



Utilising bespoke technology to assist people with intellectual
disabilities in self-managing their weight: blending a Health Psychology
and Behaviour Analytic approach

by

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I confirm that the word count of this thesis is less than 100,000 words.

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Abstract

Overweight is an on-going health challenge disproportionately experienced by people with an intellectual disability (ID). Emerging literature indicates that multi-component interventions are most effective at reducing obesity in this population. The systematic review in Chapter 2 supports this view and proposes a specific ‘Component Guideline’ to be utilised to structure future research. Mobile app technology has been developed to support weight management however, existing off-the-shelf weight management apps remain too complex for many people with an ID. This research is a pilot of ‘The HealthyTaps Programme’, an ID specific health promotion series and multi-component weight management programme utilising bespoke mobile app technology to support self-management. A series of focus groups explored the knowledge-base and lived experiences of adults with ID with regards to diet, exercise, and technology. The main findings were that research and practice would benefit from understanding the influence that internalisation of health promotion messages, effective external reinforcement systems, and positive feedback can have to support the adoption of healthier habits. Essential components in technology use for people with an ID were found to be ownership, education, support, regular access, and regular use. The findings informed the design of ‘The HealthyTaps Programme’. The pilot study of ‘The HealthyTaps Programme’ with 28 adults with ID achieved mean weight losses of -3.9%. Thirty-two percent of participants lost over -5% of their body weight which is clinically significant, and which exceeds the NICE (2014^a) guidelines for effective interventions for the general population. A replication study with 11 adults with ID, also reported in this thesis, achieved mean weight losses of -4.0%, and 27% of the participants with $\geq -5\%$ weight loss, demonstrating reliability in the intervention effects. These are extremely promising initial results that warrant further exploration, ideally with a more robust design such as a randomised control trial of The HealthyTaps Programme.

Abbreviations

BCI	Behaviour Change Intervention
BMI	Body Mass Index
CDC	Centers for Disease Control and Prevention
COS	Circle of Support
DI	Dietary Intervention
GP	General Population
HPES	Health Promotion Education Series
HPI	Health Promotion Intervention
HRQL	Health Related Quality of Life
ID	Intellectual Disability
MCI	Multi-component Intervention
MVPA	Moderate to Vigorous Physical Activity
NICE	National Institute for Health and Care Excellence
OA	Older Adults
OB1	Obese Category 1

OB2	Obese Category 2
OB3	Obese Category 3
OW	Overweight
PA+ BCI	Physical Activity + Behaviour Change Intervention
PAI	Physical Activity Intervention
PIN	Personal Identification Number
RCT	Randomised Control Trial
SD	Standard Deviation
SIGN	Scottish Intercollegiate Guidelines Network
SMART	Specific, Measurable, achievable, realistic, and timely
TLD-ID	Traffic Light Diet for Intellectual Disabilities
TTM	Transtheoretical Model of Change
WHO	World Health Organisation
YA	Younger Adults

Chapter 1 Introduction

**Introduction: Utilising bespoke technology
to assist people with intellectual disabilities in
self-managing their weight: blending a
Health Psychology and Behaviour Analytic
approach**

1.1 Introduction

1.1.1 The Issue of Obesity

Leading a healthier life involves self-management of two main areas: (i) self-management of food intake, aiming for majority of consumption to be nutritional, low calorie-dense foods; and (ii) self-management of physical activity, aiming for regular engagement in adequate levels of physical exercise (National Institute for Health and Care Excellence [NICE], 2014^a; Scottish Intercollegiate Guidelines Network [SIGN], 2010). However, the obesogenic environments we often find ourselves immersed in encourage regular consumption of calorie-dense foods, and more sedentary lifestyles (Townsend & Lake, 2017; De Castella, 2014). These increasingly common habits have led towards greater and greater numbers of overweight adults worldwide. In fact, the rapid increase in overweight adults over the last 4 decades has become one of the major public healthcare concerns globally, with some referring to the phenomenon as an epidemic (Swinburn et al., 2011).

The World Health Organisation [WHO] (2019) define overweight as “an abnormal or excessive fat accumulation that may impair health”. At present, the internationally accepted measurement of Body Mass Index (BMI) is used as the basic clinical screening tool for weight classification in adults, with a BMI of $\geq 25\text{kg/m}^2$ categorised as overweight and a BMI of $\geq 30\text{kg/m}^2$ categorised as obese (WHO, 2019; SIGN, 2010). Being overweight is correlated with increased risks of developing up to 20 co-morbid chronic diseases, such as cardiovascular disease, diabetes, hypertension, stroke, and some cancers (Guh et al., 2009; Morgan & Dent, 2010). Renehan, Tyson, Egger, Heller and Zwahlen (2008) found that with every extra 5kg/m^2 increase in BMI above normal weight the possibility of certain cancers can increase by up to 52% in men and 59% in women. The risk of developing hypertension was also found to be approximately three times higher for adults who were overweight (Dustan, 1989), and even modest weight loss of between -5% to -10% in obese patients has been shown to reduce hypertension to below medication levels (Mertens & Gaal, 2000).

In addition to chronic diseases, many other physical ailments such as back pain, joint pain, disturbed sleep, and fertility problems go hand-in-hand with carrying excess body weight, all of which negatively impact daily living and reduce physical functioning for those affected (National Heart Lung and Blood Institute (2019); Ogunbode, Fatiregun & Ogunbode, 2009). As weight increases, physical functioning becomes increasingly impaired and the ability to perform everyday tasks reduces, directly impacting quality of life. Studies examining the effects of obesity on health-related quality of life (HRQL) measures have reported decreases in both physical functioning and psychological well-being for overweight individuals when compared to normal weight individuals, with those classed as obese being most affected (Kushner & Foster, 2000; Katz, McHorney & Atkinson, 2000; Mayo Foundation for Medical Education and Research, 2019). The psychological effects of obesity are often seen to be more damaging to quality of life than physical effects, with instances and severity of anxiety and depression correlating with increases in weight (Sullivan et al., 1993; Agrawal, Gupta, Mishra & Agrawal, 2015; Kasen, Cohen, Chen & Must 2008). In a meta-analysis by Luppino et al. (2010), the link between obesity and depression was found to be reciprocal in nature, with a 55% chance of developing obesity if you suffered from depression and a 58% chance of becoming depressed if you were obese. Additionally, the association between obesity and depression was stronger than overweight and depression, supporting the hypothesis that the risk of depression increases as weight increases. Body dissatisfaction and low self-esteem are both risk factors for depression and these are also known to be associated with being obese (Kushner & Foster, 2000; Sarwer, Wadden, & Foster, 1998; Atlantis & Ball, 2008).

With the presence of social stigma and negative attitudes towards overweight individuals in Westernised societies and the constant drive to achieve “thinness”, many forms of discrimination exist, such as derogatory labelling of overweight individuals as “lazy” and “stupid”. More negative impacts of weight issues can include lower marriage prospects, reduced income ability, lower paid careers, and inaccessible healthcare treatment. Even the physical environment discriminates against people referred to as “supersized” by the one-size-fits-all mentality seen in our

public transport seating, generic sized workstations, availability of suitable clothing, and medical equipment (Puhl & Brownell, 2001; Carr & Friedmann, 2005; Gortmaker, Must, Perrin, Sobol & Dietz, 1993). In fact, these negative attitudes are so ingrained in our societies that overweight people also hold these negative attitudes towards other overweight people (Wang, Brownell & Wadden, 2004).

1.1.2 Prevalence and Economics

The WHO (2019) estimated the number of overweight adults in 2016 at approximately 1.9 billion worldwide, with approximately 650 million of these further classified as obese. Westernised countries appear to be the most affected with prevalence rates of 64.5% (30.4% obese and 34.1% overweight) in the US, 64% (29% obese and 35% overweight) in England, and 60% (23% obese and 37% overweight) in Ireland quoted in the literature (Centers for Disease Control and Prevention, 2019^a; Connolly & Davies, 2018; Department of Health/Ipsos MRBI, 2015). In Ireland, it is estimated that the direct healthcare costs (GP visits, hospital visits and medication) are 10% higher for individuals who are overweight and 30% higher for those who are obese when compared to people in the normal weight category. The indirect costs incurred by higher absenteeism rates, greater loss of productivity and increased premature mortality, are documented as being between 65 to 75% of the healthcare costs associated with overweight people in Ireland (Perry & Dee, 2012). Overall, the relative estimated economic impact that overweight adults present to governments range from \$147 billion per annum in the US, to £7.4 billion per annum in the UK, and €1.64 billion per annum on the island of Ireland (Finkelstein, Trogon, Cohen & Dietz, 2009; Morgan & Dent, 2010; Perry & Dee, 2012). If these figures are not frightening enough, the continued trajectory of obesity is estimated to increase healthcare costs by US\$48 billion/year in the US, and £1.9 billion/year in England by 2030 (Wang, McPherson, Marsh, Gortmaker & Brown, 2011). So not only is being overweight at great personal cost due to physical and mental ill-health, but it is at great cost to already overstretched healthcare budgets worldwide.

