyramid

The food pyramid is an established guide to recommended consumption from different food groups in support of healthy food for life. In Ireland the Obesity Policy and Action Plan – A Healthy Weight for Ireland (2016-2025) (DoH 2016) reviewed the recommendations from the food pyramid providing updated food guidance. Divided into 6 shelves containing a range of foods and drinks, the food pyramid provides a guide to optimal intake and portion measurement (figure 7.2).

The following is an outline of the food shelves and the recommended portions per day

Shelfs on the food pyramid

Shelf 1: Vegetables salads fruit - 5-7 portions per day

Shelf 2: Wholemeal, cereals, breads, potatoes, pasta and rice - 3-5 portions per day

Shelf 3: Milk, yoghurt and cheese – 3 portions per day

Shelf 4: Meat, fish, poultry, eggs, beans and nuts – 2 portions per day

Shelf 5: Fats, spreads and oils shelf 5 – In very small amounts

Shelf 6: Foods and drinks high in fat, sugar and salt – Small fun size servings – Not every day- maximum 1-2 per week

Measurement Guides Recommended per Day

- 200 ml disposable cup
- Palm of the hand
- Thumb size for cheeses
- 5 ml teaspoons
- slices of bread

Figure 7.1 below, the food pyramid provides guidance on foods within each of the six shelves and the recommended daily portions.

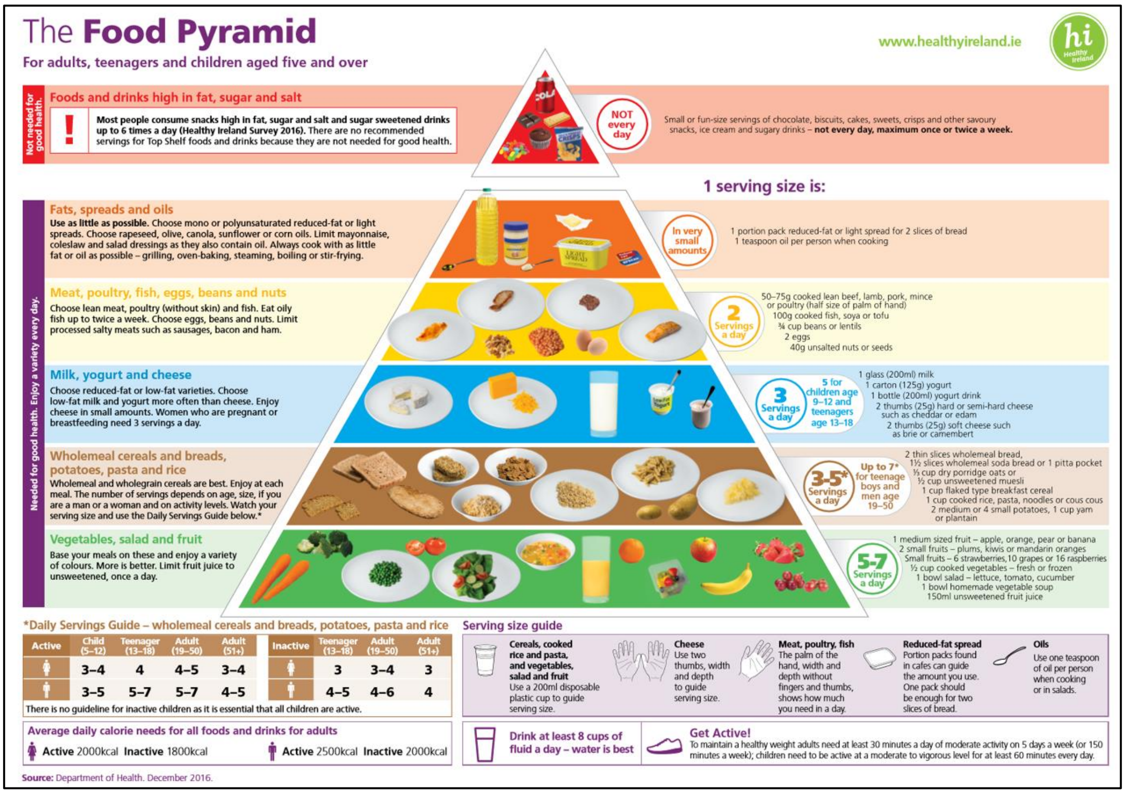


Figure 7.1 The Food Pyramid (Department of Health 2016a)

Recommendations on the Food Pyramid

Shelf 1: Vegetables, Salads and Fruits

Vegetables, salads and fruits make up this main shelf of the pyramid. It contains low calorie high fibre foods which provide an important source of vitamins and minerals as well as fibre. Foods encompassed within this shelf include fruit and vegetables. The recommended daily intake from this shelf is 5-7 portions per day (PPD). Consumption at this level of the food pyramid involves foods high in fibre and nutrients with protective effects against some diseases. The PIQ required participants to report on a medium serving as the equivalent of 2 tablespoons or 4 dessert spoons of vegetables. Fruit was measures as 1 piece of fruit or a medium serving. Both fresh and frozen vegetables were considered within this tier of the food pyramid with a medium serving of vegetables or salad the equivalent of 2 tablespoons or a dessert spoon. Within the PIQ consumption of fresh fruit was reported as well as dried, frozen and tinned fruit.

Shelf 2: Wholemeal Cereals and Breads, Potatoes, Pasta and Rice

This section of the food pyramid contains items such as wholemeal cereals, breads, potatoes, pasta and rice. Foods from this shelf provide an energy source with 3-5 portions per day recommended from this shelf of the food pyramid (Department of Health 2016a). As an energy source, additional consumption guidance recommends up to 7 portions per day for teenage boys and men between the ages of 19-50. An example of a daily serving includes 2 thin slices of wholemeal bread, 1½ slice of wholemeal soda bread or 1 pita pocket. Details of cereals on the PIQ was guided using a medium size bowl as a measure. A medium serving of potatoes, rice and pasta was measured as an estimated cup full. It must be noted however, that the variety of cereals listed on the PIQ ranged from wholemeal cereals to sugar coated cereals.

Shelf 3: Milk, Yogurt and Cheese

This food shelf includes foods which provide an important source of calcium necessary for healthy bones and teeth as well as protein for growth and repair. Foods such as yogurt and milk and cheese make up this shelf of the pyramid with up to 3 spoons, 3 cups of milk or 3 matchbox sizes of cheese recommended per day.

Shelf 4: Meat, Poultry, Fish, Eggs, Beans and Nuts

This category includes meat, fish, poultry, eggs beans and nuts. With a suggested portion size on the PIQ as a deck of cards or palm of the hand, this food group provides an important source of protein required for growth and repair and iron necessary to maintain healthy blood. It is also an important source of Omega-3 fatty acid, an essential fatty acid derived from food which is beneficial in disease protection with 2 portions per day are recommended.

The FFQ also included fish products both fresh and fortified with items such as fish with breadcrumbs or batter and meat pies also reported. Red and white meat in the form of chicken or turkey are also included as are beans, eggs and nuts. Although this shelf contains products such as bacon and sausages, daily consumption of these two particular products are not recommended.

Shelf 5: Fats, Spreads and Oils

Foods such as fats, spreads and oils are identified under Shelf 5 of the food pyramid. These items not recommended for frequent consumption, but to be limited to use as little as possible in very small amounts. Within the PIQ, this section required participants to report on their intake of butter and butter substitutes such as spreads used on bread or vegetables. It also included other dairy produce and fats such as cream, yoghurt, cheese, eggs and dressings such as mayonnaise or salad cream. For this purpose of this study, where food intake was matched to recommendations on the food pyramid, foods such as yoghurt, cheese and eggs were analysed under shelf 4 as opposed to this shelf. Sauces such as mayonnaise are situated on the 5th shelf of the food pyramid under fats, spreads and oils, although an acknowledged source of essential fats, consumption guidance is to use as little as possible and therefore were considered within shelf 5. Butter, full and low fat spreads were also recorded within this section.

Shelf 6: Foods and Drinks High in Fat, Sugar and Salt:

The final shelf of the food pyramid represents both foods and drinks high in fat, sugar and salt. This shelf, considered as shelf 6 of the pyramid consists of foods with no nutritional value for the body but contribute to obesity and some CHC. Considering the content of these food products, consumption advice is, if consumed, they should only be included in the diet in very small amounts no more than 1-2 portions per week. These products include processed foods such as sweets, crisps and fizzy drinks as well as take away foods such as chips and pizzas. Within the PIQ medium serving of sweets and snacks were reported by participants.

Drinks

Sweetened drinks contain additional calories and when consumed in excess contribute to overweight or obesity. In this study, drinks were not calculated into portions per day as the FFQ did not differential those who added sugar/sweeteners or milk to the drinks. Additionally, as overall consumption patterns for sugar sweetened drinks in this study population were low, consequently nothing could be inferred from analysis and is presented in appendix 7 of this chapter.

Food Frequency Questionnaire

In Wave 3 of the IDS TILDA study, all participants (n=609) were invited to complete a Pre Interview Questionnaire (PIQ) which held the full SLAN food frequency questionnaire (FFQ) (Morgan *et al.* 2008). This validated survey instrument was adapted for use in an Irish population from the European Prospective Investigation of Cancer (Harrington *et al.* 2008). It encompasses a series of questions on dietary consumption divided into food types over identified timeframes. The food groups listed below give an indication of the food groups included in the FFQ. This data was then mapped to the food pyramid (figure 7.1) providing an overall understanding of dietary patterns of a population of adults in Ireland relative to national intake recommendations.

The Pre-interview Questionnaire contained questions under each of the 13 food groups listed below. This data was then mapped to the food pyramid which provides recommended portions per day for dietary balance described.

FFQ 13 Food Groups:

1. Meat and meat alternatives
2. Fish and poultry
3. Bread and savoury biscuits
4. Cereals
5. Potatoes, rice and pasta
6. Dairy products and fats
7. Bread or vegetables
8. Fruit
9. Vegetables fresh, frozen or tinned
10. Sweets and snacks
11. Soups, sauces and spreads
12. Drinks
13. Other food items

Respondents reported on portions consumed per day/week/month using estimated measures to indicate "medium serving portions. These were identified based on recommended recognisable household measurements e.g., a medium serving size equated to a deck of cards or palm of hands without fingers, a slice, 200mls=disposable cup, 5ml teaspoon and measure of cheese was the size of a matchbox (figure 7.2).

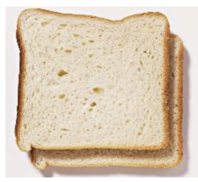
			
200 ml Disposable cup	**Matchbox size piece of cheese**	**5 ml teaspoon**	**2 slices of bread**

Figure 7.2. Image Examples of Serving Portion Sizes

Identifying Food Frequency Intake

Within this study participants were asked to recall food intake with question headings such as '*what you like to eat and drink*'. The overall aim of this questioning was to develop an understanding of the frequency of consumption of foods and drinks per portion from daily to weekly to monthly and ranging from never/less than once per month to 6+ per day by marking each line in each section. This data was based on average consumption over the previous year (table 7.1).

Table 7.1. Questions on Dietary Patterns Answers Choices (food and drinks)

Never /less than once a month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day

7.8 Data Preparation to Determine the Analysis Procedure for the FFQ

Following a review of the original Survey on Lifestyle and Attitude to Nutrition (SLÁN) FFQ the researcher was unable to identify a process for analysis of the data from the FFQ. This resulted in the progression of a process to determine the most appropriate method of analysis. This endeavour led the researcher to conduct an initial scoping exercise of the literature on data analysis from FFQs (Singnorello *et al.* 2009) to identify a computer package for analysis. However, what emerged was that these packages in the main were directed towards diet and nutrition experts engaged in developing dietary plans for patients who were unwell, including the calculation of macro and micronutrients. As the focus of this research was on food groupings to determine consumption patterns rather than developing diet plans, these products were not deemed suitable. The researcher then returned to examine the original national SLÁN survey to ascertain the process of analysis for the FFQ used within this study. A computer software program called FFQ software Version 1.0., used within this survey was led by Morgan and colleagues (Morgan *et al.* 2008). However, this software was not publicly available. The researcher then began a series of correspondence with the authors of the survey seeking guidance on data analysis. Online meetings were facilitated with the researcher who had led on the original analysis in this area. Codes were shared which were then converted into portions per day as indicated in table 7.3. The original coding of the FFQ ranged from 1-9 from never (code 1) to 6+ per day (code 9). These codes were recoded to a proportion of daily intake. Once a day was recoded as 1, all other options were re-coded on the calculated 'daily intake' (table 7.3). All items in the FFQ were re-coded in this manner irrespective of the food group they belong to, with foods then checked against the food pyramid shelves. A number of composite foods were included in the FFQ. For these foods, proportions of the daily intake were allocated to the respective shelves based on their composition. The daily food pyramid average counts were calculated based on the food frequency questionnaire with frequencies assigned to the portions.

Subsequently, each item (n=192) had to be recoded into portions per day/week/month to calculate the number of portions per day consumed by participants (appendix 7). These were then mapped to the appropriate shelf of the off the food pyramid. Based on the codes, each shelf of the food pyramid was allocated a measurement as a portion per day in terms of > than the daily recommendations, recommendations per day and < recommendations per day. These portions were further categorised into shelf count based on portions per day for analysis. In a limited number of cases there was a need to capture food groups where there was a number of food groups involved e.g. lasagne (veg/meat/pasta/sauce). This was determined individually by the researcher in advance of analysis using ingredient portion size in recipes against measures used in the FFQ. In the case of lasagne for example, portions were attributed to shelf 1-4 where meat was an ingredient and 1-3 for the vegetarian lasagne.

Table 7.2 Pyramid Food Shelf Mapped to Food Category with Portion Sizes and Conversions

Food pyramid shelf (*RDA)	Food category mapped to shelf	Portions categories	Conversion to portions per day (**PPD)
Shelf 1 -5-7 PPD	Vegetables fresh or frozen Fruit	Never or less than once a month	'Never or less than once a month'=0
Shelf 2 - 3-5 PPD	Potatoes, rice and pasta, Cereals Breads and Savoury Biscuits	1-3 per month	'1-3 per month' = 0.067 (2/30 days)
Shelf 3 - 3 PPD	Dairy Products and fats	Once a week	Once a week = 0.143 (1\7 days)
Shelf 4 - 2 PPD	Meat and meat alternatives Fish and poultry	2-4 times per week	'2-4 times per week'=0.429 (3/7days)
Shelf 5- In very small amounts	Dairy Products and fats Butter/spreads	5-6 times per week	'5-6 times per week'=0.786 (5.5/7days)
Shelf 6 - Max 1-2 per week	Sweets and snacks	Once a day	'Once a day'=1 (7/7days)
		2-3 per day	'2-3 per day'=2.5
		4-5 per day	'4-5 per day' =4.5
		5/7 per day	6+ per day=6
		6+ per day	6+ per day=6

**RDA = Recommended daily allowance **Portions per day*

7.9. Data Analysis

This data was then grouped for analysis in line with the Food Pyramid recommendations in the 2007 SLÁN in Ireland. SLÁN considers the percentage of respondents consuming the recommended number of daily portions from each shelf of the Food Pyramid. For the purpose of this study, using such groupings supported comparison of the results with the food pyramid and national daily recommended number of portions from each shelf. To achieve this, Statistical Package for Social Science (SPSS) v22 was used in this study. Initial analysis was directed towards frequency and the occurrence and distribution of missing values. Syntax was used to convert FFQ measurement Recommendations Per Day (RPD) into portions per day (PPD) consumed, as described in the previous section for comparison with the national recommendations of the food pyramid.

Pearson's chi-square test was used to determine whether significant bivariate associations (p-value <0.05) existed between being overweight or obese, the demographic characteristics and the shelves on the food pyramid. Logistic regressions were assessed based on the p-value of a likelihood ratio test (0.05 level of significance). Sex differences, age, level of ID and living circumstances were examined relative to weight status (overweight or obese) and food intake based on Recommended Daily Amount (RDA) as a Portion Per Day (PPD) grounded on the food pyramid. This study represented data on the number of portions per food product consumed per day, week or month.

7.10. Food Frequency Questionnaire Analysis

The FFQ presented foods under a number of grouped headings as previously indicated in table 7.2 which can be mapped directly back to the food pyramid. The majority of sections required a response for each food irrespective of whether consumed or not with consumption levels ranging from never/less than once per month to 6+ per day (see table 7.3).

Table 7.3 FFQ Food Groups and Serving Size

Food group	Serving size	Corresponding area on the food pyramid	Every question to be answered
Meat and meat alternatives	Medium serving	Shelf 4	√
Fish and poultry	Medium serving (size of a deck of cards or palm of hands without fingers	Shelf 4	√
Bread and savoury biscuits	One slice or one biscuit	Shelf 2	√
Cereals	One medium size bowl	Shelf 2	√
Potatoes, rice and pasta	Medium serving (about a cup full)	Shelf 2	√
Dairy Products and fats	Individual serving sizes	Shelf 3	√
Butter/spreads	Use the following in bread or vegetables	Shelf 5	
Fruit	1 fruit or medium serving	Shelf 1	√
Vegetables fresh or frozen	Medium serving 2 table spoons or 4 dessert spoons	Shelf 1	√
Sweets and snacks	Medium serving	Shelf 6	√
Soups, sauces and spreads	Soup 1 bowl Or 1 tablespoon for sauces	Shelf 1 (home made) 5	√
Drinks	Cup/glass	Shelf 1,3 or 6	
Other food items	Free text		

7.10.1. Data Quality Assurance

In order to maintain the integrity of the process for analysis of collated information through the FFQ, the researcher undertook a data quality assurance checks of a random sample (n=91) of FFQs. In respect of the sections of the FFQ requiring that each section be completed, if participants had not consumed this food in the past month for example, they could indicate this by putting a tic in the *never/less than once a month* section of the questionnaire. However, a detailed examination of the questionnaires identified anomalies.

Some of the questions remained blank as opposed to an indication of non-consumption by using the box *never/less than once a month* and the researcher suspected that this indicated that the food was not consumed, however this would need to be verified. This led the researcher to conduct a review of questionnaires in order to check the veracity of the data. A process to identify sections of the questionnaire which remained unanswered was undertaken by the researcher. Of the 91 questionnaires viewed, 14 had no missing values. The majority (n=73) of the sample had less than 10 missing values across the 159 food variables and 63 cases had less than 5 missing values. Where there were large sections of missing data, participants were then contacted by telephone to verify their data (n=29). If the 'valid' responses were consistent between the PIQ and the phone response, the phone verification was then included with the agreement of the contact person as representative of what should have been on the PIQ. Following on from the data cleaning verification process, each of the 159 food items were checked in terms of their place on the food pyramid. This enabled analysis of consumption in line with the nationally agreed recommendations based on the food pyramid (Department of Health 2016a). From each food type as indicated in the example below, food groupings were individually identified and subsequently grouped into shelves on the food pyramid. Analysis of the data showed fish for example on the FFQ grouped under fish and poultry (*Fish_and_poultry_0).* This represented the number of portions per day consumed by the respondent (*"Never/less than once a month"* to *Fish_and_poultry_6+*) with 2 portions per day from this food group recommended based on this shelf of the food pyramid.

7.11. Results

The following section presents the results of analysis commencing with participant's demographic profile followed by enquiry into each individual food group.

7.11.1. Demographic Profile

Overall, 609 participants took part in this study with the majority being female (55.8%, n=340/609). With respect to age, 11.8% (n=72/609) were <50 years, 62.6% (n=381/609) were 50-64 years, and a further 25.6% (n=156/609) were aged 65 years and older. The most frequently reported level of ID was moderate (46.2%, n=259/561), severe/profound (29.1%, (n=163/561) followed by mild ID (24.8%, n=139/561). More people lived in residential care (44%, n=268/609) than in a community group home (40.4%, n=246/609) or independent/with family (15.6%, n=95/609). In total, of those who had their weight objectively measured, seven in ten (70.9%, n=295/416) were within the overweight or obese category. Table 7.4 below presents the overall demographic profile of participants. BMI was presented in two distinct weight categories, namely normal BMI and overweight or obese. Underweight was not reported as the level was < 1%.

Table 7.4. Demographic Profile of Participants in Wave 3 of IDS-TILDA (N=609)

		Frequencies	%	Total (n)
Sex				609
	Male	269	44.2	
	Female	340	55.8	
Age				609
	<50	72	11.8	
	50-64	381	62.6	
	65+	156	25.6	
Residents type				609
	Independent/family	95	15.6	
	Community group home	246	40.4	
	Residential care	268	44.0	
Level of ID				561
	Mild	139	24.8	
	Moderate	259	46.2	
	Severe/Profound	163	29.1	
Cause of ID (DS or other)				609
	Down Syndrome	109	17.9	
Cause unknown\other\don't know\missing		500	82.1	
Weight status (BMI kg/m^2)				416
	Normal	121	29.1	
	*Overweight/obese	295	70.9	

*Only valid percentages are presented in this chapter. * Overweight and obesity is presented as one category. ** Underweight is not reported because of the low number <1%.*

7.11.2. Demographic profile of participants who were Overweight or Obese

A demographic profile of participants who reported on their BMI (N=416) is presented in table 7.5. More women were overweight or obese (56.3%, n=166/416) than men in this study (43.7%, n=129). Of all participants who were overweight or obese, the majority were at middle age (60.7%, n=179). In terms of level of ID, almost half of all overweight or obese participants had a moderate level of ID (49.5%, N=135/380) and the association was found to be statistically significant (p=<0.001). Finally, participants reported on their residents type with more who were overweight or obese living in a community group home (47.1%, n=139) and again, this was statistically significant (p=0.008*)*.

Table 7.5. Profile of Study Participants and Weight Status (Normal/overweight or obese) (N=416)

Characteristic	Normal BMI		Overweight/ Obese		P-value	Total (n=)
	n	**%**	**n**	**%**		
Gender					0.434	416
Male	58	47.9	129	43.7		
Female	63	52.1	166	56.3		
Age					0.997	416
<50	15	12.4	36	12.2		
50-64	73	60.3	179	60.7		
65+	33	27.3	80	27.1		
Level of ID					**<0.001**	380
Mild ID	22	20.6	98	35.9		
Moderate ID	51	47.7	135	49.5		
Severe/Profound ID	34	31.8	40	14.7		
Residence type					**0.008**	416
Independent/with family	18	14.9	64	21.7		
Community Group Home	46	38.0	139	47.1		
Residential Centre	57	47.1	92	31.2		

Only valid percentages are presented kin this chapter **Overweight and obesity is represented as one category ***Underweight is not reported because of the low number <1% ** Not all participants reported their level of ID*

7.11.3. Compliance with recommended daily allowance (RDA) of food groups according to the FFQ recommendations

The FFQ data was available for 584/609 participants of this study. Overall, the majority of participants were under the RDA for shelves 1 (Vegetables/salads/fruit) through to 3 (milk/yoghurt/cheese). In contrast, for shelves 4 (meat/poultry/fish/eggs/beans/nuts) to 6 (foods and drinks high in sugar, salt and fat) participants consumed over the RDA. Table 7.6 presents compliance levels across all participants. These results demonstrate that almost half of all participants (47.1%, n=275/584) consumed less than the recommended daily allowance for Shelf 1 of the food pyramid, consisting of vegetables salads fruit. In addition, 71.9% (n=419/583) consumed less than the recommend RDA from shelf 2 including wholemeal, cereals, breads, potatoes, pasta and rice. A further 53% (n=309/583) did not meet the recommendations for calcium rich products (<RDA) such as milk, yoghurt and cheese although half (51.6%, n=301/583) consumed more meat, fish, poultry, eggs, beans and nuts than recommended. Over two thirds of participants (68%, n=394/579) consumed greater than recommended daily intake for food items from shelf 5 including fats, spreads and oils. Moreover, shelf 6 containing foods not recommended for daily consumption, including those with high concentrations of fat, sugar and salt showed that almost all participants (96.2%, n=558/580) had consumption patterns exceeding daily recommendations.

In total on examining the mean number of portions per day, no participants attained the RDA of portions per shelf per day. For example, for Shelf 1, fruit and veg the mean portions consumed daily across all participants was 2.28 (SD $\pm$0.769). Data on portions based on recommended daily allowance can be viewed in table 7.6.

Table 7.6 Mean Number of Portions per Day Consumed

Food Pyramid shelf	RDA	n	%	Mean no. of portions per day	SD	Total
Shelf 1-				2.28	±0.769	584
	>RDA per day	195	33.4			
	RDA per day	114	19.5			
	<RDA per day	275	47.1			
Shelf 2-				2.49	±0.847	583
	>RDA per day	28	4.8			
	RDA per day	136	23.3			
	<RDA per day	419	71.9			
Shelf 3-				2.36	±0.762	583
	>RDA per day	172	29.5			
	RDA per day	102	17.5			
	<RDA per day	309	53			
Shelf 4 -				2.11	±0.688	583
	>RDA per day	301	51.6			
	RDA per day	110	18.9			
	<RDA per day	172	29.5			
Shelf 5 -				2.09	±0.558	579
	>RDA per day	394	68			
	RDA per day	66	11.4			
	<RDA per day	119	20.6			
Shelf 6 -				2.02	±0.194	580
	>RDA per day	558	96.2			
	RDA per day	6	1			
	<RDA per day	16	2.8			

**RDA= Recommended Daily allowance **not all participants answered all section of the SLAN*

7.11.4. Bivariate Analysis of Compliance with RDA Stratified by BMI

Overall, this analysis indicates that across all food groups overweight or obese respondents consumed less than the recommended daily intake for shelves1-4 (fruit, veg, wholemeal, dairy or meats) and exceeded what is recommended for the remaining two shelfs, 5 and 6 of the food pyramid inclusive of fats oils and food high in sugar or salt (Department of Health 2016a). This is evident for example with foods from shelf 1 (vegetables, salads and fruit) where of all those who were overweight or obese, 45.4% (n=129/402) consumed less than the RDA for that shelf. Conversely, for shelf 6 (foods high in fat, sugar and salt) almost all overweight or obese participants exceeded the RDA (96.8% (n=274/401). Full details of RDA consumption stratified by BMI can be viewed in table 7.7.

Table 7.7. Food Pyramid Portions Stratified by BMI

	RDA per day	Normal n	Normal %	Overweight/obese n	Overweight/obese %	*p*-value	Total
Shelf 1 Vegetables/salads/fruit						0.426	402
	>RDA per day	34	28.8	101	35.6		
	RDA per day	25	21.2	54	19.0		
	<RDA per day	59	50.0	129	45.4		
Shelf 2 Wholemeal cereals/breads/potatoes pasta/rice						0.141	402
	>RDA per day	9	7.6	10	3.5		
	RDA per day	29	24.6	61	21.5		
	<RDA per day	80	67.8	213	75.0		
Shelf 3 Milk/yogurt/cheese						0.516	403
	>RDA per day	34	28.6	68	23.9		
	RDA per day	18	15.1	53	18.7		
	<RDA per day	67	56.3	163	57.4		
Shelf 4 Meat/poultry/fish/eggs/beans/nuts						0.692	402
	>RDA per day	64	54.2	153	53.9		
	RDA per day	23	19.5	47	16.5		
	<RDA per day	31	26.3	84	29.6		
Shelf 5 Fats/spreads/oils						0.212	401
	>RDA per day	79	66.9	204	72.1		
	RDA per day	14	11.9	39	13.8		
	<RDA per day	25	21.2	40	14.1		
Shelf 6 Foods & drinks high in fat/sugar/salt						0.866	401
	>RDA per day	113	95.8	274	96.8		
	RDA per day	1	0.8	2	0.7		
	<RDA per day	4	3.4	7	2.5		

7.12. Analysis of Each Food Shelf in line with Recommended Daily Amount (RDA) Stratified by BMI

The following section presents a summary analysis of consumption patterns across individual shelves of the food pyramid in accordance with the demographic profile stratified by BMI and is presented using visual formats and subsequently in full at the end of each section within this chapter.

Compliance in conjunction with RDA for Shelf 1 of the Food Pyramid (Vegetables, salads and fruits) stratified by BMI:

Consumption patterns in accordance with Shelf 1 of the food pyramid, (vegetables, salads and fruit), for all participants who were overweight or obese indicate an overall compliance level of 19% (n=54/79). However, this was only marginally better for participants within the normal weight range (21.2%, n=25/79). In terms of consumption of less than the RDA, for all overweight or obese participants this was at 45.4% (n=129/188). The mean number of portions per day for the overall population from this shelf was 2.28 (SD $\pm$0.769) although the national recommendation is 5-7 portions per day.

Compliance in conjunction with RDA for Shelf 2 of the Food Pyramid (wholemeal cereals/breads/potatoes pasta/rice) stratified by BMI:

With a mean of 2.49 (SD $\pm$0.847) portions per day (PPD) for participants who presented as overweight or obese (RDA=3-5 PPD), compliance with shelf 2 of the food pyramid including foods such as wholemeal cereals, breads, potatoes, pasta and rice indicated that three quarters of overweight or obese participants consumed less that the RDA (75%, n=213/293) for this food shelf with just two in ten participants in this same weight grading adhering to RDA (21.5%, n=61/90) although this was not statistically significant (p=0.141).

Compliance in conjunction with RDA for Shelf 3 of the Food Pyramid (**milk/yogurt/cheese*****) stratified by BMI:***

Shelf 3 of the food pyramid (RDA=3 PPD) again demonstrated poor compliance with only 18.7% (n=53/71) of overweight or obese participants meeting recommended levels. Nonetheless, compliance with the RDA was even less so for participants within the normal weight range (15.1%, n=53/71). Almost six in ten overweight or obese participants consumed less that the recommended three portions per day (57.4%, n=163/230) with a mean intake of 2.36 (SD ±0.762).

Compliance in conjunction with RDA for Shelf 4 of the Food Pyramid (**meat/poultry/fish/eggs/beans/nuts*****) stratified by BMI:***

Of all of the respondents in the overweight or obese weight category, for shelf 4 (n=284), again limited compliance with the recommended 2 servings per day was reported (overall mean 2.11, SD ±0.688). Overall, 16.5% (n=47/70) of overweight or obese participants met the RDA with a further 29.6% (n=84/115) consuming less than recommended foods such as meat, poultry, fish, eggs, beans and nuts. In terms of participants in the normal weight range (n=118) compliance was also low for this food shelf with just 19.5% (n=23/70) consuming within the RDA.

Compliance in conjunction with RDA for Shelf 5 of the Food Pyramid (**Fats/spreads/oils*****) stratified by BMI:***

A similar pattern emerged with poor overall compliance with intake of recommended amounts of fats, spreads and oils. With a mean of 2.09 (SD ±0.558), only 13.8% (n=39/67) of overweight or obese participant met this RDA. In contrast, 72.1% (n=204/283) of overweight or obese participants exceeded the RDA with 14.1% (n=40/65) consuming less than is recommended from this food group (table 7.7) However, compliance was also poor in the normal weight category where 66.9% (n=79/283) of all participants in this category exceeded the RDA.