1.1.3 Overweight and Intellectual Disability

Intellectual Disability is defined as “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development” (WHO Europe, 2019). In a meta-analysis by Maulik, Mascarenhas, Mathers, Dua and Saxena (2011), the number of adults presenting with an intellectual disability was approximately 0.5% worldwide, with low to middle-income countries showing higher rates.

One of the major health concerns for adults with Intellectual Disabilities (ID) is the high risk of becoming overweight (Rimmer, Chen & Hsieh, 2011; Beange, Lennox & Parmenter, 1999). As with the general population the added physical ailments that accompany increasing weight, such as hypertension, hypercholesterolemia, cardiovascular disease, respiratory problems, diabetes and some cancers also apply to adults with ID (Sari et al., 2016; Haveman et al., 2009; CDC, 2010; Banks, 2016). Add to this the fact that adults with ID experience healthcare disparities such as accessing health professionals less due to cost, availing of standard health checks less, less engagement in physical activity, higher numbers of smokers, higher prevalence of life limiting diseases, and smaller numbers demonstrating the presence of social influences that determine good health (Krahn, Klien-Walker & Correa-de-Araujo, 2015), and this becomes a vulnerable population who have poorer physical health and limited access to effective healthcare treatments. Mental health is also a concern since incidences of depression and anxiety in adults with ID are higher than the general population (Cooper et al., 2015). Bond et al. (2020) did not find obesity to be significantly associated with depression or anxiety, however, their sample was specific to older adults aged 50+. Reid, Smiley and Cooper (2011) reported the prevalence of anxiety to be highest in adults aged between 30 and 60, and so it would be interesting to see if obesity is significantly associated with depression or anxiety for this particular age profile. Whilst there is limited evidence evaluating the effects of obesity on psychological well-being in adults with ID, the stigma of having an ID is well documented and linked to low self-esteem and depression (Paterson, McKenzie &

Lindsay, 2012; Dagnan & Sandhu, 1999). Bond et al. (2020) found that taking mood stabiliser medications was significantly associated with depression and anxiety, and since many of these types of medications are known to increase weight (Kyle & Kuehl, 2013), there is indeed some link between weight and depression for this population.

1.1.4 Prevalence and Economics for the ID Population

The prevalence of overweight quoted for the ID population varies. It is generally higher than the typical population but likewise has also increased dramatically over the last 4 decades. Table 1.1 details a sample of 17 studies between 1982 and 2016 that show the prevalence of overweight for adults with ID increasing rapidly and in fact doubling by 2010. Between 2010 and 2016 some decreases are noted, however, overall, the figures remain high. Apart from the Robertson et al. study in 2000, all the studies that compare prevalence with the general population show the ID population to be consistently higher. It should be noted, however, that the Robertson et al. (2000) study did show that women with ID were at higher risk of obesity than women in the general population. In fact, when we look at the prevalence rates of obesity in isolation in these studies, we find that not only does a similar pattern of increase occur for both populations but the prevalence of obesity in the ID population always exceeds the general population levels quoted.

Few studies exist to examine the costs associated with having an ID, and less so for costs specifically attributed to being overweight and having an ID. The estimated cost of lifetime care for someone with an intellectual disability in the US was estimated at approximately \$51.2 billion (Maulik et al., 2011), and approximately 26.7% of the total healthcare costs in the US are attributed to disability (Anderson, Armour, Finkelstein & Weiner, 2010). In Australia, the total cost per year in supporting those with ID, for families and government combined, is estimated at AU\$14.7 billion, with the families bearing approximately 77% of this cost (Doran et al., 2012). Other studies available for costs related to having an ID tend to focus on specific aspects of healthcare provision such as the costs associated with moving from institutionalised settings to community settings (McCarron et al., 2018), or the costs associated with

challenging behaviours and ID (NICE, 2015). Costs associated with being overweight and having an ID lack focus in the existing literature, and only the US appear to examine this factor providing estimates of €44 billion per annum (Centers for Disease Control and Prevention [CDC], 2010). So, similarly to the general population, better health is not only beneficial to the individual with an intellectual disability, but it is beneficial to the economy.

Table 1.1: Prevalence rates for overweight and obesity in adults with intellectual disabilities

Year	Authors	Country	No. Participants with ID	% OW+OB ID	% OW+OB GP	% OB ID	% OB GP
1982	Fox and Rotatori	US	1134	37.3	-	19.6	-
1991	Simila et al	Finland	112	33.2	-	9.8	-
1992	Bell & Bhate	UK	183	63.4	-	25.7	-
1994	Stewart et al	Australia	142	48.6	29.5	19.7	8.2
2000	Robertson et al	UK	481	43.2	56.5	19	17
2003	Hove	Norway	282	53.9	-	19.1	-
2004	Moore et al	Australia	93	68.8	-	33.3	-
2005	Emerson	UK	1304	55	-	27	-
2008	Bhaumik et al	UK	1119	48.7	-	20.7	-
2008	Melville et al	UK	945	64.4	60.5	32.9	24.2
2009	Sohler et al	US	291	70.8	-	43.3	31
2010	Stedman and Leland	New Zealand	148	79.6	67.4	51	30
2013	Haider et al	Australia	897	54.7	48.6	26.7	16.7
2014	Hsieh et al	US	1450	67.2	-	38.3	28
2014	Mikulovic et al	France	570	62.8	43.4	17.6	11.8
2016	Koritsas & Iacono	Australia	68	62.4	61.3	41	24.6
2016	Sari et al	Turkey	271	52	-	24	-

OW=overweight, OB=Obese, ID=Intellectually disabled population, GP=General Population

1.1.5 Risk Factors for Overweight in the ID Population

Fourteen of the studies included in Table 1.1 provided further examination of the individual factors associated with overweight in the ID population, as detailed in Table 1.2 below. Not only are people with an ID at higher risk of overweight than the general population, but certain groups within the ID population carry more risk. Some of the individual factors associated with greater risk are non-modifiable such as sex, level of ID, having Down Syndrome and age. Some factors have potential to be modified such as living situation, medications, dietary habits and physical activity habits (Fox & Rotatori, 1982; Simila & Niskanen, 1991; Bhaumik, Watson, Thorp, Tyrer & McGrother, 2008; Melville et al., 2008; Hsieh, Rimmer & Heller, 2014).

Table 1.2: *Studies examining prevalence rates of overweight for known risk factors*

Year	Authors	Sex	Level of ID	Down Syndrome	Age	Living Situation
1982	Fox and Rotatori	√	√			
1991	Simila et al		√			
1992	Bell & Bhate	√		√		
1994	Stewart et al	√		√		
2000	Robertson et al	√				
2003	Hove	√	√	√	√	
2004	Moore et al	√				√
2008	Bhaumik et al	√				
2008	Melville et al	√	√	√	√	√
2009	Sohler et al	√	√	√	√	
2010	Stedman and Leland	√				
2014	Hsieh et al	√	√	√	√	√
2014	Mikulovic et al	√				
2016	Sari et al	√				

Thirteen of the studies provided a breakdown of prevalence figures for males versus females, and all showed that females are more at risk of becoming overweight than males. The total prevalence rates of overweight ranged from 31.5% to 66.7% for males, and 45.7% to 82.1% for females. When obesity figures were separated, the

prevalence ranges were 9.5% to 48.3% for males and 24% to 43.2% for females. Whilst females may be seen to be the more at-risk sex, these studies also show that the number of males that are overweight and indeed obese is still considerably high.

Six of the studies examined differences in prevalence rates between levels of ID. Some studies categorised each level of ID separately (mild, moderate, severe, and profound) whilst some combined categories (mild/moderate and severe/profound). Five out of the six studies found the mild/moderate ID to be more at-risk of overweight with prevalence rates ranging from 51% to 74.3% for those with a mild/moderate ID compared with 27% to 63% for those with a severe/profound ID. When looking at obesity in particular, figures again showed that those with a mild/moderate ID were most at-risk with rates ranging from 26.6% to 46.9% compared with 9.7% to 41.8% for those with severe/profound ID. Not only is the level of ID an important factor to consider but the actual diagnosis of the individual can affect their weight status. In particular those with Down Syndrome are a high-risk group, with six of the studies showing prevalence rates between 60% and 85.4%, and obesity figures of 32% to 53.4% for this demographic. Comparisons to other diagnoses show total prevalence of overweight to be between 53.9% and 68.4%, with obesity figures between 19.1% and 42%.

Four of the studies provided comparisons between age groups, and though all of the studies used different groupings for the age categories what is apparent is that overweight and obesity prevalence both increase with age up until 60 years+ where they then begin to decrease again. Between the ages of 40 and 60 appear to be the most prominent years for weight with rates as high as 80.6% of adults with ID quoted (Sohler et al., 2009). The three studies that compared living situations also categorised differently, however, those living in more independent types of housing such as living in their own home or living in assisted accommodation were more likely to be overweight with figures ranging between 71.4% and 89.5% compared with 60% to 65.3% for those living with family, and 65.3% to 68% for those in residential settings. Obesity figures followed a similar pattern when extrapolated.

Whilst sex, level of ID, having Down Syndrome and age cannot be changed for an individual, and to a certain extent living conditions too, some of the other modifiable antecedents have potential. There may be opportunities to alter medications that cause weight gain, however, for many people the process of finding the correct type and level of medication to stabilize their moods has not been an easy one and so this may not be a viable option for some (Depression and Bipolar Support Alliance, 2020). Changing medications alone may also not produce clinical weight loss if dietary changes do not follow on from this as a result. The most accessible factors for change are alterations to diet and physical activity habits. These factors can either be controlled or influenced by others in the environment, or self-managed to promote autonomy and choice in health. Current policy promotes the move towards more self-management of lifestyle choices for adults with ID who have capacity to understand the consequences (Inclusion Ireland, 2014; National Disability Strategy Implementation Group, 2013-2015), and as such interventions must be creative in supporting adults with ID to independently make good choices with respect to diet and exercise.

The target population for the project included both sexes due to the high prevalence rates present for both. Those with a mild/moderate ID not only have increased prevalence of overweight, but also increased freedom to independently access food choices (Draheim et al., 2007). It is possible that this particular demographic of the ID population regularly makes wrong choices in relation to diet due to a lack of functional knowledge on foods and the ability to successfully self-manage these choices. For these reasons those with a mild/moderate ID were selected as the target population for this project. Adults with Down Syndrome were also sought to form part of the sample with the expectation that these results also be presented separately for comparison. The need for an adequate sample size dictated that all ages be invited to take part in the study, and since the majority of adults with ID in Ireland live at home with family, all living situations were also included.

1.1.6 Blending a Health Psychology and Behaviour Analytic Approach

The main focus of this thesis was to design and evaluate a weight management intervention specific to the needs of adults with ID and one that lent itself to self-management of lifestyle choices in relation to diet and exercise. This thesis grounded itself in the Transtheoretical Model (TTM) from health psychology but took a unique behaviour analytic approach by focussing on a behaviour change solution for the “Action Stage” of the TTM model. The TTM was deemed best choice for this project since the focus would be directly on the “Action” or solution to weight loss, but also to enable understanding that individuals may be operating at different stages of change, which may be the reason for individual differences in achievement of weight loss. The proposed intervention also considered the supporting constructs for change suggested by the TTM model such as; (i) awareness that the benefits of change outweigh the consequences of no change (decisional balance), (ii) personal belief in the ability to sustain self-management of choices (self-efficacy), and (iii) the provision of supporting mechanisms to make and maintain the change (Marks, Murray & Estacio, 2018). The “Action Stage” of the TTM model requires the individual to be engaged in making specific modifications to their lifestyle. The weight management intervention determined for use as the “Action Stage” utilised proven behaviour analytic strategies to establish and support the behaviour changes necessary for specific modifications required for weight loss.

With the need for successful weight management interventions for adults with ID firmly established, the first step of the thesis was to examine the structures and efficacy of past weight management interventions for this population. As such a systematic review of lifestyle weight management interventions was conducted and is detailed in Chapter 2 of this thesis.

Chapter 2

Systematic review of lifestyle weight management interventions for adults with intellectual disabilities

2.1 Introduction

2.1.1 Current Literature Conclusions

Lifestyle interventions promoting healthier living for adults with ID are plentiful in the current literature and there are many different intervention types, most of which are driven by the backgrounds and methodologies of the researchers involved. For example, (a) health promotion interventions are mainly conducted by those from a nursing, medical or educational background (Bergström, Hagströmer, Hagberg & Elinder, 2013; McDermott et al., 2012; Marshall, McConkey & Moore, 2003; Pett et al., 2013), (b) interventions increasing physical activity are generally from those in physiotherapy or sporting backgrounds (Boer & Moss, 2016; Son, Jeon & Kim, 2016; Casey, Boyd, MacKenzie & Rasmussen, 2012), (c) those focusing on diet tend to be from nutritional or dietician fields (Antal et al., 1988), and (d) interventions with specific behavioural change elements have psychology at their source (Melville et al., 2015; Sailer et al., 2006; Rotatori, Fox & Switzky, 1980; Saunders et al., 2011). Ultimately the goal of all these lifestyle interventions is to increase health outcomes for adults with ID, with some focusing on weight reduction as a primary outcome and some as a secondary outcome.

In two large-scale reviews of the literature for weight management interventions with the general population, both NICE (2014^a) and SIGN (2010) recommended multi-component interventions (MCI) as the treatment of choice for weight management. Interventions that are seen to be multi-component in nature must incorporate three distinct components: (1) a dietary component that reduces energy intake and improves quality of diet, (2) a component that increases physical activity, and (3) behaviour change strategies of which several are recommended in the guidelines. Reviews of weight management interventions for adults with ID are few but are growing in number and in focus (Rotatori, Switzky & Fox, 1981; Hamilton, Hankey, Miller, Boyle & Melville, 2007; Jinks, Cotton & Rylance, 2011; Spanos, Melville & Hankey, 2013^a; Harris, Hankey, Murray & Melville, 2015; Doherty, Jones, Chauhan & Gibson, 2018; Harris, Melville, Murray & Hankey, 2018^a), which will move us closer towards a treatment of choice for this population.

One of the earliest reviews concentrated on behavioural approaches to weight loss for adults with ID and reported all 12 studies resulting in weight loss, with mean weight changes ranging from -3.6lbs in 7 weeks up to -79lbs in 42 weeks (Rotatori et al., 1981). Whilst this review supports the efficacy of behavioural interventions in weight management for adults with ID it does not compare efficacy with other types of interventions, includes studies with children, and many of the studies did not incorporate informed consent procedures that would be expected today. Around 2007, the focus of available reviews shifted towards analysing the differences between components included in interventions (Hamilton et al., 2007; Jinks et al., 2011; Spanos et al., 2013^a), however, components were categorised in different ways, and with the exception of Spanos et al. (2013^a) they did not adequately compare categories to provide direction towards a treatment of choice for adults with ID. For example, in the Hamilton et al. (2007) review, interventions were categorised as; (1) weight loss interventions, (2) behavioural interventions, (3) physical activity interventions or (4) health promotion interventions depending on the components present. Each category was summarised separately and changes in weight outcomes reported, with an additional summary included on the effect of carer input also examined. Some cross-over in components between categories was present, and although each category was examined and effects on weight outcomes discussed, there was no comparison between the categories to evaluate efficacy. In the Jinks et al. (2011) review the interventions were categorised as either (1) educational or (2) educational and behavioural. Again, summarisation and general discussions around the effect on obesity reduction were provided for each category, but no comparison between components to assess efficacy were provided. A more robust example of component categorisation exists in the Spanos et al. (2013^a) review, where six component categories were devised; (1) behaviour change, (2) behaviour change plus physical activity, (3) dietary, (4) physical activity, (5) diet plus physical activity, and (6) multi-component (three or more components). In this review, the categories are summarised separately and a comparison between the intervention types is also provided. The comparison indicated that multi-component weight management interventions appear

to be the most effective for adults with ID, which mirrors the recommendations for the general population.