Compliance in conjunction with RDA for Shelf 6 of the Food Pyramid (*foods & drinks high in fat/sugar/salt*) stratified by BMI:

Shelf 6 of the food pyramid consists of foods and drinks which are high in fat/sugar/salt. Most participants exceeded the recommended consumption level of small fun size servings up to a maximum of 1-2 portions per week. Almost all overweight or obese participants (96.8%, n=274/387) consumed more than the RDA (mean PPD 2.02 (SD $\pm$ 0.194) but this excess was also evident in participants within the normal weight range whereby 95.8%, (n=113/387) consumed above the RDA with an average $\pm$0.194 PPD consumed.

7.13. Bivariate analysis of Food Shelfs Stratified by BMI and Demographics

In addition to BMI, FFQ data was analysed in terms of demographics including gender, age, level of ID and living circumstances the findings are presented in table 7.8

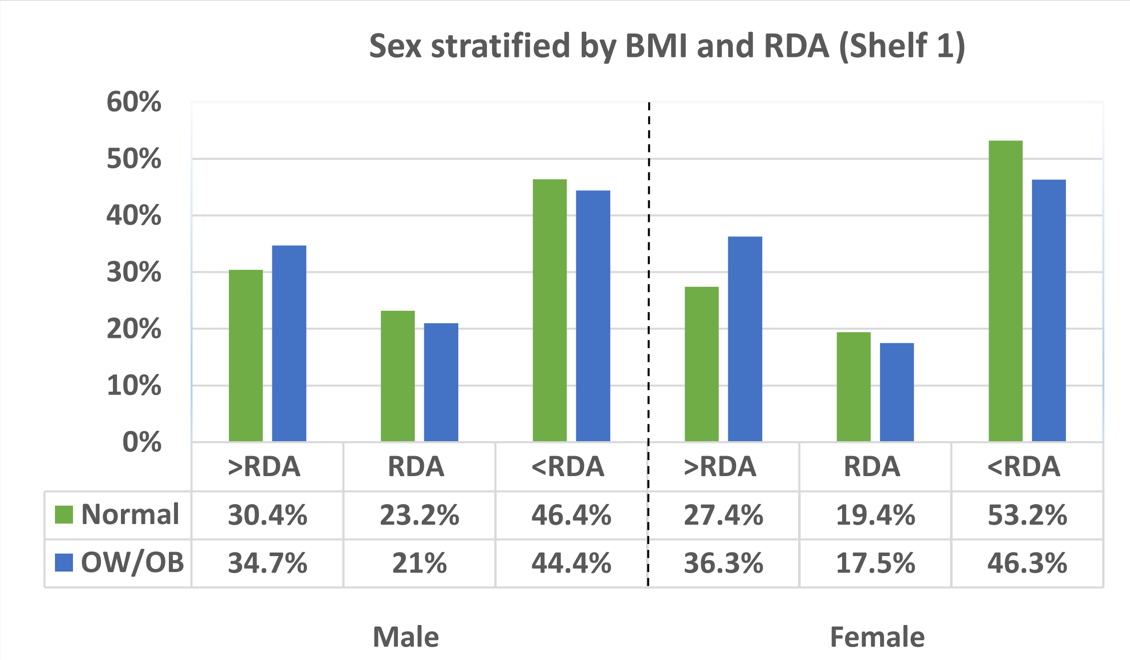
Table 7.8. Shelf 1 (Vegetables/salads/fruit) Stratified by Gender, Age, Level of ID and Residents Type

Demographics	BMI Normal							BMI Overweight/Obese							
	>RDA		RDA		<RDA		totals	>RDA		RDA		<RDA		totals	*p*-value
	n	%	n	%	n	%		n	%	n	%	n	%		
Sex														402	0.426
Male	17	30.4	13	23.2	26	46.4	56	43	34.7	26	21.0	55	44.4	124	
Female	17	27.4	12	19.4	33	53.2	62	58	36.3	28	17.5	74	46.3	160	
Age														402	0.426
Age <50	7	46.7	2	13.3	6	40.0	15	10	27.8	9	25.0	17	47.2	36	
Age 50-64	20	27.8	16	22.2	36	50.0	72	60	35.5	35	20.7	74	43.8	169	
Age 65+	7	22.6	7	22.6	17	54.8	31	31	39.2	10	12.7	38	48.1	79	
Level of ID														367	0.501
Mild	6	30.0	7	35.0	7	35.0	20	26	27.7	17	18.1	51	54.3	94	
Moderate	14	28.0	7	14.0	29	58.0	50	52	40.3	23	17.8	54	41.9	129	
Severe\profound	11	32.4	8	23.5	15	44.1	34	17	42.5	8	20.0	15	37.5	40	
Residents type														402	0.426
Independent/family	1	5.9	4	23.5	12	70.6	17	14	24.1	8	13.8	36	62.1	58	
Community group home	16	34.8	8	17.4	22	47.8	46	57	42.2	31	23.0	47	34.8	135	
Residential care	17	30.9	13	23.6	25	45.5	55	30	33.0	15	16.5	46	50.5	91	

** Requirements based on the Food pyramid **Not all participants answered all questions ***Based on recommended portion for balanced diet*

7.13.1. Bivariate analysis of shelf 1 (vegetables salads and fruit) Stratified by Gender, Age, Level of ID and Residents Type

Women who were overweight or obese consumed less than the daily recommended portion per day from Shelf 1 of the food pyramid consisting of vegetables, salads and fruits (46.3%, n=74/160) as did 44.4% (n=55/124) of males in the same weight category. Similarly, women had lower compliance levels with the RDA (17.5%, n=28/160) as did 21% (n=26/124) of males (figure 7.3).



	>RDA	RDA	<RDA	>RDA	RDA	<RDA
Normal	30.4%	23.2%	46.4%	27.4%	19.4%	53.2%
OW/OB	34.7%	21%	44.4%	36.3%	17.5%	46.3%

Figure 7.3. Sex stratified by BMI vs RDA (Shelf 1)

Two in ten overweight or obese participants at midlife (aged 50-64) met the daily recommendation for shelf 1 (20.7%, n=35/169), as did 12.7% (n= 10/79) aged 65+ and 47.2% (n=17/36) of overweight or obese participants consumed less than the recommended amount for this food group (figure 7.4).

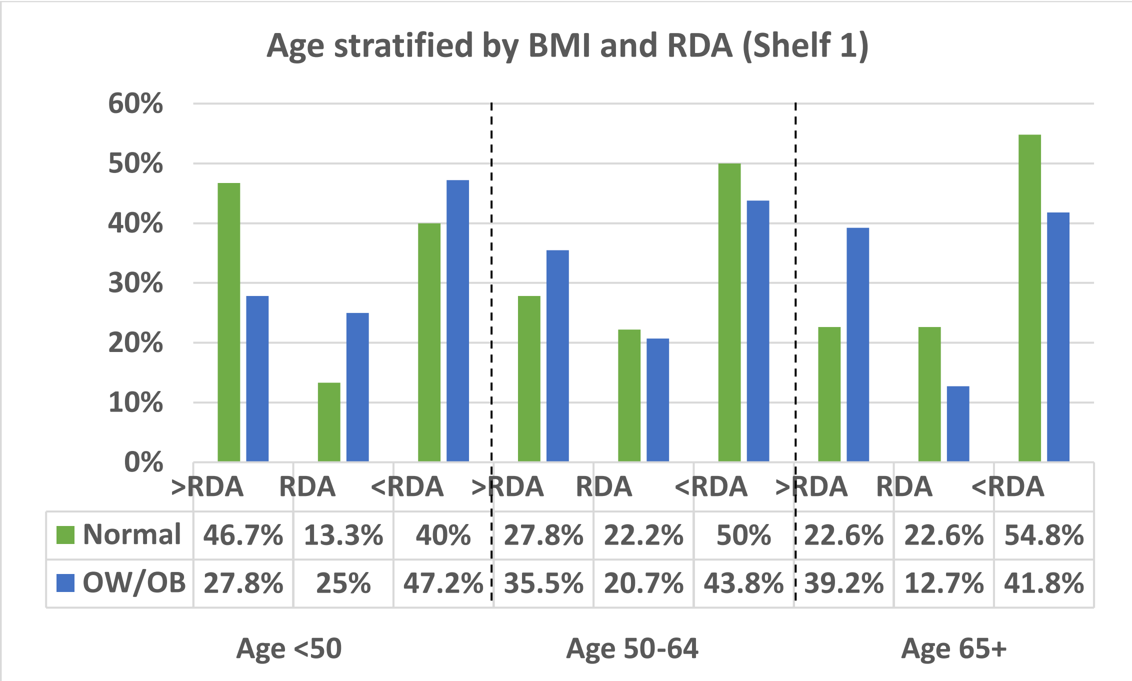


Figure 7.4. Age stratified by BMI vs RDA (Shelf 1)

Over half of all overweight or obese participants with a mild (54.3%, n=51/94), moderate (41.9%, n=54/129) or severe/profound level of ID (37.5%, n=15/40) consumed less that the RDA for shelf 1 (figure 7.5).

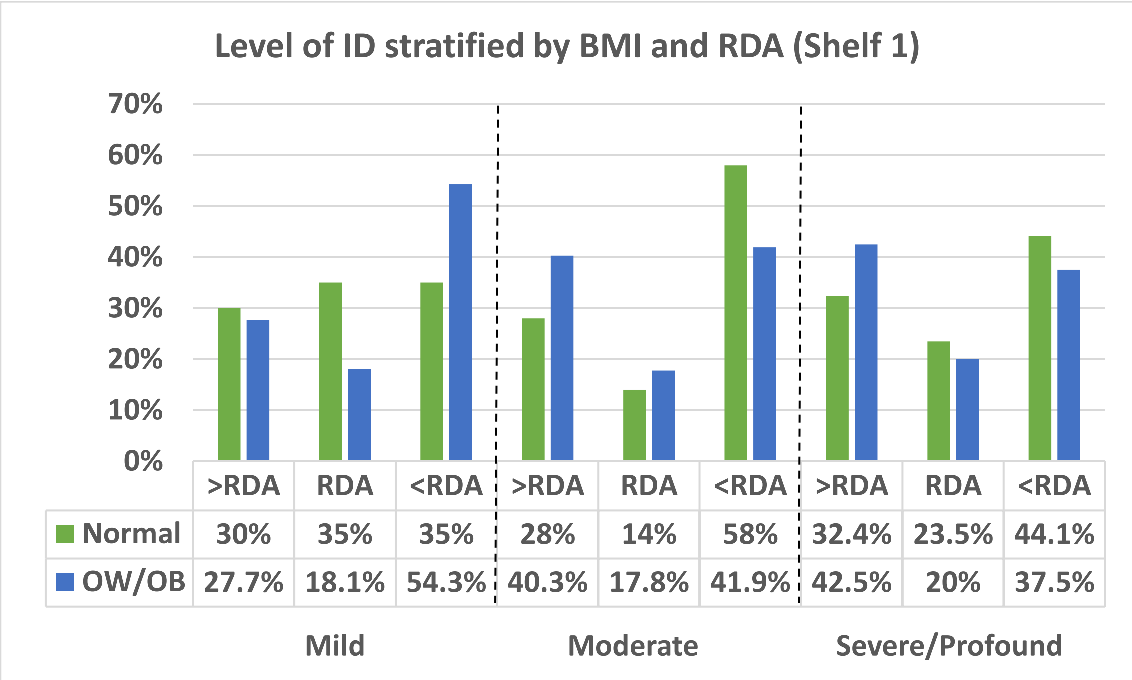


Figure 7.5. Level of ID stratified by BMI vs RDA (Shelf 1)

In terms of living arrangements, 13.8% (n=8/58) of overweight or obese participants living independently/with family met the RDA for shelf 1 as did 16.5% (n=15/91) in residential care or 23% (n=31/135) in a community group home (figure 7.6).

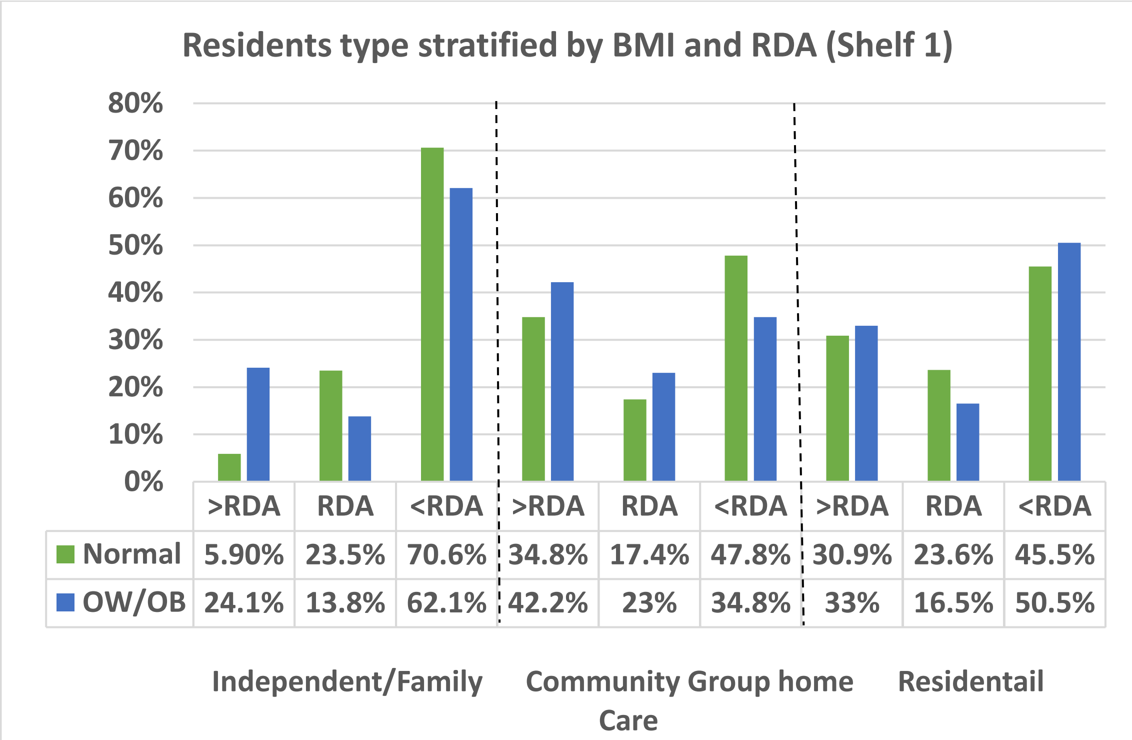


Figure 7.6. Residents type stratified by BMI vs RDA (Shelf 1)

7.14. Compliance in Conjunction with RDA for Shelf 2 of the Food Pyramid Stratified by BMI and Demographics

Data outlined below was examined in terms of participant's weight status (BM), demographics and RDA in accordance with shelf 2 of the food pyramid. Table 7.9 provides a visual representation of this data for shelf two of the food pyramid encompassing foods such as wholemeal cereals, breads, potatoes, pasta and rice.

Table 7.9. Bivariate analysis of shelf 2 (wholemeal cereals/bread/potatoes/pasta/rice) Stratified by Gender, Age, Level of ID and Residents Type

Demographics	BMI Normal							Overweigh/Obese							
	>RDA		RDA		<RDA		totals	>RDA		RDA		<RDA		totals	*p*-value
	n	%	n	%	n	%		n	%	n	%	n	%		
Sex														402	0.141
Male	5	8.9	14	25.0	37	66.1	56	3	2.4	35	28.2	86	69.4	124	
Female	4	6.5	15	24.2	43	69.4	62	7	4.4	26	16.3	127	79.4	160	
Age														402	0.141
Age <50	1	6.7	4	26.7	10	66.7	15	0	0.0	7	19.4	29	80.6	36	
Age 50-64	3	4.2	21	29.2	48	66.7	72	7	4.1	31	18.3	131	77.5	169	
Age 65+	5	16.1	4	12.9	22	71.0	31	3	3.8	23	29.1	53	67.1	79	
Level of ID														367	0.110
Mild	2	10.0	6	30.0	12	60.0	20	4	4.3	15	16.0	75	79.8	94	
Moderate	3	6.0	12	24.0	35	70.0	50	5	3.9	24	18.6	100	77.5	129	
Severe\profound	3	8.8	9	26.5	22	64.7	34	1	2.5	14	35.0	25	62.5	40	
Residents type														402	0.141
Independent/family	0.0	0	2	11.8	15	88.2	17	3	5.2	6	10.3	49	84.5	58	
Community group home	1	2.2	16	34.8	29	63.0	46	4	3.0	34	25.2	97	71.9	135	
Residential care	8	14.5	11	20.0	36	65.5	55	3	3.3	21	23.1	67	73.6	91	

7.14.1 Bivariate Analysis of Shelf 2 (wholemeal cereals and breads, potatoes, pasta and rice) Stratified by Gender, Age, Level of ID and Residents Type

Gender intake for shelf 2 of the food pyramid showed that 16.3% (n=26/160) of overweight or obese women met this RDA as did 28.2% (n=35/124) of men. Less that the RDA was reported for 79.4% (n=127/160) of overweight or obese women and 69.4% (n=86/124) of men.

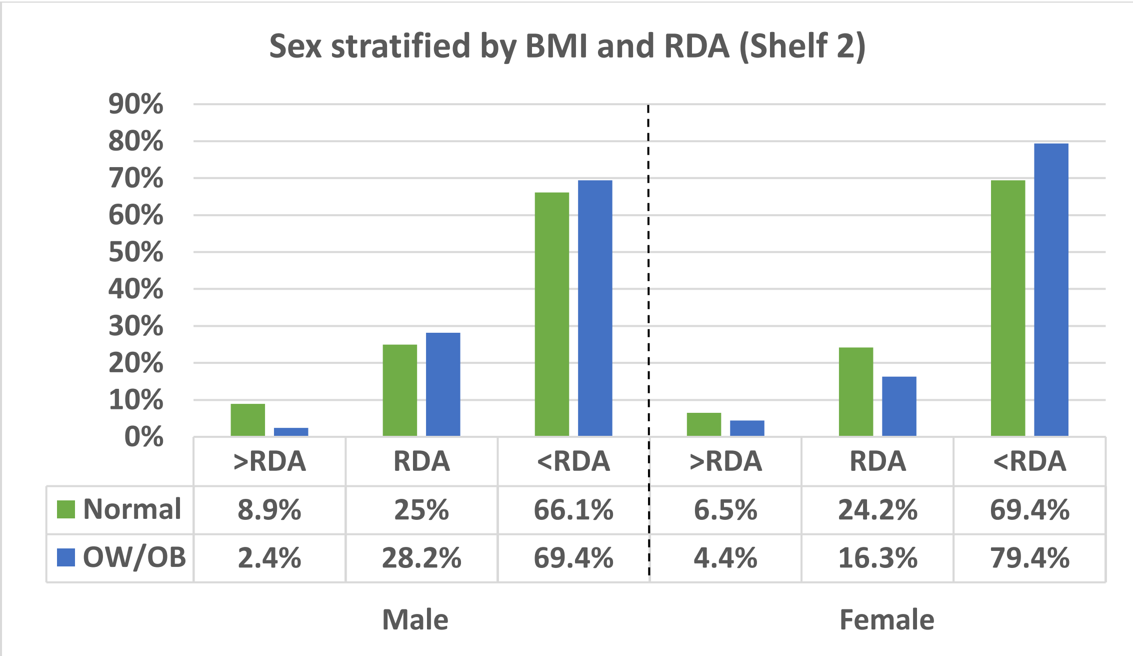
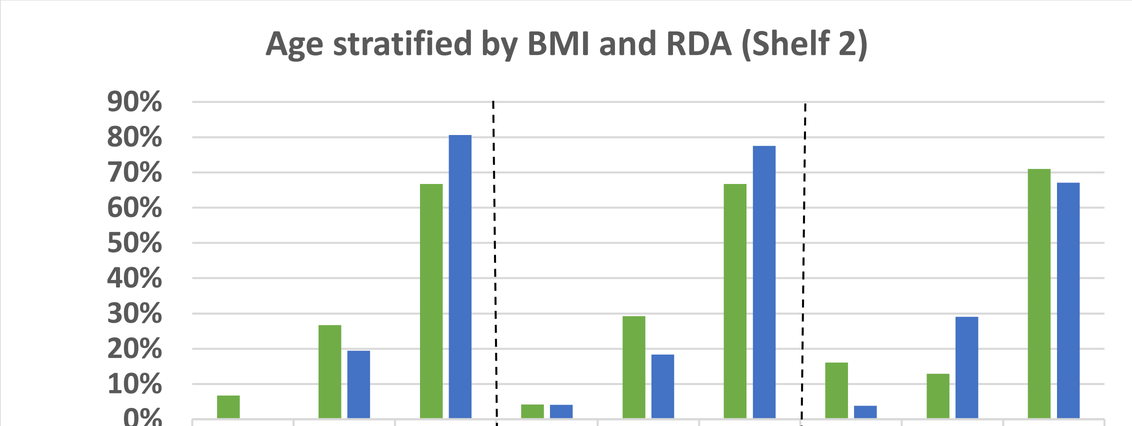


Figure 7.7. Sex stratified by BMI vs RDA (Shelf 2)

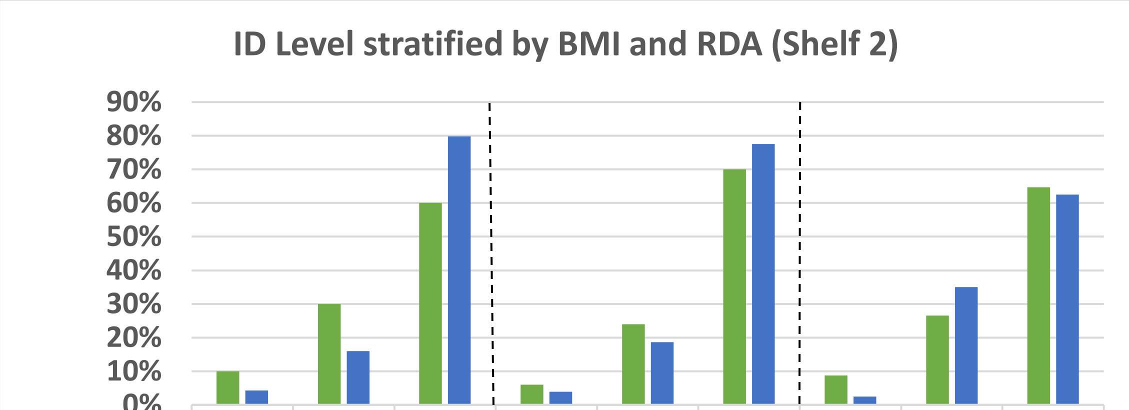
Age groups and compliance with shelf 2 of the food pyramid showed that 18.3% (n=31/169) of overweight or obese participants aged 50-54 years met the RDA with 19.4% (n=7/36) aged <50 years 29.1%, (n=23/79) aged 65+ years (figure 7.8).



	>RDA	RDA	<RDA	>RDA	RDA	<RDA	>RDA	RDA	<RDA
Normal	6.70%	26.7%	66.7%	4.2%	29.2%	66.7%	16.1%	12.9%	71%
OW/OB	0%	19.4%	80.6%	4.1%	18.3%	77.5%	3.8%	29.1%	67.1%

Figure 7.8. Age stratified by BMI vs RDA (Shelf 2)

Level of ID indicated that 16% (n=15/94) of overweight or obese participants with a mild ID met the RDA as did 18.6% (n=24/129) with a moderate or 35% (n=14/40) with a severe/profound ID (figure 7.9).



	>RDA	RDA	<RDA	>RDA	RDA	<RDA	>RDA	RDA	<RDA
Normal	10%	30%	60%	6%	24%	70%	8.8%	26.5%	64.7%
OW/OB	4.3%	16%	79.8%	3.9%	18.6%	77.5%	2.5%	35%	62.5%
	Mild			Moderate			Severe/Profound		

Figure 7.9. Level of ID stratified by BMI vs RDA (Shelf 2)

Living arrangements directed that 10.3% (n=6/58) of overweight or obese participants living independently/with family, in residential care 23.1% (n=21/91) or in a community group 25.2% (n=34/135) met the RDA (figure 7.10).

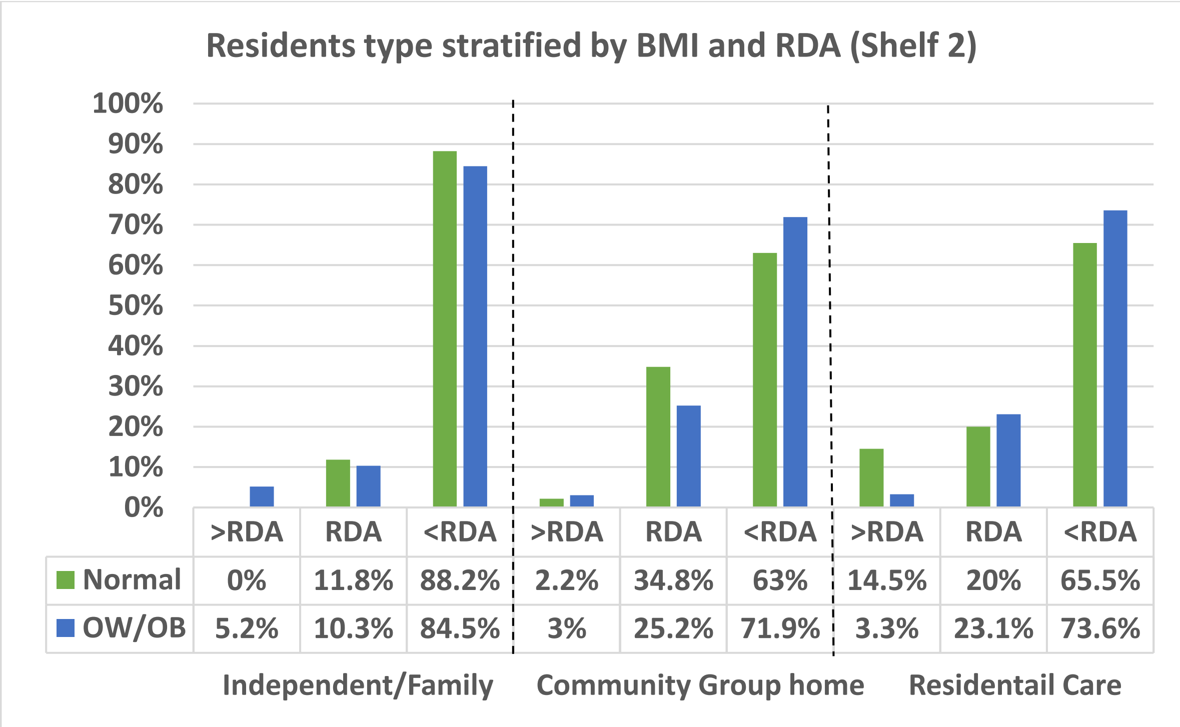


Figure 7.10. Residents Type stratified by BMI vs RDA (Shelf 2)

7.15. Bivariate Analysis of Shelf 3 (milk, yoghurt and cheese) Stratified by Gender, Age, Level of ID and Residents Type

Data outlined below was examined in terms of participant's weight status (BM), demographics and RDA in accordance with shelf 3 of the food pyramid. Table 7.10 provides a visual representation of this data for shelf three of the food pyramid encompassing foods such as milk yogurt and cheese

Table 7.10. Shelf 3 (milk, yogurt and cheese) Stratified by Gender, Age, Level of ID and Residents Type

Demographics	BMI Normal							Overweigh/Obese							
	>RDA		RDA		<RDA		totals	>RDA		RDA		<RDA		totals	*p*-value
	n	%	n	%	n	%		n	%	n	%	n	%		
Sex														403	0.516
Male	16	28.6	8	14.3	32	57.1	56	30	24.2	23	18.5	71	57.3	124	
Female	18	28.6	10	15.9	35	55.6	63	38	23.8	30	18.8	92	57.5	160	
Age														403	0.516
Age <50	5	33.3	2	13.3	8	53.3	15	5	13.9	7	19.4	24	66.7	36	
Age 50-64	23	31.5	10	13.7	40	54.8	73	45	26.6	28	16.6	96	56.8	169	
Age 65+	6	19.4	6	19.4	19	61.3	31	18	22.8	18	22.8	43	54.4	79	
Level of ID														368	0.478
Mild	4	19.0	2	9.5	15	71.4	21	19	20.2	18	19.1	57	60.6	94	
Moderate	16	32.0	7	14.0	27	54.0	50	31	24.0	22	17.1	76	58.9	129	
Severe\profound	12	35.3	9	26.5	13	38.2	34	14	35.0	8	20.0	18	45.0	40	
Residents type														403	0.516
Independent/family	0	0.0	0	0.0	18	100	18	9	15.5	6	10.3	43	74.1	58	
Community group home	10	21.7	9	19.6	27	58.7	46	29	21.5	31	23.0	75	55.6	135	
Residential care	24	43.6	9	16.4	22	40.0	55	30	33.0	16	17.6	45	49.5	91	

**Requirements based on the Food pyramid **Not all participants answered all questions ***Based on recommended portion for balanced diet*

7.15.1. Bivariate analysis of shelf 3 (milk, yogurt and cheese) Stratified by Gender, Age, Level of ID and Residents Type

Consumption patterns in line with the RDA for this food shelf showed that 18.5% (n=23/124) of overweight or obese men and 18.8% (n=30/160) of women met the RDA for this food shelf (figure 7.11).