Of the three most recent reviews available one focuses on physical activity interventions (Harris et al., 2015), whilst two review only MCIs (Doherty et al., 2018; Harris et al., 2018^a). The Harris et al. (2015) review specifically looked at randomised control trials (RCTs) for physical activity weight management interventions and found only six studies satisfying inclusion criteria. From these studies physical activity weight management interventions were shown to be ineffective for weight loss; however, only two of the studies incorporated the recommended weekly dosage of exercise for weight loss (U.S. Department of Health and Human Services, 2018), and many were of short duration. The Doherty et al. (2018) review of MCIs found only five studies that met criteria. Of these five studies only two produced clinically significant weight loss (Melville et al., 2011; Spanos, Hankey, Boyle & Melville, 2014). However, one of these studies is the original intervention (Melville et al., 2011) and the other is a secondary analysis of the same study with a comparison to the typical population (Spanos et al., 2014). When comparing the component criteria for MCIs set out by NICE (2014^a) it also becomes apparent that only the Melville et al. (2011) study has all three components required to be an MCI. When analysing the interventions of the other studies involved in the review one would be a health education study (Bergström et al., 2013), two are qualitative evaluations of interventions (Spanos et al., 2013^b; Sundblom, Bergström & Elinder, 2015), and the final study is the secondary analysis of the only true MCI included in the review (Spanos et al., 2014). The Harris et al. (2018^a) review for MCIs was specific to randomised control trials (RCTs), and again contained only six studies meeting inclusion criteria. The authors concluded that multi-component weight management interventions for adults with ID did not result in clinically significant weight loss and showed no increased efficacy when compared to treatment as usual control groups. However, again when comparing the components of the studies included against the NICE (2014^a) guidelines for components in MCIs, none of the studies fulfil the criteria. Most of the studies claiming to be MCIs used health promotion strategies for the dietary and exercise components rather than strategies that incorporate SMART

(specific, measurable, achievable, realistic and timely) goals (Breazeale, 2017) to specifically reduce caloric intake and increase physical activity, as is required of those components in MCIs.

The increased global focus on weight reduction prompted two large-scale reviews of the literature on weight management interventions for the general population. These reviews led to the production of guidelines on the identification, assessment, and management of obesity. The management of obesity concluded with recommendations for lifestyle, pharmacological and surgical interventions. Recommendations for lifestyle interventions proposed the inclusion of three specific components (dietary change, physical activity increase and behaviour change strategies), and detailed descriptions of what each component entails were provided, as have already been outlined above (SIGN, 2010; NICE, 2014^a). At present no such guidelines exist for lifestyle interventions for weight management with the ID population and as a result current research lacks direction on both the particular types of components to include, and also what constitutes each component. Because no specific component categorisation exists for researchers to draw upon, the literature reviews that are currently available have devised their own. These methods have often grouped interventions together too broadly to compare like with like, with cross-over between components leading to confusion in the evaluation. For example, in the Spanos et al. (2013^a) review the recommendations suggest that MCIs are the most effective. However, in the Harris et al. (2018^a) review this is partially contradicted by the conclusion that MCIs are not effective for weight loss with adults with ID unless they include an energy deficient diet. In reality both reviews are indicating similar results, but confusion occurs through the inclusion of studies as multi-component when in fact they do not include specific SMART goals for dietary or physical activity change and instead provide only educational information in relation to these components. Without correct and specific identification of the components included in studies, accurate grouping and effective comparison will not occur. It is therefore apparent that future research and reviews need access to specific, standardised guidelines for the categorisation of components in order to provide consistency and move towards identifying a treatment of choice for weight management for adults with

ID. Aligning the definitions of components with those that exist in the guidelines for the general population (NICE, 2014^a), will also allow for comparisons of interventions between those with ID and those without.

The most appropriate methodology used to date, which tried to capture the differences and evaluate efficacy between interventions based on the components they include, was in the Spanos et al (2013^a) review. However, alignment to the NICE (2014^a) definition for MCI components was not consistent, hence the inclusion of some studies in the multi-component category that only provided health information sessions for the dietary component. Since this review there has also been more focus on researching obesity reduction interventions for the ID population, which prompts the need for a more up-to-date systematic review to guide the definition of intervention components and provide a comparison of the efficacy of different types of lifestyle interventions in reducing weight for adults with ID who are overweight. Consequently, a further systematic review was conducted as the first stage of this research project.

2.2 A Systematic Review of Lifestyle Interventions and their Effect on Anthropometric Measures for Overweight Adults with ID

2.2.1 Aims

The primary aim of this systematic review was to compare the efficacy of different types of lifestyle interventions in reducing weight for adults with ID who are overweight. A secondary aim was to compare the outcomes of each intervention against the guidelines for effective weight loss interventions produced by NICE (2014^a), which are:

- a) 60% or more of the participants complete the intervention.
- b) The mean weight loss $\geq -3\%$.
- c) More than 30% of the participants achieve $\geq -5\%$ weight loss, which is seen to be the minimum weight loss of clinical significance.

2.2.2 Research Questions

The research questions most pertinent for examination are:

1. What are the components present within lifestyle interventions for adults with intellectual disabilities?
2. What are the effects of each type of intervention on body composition?
3. How do the outcomes for each intervention category compare with the NICE (2014^a) guidelines for effective interventions for the General Population?
4. Is there is a longer-term weight maintenance and/or follow-up component included and what are the reported effects?

2.2.3 Method

The format chosen for this systematic review was based on the Spanos et al. (2013^a) review, however, some adjustments in criteria and definitions were made as outlined below.

2.2.3.1 Database Searches

Initial searches were conducted between 30/11/2016 and 01/12/2016 on 6 Databases: PsycINFO, OVID Medline, CINAHL Plus, SCOPUS, WILEY & Web of Science. These searches were re-run between 18/09/2019 and 19/09/2019, to include the most up-to-date research available. Due to the high number of hits for Scopus and Wiley these searches were limited to abstract, title and keywords only.

Terms used in the searches included:

- OR - intellectual development disorder, intellectual disability, intellectual disabilities, developmental disabilities, developmental disability, down's syndrome, down syndrome, downs syndrome, mental retard, mental retards, mental retardation, mentally retarded, autism spectrum disorders, Asperger syndrome, autistic disorder, pervasive developmental disorder.
- AND - Obesity, overweight, body mass index

2.2.3.2 Inclusion & Exclusion Criteria for Studies

All types of quantitative studies involving lifestyle interventions that aimed to increase health outcomes for adults with intellectual disabilities were eligible for inclusion if: the participants had a diagnosis of intellectual disability, were adults over 18 years of age, had a BMI ≥ 25 kg/m², some type of health improvement or lifestyle weight management intervention was included, and some measure of impact on weight, BMI, % body fat or waist circumference (whether numerical or statement based) was included.

Studies were excluded if they included any of the following: participants with syndromes specifically attributed to obesity (Prader Willi, Cohen or Bardet-Biedl), Special Olympics participants, were pharmacological or surgical interventions, or were qualitative research.

2.2.3.3 Data Extraction

The data extraction process was undertaken by the author using the "Cochrane data collection form for intervention reviews: RCTs and non-RCTs" template (Cochrane Developmental, Psychosocial and Learning Problems, 2014). When the author had completed the data extraction process for all studies, the forms were then reviewed by a second researcher who noted any differences in coding. After the second researcher's review, differences were discussed between the author and the second researcher and agreement was reached for each study. Some of the areas assessed in the data extraction were participant recruitment processes, sampling and

randomisation biases, attrition, methodology, level of intervention detail for replication purposes, type of study, study aims and durations, and results with inclusion of statistical analyses.

2.2.3.4 Quality Evaluation

An adapted version of the Downs and Black (1998), “Checklist for Measuring Study Quality” was used to evaluate the quality of each study, see Appendix A. This particular checklist was evaluated through test and re-test procedures during its construction, and then independently assessed for validity and reliability. The checklist was independently rated as methodologically strong and appropriate to use when evaluating health care intervention studies (National Collaborating Centre for Methods and Tools, 2008). Each study was scored on 5 separate areas with a maximum available score of 27; (1) Reporting - 10 points, (2) External Validity - 3 points, (3) Internal Validity: Bias - 7 points, (4) Internal Validity: Confounding Selection Bias – 6 points, and (5) Power – 1 point. The total score for each study was converted to a percentage quality rating. Both researchers completed a separate quality assessment, engaged in discussion about differences and reached agreement on the final scores for each study.

2.2.4 Results

Thirty-four studies met the inclusion criteria for this review. The process of selection is detailed in Figure 2.1. The largest research base was in the US with 17 studies found for this review. Of the other studies five were situated in the UK, three in Spain, three in Portugal and the remaining studies were from Sweden, Hungary, Italy, Canada, Korea and Australia. Only 5 studies were categorised as RCTs, two of which were cluster RCTs. The remaining studies were quasi-experimental studies consisting of: 17 pre- and post- intervention studies with no control group, 4 pre- and post-intervention studies with a control group, 2 pre- and post- intervention studies with a comparison group, 4 repeated measures studies with no control group, 1 repeated measures study with a control group, 3 multiple-baseline studies, and 1 multi-phase

design study. Two of the studies included had multiple groups which accounts for the additional designs above (Pett et al., 2013; Fisher, 1986). Studies were rated as control group studies if the control group were taken from the same population as the intervention group or rated as comparison groups if the control group were compared to a different population such as the general population. Quality ratings ranged from 23% to 77%, with dietary interventions having the lowest mean rating at 40% (SD = 24.5, range 23% to 58%), and MCIs having the highest mean rating at 68% (SD = 11.1, range 54% to 77%). Common issues in the studies included were a lack of sampling information, no indication of the period of recruitment and whether participants were recruited within the same time frame, no randomisation of participants, lack of statistics, no blinding in place for participants or researchers, no measure of intervention fidelity, and small sample sizes with no sample size or power calculation included.