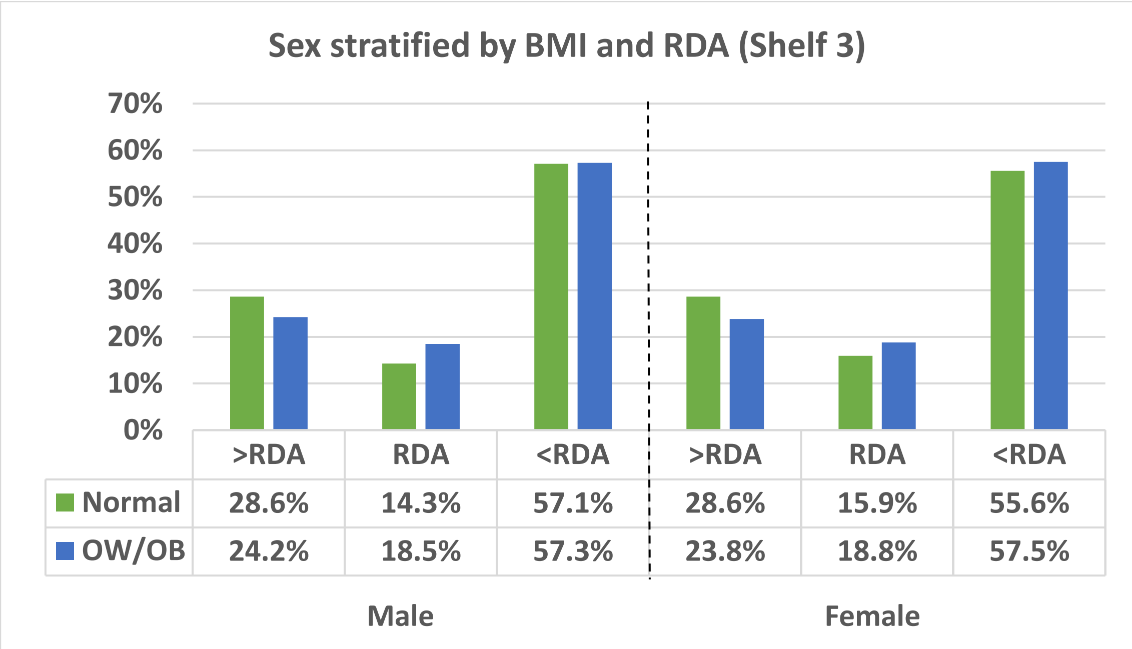
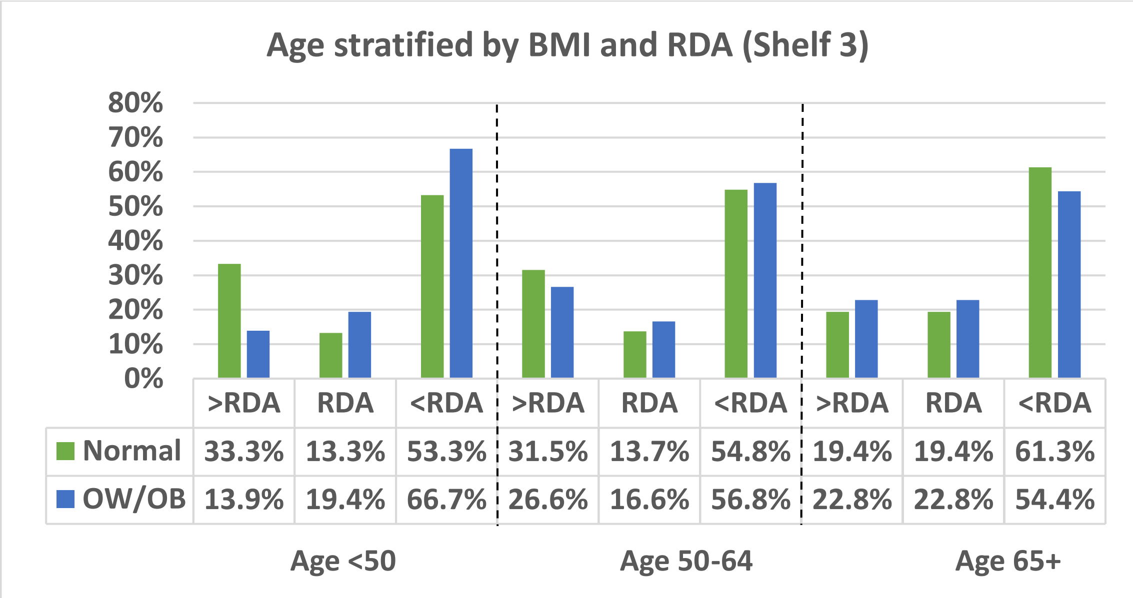


Figure 7.11. Sex stratified by BMI vs RDA (Shelf 3)

Age and compliance with shelf 3 indicated that 16.6% (n=28/169) of overweight or obese participants at midlife (aged 5-65) met the RDA, with 19.4% (7/36) aged <50 years or 22.8% (n=18/79) aged 65+ (figure 7.12).



	>RDA	RDA	<RDA	>RDA	RDA	<RDA	>RDA	RDA	<RDA
Normal	33.3%	13.3%	53.3%	31.5%	13.7%	54.8%	19.4%	19.4%	61.3%
OW/OB	13.9%	19.4%	66.7%	26.6%	16.6%	56.8%	22.8%	22.8%	54.4%

Figure 7.12. Age stratified by BMI vs RDA (Shelf 3)

Level of ID and compliance with shelf 3 showed that 17.1% (n=22/129) of overweight or obese participants with a moderate ID, 19.1% (n=18/94) with a mild ID or 20% (n=8/40) with a severe/profound ID met the RDA (figure 7.13).

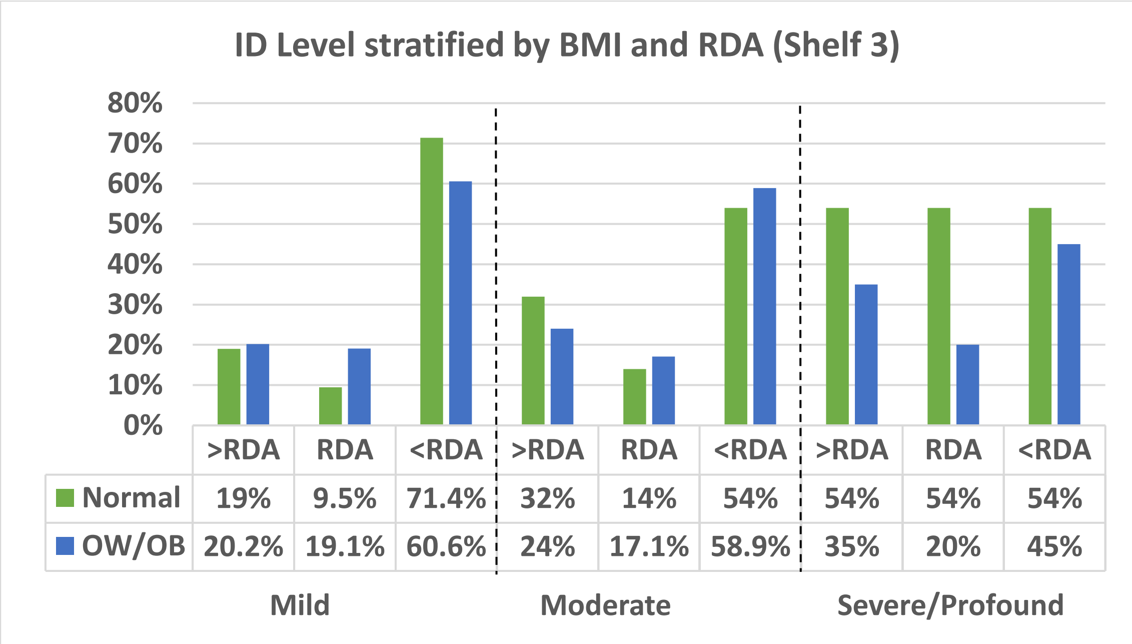


Figure 7.13. Level of ID stratified by BMI vs RDA (Shelf 3)

In terms of living circumstances and compliance with shelf 3, no participants within the normal weight range who lived independently/with family exceeded or met the RDA for this food group. For overweight or obese participants living independently/with family 10.3% (n=6/58) met the RDA as did 17.6% (n=16/91) living in residential care or 23% (n=31/135) living in a community group home (figure 7.14).

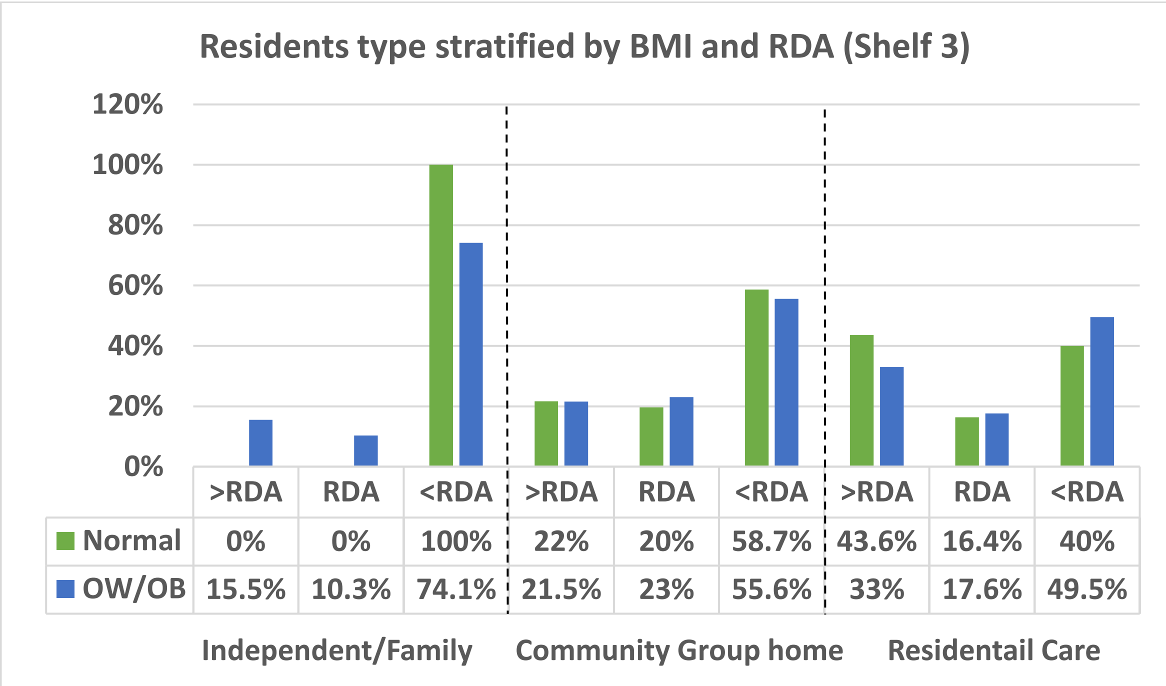


Figure 7.14. Residents type stratified by BMI vs RDA (Shelf 3)

7.16. Compliance in conjunction with RDA for shelf 4 of the Food Pyramid stratified by BMI and demographics

Data outlined below was examined in terms of participant's weight status (BM), demographics and RDA in accordance with shelf 4 of the food pyramid. Table 7.11 below provides a visual representation of this data for shelf four of the food pyramid encompassing foods such as meat, poultry, fish eggs, beans and nuts.

Table 7.11. Shelf 4 (meat/poultry/fish/eggs/beans/nuts) Stratified by Stratified by Gender, Age, Level of ID and Residents Type

Demographics	BMI Normal							Overweigh/Obese							
	>RDA		RDA		<RDA		totals	>RDA		RDA		<RDA		totals	*p*-value
	n	%	n	%	n	%		n	%	n	%	n	%		
Sex														402	0.692
Male	32	57.1	12	21.4	12	21.4	56	70	56.5	22	17.7	12	21.4	56	
Female	32	51.6	11	17.7	19	30.6	62	83	51.9	25	15.6	52	32.5	160	
Age														402	0.692
Age <50	7	46.7	2	13.3	6	40.0	15	19	52.8	5	13.9	12	33.3	36	
Age 50-64	38	52.8	19	26.4	15	20.8	72	89	52.7	33	19.5	47	27.8	169	
Age 65+	19	61.3	2	6.5	10	32.3	31	45	57.0	9	11.4	25	31.6	79	
Level of ID														367	0.442
Mild	13	65.0	4	20.0	3	15.0	20	47	50.0	20	21.3	27	28.7	94	
Moderate	25	50.0	13	26.0	12	24.0	50	72	55.8	18	14.0	39	30.2	129	
Severe\profound	18	52.9	5	14.7	11	32.4	34	22	55.0	5	12.5	13	32.5	40	
Residents type														402	0.692
Independent/family	4	23.5	5	29.4	8	47.1	17	28	48.3	6	10.3	24	41.4	58	
Community group home	28	60.9	8	17.4	10	21.7	46	32	58.2	10	18.2	13	23.6	55	
Residential care	46	50.5	15	16.5	30	33.0	91	46	50.5	15	16.5	30	33.0	91	

**Requirements based on the Food pyramid **Not all participants answered all questions ***Based on recommended portion for balanced diet*

7.16.1. Bivariate Analysis of Shelf 4 (meat, poultry, fish, eggs, beans and nuts) Stratified by Gender, Age, Level of ID and Residents Type

Overall 15.6% (n=25/160) of overweight or obese women met the RDA for shelf 4 of the food pyramid as was the case for 17.7% (n=22/56) of men. Just over half of all overweight or obese women consumed more that the RDA (51.9%, n=83/160) as did 56.5% (n=70/56) of men (figure 7.15).

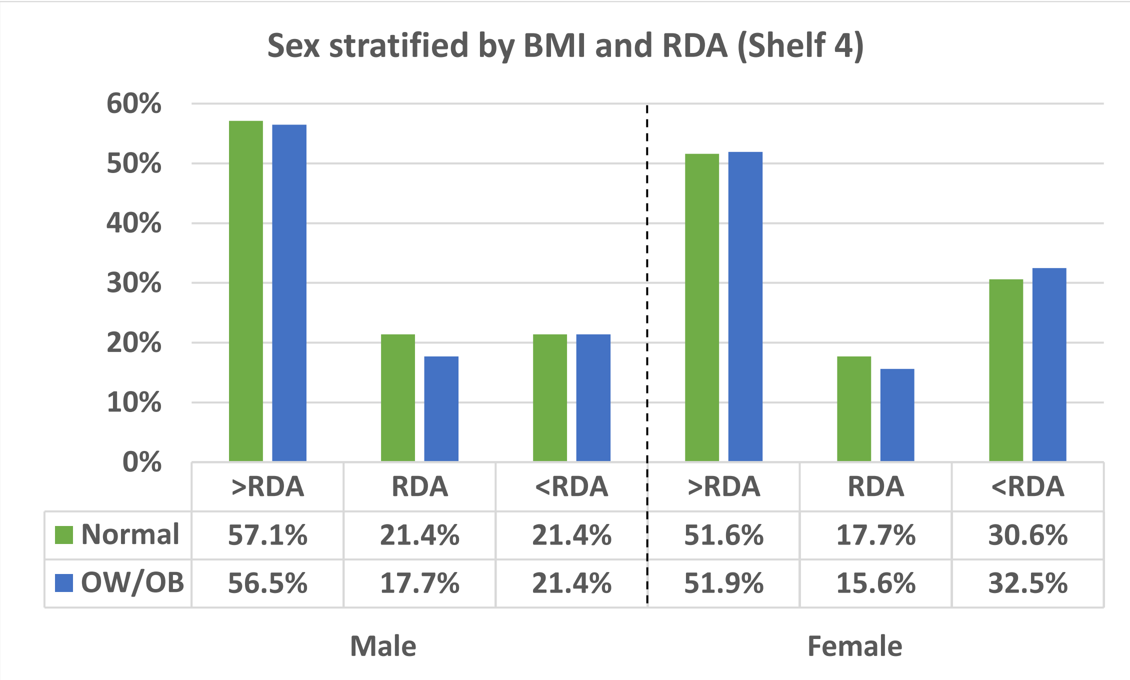


Figure 7.15. Sex stratified by BMI vs RDA (Shelf 4)

Considering age, 11.4% (n=9/79) of overweight or obese participants aged 65 years and over met the RDA as did 13.9% (5/36) aged < 50 years and 19.5% (n=33/169) aged between 50-64yrs. More than half of overweight or obese participants across each of the three age groups exceeded the RDA for this food shelf (figure 7.16).

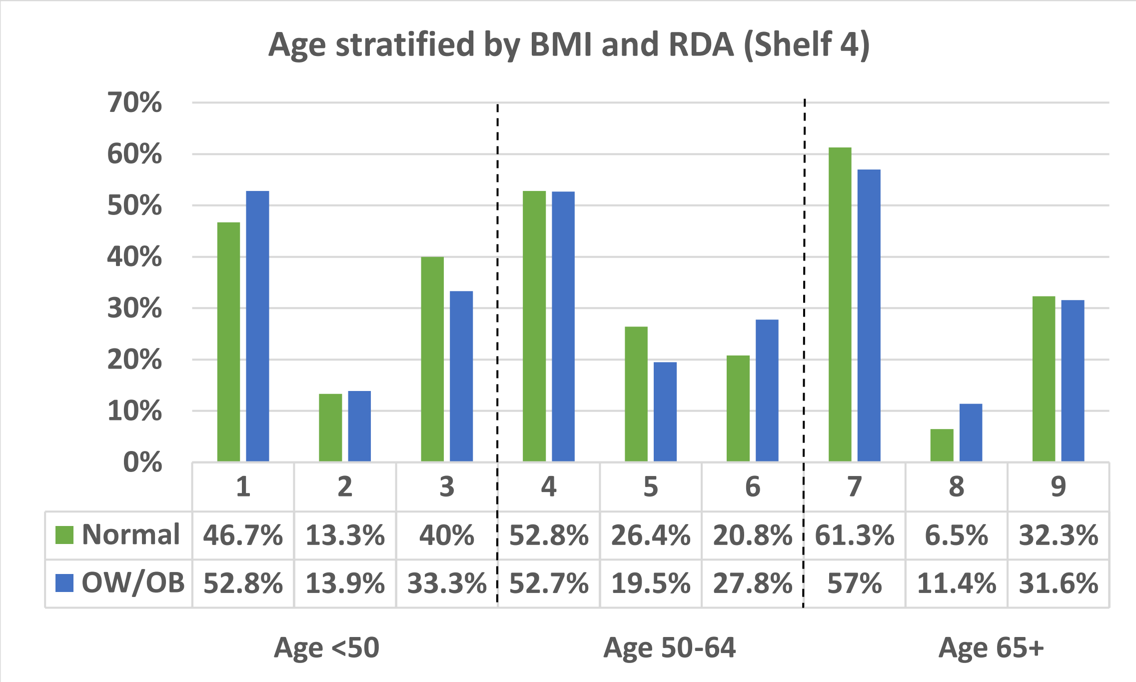


Figure 7.16. Age stratified by BMI vs RDA (Shelf 4)

When level of ID was considered, 12.5% (n=5/40) of overweight or obese participants with a severe/profound ID, 14% (n=18/129) with a moderate ID and 21.3% (n=20/94) with a mild ID met the RDA. Irrespective of level of ID at least half or more of overweight or obese participants exceeded the RDA for this food shelf (figure 7.17).

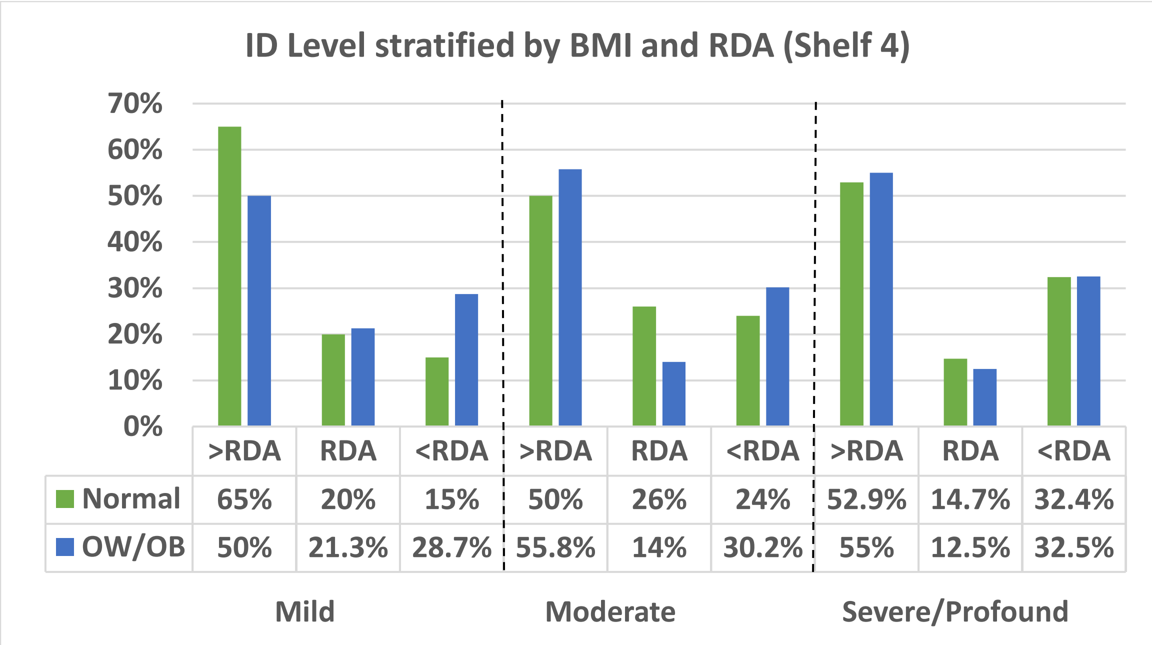
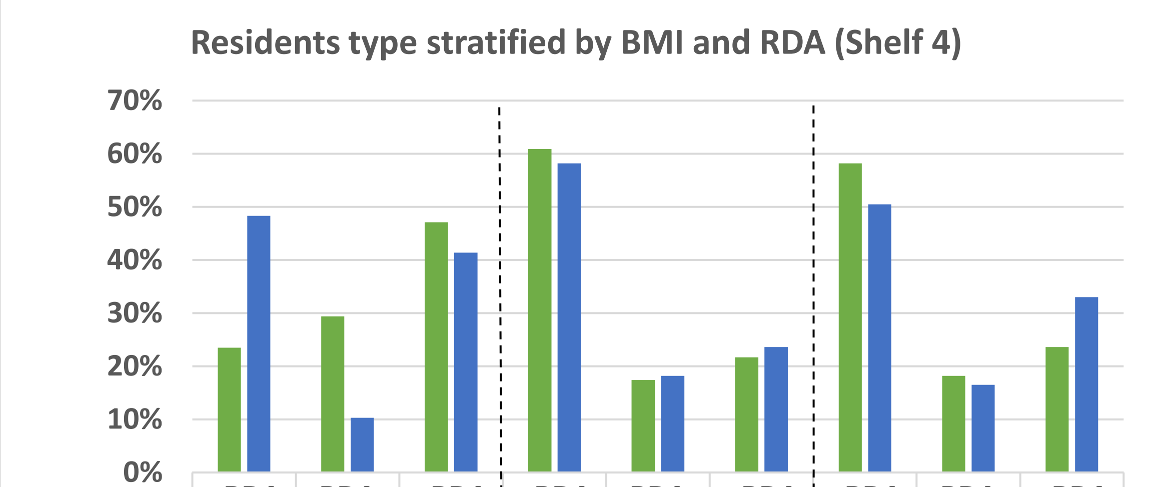


Figure 7.17. Level of ID stratified by BMI vs RDA (Shelf 4)

Overweight or obese participants who lived independently/with family exceeded the RDA for shelf 4 of the food pyramid (10.3%, n=6/58) as was the case for 16.5% (15/91) in residential care or a community group home (18.2%, n=10/55) and 58.2% (n=32/55) living in a community group home exceeded the RDA (figure 7.18).



	>RDA	RDA	<RDA	>RDA	RDA	<RDA	>RDA	RDA	<RDA
Normal	23.5%	29.4%	47.1%	60.9%	17.4%	21.7%	58.2%	18.2%	23.6%
OW/OB	48.3%	10.3%	41.4%	58.2%	18.2%	23.6%	50.5%	16.5%	33%

Figure 7.18. Residents type stratified by BMI vs RDA (Shelf 4)

7.17. Compliance in conjunction with RDA for Shelf 5 of the Food Pyramid Stratified by BMI and Demographics

Data outlined below was examined in terms of participant's weight status (BM), demographics and RDA in accordance with shelf 5 of the food pyramid. Table 7.12 below provides a visual representation of this data for shelf five of the food pyramid encompassing foods such as fats/spreads/oils.

Table 7.12. Shelf 5 (fats/spreads/oils) Stratified by Stratified by Gender, Age, Level of ID and Residents Type

Demographics	BMI Normal							Overweigh/Obese							
	>RDA		RDA		<RDA		totals	>RDA		RDA		<RDA		totals	*p*-value
	n	%	n	%	n	%		n	%	n	%	n	%		
Sex														401	0.212
Male	38	67.9	9	16.1	9	16.1	56	92	74.2	20	16.1	12	9.7	124	
Female	41	66.1	5	8.1	16	25.8	62	112	70.4	19	11.9	28	17.6	159	
Age														401	0.212
Age <50	12	80.0	2	13.3	1	6.7	15	28	77.8	4	11.1	4	11.1	36	
Age 50-64	46	63.9	9	12.5	17	23.6	72	124	73.4	22	13.0	23	13.6	169	
Age 65+	21	67.7	3	9.7	7	22.6	31	52	66.7	13	16.7	13	16.7	78	
Level of ID														366	0.357
Mild	12	60.0	5	25.0	3	15.0	20	73	77.7	14	14.9	7	7.4	94	
Moderate	36	72.0	4	8.0	10	20.0	50	22	64.7	4	11.8	8	23.5	34	
Severe\profound	22	64.7	4	11.8	8	23.5	34	24	60.0	5	12.5	11	27.5	40	
Residents type														401	0.212
Independent/family	11	64.7	3	17.6	3	17.6	17	37	63.8	12	20.7	9	15.5	58	
Community group home	36	78.3	3	6.5	7	15.2	46	109	80.7	13	9.6	13	9.6	135	
Residential care	32	58.2	8	14.5	15	27.3	55	58	64.4	14	15.6	18	20.0	90	

**Requirements based on the Food pyramid **Not all participants answered all questions ***Based on recommended portion for balanced diet*

7.17.1. Bivariate analysis of Shelf 5 (fats, spreads and oils) Stratified by Gender, Age, Level of ID and Residents Type

In terms of compliance with the RDA for shelf 5, 11.9% (n=19/159) of overweight or obese women met the RDA as did 16.1%, (n=20/124) of men. In contrast, 74.2% (n=92/124) of overweight or obese men exceeded the RDA and this was also the case for 70.4% (n=112/159) of women (figure 7.19).

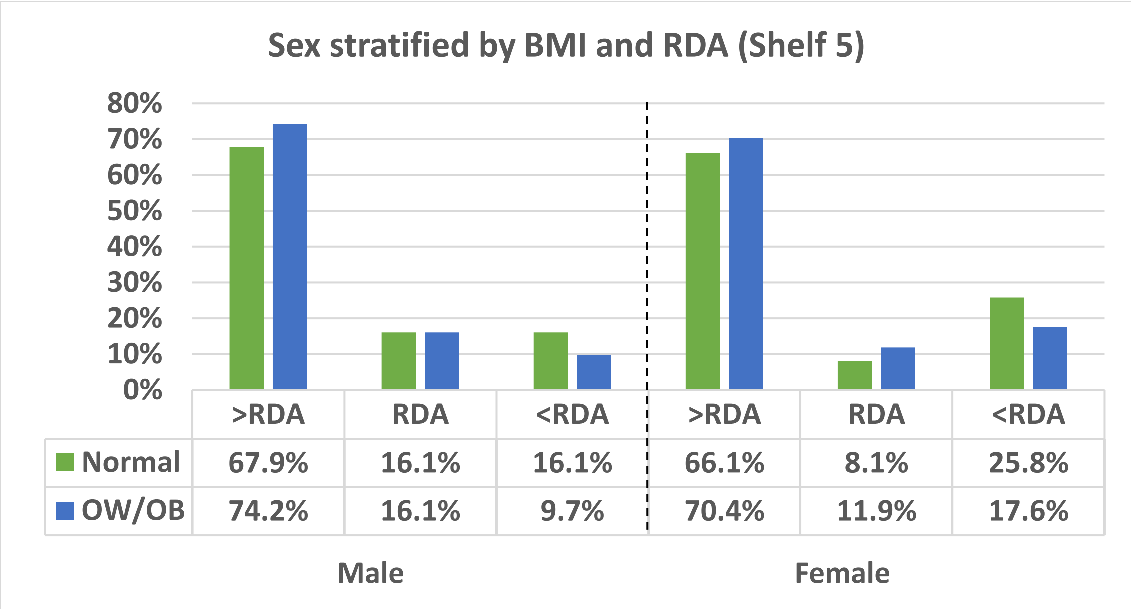
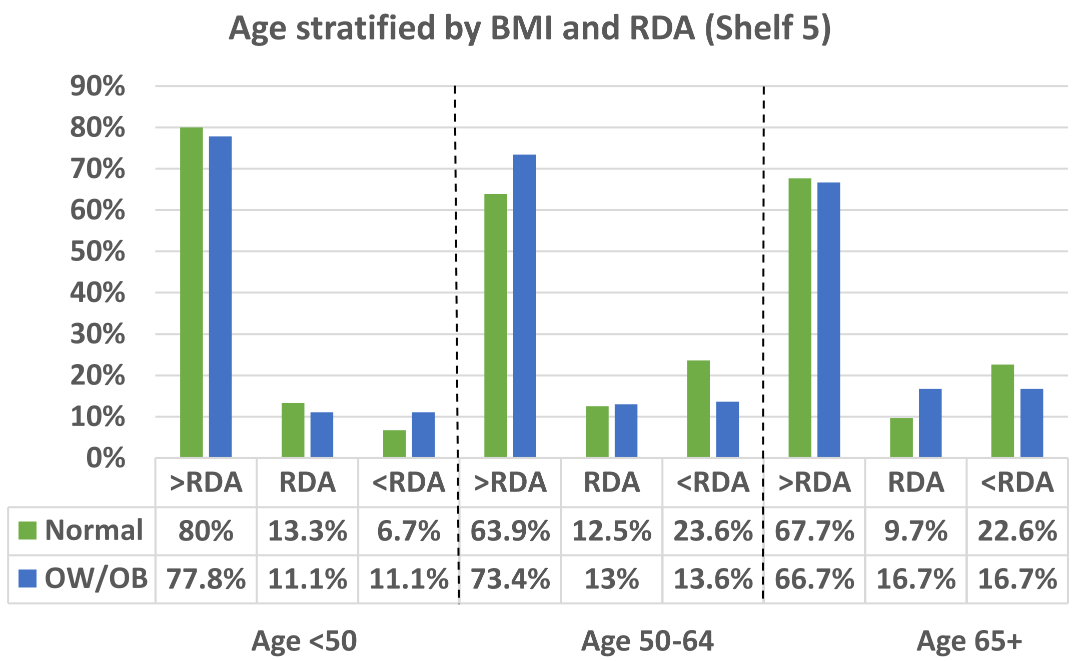


Figure 7.19. Sex stratified by BMI vs RDA (Shelf 5)

When age was considered, 11.1% (n=4/36) of overweight or obese participants aged <50 years met the RDA, as did 13% (n=22/169) aged between 50-64 years or 16.7% (n=13/78) aged 65+. Additionally, 77.8% (n= 28/36) aged <50 or between 50-64 years (73.4% n=124/169) exceeded the RDA.