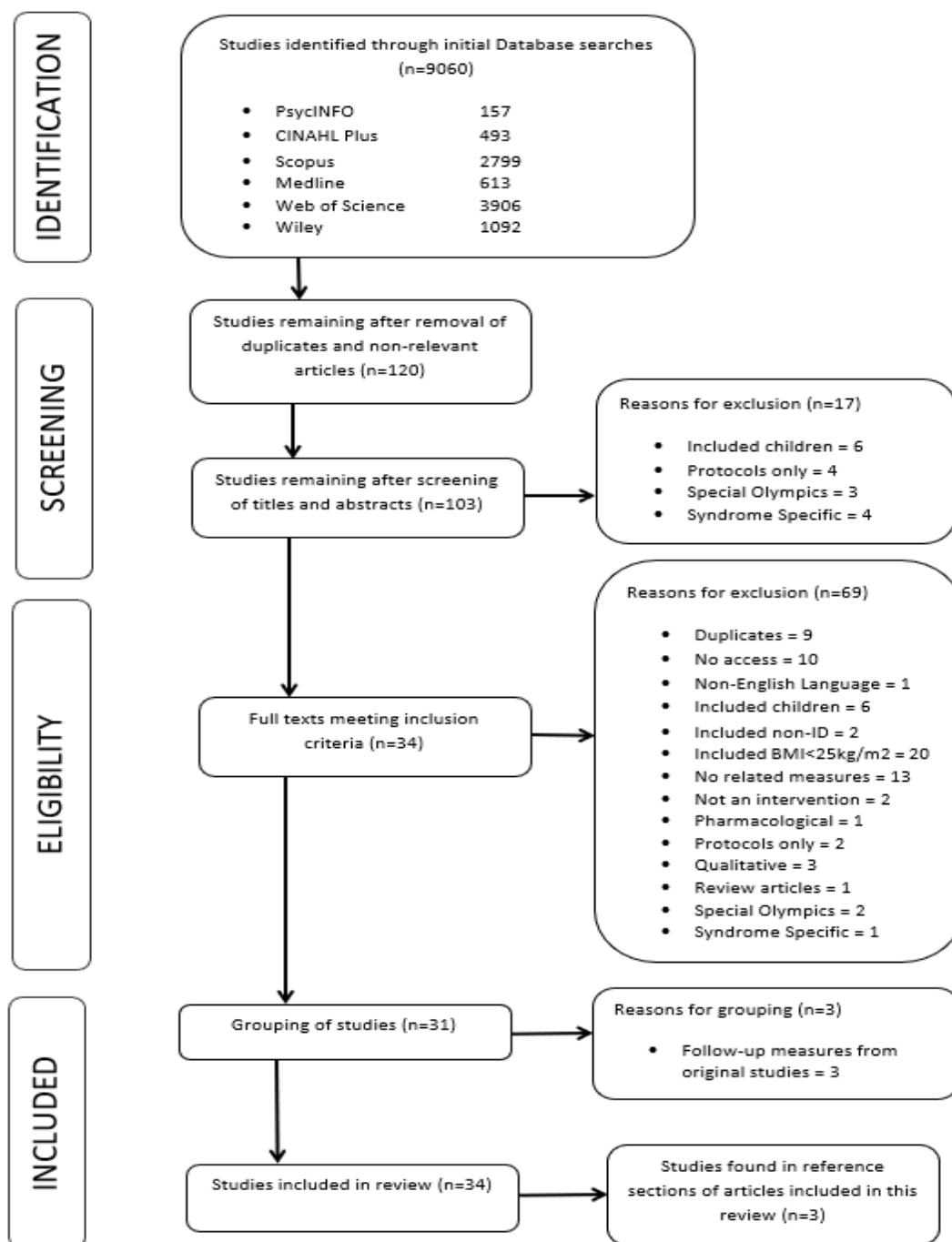


Figure 2.1: Selection process for studies included in review.

2.2.4.1 Research Question 1

What are the components present within lifestyle interventions for adults with intellectual disabilities?

Within the 34 studies reviewed, six categories of intervention types were identified, as per Table 2.1. Definitions were based on the dietary, physical activity and behaviour change guidelines listed in the NICE (2014^a) recommendations for lifestyle interventions for weight management. In these recommendations the dietary component must include a targeted reduction in energy intake which is supported by suitable professionals and intensive follow-up, and the physical activity component must use a targeted approach towards increasing activity levels towards current guidelines. Recommended behavioural strategies to support dietary and physical activity changes include, but are not limited to; self-monitoring, stimulus control, goal setting, slowing rate of eating, cognitive restructuring, reinforcement of changes, and relapse prevention. To qualify as an MCI, interventions must include all three components of diet, physical activity and behaviour change as defined above.

Table 2.1: *Categories and Definitions of Study Components*

No	Category	Definition
1	Health Promotion (HPI) (n=7*)	Information or education sessions that include education on elements of diet, physical activity, behaviour change or a mixture of all three. Education sessions can be for participants and/or caregivers.
2	Dietary (DI) (n=2)	Can include health promotion information or education sessions as above, but must also include a component where a dietary change is in place with specific SMART*** goals included, i.e., menu plan is provided, energy-deficient diet in place, plate model implemented, specific daily dietary guidelines are followed, portion sizes adhered to, etc.
3	Physical Activity (PAI) (n=9*)	Can include health promotion information or education sessions as above, but must also contain a component where a physical exercise program is implemented with specific SMART*** goals included, i.e., targets for increased steps/day, 2 x 10-minute exercise regimes per day, specific daily activity duration guidelines are followed, 2 swimming sessions per week, etc.
4	Behaviour Change (BCI) (n=9**)	Can include health promotion information or education sessions as above, but must also include at least one component of behaviour change, i.e., self-monitoring, goal setting, slowed eating pace, self-reinforcement, feedback, etc.
5	Physical Activity and Behaviour Change (PA+BCI) (n=3**)	A combination of 3 + 4 above.
6	Multi-Component (MCI) (n=6)	A combination of 2, 3 + 4 above.

*Pett et al (2013) study involves 3 groups; 1 is a Health Promotion/Education intervention and the other 2 are Physical Activity interventions.

**Fisher (1986) study involves 2 groups: one is a Behaviour Change intervention and the other is a Physical Activity + Behaviour Change intervention.

***SMART – Specific, Measurable, Achievable, Realistic and Timely

2.2.4.2 Research Question 2

What are the effects of each type of intervention on body composition?

2.2.4.2.1 Health Promotion Interventions (n=7)

Seven studies were identified as Health Promotion intervention (HPI) studies (see Table 2.2) and these involved education sessions to upskill participants on food types, nutrition, portion sizes, exercise, and behaviour change strategies. Most studies delivered the information in group settings with intervention durations ranging from 8 weeks to two years. The sessions were delivered by researchers from a range of backgrounds such as nursing, physiotherapy, and health professionals, with only one study specifically stating experience in teaching adults with ID (Bergström et al., 2013). All seven studies used intervention materials specifically designed for those with an ID, or adapted to suit those with an ID. The mean participant sample size was 111.14 (SD = 109.4) and ranged from 8 to 324, however, the two studies with larger sample sizes had attrition rates of 40% (Ewing et al., 2004; Mann, Zhou, McDermott & Poston, 2006). Four of the studies specifically aimed to reduce weight, one targeted improved physical fitness and two aimed to increase health and work routines. The mean quality rating for HPIs was 58% (SD = 15.4, range 38 to 77%).

(a) Intervention Components

Bergström et al. (2013) provided sessions to participants but also included a tiered approach of education sessions for both staff and management involved in the care of participants. Geller & Crowley (2009) used group empowerment methodology to run weekly sessions over two years where the group discussed and led activities related to healthy diet and exercise. Some of the activities involved were musical chairs as a fun way to exercise, making a dance video, cooking demonstrations, and art projects on healthy eating. One of the groups in the Pett et al. (2013) study provided an education series just to parents. The *We Can Too (WCT)* training is a short 12-week course designed to increase parental knowledge in nutrition, whilst teaching them how to model healthy behaviours and change the home environment to support changes. Another short training series by Ewing et al. (2004) implemented the *Health*

Education Learning Program (HELP) designed by a medical physician to include aspects of healthy eating, exercise, and relapse prevention. This program placed an emphasis on exercise as the biggest predictor of weight loss. The Chapman, Craven & Chadwick (2005) study was one of the lengthier durations of projects at 12 months, however, only 4 or 5 individual sessions occurred over the year in each participant's home. The information delivered during these home visits was tailored more to the person's individual circumstances than generic group information. Both Mann et al. (2006) and Marshall et al. (2003) studies were of short durations of between 6 and 8 weeks, and both utilised curriculums designed for the general population that they adapted for use with adults with ID, *Steps to Your Health (STYH)* and *Activate* respectively.

(b) Study Outcomes

Table 2.2 shows the results for studies categorised as HPI. Mean weight changes were reported in 4 studies ranging from -2.6lbs over 24 months to -7.5lbs over 6 to 8 weeks. However, only one of these studies reported a statistically significant weight loss pre- to post- intervention (Marshall et al., 2003). BMI changes were reported by 6 studies with changes ranging from -0.3 kg/m² in 8 weeks to -1.6 kg/m² in 6 to 8 weeks, with three studies reporting statistically significant changes in BMI pre- to post-intervention (Chapman et al., 2005; Mann et al., 2006; Marshall et al., 2003), and two studies showing statistically significant between group changes in BMI (Chapman et al., 2005; Ewing et al., 2004). Mean waist circumference change was only reported in one study (Bergström et al., 2013) but changes failed to reach significance pre- to post- intervention.

Table 2.2: Health Promotion Intervention (HPI) Studies

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Bergström et al. (2013), Sweden, Cluster RCT	Participants: 139, IG=73, clusters=17 (attn=9), CG=66, clusters=16 (attn=0) Weight Status: IG BMI=30.0kg/m ² (SD=7.6), CG BMI=28.5kg/m ² (SD=6.6) ID: mild/moderate Females: IG=37, CG=37 Mean age: IG=36.2 (SD=10.1), CG=39.4 (SD=11.3)	73%	12 to 16 months	1) Health Ambassador (HA) at management level for each residence, HA attended 6 x 3-hour network and information sessions. 2) Caregiver study circles with 10 x 90-min manualised sessions and discussions to improve work routines. 3) Health Promotion course for participants, 10 sessions guided by a manual.	Mean BMI change: $p = 0.430$ Mean WC change: $p = 0.130$	-	-	-
Geller et al. (2009), US, Repeated measures with no control group	Participants: n=45, (attn=2), 16 participated twice weekly, 27 participated once weekly Weight Status: BMI>25kg/m ² ID: not stated Females: n=25 Mean age: n=42.6	38%	Ave = 13.5 months max.= 24 months	1-hour x twice weekly physician led empowerment group sessions for first 12 months, reduced to 1-hour per week from 12-24 months. Group activities using "Funk" empowerment model. Monthly or two-monthly individual physician visits to measure weight, activity and diet, and discuss individual goals.	Mean weight change: -2.6lbs, $p = 0.14$	-	-	-
Pett et al. (2013)* Parent only Group, US, Pre- and post-intervention with no control group	Participants: n=8, (attn=0) Weight Status: Mean BMI=33.3kg/m ² (SD=8.0), Range (24.1-48.5) ID: mild/moderate Females: n=5 Mean age: n=22.9 (SD=4.5), Range (18-30)	77%	12 weeks	We Can Too (WCT) curriculum. For parents/caregivers. Once/week for 12 weeks for 1.5 hours. Delivered by registered dietitian, clinical social worker, MS/PhD students in nutrition and nursing. PATCH programme curricula – Parent Agency Targeting Children's Health; nutrition, health and parenting skills, environmental change, and modelling healthy behaviours.	Mean weight change: -4lbs Mean BMI change: -0.7kg/m ² No significant between group differences No significant time x group interactions were found on any outcome	-	-	Participants: 8 Duration: 3 months Post Intervention to Follow-up: Mean weight change: -2.1lbs Mean BMI change: -0.3kg/m ² Baseline to Follow-up Mean weight change: -6.1lbs (-3.1% weight loss) Mean BMI change -1.0kg/m ²

Table 2.2.: Health Promotion Intervention (HPI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Ewing et al. (2004), US, Pre- and post-intervention with comparison group	<p>Participants: n=424, IG=154, (attn=62), Comp=270 (attn=173)</p> <p>Weight Status: IG mean BMI=35.4kg/m² (SD=7.06), Comp mean BMI=38.4 (SD=8.6)</p> <p>ID: IG=mild/moderate, Comp=normal learner</p> <p>Females: IG=54.4%, Comp=84.5%</p> <p>Mean age: IG=39.7 (SD=11.5), Comp=49.9 (SD=11.48)</p>	50%	8 weeks	<p>Health Education Learning Program (HELP) 8 x 90-minute sessions. All classes began with a review of the previous week and any challenges and experiences.</p> <p>Classes 1-2: nutrition and diet, Class 3: exercise, Classes 4-5: stress reduction and cognitive restructuring, Class 6: autonomy and successful lifestyle change, Class 7: medical motivation, Class 8: relapse prevention + lapse versus relapse.</p> <p>All classes were followed by an optional brisk walk with the instructor. 2 and 4 home visits offered to set up an individual exercise program, to develop a diet plan, and to make a grocery list.</p>	<p>BMI change = % participants that decreased BMI by 0.75 units, IG=18.5%, Comp=44.3%, ^b BMI p < 0.01</p>	-	-	-
Chapman et al. (2005), UK, Pre- and post-intervention with control group Follow-up study is Chapman et al. (2008)	<p>Participants: n=88, IG=38 (attn=0), CG=50 (attn=1)</p> <p>Weight Status: IG mean BMI=34.9kg/m² (SD=5.7), CG mean BMI=28.35kg/m² (SD=6.45)</p> <p>ID: mild/moderate</p> <p>Females: n=43%</p> <p>Mean age: IG=37.13 (SD=8.75), Range (24-58), CG=43.32 (SD=10.97), Range (19-70)</p>	42%	12 months	<p>A physiotherapist was hired as a Healthy Living Coordinator (HLC) to provide input to individuals referred for support.</p> <p>4 or 5 home visits giving advice on exercise, diet, planning and health. Input also involved providing resources, working with staff and a Fighting Fit report given to all involved with individual – including GP and care manager.</p>	<p>Mean weight change: IG -3.3lbs CG +2.13lbs</p> <p>Mean BMI change: IG -0.61kg/m², p = 0.007^a, CG +0.41kg/m², p = 0.023^a</p> <p>Between group difference for input effect p < 0.05^b</p>	-	-	<p>Participants: n=73, IG=33, CG=40 Duration: 6 years</p> <p>Post Intervention to Follow-up: Mean BMI change: IG -0.4kg/m², CG +0.16kg/m²</p> <p>Baseline to Follow-up: Mean weight change: IG -5.34lbs, CG +1.34lbs Mean BMI change: IG -1.02kg/m², CG +0.61kg/m²</p>

Table 2.2: Health Promotion Intervention (HPI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Mann et al. (2006), US, Pre- and post-intervention with no control group	Participants: n=324, (attn=132) Weight Status: Mean BMI=35.38kg/m ² (SD=6.85) ID: mild to severe Females: n=128 Mean age: n=38.6 (SD=11.5)	69%	8 weeks	Steps to Your Health (STYH) curriculum: 8 weeks of a 90-minute education session each week followed by an optional brisk walk: Week 1: Nutrition 1 – emphasis on fruits and vegetables, Week 2: Nutrition 2 – emphasis on wholegrains and portion size, Week 3: Exercise, Week 4: Stress management, Week 5: Changing your way of thinking, Week 6: Communication styles (asserting preferences), Week 7: Complications of obesity, Week 8: Behaviour management	Mean BMI change: -0.3kg/m ² , p < 0.001 ^a	-	-	-
Marshall et al. (2003), UK, Pre- and post-intervention with no control group	Participants: n=20, (attn=1) Weight Status: BMI>25kg/m ² Females: 32% Age: 60% aged 30-39, 12% in 40s, 12% in 50s, 12% > 60, 1 < 20	54%	6 or 8 weeks	3 groups received 2-hour education sessions for 6 or 8 weeks, with materials for the sessions adapted from the “Activate” series by Health Promotion Agency in NI. Weight was also measured at each session.	Mean weight change: -7.5lbs, p < 0.001 ^a Mean BMI change: -1.6kg/m ² , p < 0.001 ^a	-	-	-

*Pett et al (2013) study involves 3 groups; 1 is a HPI intervention and the other 2 are Physical Activity interventions, ^a Pre to post intervention significance, ^b between groups significance.