	>RDA	RDA	<RDA	>RDA	RDA	<RDA	>RDA	RDA	<RDA
Normal	80%	13.3%	6.7%	63.9%	12.5%	23.6%	67.7%	9.7%	22.6%
OW/OB	77.8%	11.1%	11.1%	73.4%	13%	13.6%	66.7%	16.7%	16.7%

Figure 7.20. Age stratified by BMI vs RDA (Shelf 5)

Allowing for level of ID, 11.8% (n=4/34) of overweight or obese participants with a moderate, severe/profound 12.5% (n=5/40) or mild ID (14.9%, n=14/94) met the RDA for shelf 5 of the food pyramid. Considering overweight or obese participants who exceeded the RDA, 77.7% (n=73/94) with a mild ID were at this compliance level as were 64.7% (n=22/34) with a moderate or severe/profound ID (60%, n=24/40) ID (figure 7.21).

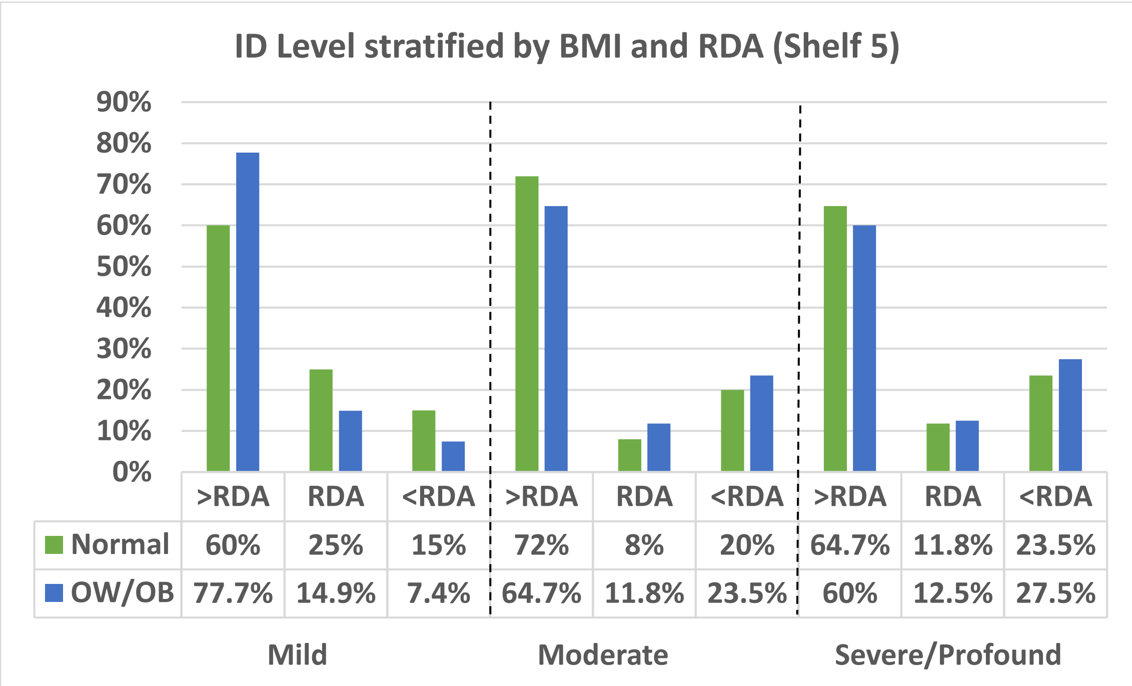


Figure 7.21. Level of ID stratified by BMI vs RDA (Shelf 5)

Compliance and residents type showed that 9.6% (n=13/135) of overweight or obese participants living in a community group home met the RDA, as did 15.6% (n=14/90) who lived in residential care or independently/with family (20.7%, n=12/58). Overweight or obese participants who lived in a community group home exceeded the RDA (80.7%, n=109/135) as did 64.4% (n=58/90) in residential care or independent/with family (63.8%, n=37/58) (figure 7.22).

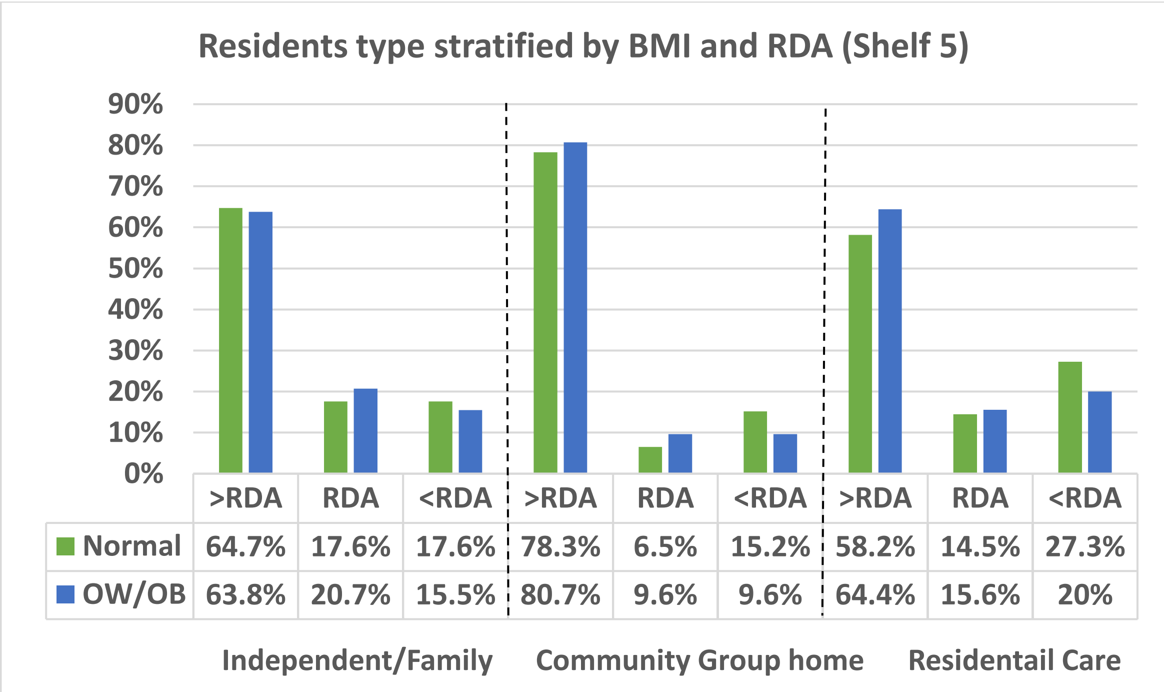


Figure 7.22. Residents type stratified by BMI vs RDA (Shelf 5)

7.18. Compliance in Conjunction with RDA for Shelf 6 of the Food Pyramid Stratified by BMI and Demographics

Data outlined below was examined in terms of participant's weight status (BM), demographics and RDA in accordance with shelf 6 of the food pyramid. Table 7.13 below provides a visual representation of this data for shelf six of the food pyramid encompassing foods such as foods and drinks high in fat, sugar and salt.

Table 7.13. Shelf 6 (foods and drinks high in fat/sugar/salt) Stratified by Stratified by Gender, Age, Level of ID and Residents Type

Demographics	BMI Normal							Overweigh/Obese							
	>RDA		RDA		<RDA		totals	>RDA		RDA		<RDA		totals	*p*-value
	n	%	n	%	n	%		n	%	n	%	n	%		
Sex														401	0.866
Male	54	96.4	1	1.8	1	1.8	56	119	96.0	0	0.0	5	4.0	124	
Female	59	95.2	0	0.0	3	4.8	62	155	97.5	2	1.3	2	1.3	159	
Age														401	0.866
Age <50	15	100	-	-	0	0.0	15	33	97.1	-	-	3	8.3	36	
Age 50-64	70	97.2	1	1.4	1	1.4	72	164	97.0	2	1.2	3	1.8	169	
Age 65+	28	90.3	-	-	3	9.7	31	77	98.7	-	-	1	1.3	78	
Level of ID														366	0.967
Mild	20	100	-	-	0	0.0	20	90	96.8	-	-	3	3.2	93	
Moderate	48	96.0	0	0.0	2	4.0	50	124	96.1	1	0.8	4	3.1	129	
Severe\profound	32	94.1	1	2.9	1	2.9	34	39	97.5	1	2.5	0	0.0	40	
Residents type														401	0.866
Independent/family	17	100	-	-	0	0.0	17	56	96.6	-	-	2	3.4	58	
Community group home	41	89.1	1	2.2	4	8.7	46	132	98.5	1	0.7	1	0.7	134	
Residential care	55	100	0	0.0	0	0.0	55	86	94.5	1	1.1	4	4.4	91	

**Requirements based on the Food pyramid **Not all participants answered all questions ***Based on recommended portion for balanced diet*

7.18.1. Bivariate Analysis of Shelf 6 (foods and drinks high in fat, sugar and salt) Stratified by Gender, Age, Level of ID and Residents Type

No overweight or obese men met the RDA for shelf six of the food pyramid with 1.3% (n=2/159) of women meeting this recommended level. Overweight or obese women (97.5%, n=155/159) and men (96%, n=119/124) exceeded the RDA (figure 7.23).

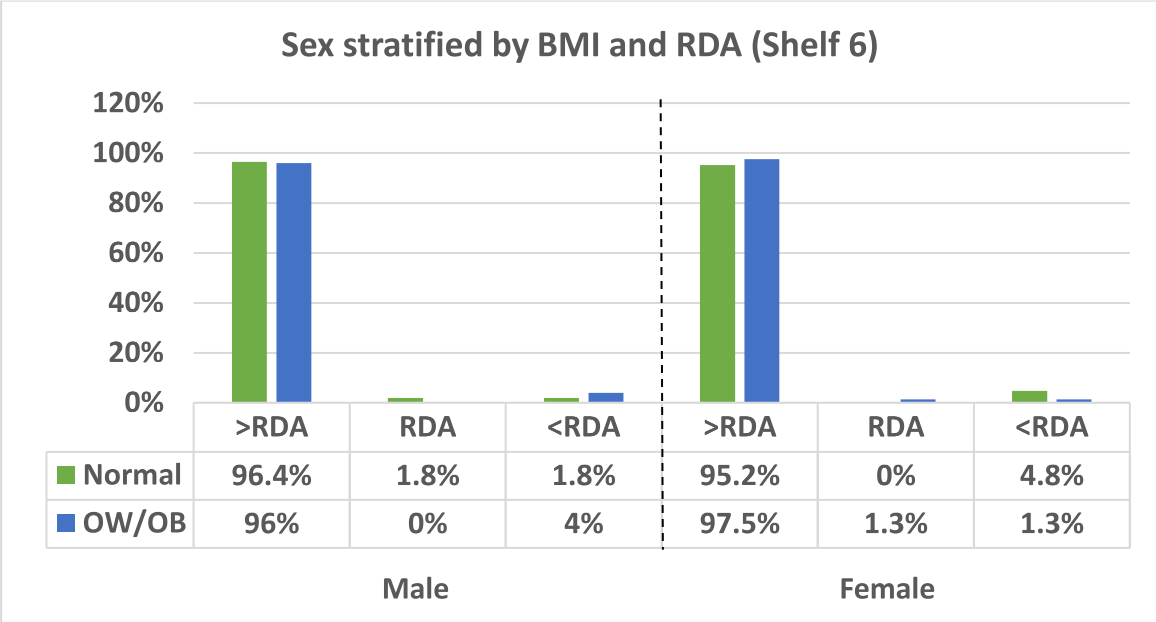


Figure 7.23. Sex stratified by BMI vs RDA (Shelf 6)

In terms of age, no overweight or obese participants aged <50 or 65+ years met the RDA for shelf 6. Almost all overweight or obese participants aged 65+ exceeded the RDA (98.7%, n=77/78) as did participants aged <50 years (97.1%, n=33/36) or aged between 50-64 years (97%, n=164/169) (figure 2.24).

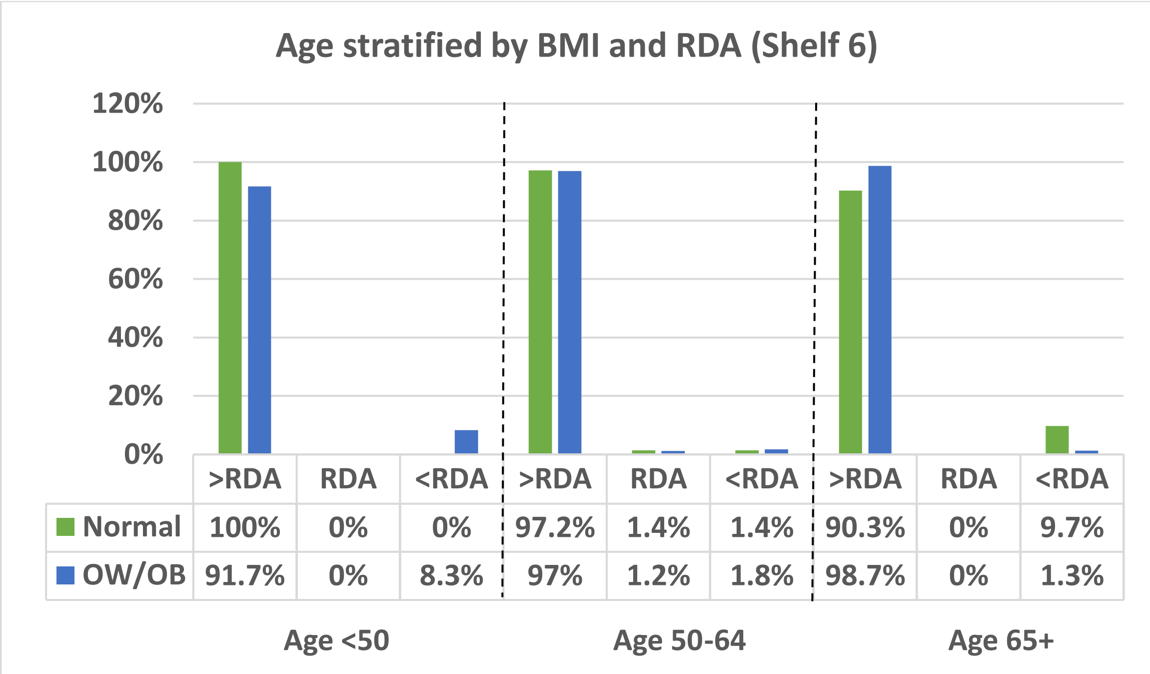


Figure 7.24. Age stratified by BMI vs RDA (Shelf 6)

In terms of level of ID, no overweight or obese participants with a mild ID met the RDA for shelf 6 with compliance evident for 0.8% (n=1/129) with a moderate or mild (2.5%, n=1/93) ID. With reference to overweight or obese participants who exceeded the RDA, this was the case for 97.5% (n=39/40) of participants with a severe/profound, mild (96.8%, n=90/93) or moderate (96.1%, n=124/129) ID (figure 7.25).

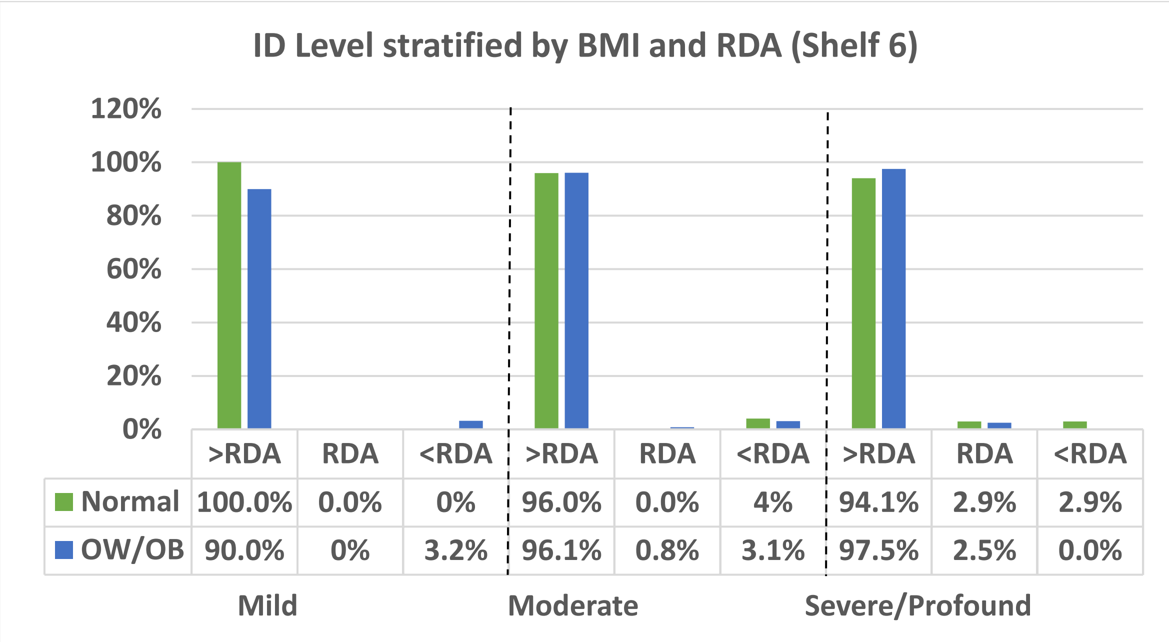
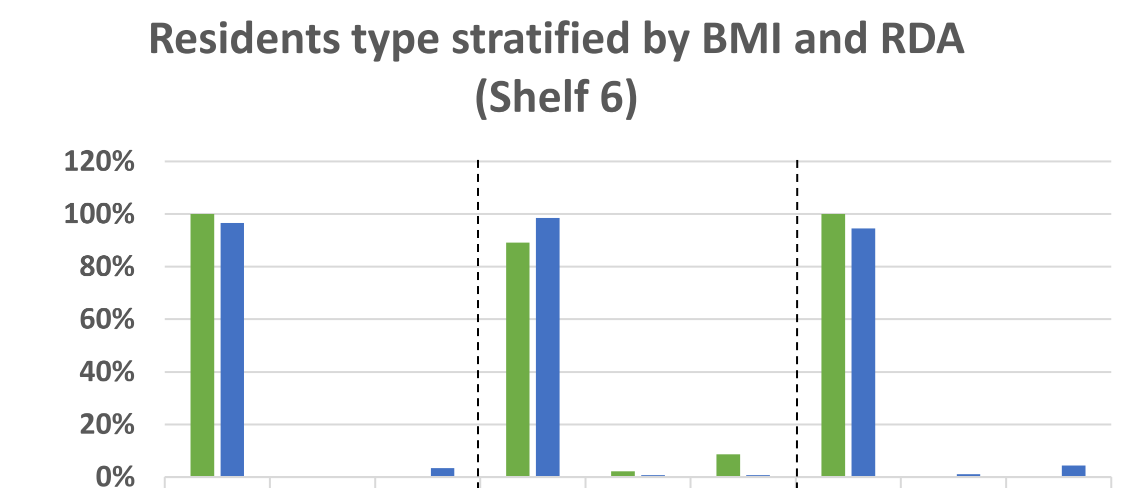


Figure 7.25. Level of ID stratified by BMI vs RDA (Shelf 6)

No overweight or obese participants who lived independently/with family met the RDA and this was the case for 0.7% (n=1/134) living within a community group home or 1.1% (n=1/91) in residential care. Almost all participants living in a community group home (98.5, n=132/134), independently/with family (96.6%, n=56/58) or in residential care (94.5%, n=86/91) exceeded the RDA (figure 7.26).



	>RDA	RDA	<RDA	>RDA	RDA	<RDA	>RDA	RDA	<RDA
Normal	100.0%	0.0%	0%	89.1%	2.2%	9%	100.0%	0.0%	0.0%
OW/OB	96.6%	0%	3.4%	98.5%	0.7%	0.7%	94.5%	1.1%	4.4%
	Independent/Family			Community Group home			Residentail Care		

Figure 7.26. Residents type stratified by BMI vs RDA (Shelf 6)

7.19. Multinomial Regression for Compliance with Recommended Intake Food Shelves for Participants who were Overweight/Obese

Using logistical regression, this study presents an indication of the statistical association of compliance with recommended food intake from 6 shelfs based on the food pyramid and objectively measured weight status (BMI) with results presented in table 7.14. When holding other predictor variables constant, participants who were overweight or obese (BMI) were 2.160 times more likely not to meet the recommended daily portion of foods from shelf 1 (95% CI [1.334-3.470] at a statistically significant level (*p*-value= <0.001); for shelf 2, 2.103 times more likely (95% CI [1.352-3.273] and statistically significant (*p*-value=<0.001); for shelf 3, 2.944 (95% CI [1.725-5.026] more likely and statistical significant (*p*-value=<0.001); for Shelf 4, 2.043 95% CI [1.241-3.365] more likely and a *p*-value=<0.005; for shelf 5, 2.786, 95% CI [1.513-5.130] more likely and statistically significant (*p*-value=<0.001) and for Shelf 6 2.000 95% CI [0.181-22.056] times more likely but this was nou statistically significant (*p*-value=0.571).

Table 7.14. Multinomial logistical regression for compliance with RDA per food shelf for participants who were overweight/obese

	BMI					
	Wald	**df**	**p-value**	**Adjusted Odds Ratio (OR)**	**95% Confidence interval**	
Shelf 1 (5-7 PPD*)	10.135	1	**<0.01**	**2.160**	1.344	3.470
Shelf 2 (3-5 PPD)	10.868	1	**<0.01**	**2.103**	1.352	3.273
Shelf 3 (3 PPD)	15.670	1	**<0.001**	**2.944**	1.725	5.026
Shelf 4 (2 PPD)	7.887	1	**<0.005**	**2.043**	1.241	3.365
Shelf 5 (In very small amounts)	10.813	1	**<0.001**	**2.786**	1.513	5.130
Shelf 6 (Not every day)	0.320	1	0.571	2.000	0.181	22.056

*~Normal weight predicted 29.4% ** Overweight or obese predicted 70.6% ***Reference category in parenthesis with all statistically significant risks in bold (p<0.05) **** RDA Recommended daily amount ***** PPD Portions per day*

7.20. Discussion

Diet is an important consideration in the drive to maintain adequate nutritional status (Ball et *al.* 2012) with under and over nutrition a problematic public health issues internationally. This study provides a unique opportunity to develop an appreciation of the food consumption profile of a sample of older adults with an ID who were overweight or obese.

In this study participants were found to be overweight and obese. As a contributory factor to overall nutritional health, diet is important to the overall health and wellbeing of people with an ID. This population are at increased risk of overweight or obesity, suboptimal health and inadequate physical activity with inclinations towards conditions such as dysphagia, neurological disorders, poor bone health and dementia (Burke *et al.* 2019; Burke *et al.* 2014; Grundi 2006). Therefore this chapter, in addressing dietary patterns in line with national recommendations based on the food pyramid (Department of Health 2016a), presents a unique insight into the diet of an adult population of people with an ID living in Ireland.

In Ireland Department of Health provides guidance on nutritional health in the form of the Food Pyramid (Department of Health 2016a) categorising foods with recommended daily proportionate intake for dietary balance providing. This provides a basis to examine dietary intake patterns in line with food groups. In this study, data was collated and analysed based on the SLÁN food frequency questionnaire (Harrington *et al.* 2008) and subsequently examined in conjunction with recommended daily allowance for each of the shelves of the food pyramid (Department of Health 2016a).

In terms of diet, these study results present divergent patterns of non-compliance where overweight and obese participants fell short of recommended intake levels for dietary balance. Overall women present with higher levels of non-compliance across most food groups although this was also apparent in men. With statistical significance indicated for almost all food groups for overweight or obese participant's intake contrasted from insufficient consumption of foods deriving health benefits, to excess consumption of products high in sugar, fat and salt exposing participants to increased chronic disease risk. This was particularly true for beneficial foods such as vegetables and fruit or protein rich foods where consumption levels less than recommended were reported. In contrast, almost all overweight or obese participants consumed in excess of national recommended intake of foods with high concentrations of fats, oils and sugar and where there is little or no nutritional value. Consequently, overall consumption patterns, particularly in problematic food groups identified in this study, shed light on contributors to overweight obesity and chronic ill health in ID.

7.20.1. Food Consumption Patterns

Overall findings from this study reveal poor levels of compliance with recommended daily intake of foods from the six shelves of the food pyramid in an older population of adults with an ID and in particular those who were overweight or obese. For example, under consumption in line with the recommendations featured across shelves 1-3 for overweight or obese participants. In contrast, an intake pattern reflective of overconsumption from shelf 5 and 6 based on the recommended portions per day was evident in participants who were overweight or obese. Overall results showed that women who were overweight had the lowest level of compliance for almost all food groups. Across the study for overweight or obese participants, non-compliance varied in all age groups. Those aged 65+ consumed < is recommended from shelf 1 but exceeding the RDA for shelf 6. For the younger age cohort (aged <50 years) non-compliance (<RDA) was evident for shelf 3 and 6 in particular.

Nevertheless, irrespective of age, non-compliance (either < or > than the RDA) was apparent across all of the food shelfs of the food pyramid. These study findings contrast in part with a previous study conducted using the SLÁN FFQ within the general population in Ireland, where although overconsumption was reported across both studies for foods high in fat sugar and salt, intake of fruit and vegetable was higher in the general population (Harrington *et al.* 2008). A further difference of note in this current study was the reporting of intake levels for people who were both overweight and obese and within the normal weight parameters (BMI).

In terms of level of ID, participants who had a severe/profound ID and were overweight or obese had low compliance in terms of shelf 1. This was also the case for those with a mild ID for shelf 2, 3 and 6 although the difference between ID levels across the food groups was marginal. Participants with a moderate ID reported intake in excess of recommended levels for shelf 6 inclusive of sweets and snacks. Finally, living independently/with family with overweight or obesity indicated low compliance with the RDA across shelf 1-4. The remaining two shelfs of the food pyramid, 5 and 6 indicated again higher than recommended consumption patterns for overweight or obese participants living in a community home or residential care. Nonetheless non-compliance was apparent across all of the food shelfs with differences only marginal.

Eating enough fruit and fibre

Considering all of the population, the findings of this study revealed that participants consumed less than the recommended 5-7 portions of vegetables salads and fruit recommended per day. The overall average consumption was 2.28 (SD +0.769) as opposed to the 5-7 portions recommended. This differs somewhat to an earlier large-scale general population based SLÁN (2007) study using the FFQ where appreciably higher levels of compliance (65%) with fruit and vegetable intake based on the food pyramid recommendations were reported (Morgan *et al.* 2007). It should be noted however, that the Food pyramid and the Recommended Daily Amounts (RDA) has since being revised from 5 portions per day (Flynn *et al.* 2012; Department of Health and Children 2005) to 5- 7 portions (Department of Health 2016a). Nonetheless, these study findings establish that women with ID who are overweight or obese consumed less that the RDA from this important food shelf 43.3% (n=74/160) although compliance was also low in men in the same weight category (44.4%, n=55/124). This also contrasts with the Irish Longitudinal Study on Ageing (TILDA), a study examining ageing within the general population where greater consumption patterns of fruit and vegetables were described in women (30%) than men (18%) (O'Connor *et al.* 2020). Similarly, a study by Daly *et al.* (2011) involving food frequency questionnaires administered across two Australian states reported higher consumption patterns of fruit and vegetables by women at 2.6 (CI 2.5-2.7) PPD as opposed to 2.1 (CI 1.9-2.2) PPD for men. Of note however, neither aforementioned studies related specifically to ID nor did they isolate weight status when addressing intake patterns. Additionally the study by O'Connor *et al.* (2020) was based proportional measures in accordance with an earlier version of the food pyramid. In terms of weight status and age, only two in ten overweight or obese participants aged between 50-64 years met the RDA for this food shelf (20.7%, n=35/169) as did 12.7% (n=10/79) aged 65+ or a quarter aged <50 years (25%, n=9/36). The above results present interesting findings in terms of mid-life, dietary patterns and the important role diet plays in overall health as population's age. The emergent pattern for women with an ID is particularly concerning given the age profile at menopause in turn linked with overweight and obesity, weight gain and metabolic disease (Kozakowski *et al.* 2015; Lizcano and Guzmán 2014). Furthermore, preventative conditions such as constipation causing pain and discomfort present particular challenges in overweight or obese population (Pourhoseingholi *et al.* 2009) and was cited in 44% of Wave 3 IDS-TILDA participants.

A small number of participants with a moderate (17.8%, n=23/94) or mild ID (18.1%, n=17/94) who were overweight or obese met this RDA of 5-7 portions from this food shelf, but again very low compliance was evident across all levels of ID. This was also the case in terms of living arrangements where more overweight or obese participants living in a community group home consumed less than the RDA (34.8%, n=47/135) as opposed to participants who met the recommended intake level (23%, n=31/135). Additionally, half of overweight or obese participants living in residential care consuming less than the RDA for this food group (50.5%, n=46/91). An earlier study by McGuire *et al.* (2007) examining health behaviours and lifestyle found that as the severity of the ID increased choice reduced. This rational may be borne out in this study where participants with a mild or moderate ID may have greater autonomy in decision making relative to food choices. Additionally, the change in lifestyle and exposure to the range of food products widely available coupled with living arrangement across ID may contribute difficulty in maintaining nutritional balance.

Bearing in mind that many people with an ID access supports, the influential role of carers in supporting autonomous decision making, including positive nutritional choices is obvious. This is supported by research Cartwright and colleagues (2015) with when studying dietary habits of day service attendees, concluding that the influence of carers in the application of autonomy and decision-making coupled with easy access to unhealthy food options exerted influence.

Foods that give you energy

The pattern of non-compliance with the Food Pyramid recommendations continued into shelf 2 which encompass foods such as potatoes, rice, pasta, cereals bread and savoury biscuits. Overall participants consumed less than the recommend 3-5 portions per day from this food shelf, with an average intake of 2.49 (SD $\pm$0.847) portions eaten per day. This level of non-compliance is greater that in an earlier population based Irish study using the FFQ where the average intake level was at 4.9 portions, one less that the RDA of 6 or servings recommended (Harrington *et al.* 2008).

Overall consistency within this food group emerged with women who were overweight or obese (79.4%, 127/160), again having high non-compliance levels (< RDA) relative to the recommended daily amount, although this was also high across males in this weight category (69.4%, n=86/124). This result reflects findings by McGuire *et al.* (2007) who, following an examination of dietary habits of people with an ID reported inadequate carbohydrate intake. Providing important sources of minerals vitamins as well as an energy source for the body, these foods are association with wellness manifest in the fortification of food staples with for example vitamins A, D and calcium as a health protective measure (World Health Organisation 2019). Vitamin D deficiency is associated with the health of bone tissue (Vranić *et al.* 2019), is also more prolific in both overweight and obese populations (Pereira-Santos *et al.* 2015). Although obtained in the main through exposure to sunlight, is also present in foods. These provide an important if limited source for people with an ID who have reportedly higher deficiency levels in comparison to the general population (Frighi *et al.* 2014).

Similarly, Vitamin C is affected by higher weight grading with greater mg/day intake recommended for people with elevated weight status (Carr *et al.* 2022). Only 18.3%

(n=31/169) of overweight or obese participants at middle age were compliant with recommended intake levels of foods including wholemeal cereals, breads potatoes past and rice. The potential effects of poor nutritional health at this important life stage where chronic ill health features in the lives of older people with an ID warrants consideration. In line with this study, research by Daily *et al.* (2011) reported similar non-compliance levels in terms of age groupings. In Daily's study, greater non- compliance was reported in people aged between 45-64 years (Daily *et al.* 2011) and 50-64 years in this study. Nonetheless, although overall number of participants aged <50 who were overweight or obese in this present study was relatively small (n=36), eight in ten (80.6%, n=29/36) consumed less that is recommended from this food group. Why this should be the case is unclear but perhaps reflective of an overall limited dietary intake pattern.

Level of ID and living circumstance once again demonstrated low compliance levels across all areas, with greater numbers of overweight and obese participants falling short of the RDA than in the normal weight category. This was the case for 16% (n=75/94) of overweight or obese participants with a mild ID and for 18.6% (n=24/129) with a moderate ID. People with an ID in Ireland are now more likely to live at home or within community group home and with autonomous decision-making and involvement in the direction of their lives more coveted. These welcome changes in lifestyle, sustained by national reports (Health Service Executive 2011) and statute (Government of Ireland 2015b) do bring challenges in maintaining positive nutritional health in the mist of obesogenic surroundings and diverse service support and informed decision-making. Compliance with food groupings within the general older Irish population are linked with social determinants such as elivated socioeconomic status (O'Connor *et al.* 2020). However, this is not comparable in a population of older Irish adults with an ID where 32% reported never experiencing education and where employment rates as low as 6.6% are reported (McCarron *et al.* 2011). Despite literacy challenges manifest in ID and the often contradictory food messages, evidence does however indicate positive outcomes for directed education programmes in support of people with an ID (Yilmaz *et al.* 2014).

Intake of calcium rich foods

Calcium derived from the diet provides and important nutritional source and is contained within shelf 3 of the food pyramid with 3 portions per day recommended. Products such as milk, yoghurt and cheese provide this rich source of calcium and again participants consumed less that the recommended daily level with only 18.7% (n=53/71) of overweight or obese participants meeting the RDA and with an average consumption of 2.36 (SD$\pm$0.762) PPD. In isolating overweight and obesity, both women (18.8%, n=30/160) and men (18.5%, n=23/124) who were overweight or obese had no appreciable difference in terms of compliance with the recommended intake level. This differs to O'Connor *et al.* (2020) where women consumed marginally more items from this food shelf than males although poor overall compliance patterns were apparent across both studies. Intake in line with recommended levels across the age ranges was again indicative of low overall compliance particularly in overweight or obese participants at midlife (16.6%, n=28/169). However, this was also the case for younger (19.4%, n=7/36) or older age cohorts (22.8%, n=18/79).

When level of ID and overweight and obesity was examined for this food group, as with age, more than half of all participants at each ID level consumed less than is recommended to maintain dietary balance. This was the case for as many as six in ten participants with a mild ID (60.6%, n=57/94) and just under that level in those with a moderate ID (58.9%, n=76/129). Associated with bone health, muscle contraction and blood clotting and in view of reported levels of debilitating bone and other chronic health conditions in older adults with an ID, this data provides an important context to level of intake based on national recommendations for healthy bones and teeth (Department of Health 2016a). Burke *et al.* (2017) described poor bone health in older populations of adults with an ID, including chronic conditions such as osteoporosis. In addition, research by Ryan *et al.* (2021) on chronic health conditions in an older population with an ID who were overweight or obese found a significant correlation between overweight and obesity and muscular skeletal disorders. Furthermore, considerations should be afforded to the impact of inadequate dietary calcium including oral health problematic in ID (Wilson *et al.* 2019; Gabre *et al.* 2003). Mac Giolla *et al.* (2015) when comparing the lack of teeth in an older group of Irish adults noted that two and a half times the number of adults with an ID had no teeth when compared with a matched general population grouping from a similar longitudinal study. Finally, when BMI was examined in terms of living arrangements, community group home was the most frequently cited living arrangement by overweight or obese participants (n=135/403) with only 23% (n=31/135) meeting this RDA. This was the case however for only one in ten participants living independently/with family (10.3%, n=6/58). Additionally, half of all overweight or obese participants living in residential care consumed less that is recommended for nutritional balance (49.5%, n=45/91). However, it is not possible to understand how this compares with other population-based studies because of the divergence with living arrangements across populations and the use of the FFQ. Nevertheless, as previously suggested the influence environment has on weight status in terms of diet as one of a number of contributory factors cannot be ignored the context of individuals with an ID.

Dietary balance and protein food sources

Shelf 4 of the food pyramid includes meat, poultry, fish, eggs, beans and nuts. These foods provide a rich source of protein, iron, zinc, and B vitamins. Protein is involved in the building and maintenance of muscle mass, iron supports regeneration of red blood cells and Omega-3 fatty acid are involved in disease protection. Overweight and obesity exerts effect on health and inadvertently influences other debilitating conditions such as bone health and mobility (Burke *et al.* 2019). Given the impact on bone health and other calcium related conditions in ID, these findings provide a base for wider exploration of the dietary intake from calcium rich foods and the bone health of older populations of people with an ID. With over half of this studies population consuming less than the recommended intake of protein rich foods, prolonged dietary deficiency of this magnitude will cause an effect. Reduced mobility or painful associated conditions bring with it the risk of social isolation already experienced by people with an ID. However, despite this, for all overweight or obese participants, only 16.5% (n=47/70) met the RDA of foods from this food shelf. Although two portions recommended per day the average consumption level in this study was 2.11 (SD$\pm$ 0.688). In contrast, compliance within the general population survey reported a 39% compliance (Harrington *et al.* 2008).

As with the other food groups, fewer women with a BMI in the overweight or obese weight range met the daily recommendations for this food group (15.6%, n=25/160) but this was also low in men with this BMI range (17.7%, n=22/56), although was also the case for women with a BMI in the normal weight range (17.7%, n=11/160). Interestingly, in excess of half of all overweight women (51.9%, n=83/160) and men (56.5%, n=70/56) consumed more than the recommended intake level of two portions per day from this group. Compliance across all age groups was low but particularly in overweight or obese younger participants (< 50 years) where only 13.9% (n=5/36) met the endorsed daily intake as did 11.4% (n=9/79) aged 65+ and less than two in ten participants with this BMI aged between 55-64 years (19.5%, n=33/169).

The potential health risks to populations of older adults with an ID in Ireland is disquieting. Efforts to extending a spotlight on childhood overweight and obesity across Europe aims to mitigate against the growing trend for excess weight in children. Ireland was selected as one of a number of European countries to be involved in a Childhood Obesity Surveillance Initiative (COSI) in 2007 where the weight status of schoolchildren was monitored over time. Results showed that one in five school aged children in Ireland were overweight or obese with girls aged 8-12 most at risk of increased weight measurement (Healthy Ireland 2008). Children with an ID were not specifically the focus of this research but given this level across schools, it is unlikely to be any better. Research by O' Shea *et al.* (2018) addressing overweight and obesity in children and youth with Downs Syndrome using both BMI and Percentage of Body fat as measures, with BMI reported over half of the males and 40% of females as overweight or obese. Although this Irish based study was limited in aetiology, progression into adult overweight and obesity is nonetheless to be expected. Moreover, harmful established eating patterns developed across childhood in all likelihood will continue into adulthood.

In this study when level of ID was considered in terms of foods from this shelf of the food pyramid, only 12.5% (n=5/40) with a severe/profound ID met the recommended level with compliance only marginally higher for all overweight or obese participants with a moderate ID (14%, n=18/129). As was the case with the previous food shelf, half or more than half of participants across all levels of ID consumed less than is recommended intake level shedding spotlight on an area for enhancement in the overall drive to improve the health of people with an ID. Only one in ten overweight or obese participants who lived independently/with family met the recommended intake (10.3%, n=6/58). This was also the case for 16.5% (n=15/91) living in residential care (18.2%, n=10/55) or in a community group home. Given these findings and the established disparity in the health of people with ID in particular areas where intake of foods listed in shelf 4 of the food pyramid with important nutritional value, merits further investigation.

An indication of the value in addressing overweight and obesity in ID using dietary intake as one contributory factor in this complex disease process, including for example muscular skeletal disorders (Emerson *et al.* 2016; Heslop and Glover 2015) hospital admissions (Doody *et al.* 2021) and premature mortality (Heslop *et al.* 2014) in ID is manifest in the results presented above. Lifestyle changes which have occurred in the past decades and ensuing welcomed autonomous decision making but needs to be supported with targeted lifestyle supports for people with an ID to improve the quality of the extended years lived evidenced in recent years.

Foods with high sugar, salt and fat content

Following this research, what is of grave concern are findings pertaining to the remaining two shelves of the food pyramid. Foods from shelf 5 consists of items recommended only in very small amounts including those with high concentrations of fat sugar and salt. Again these study findings, reveal high non-compliance levels for participants who were overweight or obese with over-consumption across both shelves noted. Of all study participants who were overweight or obese, over seven in ten (72.1%, n=204/283) exceeded the recommended daily intake of foods containing fats, spreads and oils. These items, only recommended only to be used in very small amounts with an average portion consumption level of 2.09 ($\pm$0.558). Interestingly, these findings are in sharp contrast to an earlier study by McGuire *et al.* (2007) who administered a questionnaire containing aspects of the SLAN FFQ to respondents with an ID or their proxy (N=157), reporting that only 1.2% of the sample ate fried food more than 4 times per week. In a separate study, the SLÁN survey itself when used across the general population in Ireland in 2007, reported similar findings as McGuire's study indicating a 9% response rate (Harrington *et al.* 2008). However, the Irish Longitudinal Study on Ageing (TILDA) in Ireland indicated higher levels of non-compliance in older populations reporting that 37% of the participants exceeded the recommended daily intake levels from this food shelf (O'Connor *et al.* 2020).

Including weight status, this current study, results direct that as many as 74.2% (n=92/124) of overweight or obese men exceeded the recommended intake level for shelf 5 of the food pyramid as did 70.4% (112/159) of overweight or obese women. Similarly, O'Connor *et al.* (2020) also reported higher levels of intake from these food products in men than women, although weight status was not represented in the findings. Considering age and with a targeted sample of an older population of adults with an ID, this study directed middle age (50-64 years) to be the most frequently cited age group for overweight or obese participants overall (n=169/283). Across all of the age groups, 77.8% (n=28/36) of overweight or obese participants aged <50 years exceeded the recommended intake level as did 73.4% (n=124/169) age between 50-64 years.

Overweight or obesity as chronic and life limiting condition exerts its effects on helath and transcend all life ages exposing older people with an ID to increased health risk (Bray *et al.* 2017; National Institute for Health and Care Excellence 2014). Additionally, in ID considerations needs to be afforded to level of ID and how lifestyle differences may affect dietary consumption patterns and subsequently health outcomes. In this study, in terms of level of ID, paltry compliance was evident in only 11.8% (n=4/366) overweight or obese participants for shelf 5 with a moderate level if ID and only marginally higher for those with a severe/profound (12.5%, n=5/40) or mild ID (14.0%, n=14/94). Similarly low compliance was apparent irrespective of living arrangements. Eight in ten (80.7%, n=109/135) participants with a BMI in the overweight or obese weight grading and lived in a community group home exceeded the recommended daily intake of foods from this group as was the case for 64.4% (58/90) in residential care and where only two in ten participants (n=18/58) who lived independently/with family met the RDA.

As with the previous food shelf, shelf 6 the top shelf of the food pyramid consisting of foods only to be consumed at a maximum of 1-2 times per week. Irrespective of weight grading, almost all participants in this study exceeded the recommendation of a maximum weekly intake level of once or twice for shelf 6 of the food pyramid with an average consumption with an average intake level of 2.02 (SD$\pm$=0.194) portions warranting attention. Notwithstanding this recommendation, alarmingly high level of overconsumption was evident across all respondents. This level of no-compliance was very high in overweight or obese participants where, of all the overweight and obese men (n=124) none met the recommended intake level as was the case for only 1.3% (n=2/159) of women. Similarly, no notable disparity emerged across all age groups with a BMI described as overweight or obese. In this weight category, no participants aged <50years or aged 65+ met the recommendations and only 1.2% (n=2/169) met the level of intake for dietary balance. Again non-compliance (> RDA) was dominant across overweight or obese participants where 97.5% (n=39/40) participant with a severe/profound ID exceeded the RDA as did 96.1% (124/129) with a moderate ID. Moreover, irrespective of weight grading, no participants with a mild ID met the recommended level for this food group. For all overweight or obese participants who lived in a community group home only 0.7% (n=1/134) were in line with the endorsed intake level of maximum 1-2 times per week and again no participants who lived independently/with family met the RDA.

Studies have reported lower levels of non-compliance than reported here but the food pyramid has gone under review since some earlier studies reported their findings. For example, foods from the top shelf (shelf 6) are no longer recommended for daily consumption with a change made from one portion per day to only very small amounts once or twice per week. Similarly, items from shelf 5 are now not recommended for daily consumption having changed from a recommended level of choose two in small amounts to in very small amounts with consideration to reduced fat or light spreads (Department of Health 2016a). The acknowledged diet disease relationship between overweight or obesity and foods high in sugar, salt and fat (Sari *et al.* 2016; Phillips *et al.* 2014) is disquieting for people with an ID. Nonetheless, the high consumption rates for these foods with little or no nutritional value in an older population of adults with an ID who are already exposed to health risk factors (Ryan *et al.* 2021) merits additional exploration.

Social determinants relating to dietary intake

Inclinations towards greater non-compliance levels within dietary intake recommendations reported in this study within community settings are of particular interest. Transformed service supports in ID which have transferred from intuitional models to more individualised service supports, coupled with international agreements where equality of personhood is an acknowledged right of all citizens (United Nations 2006) is to be welcomed. However, unpicking the impact subsequent lifestyle changes have on areas such as dietary patterns across wider society requires further exploration. For example, it is understood that within the general population as people and in particular women age, the loss of connection with previously held positions in food preparation within the family is acknowledged (Plastow *et al.* 2015). However, this is not the case for the majority of those with ID as living arrangements or level of support provided may be indicative of a more passive role in meal preparation. Additionally, contemporary lifestyles experienced by people with an ID with autonomous decision making rightly endorsed, necessitates support in understand of the implications poor dietary choices have on health and wellbeing. Therefore, involvement in food including preparation and cooking from an early age would provide opportunities as people with an ID as they move through life stages. This is nonetheless challenging in environments with ready access to convenience foods and support teams that may not have the level of understanding of nutritional health required to impart knowledge.

7.20.2. Recommendations towards Positive Nutritional Health

Embedding, lifestyle changes is challenging. In the case of dietary alterations, the rationale for change requires understanding of the correlation between dietary intake and effects of foods on the systems of the body. In ID, where literacy limitations feature, an adapted approach administered over time is required. Therefore, consideration to carers understanding of nutritional balance and associated health benefits for people with an ID, interwove with the right to independent decision making is recommended. This need is revealed in research by Özdemir *et al.* (2022) who described the correlation between carer's personal dietary habits and their influence on those they support coupled with their acknowledged need for further educational support to drive positive nutritional health. Mandating education programmes on diet and nutrition for health and social care professionals would contribute to understanding of the need for an overall wellness approach to problematic overweight and obesity.

In addition, in Ireland the National Obesity Strategy (Department of Health 2016c) recognising at risk groups including people with a disability also recommend bespoke integrated support and treatment models for people with disabilities. Therefore, as a first step to action within an Irish context, full implementation of the HSE Food, Nutrition and

Hydration Policy for Adults Accessing Disability Services (2020) in all services nationally should occur.

Highlighting the importance of available programmes at levels dependent on the context of the support required, education provides one of the four key priority areas for the HSE National Clinical Programme for obesity. Given the unique lifestyle supports available to people with an ID and consequences of poor nutritional health, programmes focused on health promotion, illness prevention diet and nutritional health needs to be examined in terms of support teams.

The findings of this study pertain to non-adherence with the recommended dietary intake older population of people with an ID based on national standards. However research focused on other lifestyle characteristics affecting weight status and ultimately health is evidentially necessary. In recognition of the importance of physical activity but also the challenges people with an ID experience accessing active public spaces including toilet facilities, change should be examined at a government level to enable all its citizens have readily accessible spaces to be active in. Legislation in support of independent participation in day to day life for all its citizens has existed for some time in Ireland in the form of the United Nations Convention on the Rights of Persons with Disabilities and Disability Act 2005 with building regulations introduced in 2017. These pieces of legislation require equity of all citizens and accessible public spaces. However, despite the passage of time although change has occurred, there is still much to be done to realise these goals.

7.21. Conclusion

This study presents a collective impression of dietary intake patterns of a sample of older adults with an ID in Ireland who are overweight or obese. Results address age, gender difference as well as living arrangements and ID level. Achieved by collating data from a food frequency questionnaire subsequently mapped to recommendations based on the Food Pyramid (Department of Health 2016a). These research findings contribute to a limited pool of existing population based comparative studies and this author's knowledge, it is the first examination of dietary patterns in a sample of older adults with an ID in Ireland using the full SLÁN food frequency instrument which is comparative to a further longitudinal general population study on ageing (TILDA). Although the focus of this study was people with an ID who were overweight or obese, TILDA represents general population finding and does not isolate populations who were overweight or obese. Nutritional status is positively correlated with overall health with progressive healthy ageing extending its benefit across society as a whole. This association between healthy ageing and nutritional intake is noteworthy as population's age. Both the personal and societal cost of poor health outcomes in older age is manifest in health systems globally. Therefore, combining measures of weight with dietary data offers a valuable insight into diet as one significant factor contributing to the overall health of older people with an ID who present with weight measures outside the recommended parameters. The findings of this study present a foundation from which to propel further research on the impact living arrangements and lifestyle factors have on diet and subsequent weight status of an older population of people with an ID.

CHAPTER 8: CONVERGING INSIGHTS: SYNTHESISING KEY FINDINGS AND SHAPING FUTURE DIRECTIONS IN ADDRESSING OVERWEIGHT AND OBESITY AMONG INDIVIDUALS WITH INTELLECTUAL DISABILITIES

"Success is no accident. It is hard work, perseverance, learning, studying, sacrifice and most of all, love for what you are doing"
Pele

8.0. Chapter Summary

Correlations between overweight and obesity and chronic disease among people with an ID are not filly established. This extensive examination of overweight and obesity in older adults with an ID presents original information relating to health and dietary patterns. In appraising the study findings based on the research questions posed, areas for consideration and development are presented within the following chapter. Recommendations include proposals for health, education, policy and research.

This research is only the beginning, but an important foundation from which many interconnected areas can be further scrutinised. It is the researcher's intent to continue this work as part of IDS-TILDA and with her role in the Health Service Executive, in particular ongoing monitoring of overweigh and obesity in older populations of people with an ID and evident risk to the health of women at menopause.

8.1. Introduction

In order to establish the state of the science of overweight and obesity among older adults with ID in Ireland, its health consequences and diet as contributory factors for overweight and obesity, the researcher addressed the following questions:

1) What is the prevalence of overweight and obesity among older adults with ID in Ireland?
2) What are the consequences of overweight and obesity on individual's physical health?
3) What are the physical health implications for women with an ID who are overweight or obese?

4) What are the dietary habits of an older population of people with an ID who are overweight or obese?

5) Are there specific dietary factors that contribute to overweight and obesity among individuals with ID in Ireland?

Taking evidence for overweight and obesity amassed across this study into account, recommendations, segmented into health, education, policy and research (figure 8.0) are contextualised within the following text addressing the research questions posed.

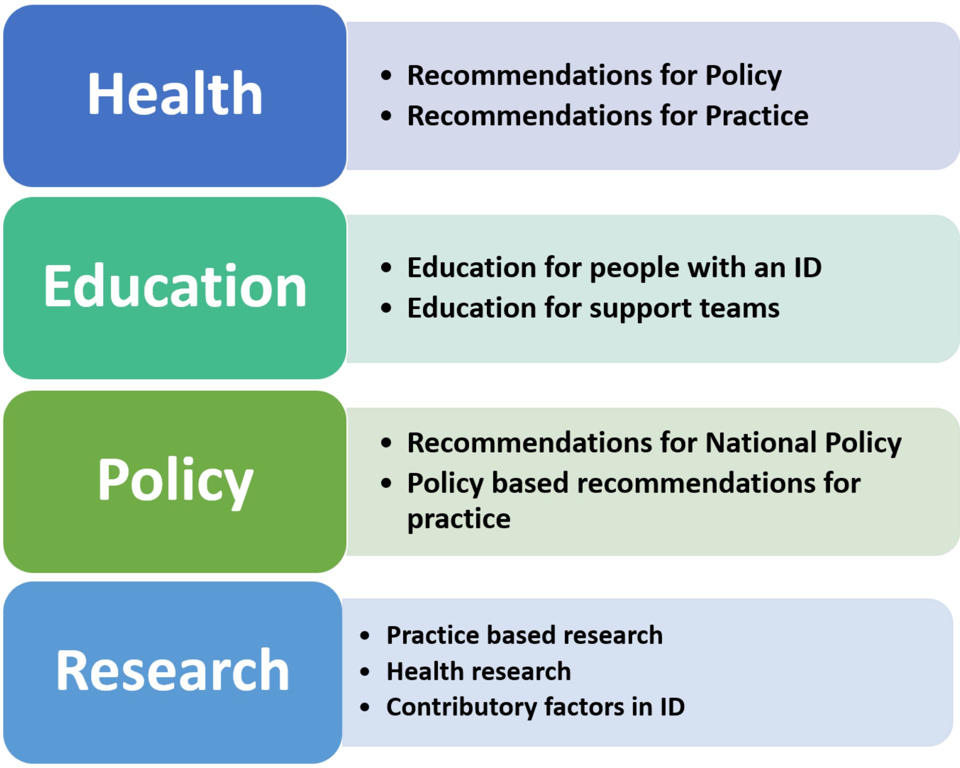


Figure 8.0. Recommendations

8.2. The prevalence of overweight obesity among older adults with ID in Ireland

Overweight and obesity is a chronic disease presenting internationally recognised challenges. However, there is limited understanding of the prevalence and impact of this disease on older populations with an ID. To address this deficit, an examination of international prevalence studies for overweight and obesity was undertaken. Guided by a systematic literature review process, this study found measurements for overweight and obesity ranged from BMI to Percentage of Body Fat (Moore *et al.* 2004) to Waist to Hip Ratio (deWiter *et al.* 2012), Waist Circumference (Kinnnear *et al.* 2018; *Foley et al.* 2017) and Skinfold thickness (deWiter *et al.* 2012), although all of the studies used BMI as a measure. Broader inconsistencies in approaches to data collection were also apparent across the studies. These ranged from self-reporting to data extraction, databases or disparate study populations. Studies included people with an ID, people with Down syndrome compared with ID of other aetiology or ID and general population data. One case control study examined people with Down syndrome only (Melville *et al.* 2005). As with aetiology, variance in sample sizes was also apparent and reflective of the approach to data collection. With the exception of one study with a participant commencement age of 16 years (Kinner *et al.* 2018), all studies involved data from adults with an ID. Interestingly none of the studies presented Irish population data.

Collective understanding of critical population data contributes to judicious service planning. However, the reported variation in approaches to measurement within the literature examined impeded determination of overall population prevalence. Nonetheless, across all studies, overweight and obesity prevalence was high and notable so for women. In Ireland, the absence of such prevalence data hinders evidence based population health planning and targeted solution focused treatments. Therefore, this study recommends the identification and reporting of nationally agreed standard measurements for overweight and obesity in ID.

Assembling prevalence statistics on existing national data collation systems used in ID such as the National Ability Support System (NASS) should be considered.

8.3. Risk Factors for Overweight and Obesity among Older Adults with an ID

This study, in ascertaining prevalence for overweight and obesity illustrated distinct risk factors in ID. These risks are represented as non-modifiable and modifiable risks amenable to change. Sex as a non-modifiable risks indicated greater prevalence of overweight and obesity in women with an ID. This was also borne out in this current study when based on objectively measured BMI, 72% of women were overweight or obese as opposed to 65% of males. These findings reflect other research in ID (Hsieh *et al.* 2014; Stancliffe *et al.* 2011; Bhaumik *et al.* 2008) but contrast to some general population studies where obesity is more frequently reported in males (Leahy *et al.* 2014; Berghöfer *et al.* 2008). Moreover, the age profile of women in this study at menopause, a life stage which presents with its own risks to women's health. Of all of the women in this current study who reported their menopause status (N=350), 75% experienced menopause and 75% of those women at menopause with objectively measured BMI were overweight or obese. Furthermore, waist circumstance measures indicating metabolic disease risk were also high in women reporting menopause (76%).

As with gender, aetiology was highlighted as a particular risk in ID and one not reflected in general population data. In particular Down syndrome (Kinnear *et al.* 2018; Nixon *et al.* 2018; Krause *et al.* 2016; Hsieh *et al.* 2014) and Prader-Willi (Khan *et al.* 2018), where people presenting with these conditions were more likely to be exposed to high prevalence of overweight and obesity. Given the unique circumstances associated with such conditions, focused research with bespoke solutions is endorsed.

A further risk in weight management highlighted within the literature but one not unique to ID involved physical activity. Low activity (Burke *et al.* 2014) and high levels of sedentary behaviour (Lynch *et al.* 2021) are described in adult ID populations. Why this is the case in ID although not fully understood may involve physical limitations, personal motivation and understanding of the risk benefit relationship within environments which may not cater to personal need. Although not the focus of this current study, inactivity is a key contributor to overweigh and obesity. In support of active engagement, the surrounding physical environment needs to be available to people with an ID with appropriate safe access and personal care facilities freely available. Within an Irish context, environmental barriers and enablers to activity in ID should be examined further. Local development plans within county councils for example could host bespoke consultation with people with an ID at the planning phase. This would provide opportunities to understand some unique obstacles to activity experienced by people with an ID. Additionally, based on the risk factors presented in this study, an evaluation of the physical activity of people with an ID who are overweight or obese is recommended.

Medications also affect weight status and were recognised within the literature as an associated but adjustable risk. Poly and hyper polypharmacy is omnipresent in ID (O'Dwyer *et al.* 2016). These medications include drug classes used to treat depressive illness (O'Dwyer *et al.* 2018; Ranjan *et al.* 2018) a condition also indicated in overweight or obesity. In this study, seven in ten participants who were overweight or obese report a Dr diagnosed mental health illness. Although not statistically significant, participants would have been in receipt of medications to treat the condition. The cumulative effect of overweight, obesity, mental health and the side-effects of medications presents a complex picture for people with an ID living with overweight or obesity and is deserving of further enquiry.

As with mental health, socioeconomic status was isolated within the literature as a significant contributor to overweight and obesity (Lee *et al.* 2019; Abarca-Gómez *et al.* 2017; Cohn 2013). Maternal obesity and educational attainment present significant risk for childhood obesity (2016), although dependent on the country's metrics for health and living standards (Dinsa *et al.* 2012). Within the literature, this did not materialise as a significant risk in ID. Nonetheless, when compared with the general population, lifestyle patterns of people with an ID can be unique in areas including living arrangements, level of educational attainment and subsequent earning capacity. For example participants of this study lived independently/with family, in a community group home or residential care. In terms of weight status, findings reveal that most overweight or obese participants (78%) lived independently/family or in a community group home (74%). Each of these residential settings differ in terms of level of support and household costings. Nonetheless, a wider understanding of the effect socioeconomic status has on overweight and obesity in ID in all probability should involve modified indicators framed to reflect social constructs in ID.

Allowing for the aforementioned prevalence and risks associated with overweight and obesity in older people with an ID, this study sought to determine the consequences on physical health, extending enquiry to women's health

8.4. The consequences of overweight and obesity on the physical health of adults with an ID

Overweight and obesity is a chronic disease with far reaching consequences intensifying the risk of developing further Chronic Health Conditions (CHC). However, its impact on the health of people with an ID is not fully established. Indicators for health include body composition within recommended parameters, with level of years spent in good health reflective of mortality (WHO 2020). Optimal functional capacity is core to positive ageing (WHO 2020). Nonetheless this life stage presents credible risks for developing additional disability (Nam *et al.* 2020). This study's ageing population were overweight or obese and experienced CHC. Statistically significant associations were found with GIT disorders (59%), respiratory disease (89%) and musculoskeletal disorders (57%).

Acknowledging overweight and obesity as problematic to the health and wellbeing of people with an ID is a primary step towards effective solution-focused change. The persistent nature of this disease across the life course, from childhood through into adulthood (Lau *et al.* 2007) with correlated co-morbidities requires preventative strategies in the early years. The Healthy Weight for Children HSE Action Plan 2021 – 2023 includes targeted actions for children and their support networks with preventative lifestyle behaviour targets. However, given the circumstances unique in ID such as aetiology, level of education attainment, living arrangements and communication disparity, this programme should be extended for adults with a particular chapter for ID.

Motivation for lifestyle change in addressing problematic weight status and subsequent effects on health, is an important factor in driving improved outcomes. For adults with an ID, lifestyle modifications require an appreciation of the risk of excess weight to their overall health and wellbeing. Personal awareness of problematic weight has been shown to be limited in ID. Findings of a study by Buke *et al.* (2014) reported that although 66% of people with an ID were overweight or obese, 60% thought their weight was satisfactory. Other research shows that although people with an ID recognise healthy and unhealthy foods, equating this understanding with effects on overall health presents challenges (Smyth and Belle 2006). Therefore, extending research on perceptions of adults with an ID to overweight and obesity is advocated. Furthermore, facilitative conversations within supportive environments such as the persons own home, enable adaption of language to meet individual communication and learning styles and are endorsed as a first step towards solution focused support. As experts in their own lives, such opportunities enable prospective action led by the person with an ID. However, this requires access to support workers with an understanding of the fundamental implications excess weight has on the health and well-being of people with an ID.

The use of an evidence based assessment process across services where supports are provided should be available. Anthropometric measures for BMI and waist circumference, as well as measures for associated chronic diseases where indicated, such as those identified within this study should be considered within this assessment structure. Current Irish Health Policy is based on receipt of the appropriate care at the correct time and location (Government of Ireland 2021). Primary care services delivered within General Practice (GPs) include a range of supports from diagnostics, prescription medications to preventative medical support. Comprehensive annual health checks for people with an ID, although not mandated in this jurisdiction are proven to be beneficial (Carey *et al.* 2017; Robertson *et al.* 2014) and as an illness preventative strategy have shown to influence survival rates (Kennedy *et al.* 2022). Such assessments of health should be available to people with an ID residing in Ireland when presenting to general practice. This assessment inclusive of biomarkers for cardio metabolic risk, fasting lipid profile and HbA_{1C} in overweight or obesity adults with an ID enables evidence based treatments. This level of health surveillance within primary care reduces the risk of late disease presentation or diagnostic overshadowing (Javaid *et al.* 2019).