(c) Study Limitations

Some of the limitations of the studies in this category are the small sample sizes, a lack of control groups to compare intervention effects, and no randomisation for those that did have control groups, except for Bergström et al. (2013). The large variation in durations also presents a confounding variable when comparing results between interventions and also against other types of interventions. In addition, there is a lack of concrete measures employed and reported to assess whether participants understood, generalised, and retained the information provided in a way that will promote long-term functional change.

2.2.4.2.2 *Dietary Interventions (n=2)*

Two studies were identified as Dietary intervention (DI) studies (see Table 2.3) and these involved targeted and monitored changes to diet for the participants. Both studies involved the provision of calorie-controlled meals, with the Antal et al. (1988) study involving participants residing in services, and the Zoppo and Asteria (2008) study involving participants who attended day services only. Participant sample sizes were 15 and 50 respectively, and intervention durations were 9 months and 1 month, respectively. Both studies had the specific aim of weight reduction. The mean quality rating for DIs was 40% (SD = 24.5, range 23 to 58%).

(a) Intervention Components

The Antal et al. (1988) diet targeted a 4.2 to 4.6MJ energy input and participants received all their meals via a 30-day calorie-controlled menu delivered to them in a separate room at mealtimes in the service centre. The Zoppo and Asteria (2008) diet followed WHO guidelines for hypolipemic-hypocaloric diets where each meal should consist of 60% carbohydrates, 25% lipids and 15% protein, and which was delivered during the day in services but relied on parental support for evening meals, of which only 40% of parents provided.

(b) Study Outcomes

Table 2.3 shows the results for studies categorised as DI. Mean weight changes were reported by both studies at -33.1lbs over 9-months and -30.9lbs over 1-month, respectively and both demonstrated statistically significant weight losses pre- to post-intervention. However, the Zoppo and Asteria (2008) study results only reflected the participants that had parental support (40%). BMI changes were -6.2 kg/m² in 9 months and -5.0 kg/m² in 1-month respectively, with both demonstrating statistical significance in BMI changes pre- to post- intervention. Again, the Zoppo and Asteria (2008) results are for those participants that had parental support. For those that did not, either no change to BMI or increased BMI was reported. This may reflect the importance of caregiver support on weight loss, since this cohort of participants may not have followed the recommended diet at home.

(c) Study Limitations

The lack of studies available under this category is a limitation in terms of evaluating the overall category effect. Again, sample sizes are small, durations differ dramatically and there are no controls to compare results with. An additional limitation is the lack of autonomy and choice that a forced and controlled diet entails and the ethical concerns that this raises with a vulnerable population.

Table 2.3: Dietary Intervention (DI) Studies

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Antal et al. (1988), Hungary, Repeated measures with no control group	Participants: n=15, (attn=0) Weight Status: Mean BMI=34.5kg/m ² (SD=4.8) ID: idiot, imbecile, debilitate & oligophren Females: n=10 Mean age: n=40.1 (SD=13.8)	58%	1 month	Meals were provided in a separate room to participants for 1 month prior to intervention. During intervention a 30-day rotating menu with 4.2-4.6 MJ energy was provided daily, and quantity consumed measured twice per week.	Mean weight change: -33.1lbs, (SD=7.8) Mean BMI change: -0.2kg/m ² , (SD=1.5)	-	-	-
Zoppo et al. (2008), Italy, Pre- and post-intervention with no control group	Participants: n=50, (attn=30 due to lack of parental support) Weight Status: 12% overweight and 88% obese ID: none given Females: 58% Mean age: n=39 (SD=9)	23%	9 months	Hypolipemic-hypocaloric diet (60% carbohydrates, 25% lipids and 15% protein) meals provided during the day in residential schools and at home in the evenings. 40% of participants had parental support.	Mean weight loss for the group that had parental support: -30.9lbs, p < 0.00001 ^a Mean BMI change for group that had parental support: -5kg/m ² , p < 0.00001 ^a No change in non-supported group.	-	-	-

^a Pre to post intervention significance, ^b between groups significance.

2.2.4.2.3 *Physical Activity Interventions (n=9)*

Nine studies were identified as Physical Activity intervention (PAI) studies (see Table 2.4) and these involved varying interventions to increase the amount of physical activity engaged in regularly by participants. Most of the exercise programs were performed as a group, with the exception being in the Silva et al. (2017) study where Wii exercises were performed individually or with a partner depending on the game played. Interventions ranged from approximately 8 to 28 weeks in duration, and five of the studies reported appropriately qualified professionals as supervising the implementation of the interventions. The mean participant sample size was 14.2 (SD = 7.4) and ranged from 5 to 27. Five of the studies aimed to increase aspects of physical fitness with secondary outcomes looking at the effects on body composition. The remaining four studies aimed to reduce weight, BMI and/or % body fat with Ordonez et al. (2014) also aiming to reduce inflammation in pre-menopausal women with Down Syndrome. The mean quality rating for PAIs was 63% (SD = 8.9, range 46 to 77%).

(a) Intervention Components

Ordonez et al. (2014), Mendonca, Pereira and Fernhall (2011), and Mendonca and Pereira (2009) all involved aerobic exercise sessions on ergometer equipment such as treadmills, rowers, and stationary bikes. An additional feature included in the Mendonca et al. (2011) study was strength training involving set repetitions on resistance equipment. Both Casey et al. (2012) and Pérez, Carral, Costas, Martínez and Martínez-Lemos (2018) employed water-based activity programs such as swimming and water jogging. Son et al. (2016) and Schurrer, Weltman and Brammell (1985) chose walking or jogging programs as interventions, which are known to be successful in meeting recommended physical activity levels in adults (Rafferty, Reeves, McGee & Pivarnik, 2002). One novel exercise intervention using a Wii console involved a combination of both aerobic exercise games and balance or strength games (Silva et al., 2017). The guidelines for physical activity for adults with ID recommend from 150 to 300 minutes per week of moderate-vigorous intensity exercise (U.S. Department of Health and Human Services, 2018). Five of the studies

met the weekly physical activity guidelines with four of these opting for three x 1-hour sessions each week (180 minutes) and one study opting for three x 100-minute sessions each week (300 minutes). The remaining studies did not meet the guidelines with weekly durations ranging from 90 minutes to 120 minutes and one study not reporting session durations.

(b) Study Outcomes

Table 2.4 shows the results for studies categorised as PAI. Mean weight changes were reported in 8 studies with changes ranging from +1.6lbs over 12 weeks to -7.9lbs over 23 weeks. Only two studies reported statistically significant weight losses pre- to post-intervention (Son et al., 2016; Schurrer et al., 1985), with one study showing statistically significant between group differences (Pett et al., 2013). BMI changes were also reported by 8 studies with changes ranging from +0.18 kg/m² in 12 weeks to -1.1 kg/m² in 12 weeks. Only one study demonstrated statistically significant changes in BMI pre- to post- intervention (Son et al., 2016), and one further study showed between groups significant decrease (Pett et al., 2013). Percentage body fat changes were reported in 6 studies with changes ranging from 0% in 12 weeks to -4.4% in 16 weeks. Three studies reported statistically significant changes in % body fat from pre- to post- intervention (Ordonez et al., 2014; Son et al., 2016; Mendonca et al., 2009), and one study reported statistically significant between group differences (Ordonez et al., 2014). Mean waist circumference change was reported in four studies with changes ranging from +0.5cm in 12 weeks to -7.87cm in approximately 8 weeks. Three studies reported statistically significant changes pre- to post- intervention (Ordonez et al., 2014; Son et al., 2016; Silva et al., 2017), and only Ordonez et al. (2014) reported significant between groups differences.