At a community service level, people with an ID who are overweight or obese should have access to Specialists and Advanced Nursing practice services provided by Registered Nurses Intellectual Disability (RNID), employed in both services and primary care. This specialist and advanced nursing service facilitates timely advanced assessment, interventions and support at an expert nurse level with the person and their support network. Accessing service supports not only encompasses physical access but access to adapted communication styles and reasonable accommodations. This expert nursing services for both children and adults with ID enables both preventative and management strategies tailored to meet individual needs. Furthermore with a focus on advocacy, the RNID can provide bespoke assistance for individuals in accessing main stream health systems.

Referral pathways should be developed where based on assessment of need, specialist service supports inclusive of dietetics and the full range of treatment options publically available are accessible to people with an ID. In Ireland, the National Clinical Programme for Obesity identifies a tiered approach to obesity recognition, treatment and overall management with a cross-sectoral approach favoured. This model identifies high-risk populations including people with an ID. Nonetheless, people with an ID require support to avail of these valuable services. Mapping engagement with treatment supports for adults with an ID, including weight loss treatments such as contemporary weight loss medicines and more invasive surgical treatments would contribute data on service supports access by people with an ID. This recommendation is not intended to segregate people with an ID but in recognition of the concerning prevalence and unique context of overweight and obesity in ID. In addition, it contributes to indicators for improved health and wellbeing and the formation of specific targets for people with an ID. Lastly, the involvement of people with an ID as ambassadors of this clinical programme is endorsed.

The collation of accurate national data on the effects overweight and obesity has on health in ID is indicated. This level of data collection provides evidence of the depth of this challenge in ID and could support advancement of a case for service developments with supports targeted towards the specific needs of people with an ID. The National Quality Assurance and Improvement System (NQAIS) Clinical system is a platform used in Public Hospitals in Ireland to collate data on admissions to hospital. Data extracted from this system relative to overweight and obesity in ID where indicated as a primary or secondary condition on admission, would provide a supportive insight into the health of people with an ID who attend hospital services. To this end, it is recommended that this NQAIS data is analysed within scheduled timeframes to determine overweight and obesity prevalence in people with an ID admitted to acute hospital services in Ireland. Planned reporting of such data is critical to both population health and service planning is recommended.

8.5. The physical health implications for women with an ID at menopause who are overweight or obese

The chronic disease profile associated with overweight and obesity in ID differs somewhat to the general population; moreover for women with an ID. This study presents important information on the health of women with an ID at menopause. The proliferation of problematic weight status in women with an ID both in the literature (Burke *et al.* 2014; Heish *et al.* 2014; Bhauik *et al.* 2008; Melville *et al.* 2007) and this study is particularly alarming. With over seven in ten women overweight or obese and the majority aged between 50-64 years, menopause as an important life stage was examined. This was reported by participants as pre (reporting continuation of menses) and post (self-reported 12 months amenorrhea) menopause. This life juncture can be challenging for women and a time when health is compromised. However the evidence base addressing overweight, obesity and menopause is deficient. Degrading oestrogen levels increase propensity to both weight gain and problematic visceral fat (Numao *et al.* 2020). In this study 75% of the women at menopause were overweight or obese. Similarly 75% had a waist circumference which exposed them to increased metabolic disease risk.

Considering the unique contemporary lifestyles of women with an ID, a worrying finding of this study was the statistically significant association between level of ID, resident's type and menopause in overweight or obese women. Identified links between living arrangements and weight status are noteworthy. More women at menopause who were overweight or obese lived in a community group home (46%) or residential care (38%) and over half (53%) had a moderate ID. Although no inference can be taken from these findings, lifestyle changes, principally occurring in the past two decades may contribute to the reported increased weight status. Contextualised within a changed model of service support with autonomous decision making legislated for (Government of Ireland 2015b) and where women with an ID have greater autonomy in decision making, although welcomed presents challenges; moreover, exposure to obesogenic environments with an abundance of foods and drinks high in sugar, salt and fat content with little or no nutritional value. Furthermore the limited activity and level of sedentary behavior reported in ID (Lynch *et al.* 2021) presents a worrying cumulative profile for the future health of women with an ID. Although this study did not examine causal relationships between lifestyle factors and weight status, a more longitudinal approach to analysis would address such issues and is endorsed.

With overweight and obesity featuring in the lives of women with an ID at menopause, an effect on health is probable. In this study using both BMI and waist circumference measures in conjunction with Dr diagnosed CHC these were shown to occur more frequently in overweight or obese women at menopause compared with women with a normal BMI. In particular GIT disorders (30%), neurological disease (33%) and musculoskeletal disorders (30%) were statistically significantly associated with a BMI in the overweight or obese grading. In terms of waist circumference measures, this was also the case for GIT (37%) and Neurological disease (32%).

The significance of weight status in GIT disorders revealed in this study, mirrors what is reported in the literature. Treatable conditions posing health risk with symptoms synonymous with pain and discomfort such as gastroesophageal reflux disease (GERD) (Galli-Carminati *et al.* 2006; Böhmer *et al.* 2000) and constipation (Mathew *et al.* 2021; Robertson *et al.* 2018) are reported in ID. However, associated symptoms of pain and discomfort require descriptive language to convey symptoms which may elude some women with an ID. It is reasonable therefore to purport that under reporting in this population occurs. Screening for such disorders as part of baseline health assessment in women with an ID is fitting with particular focused attention during menopause.

Similarly, doctor diagnosed neurological conditions in overweight or obese women at menopause warrants attention. Dementia for example is prolific in ID (Perera *et al.* 2020; Tyrrell *et al.* 2001) moreover for people with Down syndrome (McCarron *et al.* 2017) with overweight and obesity confounding this risk. In light of the 2017 Lancet Commission on dementia prevention, where obesity was highlighted as a contributing factor but nonetheless one responsive to change, (Livingston *et al.* 2020), addressing problematic weight in this population of women is imperative.

Lifestyle modifications required to address the health of women with an ID at menopause necessitates targeted action at many levels from policy to practice and one where early intervention positively impacts future health outcomes. Three in ten women in this study with musculoskeletal disorders at menopause were overweight or obese. Prevalence was slightly higher when waist circumference was the measure used (33%). Poor bone health is described in ID, moreover in women with an ID (Burke *et al.* 2019) and within the age range associated with menopause (Li 2022). Dietary habits are important to bone health, with dietary deficits affecting bone metabolism (Heaney and Layman 2008) and are described in menopause (Harper, 2017). Therefore surveillance of the musculoskeletal health of women with an ID at menopause is an important consideration for health and specifically fragility and fractures.

The most effective strategies endorsing progressive musculoskeletal health for women with an ID are those which begin in childhood. With a quarter of children (aged 3-9 years) overweight or obese (Smyth *et al.* 2017) and dietary patterns established in childhood forming foundations for bone health in later life, it is critical that children with an ID are visible in national policy targets and action plans including the national obesity strategy (Department of Health 2016c). This is pressing given the documented mortality rate in women with an ID (Flygare Wallén *et al.* 2017; McCarron *et al.* 2015; Heslop *et al.* 2014) and where McCarron *et al.* (2015) for example, reported this differential to be as much as four times higher compared with general population data. Results from this current study therefore contribute new and valuable insights into the health of women at menopause who are overweight or obese and should be examined longitudinally ascertaining changes over time. Targeted analysis on lifestyle factors impacting such chronic diseases in older populations of overweight or obese women at menopause would help inform future service planning and is recommended. Furthermore highlighting menopause as a poorly researched but critical life phase for women with an ID provides and evidence base to anchor targeted measures.

Although CVD is a leading cause of hospital admission (Doody *et al.* 2021) and death in ID (Iffland *et al.* 2023; Cooper *et al.* 2004), this was not statistically significant for the women in this study. Nevertheless, almost six in ten overweight or obese women at menopause had CVD and a waist circumference which exposed them to metabolic disease risk. Despite limited related research in ID, actions addressing cardiac health indicate positive outcomes (Holly and Sharp 2014) and should be monitored in this population of women. Furthermore, an examination of the variance in cardiac health for overweight or obese women at menopause within the general population and women with an ID could provide valuable insight into lifestyle factors affecting heart health. For example, personal stressors are not only implicated in obesity but in cardiac health (Osborne *et al.* 2020) but are not well researched in ID. Similarly given the high prevalence of overweight and obesity in ID, levels of hypertension are relatively low (Burke *et al.* 2014) when compared with general population data (Murphy *et al.* 2016). Why this is the case is unclear, but again may provide valuable insights for population health. Physical activity is core to cardiac health and suggested weekly activity objectives established for positive heart health, if indicated could be modified for older women with an ID, but should nevertheless remain ambitious.

Although reported in almost six in ten overweight or obese women at menopause, surprisingly metabolic disease was not found to be statistically significant. Given the overweight, obesity metabolic disease risk reported in the general population (Kirkman *et al.* 2012), this is a noteworthy finding. However in results reported, it should be acknowledged that findings are based on reported Dr diagnosed conditions only and not biological markers as these did not form part of data collection for this study. Therefore, the possibility of underreporting of diseases such as diabetes in this population of women cannot be discounted. The inclusion of biomarkers such as fasting lipid profile and HbA_{1C} in future IDS-TILDA study waves could alleviate this risk and is recommended.

A further CHC examined in this study and implicated in mortality among people with an ID is respiratory disease (Iffland *et al.* 2023; Cooper *et al.* 2004), although low prevalence was reported for overweight or obese women at menopause in this study. Nevertheless, when conveyed, almost all were overweight or obese and had an at risk metabolic disease profile. This result is somewhat surprising considering that respiratory disease is the most dominant reason for admission to acute hospitals in Ireland by people with an ID (Doody *et al.* 2021). Although not reflected in this study, it does require monitoring. The relatively low reported levels of the disease may reflect some lifestyle choices such as smoking. Comparative low levels of smoking are reported in ID (McCarron *et al.* 2011) and within general population where reported this tends to be greater for men (Cronin *et al.* 2011).

Similarly mental health arose for 56% of women in this study at menopause who were overweight or obese although again the association was not significant. This correlates with literature for both overweight, obesity (Avila *et al.* 2015; Preiss *et al.* 2013) and menopause (Vivian-Taylor and Hickey 2014). Worryingly women with an ID have been shown to experience higher rates of depressive illness (Mulryan *et al.* 2014) and for women at menopause this is hardly surprising considering the range of both physical and psychological difficulties they experience (Makara-Studzińśka *et al.* 2014). The inclusion of menopause in assessment and support planning for women with an ID is critical. Health surveillance and facilitative support for women at menopause with medical assessment and symptom control inclusive of hormone treatments is recommended.

This research sought to understand overweight and obesity in older women with and ID and the impact on their health status. The effect was contextualised within an important life stage namely menopause. Considering mortality in women with an ID coupled with these research findings, it is reasonable to infer that weight status is problematic for women with an ID at menopause. This research does present important foundational research for longitudinal analysis examining consequential suboptimal health experienced by women with an ID. The benefit of targeted health approaches in this population is manifest and bespoke targeted sexual health programmes for women with an ID are recommended. These programmes should raise awareness of menopause and overall health for women with an ID. In setting the narrative for policy, planning and service development for women with an ID into the future, this study recommends longitudinal analysis to affirm the relationships and causation of CHC among women with ID experiencing menopause. In addition, an examination of sex variances for overweight or obese adults with an ID is advocated considering the results of this and other studies highlighting health disparity.

8.6. The dietary habits and contributory factors of an older population of people with an ID who are overweight or obese

Further interconnected contributory factors impacting weight status and overall health in ID involves nutritional health. Diet is core to positive overall nutritional health (Ball et *al.* 2012) and plays a critical role in the maintenance of weight status. The persistent proliferation of problematic weight internationally is of public health concern. Nonetheless, this chronic disease is somewhat modifiable resulting in tangible improved health outcomes. This distinctive study provides a unique opportunity to understand the dietary profile of older adults with an ID living in Ireland who were overweight or obese. This data contributes to our understanding of dietary deficiencies known to impact health and subsequent mortality in ID (Reppermund and Walker 2021; Iffland *et al.* 2013). Nevertheless, lifestyle challenges befall ID inclusive of physical inactivity with inclinations towards chronic disease all of which good nutritional health can exert a positive effect.

In this current study, participant's data drawn from a Food Frequency Questionnaire (FFQ) was analysed in conjunction with national guidance for dietary balance based on recommendations in the form of a food pyramid. Findings offer a first time overview of the dietary patterns of people with an ID who were overweight or obese as they pertain to national recommendations for dietary balance. Data analysis established poor overall compliance with recommendations across all food groups.

Participants consumed less than the recommended intake for shelves of the food pyramid containing important foods providing essential nutrients for balance such as fruit and vegetables or protein for growth and repair. Accounting for sex difference, women consumed less than the recommended daily intake than men including vegetables, salads and fruits. Considering the health profile of women previously described at an important life stage such as menopause, this finding is disquieting.

Although consumption of protein rich foods required for growth, repair and containing iron necessary to maintain healthy blood including meat, poultry, fish, eggs beans and nuts exceeded the recommended two portions per day, compliance with the RDA for this food shelf was the closest to national recommended standards (Department of Health 2016a). Again more women than men in the study who were overweight or obese exceeded this RDA.

In sharp contrast to shelf 1, overconsumption of highly processed foods laced in sugar, salt and fat exceeded recommended levels. Such products are not endorsed for frequent consumption with recommendations advocating use as little as possible in very small amounts. However, in this overweight or obese study population, products such as butter, vegetable oils and dressings like mayonnaise and coleslaw far exceeded the RDA with an average daily consumption of 2.09 portions. Within this food group and in contrast with other groups, men exceeded the daily recommended levels compared with women although the level of non-compliance across both sexes was high. Similarly over consumption foods and drinks high in fat, sugar and salt endorsed for occasional use in small amounts (no more than 1-2 servings per week) were frequently consumed by participants who were overweight or obese. Again almost all overweight or obese women exceeded this recommended intake level. Of interest but not surprising was that no participants aged <50 years of age or aged 65+ who were overweight or obese met this RDA.

In view of the presenting dietary compliance challenge in ID and obesogenic environments with abundant access to highly processed foods, the need to examine diet as a contributory factor in overweight and obesity in ID was never more pressing. In addition, in view of associated health effects, this dietary data provides a critical understanding of dietary patterns in ID. Moreover they may go in some way support to our insight into factors affecting problematic weight and subsequent ill health in women with an ID. Therefore, repeating the full SLÁN survey instrument in further waves of IDS-TILDA to examine patterns over time is recommended.

In ID, constrained exposure to natural food environments within the home, coupled with the regular involvement in the purchase and preparation of food is limiting. Despite the acknowledged benefits of nutritional education (Yilmaz *et al.* 2014), diminished opportunities for new learning, understanding food content and risks associated with consumption of heavily processed foods indicates risk in ID. Although this study addressed dietary patterns, an examination of the macronutrients of the IDS-TILDA population is recommended to offer a deeper appreciation of quality in the food consumed based on the recommendation for healthy nutrition.

Overweight and obesity is predicated on a range of dynamics making it a difficult challenge in the lives of people with an ID. In order to effect change, a developed appreciation of food, dietary choices and corresponding health impact is required. Although evidence does suggest that people with an ID have knowledge of food, understating its potential impact is lacking (Smyth and Belle 2006). The complex descriptive language used across diet and nutrition may elude people with an ID, in particular where literacy challenges feature. Moreover, the abundance of foods especially heavily processed convenience foods makes positive dietary choices difficult. This is not helped by food labelling with its complex presentation requiring at the very least literacy and numeracy skills. In the interest of public health, approaches to food labelling should be adapted beyond the existing colour coded warning system evident on some food packaging. Considering the contemporary lives of people with an ID coupled with literacy and numeracy challenges, access to food labelling information using facilitative formats supports informed decision making and is critical in the drive for improved health and wellbeing in ID. Furthermore, working collaboratively with supermarkets to provide visual display guides for colour food labelling would not only be beneficial to people with an ID but enable the commercial sector to meet some of their goals towards inclusivity.

Within an educational context, in Ireland given that completion of the full school cycle by people with an ID is limited, opportunities to actively engage in diet and nutritional education is narrow. Therefore extending opportunities into adulthood endorsing a whole systems approaches to nutritional health through education is recommended. Furthermore, supporting people with an ID to become ambassadors of health including nutritional health is evidentially beneficial and advocated based on the findings of this study. Such programmes should take a total communication approach. Community cooking programmes as a matter of course should be accessible and availed of by people with an ID. This requires that materials and programmes meet the diverse needs of people with an ID and in formats which facilitate active engagement and learning. This also requires support from a workforce with an appreciation of the risks poor dietary choices have on the health of people with an ID.

Education is listed as one of the four key priority areas for the HSE National Clinical Programme for obesity with recommendations endorsing assimilation of such education programmes into formal training curricula. In 2020 the HSE launched a policy and tool kit titled: Food, Nutrition and Hydration Policy for Adults Accessing Disability Services and an education programme for support staff currently available on the health services learning platform HSELanD. However, this and other related programmes are not currently mandated for staff providing support to people with an ID. Contextualising the contemporary the lives of people with an ID, their diverse support requirements and living arrangements coupled with the negative consequences of poor nutritional health, educational programmes focused on diet and nutritional health should be mandated for support workers. Additionally programmes addressing dysphagia and risk feeding should also be made available as they are critical to the overall health and wellbeing of people with an ID.

Lifestyle factors can be adapted to include learning experiences for people with and ID. The onset of online shopping service, although presenting convenience, poses the risk of lost opportunity for people with an ID to engage in-store shopping with exposure to sights, smell and touch from a variety of foods. Additionally, the opportunity to enhance decision-making skills relative to available visible choice is restricted when on shopping online. This is also the case for naturally occurring opportunities for social engagement. Therefore augmenting support workers understanding of these potential shortfalls provides as platform to open and engage in discussions around the food environment, food sources and content.

8.7. Overweight and Obesity; the Path to Future Health and Wellbeing

In examining overweight and obesity in older adults with an ID, this extensive study highlights not only the challenge excess weight brings but presents novel information relating to health and dietary patterns. In doing this, the researcher exposed areas for consideration and development. Overweight and obesity is a very complex pervasive problem affected by number of dynamics, some of which are presented here. Addressing the imposition of this disease on the overall health and wellbeing of people with an ID and in particular women at menopause, necessitates collective recognition and action. Furthermore, bearing in mind the unique circumstances of the lives of people with an ID, approaches extending beyond but including diet and exercise as traditional approaches to this disease needs to occur. This research therefore is only the beginning but an important foundation from which many other connected areas can be further scrutinised.

8.8. Areas for Further Research

Contributory factors for overweight and obesity as a chronic disease are multifaceted. This current research provides a critical foundation describing the extent of this challenge in ID, the impact on health and a unique examination of the health of women at menopause and dietary patterns in a population of older adults with an ID who are overweight or obese. Nonetheless, there are many other areas warranting research advancement as presented within the previous text and in table 8.0.

Table 8.0. Prospective Areas for Future Research

Research area	Proposed research
Biological	What are the biomarkers for overweight or obesity in a population of adults with an ID? What are cardio metabolic risk factors in ID populations? An examination of fasting lipid profile and $HbA_{1C.}$ Conduct an exploration of genetic predisposed to overnight and obesity in ID.
Dietary and nutrition	An examination of the macronutrients of the IDS-TILDA population. A repeat of the full SLÁN survey in IDS-TILDA to examine patterns over time. An examination of food labelling and its accessibility to people with an ID who have literacy challenges and the investigation into more effective systems to enable people with an ID access to information to support decision-making.
Health and overweight and obesity	Using the National Quality Assurance and Improvement System (NQAIS) Clinical system to collate and analyse data on admissions to Irish Hospitals by people with an ID where overweight and obesity is implicated in the admission as a primary or secondary condition. Conduct follow-up data analysis on CHC experienced by people with an ID who are overweight or obese.
Physical activity	An examination of physical activity and people with an ID who are overweight and obese. An examination of the barriers and enablers to activity in ID. Research intothe impact physical activity has on weight management and overall health.

Research area	Proposed research
Weight management programmes	What is the level of engagement in weight management programmes in ID?
	What paths to treatment supports are available and availed of by adults with an ID?
Insight	What are the perceptions of adults with an ID relative to overweight and obesity?
	Conduct an examination of motivation for lifestyle change to address weight status.
	What are the perceptions of the impact of overweight and obesity on adults with an ID by carers and their supportive role?
Sex	Further examination of overweight and obesity in women at menopause, cause and impact.
	Further examination of sex variances for overweight or obese adults with an ID.
Medications	Examine medications used by older adults with an ID for which increased weight status is indicated.
	In addressing the reported level of mental ill health, examine the impact medicines used to treat mental illness have on weight management in ID.
Weight loss treatments	Examine the use of contemporary weight loss treatments by people with an ID including medicines and more invasive available surgical treatments.
Mental health	Examine the impact of mental health and overweigh or obesity in adults with an ID including motivational factors for change.
Quality of life	Investigate the impact overweight and obesity has on the lives of adults with an ID.

Research area	Proposed research
Economics	Conduct a review of the economic impact of overweight and obesity in ID.

8.9. Raising Awareness of Overweight and Obesity in ID

One of the challenges in addressing overweight and obesity in ID is the lack of evidence indicating a call to action. With almost seven in ten participants of the IDS-TILDA study Wave 2 either overweight or obese, this chronic disease has a strong foothold in ID. However, addressing this multi-layered chronic disease is in itself a challenge. This is recognised in national policy where for example A Healthy Weight for Ireland: Obesity Policy and Action Plan 2016 – 2025 references multi-sectoral involvement in policy based solutions ranging from health, education to transport and the food industry and local government (Department of Health 2016c). The need to include people with an ID in solution focused planning is critical as the most effective ambassadors in the drive for inclusive change.

Assessment of weight status is the first step in ascertaining a wider appreciation of the prevalence in ID. This comprehensive assessment should typically include aetiology, anthropometric measures for BMI and waist circumference, existing chronic health conditions, dietary and lifestyle patterns inclusive of activity levels and medications with a focus on treatments where increased weight status is shown to be a potential outcome. In addition and in consultation with the GP, targeted blood sampling where overweight and obesity is indicated to support the diagnostic process. This could include fasting lipid panel, liver function, thyroid and fasting glucose (HbA1c). Data from this holistic assessment should then be used to inform a strategic approach to planning for improved outcomes with the individual. Areas for assessment are presented graphically in figure 8.1 and 8.2. The determination of a treatment plan will vary in accordance with the outcome of an individual assessment. This data with other mitigating factors should be formatted with ambition and the drive to effect positive outcomes for the person.

Figure 8.1. Assessment to Guide Holistic Planning

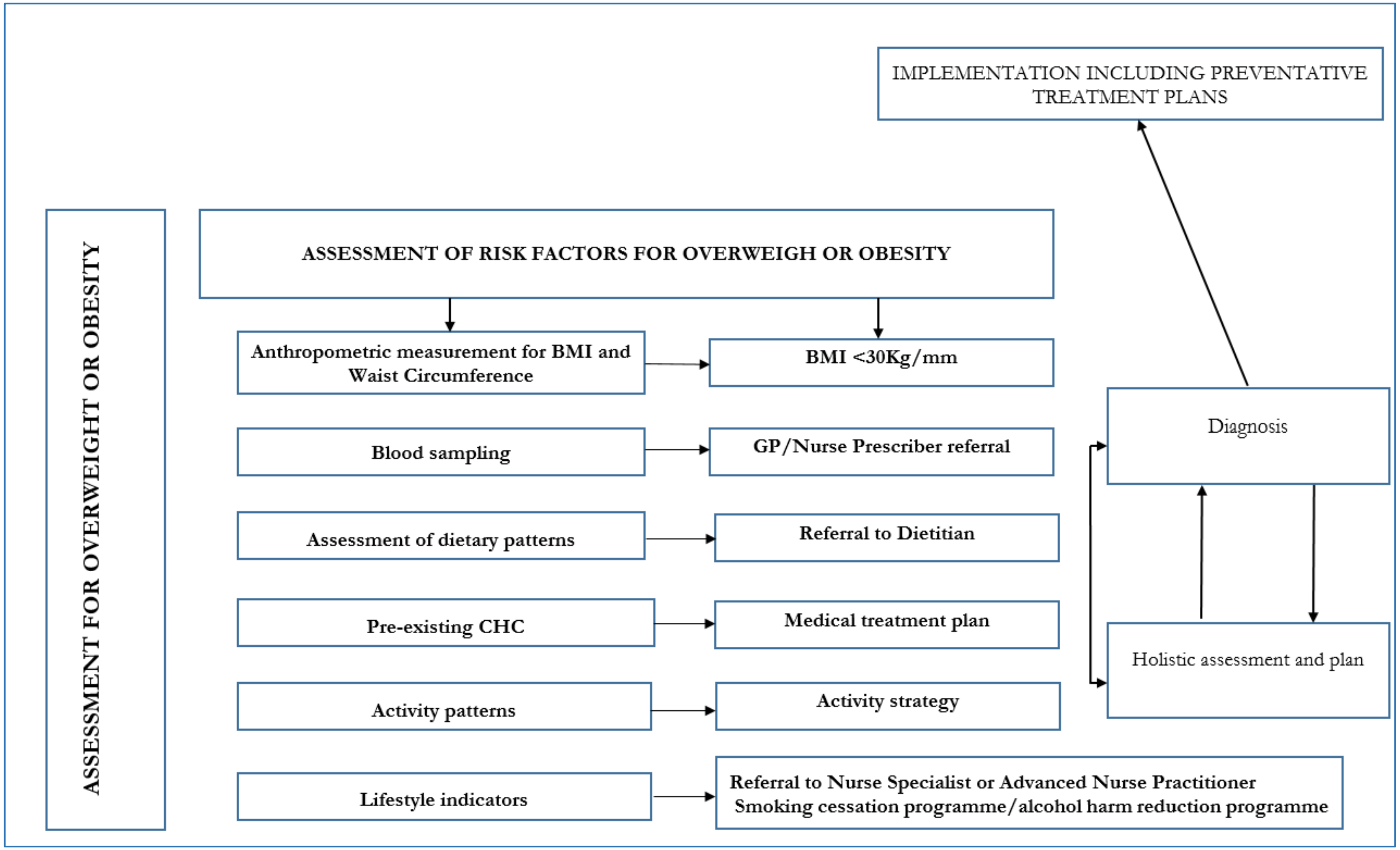


Figure 8.2. Holistic Assessment for Practice

REFLECTIONS ON MY RESEARCH JOURNEY

Now as I near the end of this research study examining overweight and obesity in older adults with an ID and reflect on my journey, I am taken aback by my growth and learning during this time. Although I was familiar with the IDS-TILDA study when embarking on this research enquiry, I hadn't initially realised the extent of the opportunity involvement in a large scale longitudinal study afforded me; particularly in addressing complexities associated with overweight and obesity. This research process has led to the development of skills and abilities as I navigated the challenges presented to me during my PhD that I will hold dear as I progress though life and my career.

My greatest privilege during this research was meeting the participants who I interviewed during the data collection phase. I was welcomed into their home, met family members, drank tea and had a glimpse into their lives. I did however needed to have a flexible approach to the interview and drew both on my skills as a nurse and my previous research experience. The need to do justice to this research on their behalf became a personal driver for me and I thought of them especially during my most stressful study periods.

The expert supervision I was privileged to have during the study formed the foundation for a deeper level of thinking and learning. I could not have had more constructive expert guidance or felt more supported by supervisors willing me to succeed. When they challenged my thinking, as I progressed through the study I understood why and this resulted in a deep appreciation of my research topic and the research process. At the outset, my skills in quantitative research methodologies was very limited having focused my previous research on qualitative analysis. However, with an abundance of trepidation and great support from experts on the IDS-TILDA team, this steep learning curve afforded me an understanding of the language and process involved in quantitative research, uncovering information I would not have otherwise grasped. Reflecting on my initial fear of SPSS, I wonder if I wasted time shy of asking for assistance but I take the learning from that experience. I can also raise it with others and do so within my current role encouraging educators and researchers to provide information sessions for nurses and midwives focusing on the interpretation quantitative research from papers.

There are a plethora of factors affecting weight status from exercise to medications and IDS-TILDA collects data on all of these areas. Although guided by the literature, it did take me time and guidance from my supervisors to develop my particular focus for this research and I could have included all of the aforementioned areas. In order to do justice to the topic, once I embedded my direction, I felt progression was somewhat smoother and I really began to enjoy the study. I had a great teacher in the form of a librarian during my systematic literature review process and this review set the foundations from which to base the focus of my study. I was both surprised and saddened to see women feature so prominently in the literature. I had not anticipated this at the outset of my research journey. I have spent time reflecting on the women I had supported during my career and remain troubled by thoughts of their silent suffering in the face of menopause and my historic lack of knowledge on the topic. However, the evidence base produced as part of my study offers me solace, as I am now in a position to be able to heighten awareness of the poor health outcomes for women with an ID at menopause who are overweight or obese. I am also enthusiastic about the prospect of the next phase of this work and feel a sense of responsibility not to hold this learning but to share it widely.

My process of discovery for dietary data analysis was not without its challenges. In the absence of an existing process, I needed to find a way forward for this analysis. Discovery took time but helped me gain a deeper understanding of the dietary data, systems of analysis and measurement against a national standard. Had there been an existing process readily available, I feel my results and its presentation would have been somewhat limited.

Although there is a sense of relief and personal pride in my research, the need to continue telling the story of overweight and obesity in ID remains forefront in my mind. I think of all the wonderful people with an ID I have and will meet and the health disparities they encounter, the silent suffering and premature mortality. Although I worry that I will leave this research behind, my continued involvement with IDS-TILDA and the relationships I have forged will be a positive reminder of importance of this work. The knowing, based on my research will also drive me forward to try influence changes in policy and practice so that the future is brighter for the next generations of people with an ID.

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APPENDICES

Appendix 1: Quality Assessment

THE NATIONAL INSTITUTE OF HELATH (NHI) GUIDELINES FOR ASSESSING STUDIES

1. QUALITY ASSESSMENT OF CASE SERIES STUDY

Study 1: *Moore, K., McGillivray, Illingworth, K. (2004) An investigation into the incidence of obesity and underweight among adults with an intellectual disability in an Australian Sample, Journal of Intellectual and Developmental Disability, 29 (4), 306-318.*

Criteria	Yes	No Other (CD,NR,NA)*	Notes
1. Was the study question or objective clearly stated?	Y		
2. Was the study population clearly and fully described, including a case definition?	Y		– People with an ID from specific region in Australia – Participants lived in different settings from residential/home/independent living/community – Date of data collection not specified in this study. – 265 Participants approached to participate but 93 engaged with the study – 93 Participants (41 F/52 M) – Age difference (M=31.46 years, SD =9.62, range 18-63) – (M=33.57 years, SD=9.26, range 19-58) – $(t_{(76)} = 0.98, p > .0.5)$
3. Were the cases consecutive?	Y		
4. Were the subjects comparable?	Y		– All had an ID and were from a particular region. Levels of ID differed – Age profile was adults
5. Was the intervention clearly described?	Y		– BMI Measured for M/F (Quentelet Ratio) and WHO (2007) guidelines – Percentage of Body Fat measured for Males only
6. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?	Y		– BMI based on WHO recommendations – PBF based on Kelly and Rimmer (987) for M only

Criteria	Yes	No Other (CD,NR,NA)*	Notes
7. Was the length of follow-up adequate?		N/A	No follow up
8. Were the statistical methods well-described?	Y		– Analysis using SPSS (V11) – Level of significance .05 – Sex differences identified
9. Were the results well-described?	Y		– Yes for both BMI and PBF – Males and females differentiated – Not able to determine level if ID accurately – Correlated BMI with PBF in M – Differentiated within living circumstances

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: Good Study
Rater #2 initials:
Additional Comments (If POOR, please state why):

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

2. QUALITY ASSESSMENT OF CASE SERIES STUDY

Study 2: *Foley, J., Lloyd, M., Turner, L. and Temple, V. (2017) Body Mass Index and Waist Circumference of Latin American Adult Athletes with Intellectual Disability, Salud Públicia de México, 59(4), 416-422.*

Criteria	Yes	No Other (CD,NR,NA)*	Notes
1. Was the study question or objective clearly stated?	Y		– Objective of the study to examine BMI and Waist Circumference in Latin American Athletes – Explore the association of age and sex with obesity
2. Was the study population clearly and fully described, including a case definition?	Y		– Study population from initial 4,174 – Aged between 18-64 – Special Olympians – Latin American Athletes with BMI and WC within a predefined range – Data cleansing process described
3. Were the cases consecutive?	Y		Age was a continuous variable
4. Were the subjects comparable?	Y		– Greater proportion of Males (2,683M/1,491F) BMI – 1,233M and 637F had weight recorded – All part of the International Special Olympic Programme
5. Was the intervention clearly described?		N/A	No intervention recorded BMI and WC measures analysed
6. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?			– BMI based on WHO recommendations – Waist circumference cut off – WC≥94 M and WC≥90 F
7. Was the length of follow-up adequate?		N/A	No follow up one point of measurement taken
8. Were the statistical methods well-described?			– Binary logistical regression analysis was used the – association between sex related differences

Criteria	Yes	No Other (CD,NR,NA)*	Notes
			– Chi-squared analysis used to link BMI and WC to Sex – X^2 =49.80 p<.001 – BMI based on WHO recommendations – Waist circumference cut off – WC≥94 M and WC≥90 F
9. Were the results well-described?			– Females most at risk of both increased BMI and abdominal obesity – Advancing age is a risk of overweight and obesity in people with an ID

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: Good Study
Rater #2 initials:
Additional Comments (If POOR, please state why):

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

3. QUALITY ASSESSMENT OF CASE SERIES STUDY

Study 3: *Melville, C.A., Cooper, S.A, McGrother, C.W., Thorp, C.F. and Collacott, R. (2005) Obesity in Adults with Down syndrome a case control study, Journal of Intellectual Disability Research, 49(2), 125-133.*

Criteria	Yes	No Other (CD,NR,NA)*	Notes
1. Was the study question or objective clearly stated?	Y		– The aim of the study was a comparative analysis of – overweight and obesity in a population of people with – an ID and comparatively analyse this sample to a matched population with non DS ID
2. Was the study population clearly and fully described, including a case definition?	Y		– People with DS and a matched sample of people with a non DS ID – 117 (47.4%) F 130 (52.6%) M – Mean age of those with DS 37.24 (Range-20-69 SD- 10.46) – Control group Mean age 37.23 years (Range 20-65 SD-10.51) – 2% of each of the 2 groups ere living independently
3. Were the cases consecutive?	Y		
4. Were the subjects comparable?	Y		– 247 matched pairs participated in the study with no significant difference between Sex and age – Matched pairs considered living arrangements – 4 year age difference between only one of the matched controls
5. Was the intervention clearly described?	Y		BMI calculated using Height and weight measured
6. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?	Y		– BMI based on WHO recommendations (calculated from Height and weight measurements) – Height and weight measured (by one trained practitioner) weight measured using calibrated scales with shoes and clothes
7. Was the length of follow-up adequate?		N/A	

Criteria	Yes	No Other (CD,NR,NA)*	Notes
8. Were the statistical methods well-described?	Y		– Participants identified from regional database and data collected between 1992-1993 – Matched pairs identified – those with DS and those who have other ID – Pairs matched according to age and living circumstances – Data from the matched pairs analysed using SPSS v10.1 – Comparison data using Health survey for England 1993
9. Were the results well-described?	Y		– Results highlight greater risk for women with DS to overweight and obesity – No significant difference in the male comparator group

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: Good Study
Rater #2 initials:
Additional Comments (If POOR, please state why):

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

4. QUALITY ASSESSMENT OF COHORT AND CORSS-SECTIONAL STUDY

Study 4. *Kinnear, D., Morrison, J, Allen, L., Henderson, A., Smiley, E. and Cooper, S-A (2018) Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross sectional study, British Medical Journal, accessed on line http:bmjopen.bmj.com/ on February 11, 2018.*

Criteria	Yes	No CD, NR, NA*	Notes
1. Was the research question or objective in this paper clearly stated?	Y		The aim of this study was to examine the extend of multimorbidity and the prevalence of physical health identifying the top 20 most prevalent physical health conditions and link these to participants age, Sex, level of ID and DS
2. Was the study population clearly specified and defined?	Y		– Population was adults aged 16 year and over with an ID in particular geographic region of Scotland. – Participants recruited to study between 2002-2004 and all were know to their GP
3. Was the participation rate of eligible persons at least 50%?	Y		1562 originally recruited and 1023 identified as eligible (consent obtained) (65%)
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 pre-specified and applied uniformly to all participants?	Y~		– Participants were recruited from the same region and within an identified time period (2002-2004) – Exclusion criteria were not specifically identified within this paper
5. Was a sample size justification, power description, or variance and effect estimates provided?		No	– Sample size of 1023 (562 men (54.9%) and (461 women (45.1%) – Mean age 43.9 years (16-83 years) – 18.2% DS (48.9% M) and (51.1% F) – Mean age of those with DS 44.1 years – Participants needed to have exposure to more than one health condition to be counted

Criteria	Yes	No CD, NR, NA*	Notes
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	Y		– The exposure of interest was the presence of one or more health conditions – Data was extracted from primary care records – Following this they completed targeted physical health checks
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?		N	– Measures taken at the same time – Measured at one point in time
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)?		N	– This is not relevant to the method used within the study – Measuring the existence of a multiple conditions to determine their prevalence
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Y~		– Reported structured format for data collection form medical records used (format not shown) – Phlebotomy protocol used (*C21st Health Check*) – Physical exam – Height, weight and waist circumference – BP X 3 – Pulse rate and rhythm – Study reported that "most" assessments were conducted using standardised tests but not all referenced (eye examination method and hearing reported)
10. Was the exposure(s) assessed more than once over time?		No	Measures taken at a point in time

Criteria	Yes	No CD, NR, NA*	Notes
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Y		– Diseases were classified in accordance using the International Statistical Classification of Diseases and Related Health Problems (ICT-10)
12. Were the outcome assessors blinded to the exposure status of participants?	Y		Six nurses reviewed case records and then went on to conduct assessments
13. Was loss to follow-up after baseline 20% or less?		NA	No follow up in this study
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Y		– Data analysed using SPSS (V22) – Demographic data analysed using descriptive statics – Twenty binary logistic regressions were conducted to determine if there were any association between the 20 dependent variables (most prevalent physical health conditions) and independent variable of age Sex level if ID and DS – This study accounted for checks and assessments process relative to Multimorbidity – Obesity the second most prevalent health condition

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: Good
Rater #2 initials:
Additional Comments (If POOR, please state why):

5. QUALITY ASSESSMENT OF COHORT AND CORSS-SECTIONAL STUDIES

Study 5. *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, Research in Intellectual Disabilities, 33, 398-405.*

Criteria	Yes	No CD NR NA*	Notes
1. Was the research question or objective in this paper clearly stated?	Y		– Aim of the study to examine the prevalence of overweight and obesity in older adults with an ID and compare to general population sample – Examine the association between overweight and obesity and treatment characteristics – BMI – Waist circumference – WHR – Ski fold thickness – This data would then be compared to the general population
2. Was the study population clearly specified and defined?	Y		– 1050 people participated in the assessment aspect of the study – 945 engaged with a physical examination – Inclusion of those 50 years and older - Mean age 61.5 years – Sex distribution M 51.0% F 49.0% – 14% DS and 15.8% Autism – Level of ID reported – Data on Sex age and level of ID/DS/Autism, use of antipsychotic medication
3. Was the participation rate of eligible persons at least 50%?	Y		– 2150 eligible people with an ID from 3 participating organisations invited to participate in the study – 1069 consent obtained – 1050 participated in the assessment process – 945 participated in the physical exam
4. Were all the subjects selected or recruited from the same or similar populations (including the same time	Y		– Selected from 3 specific organisations in the Netherlands – Range of borderline to severe ID

Criteria	Yes	No CD NR NA*	Notes
period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?			– Living circumstances from central services to independent living – Time period for data collection not specified but one point of data collection – Those over the age of 50 with ID/DS/Autism
5. Was a sample size justification, power description, or variance and effect estimates provided?			– Those recruited were participants in wider study – The matched sample from the general population had data compared to BMI only (no information on their recruitment process available in the article but referenced elsewhere) and data gathered through phone interviews
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	Y		– The exposure of interest included measures of BMI Waist circumference waist to hip ratio (WHR) and skin fold thickness – SPSS 17.0 was used to analyse data – chi-squared analysis was used to explore the difference between population groups – Univariat logistical regression was used to assess BMI and waist circumference – Univariat linear regression used for body composition
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?		N/A	– No time indicated in the study. Data was collected at one point in time
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)?	Y		– Variables were measure using predetermined techniques e.g measurement of level of physical activity using a pedometer and defined baseline – Activity of daily living were measured using Batrhel index and instrumental activities of daily living using Lauton and Brody (1969)
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and		Y~	– For the population of people with and ID trained assistants carried out measurements – Body height measured – Seca sadiometer and non stretchable flexi tape for non-

Criteria	Yes	No CD NR NA*	Notes
implemented consistently across all study participants?			ambulant- Chumela's formula to calculate height – WHO 1995 recommendations used for – BMI/Waist Circumference/ Waist-to-hip-ratio – Skin fold thickness (Harpenden) – Physical activity using pedometers – However for the comparator group BMI was used as a comparator but no data available within the study to indicate how this data was collected
10. Was the exposure(s) assessed more than once over time?		N	
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?		N	– No data available within the study on how BMI was collated for the comparator group (non ID clients)
12. Were the outcome assessors blinded to the exposure status of participants?		NA	
13. Was loss to follow-up after baseline 20% or less?		N/A	
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Y		– In the population of people with an ID: – Sex, level of ID, living arrangements, activity, smoker or not physical activity and use of antipsychotics were the variables measured – Multicollinearty identified correlation between Level of ID ADL's and IADIL's *($p<0.001$)* – BMI the measure for the comparator group of general population studied
Quality Rating (Good, Fair, or Poor)			

Criteria	Yes	No CD NR NA*	Notes
Rater #1 initials: Fair (data for the comparator group poor)			
Rater #2 initials:			
Additional Comments (If POOR, please state why):			

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

6. QUALITY ASSESSMENT OF CASE SERIES STUDY

Study 6: *Bhaumik, S., Watson, J.M., Thorp, C.F., Tyrer, F., and McGrother, C.W. (2008) Body Mass index in adults with intellectual disability: distribution, association and service implications; population based prevalence study, Journal Compilation, 52(4), 287-298.*

Criteria	**Yes**	**No CD NR NA***	**Notes**
1. Was the study question or objective clearly stated?	Y		The aim of the study was to describe the distribution, association and service implications of BMI in a population of adults with an ID
2. Was the study population clearly and fully described, including a case definition?			– Adults on Lestishire LD register who had a health check between a defined period (within 2yrs of July 1998) followed by a home interview within 3 years – People with an ID over the age of 25 from a LD register who had a health check within two years of July 1998 – Exclusion criteria described – ID POPULATION - 661M and 458F of those on the register eligible (living in residential care)
3. Were the cases consecutive?			Chi-squared test used to ascertain the difference between M&F
4. Were the subjects comparable?	Y		– ID Data collected by physician (free health checks offered between 1987 and 1999 to over 19 yrs but this study confined to those over the aged of 25 years (*to match the general population study (DOH Health Survey for England 1998*): – 15% M with ID were obese compared to 19% M in the general population – 32%F with ID were obese compared to 23% in the general population – 29% F OB (*P<0.001*)and 15% M OB – Overall prevalence for ID 28% OW and 20.7% OB
5. Was the intervention clearly described?	Y		BMI ising Quentelets formula (WHO 1995) for the ID population
6. Were the outcome measures clearly defined, valid, reliable, and	Y		– Logistic regression modelling – 95%Confidence interval for the risk of obesity compared to the normal population

Criteria	Yes	No CD NR NA*	Notes
implemented consistently across all study participants?			
7. Was the length of follow-up adequate?		NR	
8. Were the statistical methods well-described?	Y		– Used Stata v9 software – Logistically regression modelling – Likelihood ratio test was applied to determine levels of significance (*P-values*) – SMR in M (0.80; 95%CI O.64-1.00) (slightly lower) – SMR in F (1.48; 95%CI 1.23-1.77) – DS more likely than expected to be obese SMR (1.39; 95%CI 1.06-1.82) – *SMR=Standard Mortality Ratio
9. Were the results well-described?	Y		– 28% overweight and 20.7% obese – Comparator data for the general population provided – 74% under 50yrs 50.88% White and 59% lived in residential care – Characteristics of the study population (ID) described – Risk factors identified for ID = type of accommodation; feeding skills; sex; hypertension; DS;CP – Living independently or with family at home; F; DS; hypertension ^risk – Compared to GP women with an ID and those with DS more at risk (but not men) – Univariate analysis ID and mild ID risk

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: Good
Rater #2 initials:
Additional Comments (If POOR, please state why):

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

7. QUALITY ASSESSMENT OF CASE SERIES STUDY

Study 7: *Hsieh, K., Rimmer, J.H. and Heller, T. (2014) Obesity and associated factors in adults with intellectual disability, 58(9), 851-863.*

	Yes	No Other (CD,NR,NA)*	Notes
1. Was the study question or objective clearly stated?	Y		– Relationship between modifiable and non modifiable risk factors/antecedents for obesity – 4 primary research questions
2. Was the study population clearly and fully described, including a case definition?	Y		– Baseline data examined form 4 yr longitudinal study (n=1450) – 800 M (55.2%) and 650 F (44.8%) participated – Age range 18-89 – Majority white (88.5%) employed (60.4%) – Lived in moderately supported residential types with family, relatives or guardians (57.4%) – Chi-squared analysis indicated not significant group difference between age race level of disability – Data compared to general population from National Health Interview Survey – Parents and staff working in service & volunteers provided information – Data was compared with 2010 NHIS Higher overall prevalence in people ic ID 38.3% V 28% and was higher across all age groups – Women 42.3% V 27.7% and Men 34.3 V 28.3% Morbid obesity F 10.9% V 5.4% – Morbid obesity M 4.5% V 3%
3. Were the cases consecutive?	Y		– Data analysed from convenience sample participants of an existing longitudinal study
4. Were the subjects comparable?	Y		– Age range over represented in 18-39 (61% V 38%) – Under represented 60+ (8% V 28%) – F 45% M55% V F56% M44%
5. Was the intervention clearly described?	Y		– Survey distributed to 2841 (paper) and 659 (on line) – 1619completed (1183 paper and 436 on line) – 1450 eligible for analysis
6. Were the outcome measures clearly defined, valid, reliable, and implemented	Y		– Dependant variable = obesity – Independent variables = nonmodifiable antecedents

	Yes	No Other (CD,NR,NA)*	Notes
consistently across all study participants?			– Modifiable risk factors and environmental factors – BMI – Measured (informant reported) – OW= BMI ≥25 and <30 kg/m² OB ≥30 MO ≥40kg/m²
7. Was the length of follow-up adequate?		N/A	– No follow up
8. Were the statistical methods well-described?	Y		– Descriptive statistics used to examine body weight status and prevalence of OB – Univariate logistical regression – *P* value cut off of 0.25 (resputed in the elimination of some variables smoking; S Olympics; fast food intake; mobility – Multivaraite logistic regression (block entry method) *P* value of *.05* used for analysis
9. Were the results well-described?	Y		– Combined (M%F) OW was 38.3% and OW 28.9% respectively – Prevalence of Obesity for F 43.2% & M 34.3% – Overweight M 31.6% F 25.2% – OB highest in the 40-59 yr age group – Morbid Obesity double for F 10.9% V 4.5% M – Data provided as per age group; Sex; diagnosis; resident type; level of ID – Obesity more prevalent in DS (53.4%) MO (10.4% V 8.1%) – Lower rates in those with severe/profound ID (26.1%) Moderate/mild/borderline ID 43.9% – Living independently or supportive living (41. %) MO – 9.3%)

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: Good Study
Rater #2 initials:
Additional Comments (If POOR, please state why):

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

8. QUALITY ASSESSMENT OF CASE SERIES STUDY

Study 8: *Belle, A.J. and Bhate, M.S (1992) Prevalence of overweight and obesity in Down's syndrome and other mentally handicapped adults living in the community, Journal of Intellectual Disability Research,* ***36,*** *359-364.*

Criteria	Yes	No CD NR NA*	Notes
1. Was the study question or objective clearly stated?	Y		– To ascertain the prevalence of OW/O in ID population. Title identifies ID and DS. Within the study the findings are compared to general population figures but this is not identified in the title or abstract
2. Was the study population clearly and fully described, including a case definition?	Y~		– All live in a single health district in the UK – Either live at home (majority) attend day service or live in hostels or supervised flatelets – Level of ID from Mild to profound ID – 211 adults (119 M (56.39%) & 92 (43.6%) in day services but data collected from **183** adults (86.72%) – Sample included 58 people ic DS (31.69%) – 78 F (42.62% F) with 24 (30.76%) DS – 105 M (57.37%) with 34 (32.38%) DS – Data compared to general population figures but no details of the numbers/sex/age of those involved offered
3. Were the cases consecutive?		NR	
4. Were the subjects comparable?	Y		– Difficult to ascertain in relation to the general population as the figures for those not provided. – Comparable figures for ID population – Sample included 58 people ic DS (31.69%) – 78 F (42.62% F) with 24 (30.76%) DS – 105 M (57.37%) with 34 (32.38%) DS
5. Was the intervention clearly described?	Y		– BMI – Metropolitan Insurance Company (1960) – Cut off applied across the study to support comparability with general population cut off for BMI
6. Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?		No	– BMP calculated from height and weight measurements but no indication whether by researcher or by proxy and no data on equipment or process

Criteria	Yes	No CD NR NA*	Notes
7. Was the length of follow-up adequate?		NR	
8. Were the statistical methods well-described?		No	Tables were summarised but no detail provided
9. Were the results well-described?	Y~		– Statistics presented with BMI combined rate for overweight and obesity (*n*=183). – Data was further divided into rates for Males (*n*=105) Down Syndrome Males (34) Normal male population (100%) – and females (*n*=78) Down Syndrome Males (24) Normal male population (100%) – However the origin of the 100 % general population comparator is not explained

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: Fair
Rater #2 initials:
Additional Comments (If POOR, please state why):

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

9. QUALITY ASSESSMENT OF COHORT AND CORSS-SECTIONAL STUDIES

Study 9. *Stancliffe, R., Larkin, K.C., Larson, S., Engler, J., Bershadsky, J., Taub, S., Fortune, J. and Ticha, R. (2011) Overweight and Obesity among adults with Intellectual disabilities who use intellectual disability/developmental disability services in 20 US States, American Association of Intellectual and Developmental Disabilities, 116(6), 401-418.*

Criteria	Yes	No CD NR NA*	Notes
1. Was the research question or objective in this paper clearly stated?	Y		– Aim of the study to compare the prevalence of – Obesity in people with an intellectual disability and from and the general US adult population. Comparisons by age, Sex and ethnicity
2. Was the study population clearly specified and defined?	Y		– People with an ID were recruited from National Core Indicator (NCI) survey taken from 2008-2009 and for the general population from the National Health And Nutrition Examination (NHANES) survey data collated from 2007-2008. Average age 43.48 (20-93) – Comparative information by age, racial groups
3. Was the participation rate of eligible persons at least 50%?	Y		– Study population of 8911 adults over 18 from 20 states (average participation per state 578). Original population 11,569 (99 excluded because of missing data age and 208 sample members 18 or 19 because the general population sample included adults overv20 further 421 participants excluded because of missing data and those with no id) – 8,911 participants with an ID
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?	Y		Comparator group categories matched to the general population

Criteria	Yes	No CD NR NA*	Notes
5. Was a sample size justification, power description, or variance and effect estimates provided?			One way analysis of variance (ANOVA) identified a significant difference between diagnostic group $f(3,8268)=116.38$, $p<.001$ (homogeneity tainted) Tamahones T2 test used to compare groups
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	Y		Data on weight and height pre-existed and from this data Body Mass Index (BMI) was calculated
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?		N/A	One point in time
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)?	Y		The comparison between people with an ID and the general population were measured in by age group and racial grouping.
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			BMI for people with an ID calculated from existing height (feet and inches) and weight measurements (Ib's) BMI = (IB) X 703 Height $(ft)^2$
10. Was the exposure(s) assessed more than once over time?		N	
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?		N	

Criteria	Yes	No CD NR NA*	Notes
12. Were the outcome assessors blinded to the exposure status of participants?		NA	
13. Was loss to follow-up after baseline 20% or less?		N/A	
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Y		

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: Fair (data for the comparator group poor)
Rater #2 initials:
Additional Comments (If POOR, please state why):

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

Appendix 2: Articles for Review (n=36)

Article authors and title	Considered for further Review	
	YES	NO
Batista, L.R.V., Moreira, E.A.M., Rauen, M.S., Corso, A.C.T. and Fiates, G.M.R. (2009) Oral health and nutritional status of semi-institutionalized persons with mental retardation in Brazil, *Research in Developmental Disabilities,* 30(5), 839-846.		√
Bazzano, A.T., Zeldin, A.S., Diab, I.R.S; Garro, N.M., Allevato, N.A. and Lehrer, D.(2009), The Healthy Lifestyle Change Program: A pilot of a community-based health promotion intervention for adults with developmental disabilities, *American Journal of Preventive Medicine,* 37(6), 201-208.		√
Bégarie, J., Maïano, C., Leconte, P., & Ninot, G. (2013) The prevalence and determinants of overweight and obesity among French youths and adults with intellectual disabilities attending special education schools, *Research In Developmental Disabilities*, 34(5), 1417.		√
Belle, A.J. and Bhate, M.S (1992) Prevalence of overweight and obesity in Down's syndrome and other mentally handicapped adults living in the community, *Journal of Intellectual Disability Research*, 36, 359-364.	√	
Bhaumik, S., Watson, J.M., Thorp, C.F., Tyrer, F. and McGrother, C.W (2008) Body mass index in adults with intellectual disability: Distribution, associations and service implications: A population-based prevalence study, *Journal of Intellectual Disability Research,* 52(4), 287-298.	√	
Chen, A.Y., Kim, S.E., Houtrow, A.J. and Newacheck, P.W. (2010) Prevalence of obesity among children with chronic conditions, *Obesity,* 18(1), 210-213.		√
Choi, E., Park, H., Ha, Y., & Hwang, W. (2012) Prevalence of Overweight and Obesity in Children With Intellectual Disabilities in Korea, *Journal Of Applied Research In Intellectual Disabilities*, 25(5), 476.		√
Cohn, T., Grant, S. and Faulkner, G.E. (2010) Schizophrenia and obesity: Addressing obesogenic environments in mental health settings, *Schizophrenia Research*, 121(1-3), 277-278.		√
Cooper, S-A., Smiley, E., Morrison, J., Williamson, A. and Allan, L. (2007): An epidemiological investigation of affective disorders with a population-based cohort of 1023 adults with intellectual disabilities, *Psychological Medicine*, 37(6), 873-882.		√

Article authors and title	Considered for further Review	
	YES	NO
de Winter, C., Bastiaanse, L., Hilgenkamp, T., Evenhuis, H., & Echteld, M. (2012) Overweight and obesity in older people with intellectual disability, *Research In Developmental Disabilities*, 33(2), 398-405.	√	
De, S., Small, J., Baur, L.A. (2008) Overweight and obesity among children with developmental disabilities, *Journal of Intellectual and Developmental Disability,* 33(1), 43-47.		√
Devapriam, J., Anand, A., Raju, L.B. and Bhaumik, S. (2009) Monitoring for metabolic syndrome in adults with intellectual disability on atypical antipsychotic drugs, *British Journal of Developmental Disabilities,* 55(108), 3-13.		√
Emerson, E., Robertson, J., Baines, S., & Hatton, C. (2016) Obesity in British children with and without intellectual disability: cohort study, *BMC Public Health*, 16(1), 1-10.		√
Foley, J., Lloyd, M., & Temple, V. (2013) Body Mass Index Trends Among Adult U.S. Special Olympians, 2005-2010, *Adapted Physical Activity Quarterly*, 30(4), 373-386.	√	
Garaulet, M,. Ordovás, J,. M. Madrid, J. A. (2010) Prevalence of overweight in adolescents with intellectual deficiency. Differences in socio-educative context, physical activity and dietary habits, *International Journal of Obesity,* 34(12), 1667-1683.		√
Gazizova, D., Puri, B., Singh, I., & Dhaliwal, R. (2012) The overweight: obesity and plasma lipids in adults with intellectual disability and mental illness, *Journal Of Intellectual Disability Research*, 56(9), 895.		√
Harris, N., Rosenberg, A., Jangda, S., O'Brien, K. & Gallagher, M. (2003) Prevalence of obesity in International Special Olympic athletes as determined by body mass index, *Journal Of The American Dietetic Association*, 103(2), 235-237,		√
Haveman, M., Heller, T., Lee, L., Maaskant, M. Shooshtari, S., Strydom, A. (2010) Major health risks in aging persons with intellectual disabilities: An overview of recent studies, *Policy and Practice in Intellectual Disability*, 7(1), 59-69.		√
Holcomb, M.J. Pufpaff, L.A., McIntosh, D.E. (2009) Obesity rates in special populations of children and potential interventions, *Psychology in the Schools,* 46(8), 797-804.		√
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Article authors and title	Considered for further Review	
	YES	NO
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Article authors and title	Considered for further Review	
	YES	NO
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Appendix 3: Estimating Height from Ulna Length Height (m)

Estimating Height from Ulna Length Height (m)

Men <65	1.94	1.93	1.91	1.89	1.87	1.85	1.84	1.82	1.80	1.78	1.76	1.75	1.73	1.71
Men >65	1.87	1.86	1.84	1.82	1.81	1.79	1.78	1.76	1.75	1.73	1.71	1.70	1.68	1.67
Ulna length	32.0	31.5	31.0	30.5	30.0	29.5	29.0	28.5	28.0	27.5	27.0	26.5	26.0	25.5
Women <65	1.84	1.83	1.81	1.80	1.79	1.77	1.76	1.75	1.73	1.72	1.70	1.69	1.68	1.66
Women >65	1.84	1.83	1.81	1.79	1.78	1.76	1.75	1.73	1.71	1.70	1.68	1.66	1.65	1.63
Men <65	1.69	1.67	1.66	1.64	1.62	1.60	1.58	1.57	1.55	1.53	1.51	1.49	1.48	1.46
Men >65	1.65	1.63	1.62	1.60	1.59	1.57	1.56	1.54	1.52	1.51	1.49	1.48	1.46	1.45
Ulna length	25.0	24.5	24.0	23.5	23.0	22.5	22.0	21.5	21.0	20.5	20.0	19.5	19.0	18.5
Women <65	1.65	1.63	1.62	1.61	1.59	1.58	1.56	1.55	1.54	1.52	1.51	1.50	1.48	1.47
Women >65	1.61	1.60	1.58	1.56	1.55	1.53	1.52	1.50	1.48	1.47	1.45	1.44	1.42	1.40

Appendix 4: Data Access Protocol

Data Use Protocol and Procedure of the Intellectual Disability Supplement of The Irish Longitudinal Study on Ageing (IDS-TILDA) May 2017

Intellectual Disability Supplement to TILDA,
Trinity College Dublin, The University of Dublin,
School of Nursing & Midwifery,
No. 2 Clare St,
Dublin 2,
Ireland

Telephone: (01) 896 3186 / (01) 896 3187
Fax: (01) 8963001

Email: idstilda@tcd.ie

Developed and reviewed by	Review Date
Prof. Mary McCarron, Prof. Philip McCallion, Eilish Burke	24/10/2011
Prof. Mary McCarron, Prof. Philip McCallion, Dr Rachael Carroll, Eilish Burke	12/03/2014
Prof. Mary McCarron, Prof. Philip McCallion, Dr Rachael Carroll, Dr Máire O’Dwyer, Eilish Burke	16/07/2015
Prof. Mary McCarron, Prof. Philip McCallion, Dr Rachael Carroll, Dr Mary-Ann O’Donovan, Dr. Eilish Burke	09/05/2017

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1.0 Protocol Statement

This policy will provide guidance on the use of IDS-TILDA research project data findings and results for the IDS-TILDA research team itself, for PhD/MD master's students and any person with whom the PIs may collaborate in the development of peer reviewed articles, presentations or any electronic or other dissemination.

In support of fundamental research ethical principles requiring the safeguarding participant confidentiality and strict adherence to fundamental precepts of research integrity, all access to, use of and publications from IDS-TILDA data will be managed and approved by the IDS-TILDA PIs supported by the project manager and the data manager.

2.0 Background

Currently, the IDS-TILDA dataset is only available with the permission of the PIs. With suitable protection the investigators will consider to access the dataset as they recognise the criticalness that publications from IDS-TILDA data be developed including by students and collaborators to (1) increase knowledge about the ageing of people with intellectual disability across a range of disciplines, (2) support the training of researchers, (3) influence consideration of key policy concerns and (4) offer data reports likely to encourage support for subsequent waves of data collection for the benefit of people with ID.

3.0 Definition of Terms

IDS-TILDA: Intellectual disability supplement to the Irish longitudinal study on ageing in Ireland hereinafter referred to as the project.

Investigators or PIs: Refers to the principal investigators Professor Mary McCarron and Professor Philip McCallion.

Research team member: All staff employed in the IDS-TILDA research study project either full time, part-time or under a contract basis as well as PhD/MD/Master's students supervised by the PIs.

Collaborators: All persons invited to contribute, write and work in a joint intellectual capacity with the IDS-TILDA team and investigators.

Public Use Dataset: At a future time the IDS-TILDA team will make the IDS-TILDA dataset available in an appropriate data archive. The specific protocol for the use of such a dataset will be posted there. In the interim, there is no public use dataset.

4.0 Scope of the Protocol

The protocol applies to all uses of the data other than by the investigators and research team staff they designate. The scope of this document may be amended in light of any future developments.

5.0 Purpose of the Protocol

The purpose of this policy is to provide all IDS-TILDA research team members, PhD and masters students and collaborators clear guidance regarding the use of project data to include all analyses, publications, oral presentations, electronic dissemination and/or other dissemination of the data.

6.0 Data User Roles and Responsibilities

All persons wishing to have access to data shall complete an IDS-TILDA Contract of Agreement and Data Access Request Form and furnish this to the investigators Prof. Mary McCarron and Prof. Philip McCallion (hardcopy and email).

Until such times as data files are posted as a public use dataset, the IDS-TILDA Contract of Agreement and Data Access Request Form must include (1) specification of a time period to access the data, (2) explanation of the research question and related analyses, (3) intended type of publication/dissemination, (4) a signed agreement that all PI stated restrictions on use will be adhered to and that a copy of the final data analysis file will be provided to the PIs for the IDS-TILDA data archive (5) acknowledgement in all products that IDS-TILDA is the source of the data, using the language provided by the investigators and (6) acknowledgement that the principal investigators will be the final arbitrator for all publication and data access related decisions.

6.1 Access to Data Concerns

Conducting research carries the responsibility to protect the confidentiality and privacy of participants. Access to data will therefore be carefully managed and granted to appropriate persons on the sole discretion and permission of the investigators. All data furnished shall be logged and tracked by the data manager in the IDS-TILDA office. All persons wishing to access data shall do so in adherence to the IDS-TILDA Contract of Agreement and Access to Data Procedure.

6.2 Data Access and Use by Investigators, Research Team members, Designated Collaborators and Investigator – supervised MD/PhD students

In providing access to the data the investigators reserve the right to directly write articles themselves, support PhD/MD students they supervise in the development of approved theses, and work with research team members and approved collaborators on the development of additional articles.

1. After receiving signed approval for the project proposal (see Permission to Access Data Proposal form) the research team member, collaborator or supervised PhD/MD/Master’s people with student will request the specific variables to be used in the proposed analysis.

2. Data will be accessed on secure computers located in the IDS-TILDA office[1].
3. These exceptional circumstances will ONLY refer to qualitative data access.
4. At all times access to the main IDS-TILDA quantitative dataset will occur at the IDS-TILDA office level ONLY.
5. Permission to access will ONLY be for the approved variables and timeframe.
6. No data shall be removed, copied or accessed outside the IDS-TILDA office.
7. Agreement to the terms of this protocol and procedure is understood on signature of the Data Access Proposal Form.

Access to the data is granted with the additional understanding that the investigators will have the opportunity to be among the authors on all publications, determine the scope of each article, authorize order of authorship, and establish the timelines for publication. These requirements are further specified in 6.3 and 6.4.

6.3 Authorship

For PhD/MD students and research staff, the investigators shall authorise all aspects of the proposed publications. This includes the content of the paper, early discussion of publication and authorship practice for the work, the appropriate authorship, the place of publication, the protection of intellectual property rights, and any release of results on the Internet.

An approved thesis will be the work of the PhD/MD student and will be completed within a timeline agreed with the investigators.

Articles by research team members and designated collaborators as well as articles resulting from PhD/MD theses are encouraged by the investigators and the scope, content, timeline for completion and order of authorship of articles to be completed will be negotiated in advance with the investigators. In particular, the investigators reserve the right to take back control of an article if agreed timelines are not met. This may include changing the originally agreed order of authorship.

The investigators will be the final arbitrators of all related decisions.

6.4 Criteria for authorship.

To be recognized as an author, a research team member, collaborator or PhD student shall

[1] *In the case of exceptional circumstances and only on the written agreement of both P.I's will any alternative arrangement to data access be facilitated. In all cases, data should always be on secure, encrypted laptop belonging to IDS-TILDA.*

- Contribute substantially to the IDS-TILDA creative process within any of the following areas: generation of hypotheses, data collection, analysis or interpretation of data.
- Contribute substantially to the preparation of the article to be published either through preparation of drafts or through critical revision.
- Accept in writing the final draft and be prepared to take public responsibility for the content.
- Meet the specific requirements for authorship required by any journal considered for publication.
- Within reasonable limits accept responsibility for the contents of the report as being based on honest research.

For members of the research team, designated collaborators and/or by PhD/MD students supervised by the investigators, the investigators must have the opportunity to review and approve the final version of any article/presentation/report to be submitted for publication or other type of dissemination.

7.0 Data Access Procedure for Non-Research Team Members or Investigator supervised PhD/MD students

After receiving signed approval from the investigators for the project proposal (see Permission to Access Data Proposal form).

1. Researcher or PhD/MD student (with a co-sign by their supervisor) will complete a variable request form (approved list will be available on confirmation of proposal) and submit the form to the data manager. Should the researcher seek variables beyond the approved list (e.g., identifiable variables such as open questions) a separate request shall be made to the investigators, cc the project and data managers.
2. The Project Manager will obtain related access permissions to the Drive on the secure IDS-TILDA server (this will require at least one week after receipt of data access approval).
3. On receipt of access permission the Data Manager will set up a secure folder with the data set requested.
4. The dataset is then available to access on a computer available in the IDS-TILDA office; the procedure for doing this will be demonstrated on the first day at the office.
5. All analysis shall be undertaken in the IDS-TILDA office, to that end approved researchers and PhD/MD students must arrange dates for 'hot desk' access (this

can be arranged when requesting folder setup) by liaising with the executive officer, Ms Madeline Smyth at msmyth2@tcd.ie or idstilda@tcd.ie or through the project or data managers.

6. No data shall be removed, copied or accessed except within the assigned folder on the secure J drive.
7. No data shall be removed, copied or accessed outside the IDS-TILDA office.
8. Agreement to the terms of this protocol and procedure is understood on signature of the Data Access Proposal Form.

The investigators will be the final arbitrators of all related decisions.

References

An Bord Altranais (2007) *Guidance to Nurses and midwives regarding Ethical Conduct of Nursing and Midwifery Research*. An Bord Altranais: Dublin.

Trinity College Dublin (2009) Policy on Good Research Conduct accessed on https://www.tcd.ie/research/dean/TCDGoodResearchPractice.pdf 24.10.2011.

Appendix 5: Family Information Pack

Intellectual Disability Supplement to TILDA

Trinity College, School of Nursing & Midwifery,
2 Clare Street, Dublin 2.
Tel: + 353 1 896 3186/3187
Fax: + 353 1 896 3001 Email: idstilda@tcd.ie

Dear family member/guardian,

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is a study on ageing in persons with intellectual disability in Ireland. The study is being carried out by Trinity College, Dublin. It the first longitudinal study of adults with an intellectual disability to run in tandem with a national longitudinal study on ageing in the general population.

For over 10 years, IDS-TILDA has been exploring the health, well-being and social inclusion of more than 700 people with intellectual disability aged 40 years and above as they grow older. As we now enter our fourth wave of data collection, we are looking to increase the number of participants in our study.

Your family member has been randomly selected to take part in IDS-TILDA. Participation is voluntary. However, this is an important study for informing future policy and service provision, and we will get better information as we increase the number of people taking part.

The study will involve three main elements:

1. A **questionnaire** to collect some information on health and other issues;
2. A face-to-face **interview** with one of our researchers; and
3. A **health assessment** with one of the nurses working on the study.

Your family member may be supported to participate in all of the above. The enclosed information leaflet provides further details about the study.

Intellectual Disability Supplement to TILDA
Trinity College, School of Nursing & Midwifery,
2 Clare Street, Dublin 2.
Tel: + 353 1 896 3186/3187
Fax: + 353 1 896 3001 Email: idstilda@tcd.ie

In addition to direct consent from your family member (where this is possible), we also ask for your agreement to their participation in the study. If you are happy for them to take part in IDS-TILDA, please sign the enclosed agreement form. Signed consent and agreement forms should be returned in the stamped addressed envelope provided.

If your family member takes part in the study, one of our researchers will phone to arrange a suitable time and place to do the interview with them. The researcher will also send out a questionnaire for them to complete in advance of the interview. Separately, a nurse will also be in contact to arrange their health assessment.

In the meantime, if you have any questions, please do not hesitate to contact me or a member of the research team on 01-896 3186 / 3187.

Yours sincerely,

Prof. Mary McCarron.

Professor Mary McCarron
Principal Investigator
Intellectual Disability Supplement to TILDA

What is the study about?

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is the most comprehensive study on ageing in persons with intellectual disability ever undertaken in Ireland. The study is being carried out by Trinity College Dublin and is the first longitudinal study of adults with an intellectual disability to run in tandem with a national longitudinal study on ageing in the general population (TILDA).

For over 10 years, IDS-TILDA has been exploring the health, well-being and social inclusion of more than 700 people with intellectual disability as they grow older. This information is used to inform the policy and services that affect the lives of people with intellectual disabilities in Ireland.

We interview our participants every three years, and will return for the fourth visit starting in September 2019. As we enter our fourth wave of data collection, we are looking to increase our number of study participants. So we are now inviting more people with an intellectual disability to take part in the study.

How are participants selected for the study?

Study participants were randomly selected from the National Intellectual Disability Database (NIDD).

People registered on the database who have an intellectual disability and who are aged 40 years or more may be selected to take part in the study. Those invited to take part in the study were randomly selected from this database by the Health Research Board.

Does the person with intellectual disability that is selected have to take part?

No. Taking part is voluntary. However, this is an important study for informing future policy and service provision, and we will get better information as we increase the number of people taking part. Those who agree to take part in the study are free to withdraw at any time if they choose.

What if the person with intellectual disability does not take part?

If the person with an intellectual disability does not take part or later decides to withdraw, their decision will in no way affect the current or future services or supports offered to them.

What does the study involve?

The study will involve two main elements:

1. A survey of health and other issues;
2. A face-to-face interview with one of our researchers; and
3. A health assessment with one of the nurses working with the study.

What does the interview involve?

A researcher with experience of working with people with intellectual disabilities will visit the participant to interview them. The interview will include questions about their health, lifestyle, living circumstances and quality of life.

Participants who are unable to give this information on their own can be supported in their interview. In such cases, they may ask someone (for example, a family member, guardian, key worker or advocate) to support them in giving this information.

Participants will also be asked to perform a number of tasks, such as:

- brushing their hair
- writing their name
- naming colours

The interview usually takes around 2 hours. However, this will vary for each person. Participants may take breaks during the interview or arrange a second visit if necessary.

What does the health assessment involve?

A nurse will visit the service and invite the participant to do a health assessment with them. The nurse will contact them to arrange a suitable time. The health assessment takes a range of important health measures, including:

- A small blood sample from a finger prick
- Breath test
- Teeth and mouth check
- The food the person eats
- Foot exam
- Blood pressure
- Height and weight measures
- Waist, hips and leg measures
- Timed stand-up and walk
- Grip strength
- Bone health
- Questions to test my memory

The health assessment will take about one hour in total.

Are there any risks involved?

There are no known risks involved in this study. We will explain each stage of the study to the person with intellectual disability using accessible materials. At all times, the well-being of participants will take priority over research activities. If the person with an intellectual disability tells us or indicates that they do not want to take part, or decides to withdraw, we will fully respect their decision.

Is the study confidential?

Yes. We will treat all information as strictly confidential and we will not publish the name of the participant or pass it on to anyone outside of the research team. The Faculty of Health Sciences Research Ethics Committee, of Trinity College, Dublin, has approved this study and ensured that proper safeguards are in place.

Who is involved in the study?

This study has been set up by people who have a lot of experience working with people with intellectual disability. The advisory team includes family members, researchers, nurses, doctors, psychologists, psychiatrists, and service providers.

People with intellectual disabilities also play an important role in our advisory team through participation in consultative workshops, which are run throughout the country.

Where can I get more information?

If you would like to know more about the study please contact:

Ms Margaret Haigh
Project Manager
Phone: 01- 896 3186/3187
Email: haighm@tcd.ie

Or write to:

IDS-TILDA,
Trinity College,
School of Nursing & Midwifery,
2 Clare Street,
Dublin 2.

The Intellectual Disability Supplement to TILDA is funded by the Health Research Board.

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)




Trinity College Dublin

Appendix 6: Calculation of Portions per day (PPD) from the Variables

Sample documentation of variables

Variable name: Average_daily_veg_shelf_count; Average_daily_carbs_shelf_count; Average_daily_dairy_shelf_count; Average_daily_protein_shelf_count; Average_daily_fats_shelf_count; Average_daily_sweets_shelf_count

Description: Daily food pyramid average counts based on the food frequency questionnaire with the following frequencies:

'Never or less than once a month'=0

'1-3 per month' =0.067 (2/30days)

'Once a week'=0.143 (1/7days)

'2-4 times per week'=0.429 (3/7days)

'5-6 times per week'=0.786 (5.5/7days)

'Once a day'=1 (7/7days)

'2-3 per day'=2.5

'4-5 per day'=4.5

6+ per day=6

Code used to create these variables:

- NAs in the FFQ are = 0 on the food pyramid shelves.
- 12 people said they drink other milk (non dary/soya) Their mls were not counted in the food pyramid dairy shelf.
- Marmite was put in the sugar/salt shelf.

Extra note on milk:

Milk was treated differently as follows.

Food pyramid 1 measure =200mls

FFQ Measures Daily Intake(mls)

The FFQ reads

How much milk do you use each day?

PLEASE TICK ONE BOX

Less than half a pint

250ml (half pint)

568ml (1 pint)

One litre

More than one litre

This was converted to Average Daily Intake :

< ½ pint 150/200 0.75

250 ml (half pint) 250/200 1.25

568ml (1 pint) 568/200 2.84

One litre (1.75 pints) 1000/200 5

More than one litre 11372/200 (calculated from 2 pints) 5.7

daily_milk_intakes = c(150/200 ,250/200,568/200,1000/200,11372/200)

Variables used to create these new variables:

Average_daily_sweets_shelf_count:

[1] "Q3E_Dairy_desserts" "Q3I_Biscuits_chocolate"

[3] "Q3I_Biscuits_plain" "Q3I_Tea_1"

[5] "Q3I_Cakes" "Q3I_Buns_pasteries"

[7] "Q3I_Fruit_pies" "Q3I_Sponge_puddings"

[9] "Q3I_Milk_puddings" "Q3I_Ice_cream"

[11] "Q3I_Chocolates" "Q3I_Sweets"

```
[13] "Q3I_Suggar_added"           "Q3I_Sugar_substitute"
[15] "Q3I_Crisps"                 "Q3I_Peanuts"
[17] "Q3J_Soup_meat_tinned_packet"  "Q3J_Marmite_Bovril"
[19] "Q3J_Jams"                   "Q3J_Peanut_butter"
[21] "Q3K_Cocoa"                  "Q3K_Fizzy_drinks_low_calorie"
[23] "Q3K_Fizzy_drinks"           "Q3K_Fruit_juice"
[25] "Q3K_Fruit_squash"
```

Average_daily_veg_shelf_count;

```
[1] "Q3_Lamb_stew"                "Q3D_Lasagne_meat"
[3] "Q3D_Moussaka"                "Q3D_Pizza"
[5] "Q3E_Quiche"                  "Q3G_Apples"
[7] "Q3G_Pears"                   "Q3G_Oranges"
[9] "Q3G_Grapefruit"              "Q3G_Bananas"
[11] "Q3G_Grapes"                 "Q3G_Melon"
[13] "Q3G_Peaches"                "Q3G_Aprocots"
[15] "Q3G_Strawberries"           "Q3G_Fruit_tinned"
[17] "Q3G_Fruit_dried"            "Q3G_Fruit_frozen"
[19] "Q3H_Carrots"                "Q3H_Spinach"
[21] "Q3H_Broccoli"               "Q3H_Brussel_sprouts"
[23] "Q3H_Cabbage"                "Q3H_Peas"
[25] "Q3H_Courgettes"             "Q3H_Cauliflower"
[27] "Q3H_Parsnips_turnips"       "Q3H_Leeks"
[29] "Q3H_Onions"                 "Q3H_Garlic"
[31] "Q3H_Mushrooms"              "Q3H_Sweet_peppers"
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[33] "Q3H_Lettuce" "Q3H_Cucumber_celery"

[35] "Q3H_Tomatoes" "Q3H_Sweetcorn"

[37] "Q3H_Beetroot" "Q3H_Coleslaw"

[39] "Q3I_Fruit_pies" "Q3J_Soup_vegetable_fresh"

[41] "Q3J_Soup_vegetable_packet_tinned" "Q3J_Soup_meat_fresh"

[43] "Q3J_Soup_meat_tinned_packet"

Average_daily_carbs_shelf_count;

[1] "Q3_Breaded_chicken" "Q3_Savoury_pies"

[3] "Q3_Fish_batter" "Q3_Fish_bread_crumbs"

[5] "Q3_Fish_fingers" "Q3B_White_bread"

[7] "Q3B_Brown_bread" "Q3B_Wholemeal_bread"

[9] "Q3B_Crackers" "Q3B_Crisp_bread"

[11] "Q3B_Pancakes_muffins_oatcakes" "Q3B_Baguette"

[13] "Q3C_Porridge" "Q3C_All_bran"

[15] "Q3C_Branflakes" "Q3C_Oatmeal"

[17] "Q3C_Cornflakes" "Q3C_Muesli"

[19] "Q3C_Sugar_coated" "Q3C_Fortified_cereal"

[21] "Q3D_Potatoes_boiled" "Q3D_Potatoes_mashed"

[23] "Q3D_Chips" "Q3D_Potatoes_roast"

[25] "Q3D_Potato_salad" "Q3D_White_rice"

[27] "Q3D_Brown_rice" "Q3D_Pastas"

[29] "Q3D_Wholemeal_pasta" "Q3D_Lasagne_meat"

[31] "Q3D_Moussaka" "Q3D_Pizza"

[33] "Q3D_Macaroni" "Q3E_Quiche"

[35] "Q3I_Sponge_puddings" "Q3J_Soup_vegetable_packet_tinned"

[37] "Q3J_Soup_meat_tinned_packet" "Q3J_Sauces"

Average_daily_dairy_shelf_count;

[1] "Q3B_Pancakes_muffins_oatcakes" "Q3D_Lasagne_meat"

[3] "Q3D_Moussaka" "Q3D_Pizza"

[5] "Q3D_Macaroni" "Q3E_Yoghurt"

[7] "Q3E_Dairy_desserts" "Q3E_Cheddar_cheese"

[9] "Q3E_Cheddar_cheese_low_fat" "Q3E_Quiche"

[11] "Q3I_Sponge_puddings" "Q3I_Milk_puddings"

[13] "Q3J_Soup_meat_tinned_packet" "Q3J_Sauces"

[15] "Q3J_Cheese_sauce_gravy" "Q3J_Tomato_sauce"

[17] "Q3J_Pickles_chutney" "Q3K_Cocoa"

[19] "Q3K_Horlicks_Ovaltine"

Average_daily_protein_shelf_count;

[1] "Q3_Beef_roast" "Q3_Beef_steak"

[3] "Q3_Beef_mince" "Q3_Beef_stew"

[5] "Q3_Beef_burger" "Q3_Pork_roast"

[7] "Q3_Pork_chops" "Q3_Pork_slices_steak_escalopes"

[9] "Q3_Lamb_roast" "Q3_Lamb_chops"

[11] "Q3_Lamb_stew" "Q3_Chicken"

[13] "Q3_Breaded_chicken" "Q3_Bacon"

[15] "Q3_Ham" "Q3_Corned_beef"

[17] "Q3_Luncheon_meats" "Q3_Sausages"

[19] "Q3_Savoury_pies" "Q3_Heart_kidney"

[21] "Q3_Fish_batter" "Q3_Fish_bread_crumbs"

[23] "Q3_Fish_baked_griller" "Q3_Fish_fingers"

[25] "Q3_Fish_other" "Q3A_Oily_fish_fresh"

[27] "Q3A_Oily_fish_canned" "Q3A_Shellfish"

[29] "Q3A_Canned_sardines" "Q3D_Lasagne_meat"

[31] "Q3D_Moussaka" "Q3E_Eggs"

[33] "Q3E_Quiche" "Q3H_Beans"

[35] "Q3H_Beansprouts" "Q3H_Baked_beans"

[37] "Q3H_Tofu" "Q3I_Peanuts"

[39] "Q3J_Soup_meat_fresh" "Q3J_Soup_meat_tinned_packet"

Average_daily_fats_shelf_count;

[1] "Q3_Fish_batter" "Q3_Fish_bread_crumbs"

[3] "Q3D_Potatoes_roast" "Q3D_Potato_salad"

[5] "Q3D_Pizza" "Q3E_Cream"

[7] "Q3E_Salad_cream_light" "Q3E_Salad_cream"

[9] "Q3E_Other_salad_dressing" "Q3F_Butter"

[11] "Q3F_Butter_light" "Q3F_Sunflower_margarine"

[13] "Q3F_Margarine_low_fat" "Q3F_Cholesterol_lowering_spreads"

[15] "Q3F_Cream_and_vegetable_oil_spread" "Q3F_Olive_oil_spread"

[17] "Q3I_Peanuts" "Q3J_Soup_meat_fresh"

[19] "Q3J_Soup_meat_tinned_packet"

Appendix 7: Sugar Sweetened Beverages

In addition to food intake, body weight is affected by consumption of sugar-sweetened beverages (Harrington *et al.* 2020). Energy dense drinks are alcohol free products with sugar and caffeine among its main ingredients (Government of Ireland 2019). These sugar-sweetened beverages (SSB) also include drinks containing additional calories such as sucrose or fruit juice concentrates (WHO 2015). Disproportionate consumption of high-sugary energy drinks is an acknowledged barrier in the global race against overweight and obesity (Malik and Hu 2022; Te Morenga *et al.* 2013). The past twenty years has seen a discernible growth in the energy drinks market both globally and in Ireland. Reported sales of energy drinks were appraised in 2012 to be over 12.5 billion US dollars demonstrating a 60% increase over a 4 year period from 2008 (Breda *et al.* 2014). In Ireland, the number of energy drink products available increased from 10 products in 2000 to 39 products by 2015 (Government of Ireland 2017). In the UK there was a 155% increase in overall consumption of high sugary drinks reported from 2006-2014 (Visram *et al.* 2015). The World Health Organisation (2015) noted the potential positive benefits of fiscal policies on patterns of dietary consumption recommending the application of Sugar Sweetened Tax as part of an overall measure in addressing health. The Irish Government, in an effort to tackle rising levels of overweight and obesity introduced a specific tax on these readily available high sugary dense drinks. Since 2018, this Sugar Sweetened Drinks Tax (SSDT) is applied to manufacturers of these products in accordance with the volume of sugar-sweetened beverages they produce or import. Duties are set at a rate of 5g of sugar and below 8g per 100ml where products were taxed at a rate of 16.26c per litre and a second higher rate provided for those above 8g per 100ml taxed at 24.39c per litre (Government of Ireland 2017). A similar tax is in place in the UK and many other countries (WHO 2015).

Methodology

Participants record the type and regularity of consumption from a range of drinks options. Therese included tea, coffee, soft drinks both fizzy both low calorie or diet drinks as well as fruit juices and fruit squash. The questions were asked in terms of the level of daily (ranging from once per day to 6+ per day)/weekly/monthly intake. These were measured as cups per day (tea/coffee) or per glass or small glass in terms of fruit squash or pure fruit juices and are itemised within different shelves of the food pyramid. For example, unsweetened fruit juice recommended consumption is limited to a once per day limit and is listed on the first shelf of the food pyramid. In contrast, fuzzy drinks, confined to the top shelf of the food pyramid are recommended only for occasional intake.

Consumption pattern analysis

Analysis indicated that tea was the drink consumed most frequently by participants, with 4-5 cups per day the most regularly occurring intake measure reported. More cups of tea were drank 4-5 times per day by participants who were overweight or obese (70.8%, n=85/120) than those with a normal BMI (29.2%, n=35/120). On the opposite end of the tea intake level of never/less than once a month, consumption levels were comparatively low as is indicated in table 8.1 below. It should be noted that this question within the food frequency questionnaire did not include detail on tea with sugar or sweeteners added nor the type of milk (low or full fat) if any added to the tea.

Coffee consumption overall was relatively low and when reported, never\less than once per month was the most reported level overall (n=175/388). When consumed, more frequent reported intake of one cup per day was reported in overweight or obese participants (66.7%, n=38/57) than by participants with a normal BMI measure (33.3%, n=19/57).

Low calorie soft fizzy drinks were consumed never/less than once per month (n=138/383) and again the majority of those who reported this frequency (71.0%, n=98/138) were overweight or obese compared with 29.0% (n=40/138) within the normal weight range. Low consumption levels of fizzy soft drinks was reported where the majority of overweight or obese participants reported never/less than once per month (75.4% (n=156/207) as did 24.6%, (n=51/207) within the normal weight range. Additionally, seven in ten overweight or obese participants had fizzy soft drinks once per week (70.7%, n=41/58) as did 29.3% (n=17/58) in the normal weight, although the overall reported levels were relatively low (*p* value = 0.021).

In terms of intake of pure fruit 70.9% (n=100/141) of overweight or obese participants reported never/or once per month drinks followed by once per day (77.2%, n=71/92) compared with 22.8% (n=21/92) within the normal weight category. Finally fruit squash was consumed at least once per day by 76.7% (n=46/60) of participants with a BMI in the overweight or obese range compared with 23.3% (n=14/60) with a normal BMI.

Consumption of Drinks

As may be expected for a population based in Ireland, tea was the drink most frequently consumed drink by participants of this study. Although sugar and milk added to tea was not measures as part of this study, therefore its dietary impact is not apparent. However, if the average 4-5 cups consumed per day include a teaspoon of sugar (4.2 grams per spoon), this would equate to an additional 21 grams of sugar per day in tea alone. What was also interesting in this study was that intake at this level was most frequently reported in participants who were overweight or obese (70.8%, n=85/120) as opposed to those with a normal BMI (29.2%, n=35/120).

Overall coffee consumption was low but when consumed was again reported more frequently in overweight or obese participants (66.7%, n=38/57) although this measure was never/less than once a month so actual consumption of one cup per day cannot be inferred from these findings.

Another interesting finding was the low reported intake of fizzy soft drinks. Problematic consumption of sugary drinks has influenced legislative changes with the imposition of additional sugar based tax. In this study however, the most frequently cited consumption level was never/less than once per month. Nonetheless, seven in ten overweight or obese participants had fizzy soft drinks once per week (70.7%, n=41/58) as did 29.3% (n=17/58) with a normal BMI although the overall reported levels were relatively low this was statistically significance (*p* value = 0.021). It would be interesting to monitor this longitudinally to ascertain if over time, consumption pattern changes in line with lifestyle changes. Finally, fruit quash was a popular drink for participants with over three quarters of overweight or obese participants having this drink at least once per day.

Appendix 7A: Drinks Consumption by Recommended Daily Allowance (RDA) (per cup/glass)

	n	%	n=	%		
Tea (cup)					**397**	0.063
Never//less than once per month	19	47.5	21	52.5	40	
1-3 per month	1	33.3	2	66.7	3	
Once per week	0	0	5	100	5	
2-4 per week	1	11.1	8	88.9	9	
5-6 per week	6	50	6	50	12	
Once per day	9	23.7	29	76.3	38	
2-3 per day	26	23.6	84	76.4	110	
4-5 per day	35	29.2	85	70.8	120	
>6 and <8 per day	20	34.5	38	65.5	58	
9+ per day	0	0	2	100	2	
Coffee (instant) (cup)					**388**	0.118
Never//less than once per month	57	32.6	118	67.4	175	
1-3 per month	3	11.1	24	88.9	27	
Once per week	10	41.7	14	58.3	24	
2-4 per week	6	17.6	28	82.4	34	
5-6 per week	6	42.9	8	57.1	14	
Once per day	19	33.3	38	66.7	57	
2-3 per day	9	20.9	34	79.1	43	
4-5 per day	2	22.2	7	77.8	9	
6+ per day	1	20	4	80	5	
Low calorie or diet soft fizzy drinks (glass)					**383**	0.684

	n	%	n=	%		
Never//less than once per month	40	29	98	71	138	
1-3 per month	22	40	33	60	55	
Once per week	20	27	54	73	74	
2-4 per week	18	28.1	46	71.9	64	
5-6 per week	4	40	6	60	10	
Once per day	6	20.7	23	79.3	29	
2-3 per day	3	30	7	70	10	
4-5 per day	1	33.3	2	66.7	3	
Drinks - fizzy soft drinks (glass)					**378**	**0.012**
Never//less than once per month	51	24.6	156	75.4	207	
1-3 per month	25	46.3	29	53.7	54	
Once per week	17	29.3	41	70.7	58	
2-4 per week	10	28.6	25	71.4	35	
5-6 per week	4	50	4	50	8	
Once per day	1	7.7	12	92.3	13	
2-3 per day	2	66.7	1	33.3	3	
Drinks - pure fruit drinks (small glass)					**378**	0.204
Never//less than once per month	41	29.1	100	70.9	141	
1-3 per month	14	32.6	29	67.4	43	
Once per week	11	33.3	22	66.7	33	
2-4 per week	14	29.8	33	70.2	47	
5-6 per week	6	37.5	10	62.5	16	
Once per day	21	22.8	71	77.2	92	
2-3 per day	5	50	5	50	10	

	n	%	n=	%		
4-5 per day	0	0	3	100	3	
6+ per day	2	100	0	0	2	
Drinks – fruit squash (small glass)					**381**	0.244
Never//less than once per month	38	26.4	106	73.6	144	
1-3 per month	13	44.8	16	55.2	29	
Once per week	7	23.3	23	76.7	30	
2-4 per week	10	32.3	21	67.7	31	
5-6 per week	5	23.8	16	76.2	21	
Once per day	14	23.3	46	76.7	60	
2-3 per day	20	37	34	63	54	
4-5 per day	4	57.1	3	42.9	7	
Once per day	1	20	4	80	5	