Table 2.4: Physical Activity Intervention (PAI) Studies

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Ordóñez et al. (2014), Spain, RCT Follow-up study is Rosety-Rodriguez et al. (2014)	Participants: n=20, IG=11 (attn=0), CG=9 (attn=0) Weight Status: (Mean BMI) IG 30.2kg/m ² (SD=0.9), CG 30.7kg/m ² (SD=0.8) ID: mild & Down Syndrome Females: 100% Mean age: IG=24.7 (SD=3.6) Range (19.4-29.1), CG=25.1 (SD=3.9) Range (20.8-29.6)	65%	10 weeks	Aerobic treadmill intervention for 3 sessions per week: 10-15 min warm-up, 30 to 40 min treadmill exercise (increasing by 2.5 mins every 2 weeks) at 55-65% peak heart rate, 5-10 min cool down. Control group were treatment as usual.	Mean BMI change: IG -0.4kg/m ² , CG +0.2kg/m ² , Mean % Body Fat change: IG -3.9%, p < 0.05 ^a , CG +0.1%, p < 0.05 ^b Mean WC change: IG -3.2cm, p < 0.05 ^a , CG +0.2cm, p < 0.05 ^b	-	-	Participants: n=20, IG=11, CG=9 Duration: 6 months Post Intervention to Follow-up: Mean % Body Fat change: IG +2.63%, CG +0.1%, Mean WC change: IG +2.9cm, CG -0.1cm Baseline to Follow-up: Mean % Body Fat change: IG -1.3%, p<0.05 ^a , CG +0.2%, Mean WC change: IG -0.3cm, CG +0.1cm
Casey et al. (2012)*, Canada, Pre- and post-intervention with no control group	Participants: n=7 (attn=0). Weight Status: Mean BMI=30.6kg/m ² (SD=5.8) ID: none given Females: n=2 Mean age: 41.7 (SD=14.5) Range (21-57)	58%	13 weeks	Aquatic exercise including aqua jogging, water polo and lap swimming 3 times per week. 10-15 min warm-up, endurance exercises increasing from 15 to 25 to 35 mins every 4 weeks, and 10 min low intensity cool down. Weekly education sessions for staff and participants on dietary factors.	[1] Mean Weight Change (lbs): -4.3lbs [1] Mean BMI change: -0.6kg/m ² , p = 0.55 [1] Mean % Body Fat change: -1.1%, p = 0.11	-	-	-
Pett et al. (2013)*, Young Adults only Group [1], US, Pre- and post-intervention with control group (YWC only). Young Adults and Parents Group [2] Pre- and post-intervention with no control group (YWC + WCT)	Participants: n=12, (attn=1) Weight Status: Mean BMI=39kg/m ² (SD=8) Range (29.3-50.4) ID: none given Females: n=7 Mean age: 23.6 (SD=3.1) Range (19-30) Participants: n=11, (attn=0) Weight Status: Mean BMI=37.3kg/m ² (SD=5.2) Range (32.1-46.7) ID: none given Females: n=6 Mean age: 25.6 (SD=4.8) Range (19-33)	77%	12 weeks [1] & [2] Group 2 acts as control group for Group 1	Yes We Can (YWC) curriculum for the young adults [1] & [2]. Twice a week for 0.75 hours of health education adapted from the manual "Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities" + 0.75 hours of physical activity with a warm-up then aerobics, muscle strength and endurance, and flexibility. We Can Too (WCT) curriculum. For parents/caregivers [2]. Once/week education session for 1.5 hours using PATCH programme curricula – Parent Agency Targeting Children's Health, nutrition, health and parenting skills, environmental change, and modelling healthy behaviours.	[1] Mean weight loss: IG -6lbs Range (-1 to -17.8lbs), CG -1.6lbs Range (+8 to -0.8lbs), p = 0.03 ^b [1] Mean BMI change: IG -1.1kg/m ² Range (-3 to -0.2), CG +0.3kg/m ² Range (-1.9 to +1.4), p = 0.04 ^b [2] Mean weight loss: -1.8lbs [2] Mean BMI change: -0.3kg/m ²	-	-	Participants: 3 months Post Intervention to Follow-up: [1] Mean weight change: +0.7lbs [1] Mean BMI change: +0.2kg/m ² [2] Mean weight change: +0.5lbs [2] Mean BMI change: +0.1kg/m ² Baseline to Follow-up: [1] Mean weight change: -5.3lbs [1] Mean BMI change: -0.9kg/m ² [2] Mean weight change: -1.3lbs [2] Mean BMI change: -0.2kg/m ²

Table 2.4: Physical Activity Intervention (PAI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Son et al. (2016), Korea, Repeated measures with no control group	Participants: n=9, (attn=0) Weight Status: IG mean BMI=26.8kg/m ² (SD=3.6) ID: Level 1, level 2 and level 3 Females: not given Mean age: 42.3 (SD=10.5)	65%	16 weeks	Walking program three times per week for 100 minutes per session, with additional warm-up and cool-down periods of 10 minutes.	Mean weight change: -5lbs, p < 0.001 ^a Mean BMI change: -0.9kg/m ² , p < 0.01 ^a Mean % Body Fat change: -4.4%, p < 0.01 ^a Mean WC change: -2.2cm, p < 0.001 ^a	-	-	-
Mendonca et al. (2011), Portugal, Pre- and post-intervention with comparison group	Participants: n=25, IG=13 (attn=0), CG=12 (attn=0) Weight Status: (mean BMI) IG 29.3kg/m ² (SD=3.7), CG 26.6kg/m ² (SD=4.5) ID: none given Females: IG=3, CG=3 Mean age: IG=36.5 (SD=5.5), CG=38.7 (SD=8.3) Range (19-33)	62%	12 weeks	Three group exercise sessions per week. Two days of combined (endurance and resistance) exercise and 1 day of endurance only exercise. Endurance was performed on a treadmill for 40-mins and resistance was two rotations through 9 exercises for resistance (up to 15 repetitions on each) with only 30 secs rest in between each.	Mean Weight change: IG -1.9lbs, CG +0.5lbs Mean BMI change: IG -0.4kg/m ² , CG 0 Mean % Body Fat change: IG 0, CG +0.6% No significant between group differences.	-	-	-
Schurrer et al. (1985), US, Pre- and post-intervention with no control group	Participants: n=5, (attn=0) Weight Status: not stated ID: mild/moderate Females: n=3 Mean age: 25.2 (SD=5.9)	46%	23 weeks	Walk-jogging programme provided four to six times per week with optional attendance.	Mean body weight change: -7.9lbs, p < 0.05 ^a 4 out of 5 participants lost weight	-	-	-
Mendonca et al. (2009), Portugal, Pre- and post-intervention with no control group	Participants: n=12, (attn=0) Weight Status: Mean BMI=27.3kg/m ² (SD=11.2) ID: Down Syndrome Females: none Mean age: 34.5 (SD=7.0) Range (21-49)	58%	28 weeks	Exercise program performed twice per week consisting of 5-min warm-up of dynamic activities, 40-mins of ergometer equipment (treadmill, stepper, stationary bike, and rower), 5-min dynamic cool down.	Mean weight change: -0.7lbs, no significance Mean BMI change: -0.1kg/m ² , no significance Mean % Body Fat: -3.8%, p < 0.01 ^a	-	-	-

Table 2.4: Physical Activity Intervention (PAI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Pérez et al. (2018), Spain, Pre- and post-intervention with no control group	<i>Participants:</i> n=14, (attn=0) <i>Weight Status:</i> Mean BMI=30.7kg/m ² (SD=4.1) <i>ID:</i> Down Syndrome + moderate (n=7) and severe (n=7) <i>Females:</i> 50% <i>Mean age:</i> 37.07 (SD=7.34)	69%	12 weeks	Water based activity sessions for 45 mins twice per week. 15-min Warm-up; breathing exercises, then kicking legs whilst holding on to side of pool and increasing intensity. 30-min Main exercise; crawl stroke with arms, crawl stroke with legs, backstroke legs. 5-min Cool Down; higher temp pool or jacuzzi	Mean weight change: +1.6lbs, Mean BMI change: +0.18kg/m ² Mean WC change: +0.5cm	-	-	-
Silva et al. (2017), Portugal, RCT	<i>Participants:</i> n=27, IG=14 (attn=2), CG=13 (attn=0) <i>Weight Status:</i> (Mean BMI) IG 32.2kg/m ² (SD=6.35), CG 32.04kg/m ² (SD=6.92) <i>ID:</i> Down Syndrome <i>Females:</i> not given <i>Mean age:</i> none given	69%	2 months	Intervention group completed 22 sessions (3 x 1-hour sessions per week). Individual sessions used Wii Fit Balance Board and suitable games, and joint sessions used Wii games targeting aerobic endurance. Control Group were treatment as usual.	Mean weight change: IG -3.4lbs, CG -0.79lbs, Mean BMI change: IG -0.22kg/m ² , CG -0.15kg/m ² Mean % Body Fat change: IG -1.1%, CG +0.11%, p = 0.06 ^b Mean WC change: IG -7.87cm, p = 0.008 ^a CG -2.88cm	-	-	-

*Casey et al (2012) study had 8 participants but one was removed from this analysis due to a baseline BMI<25kg/m², **Pett et al (2013) study involves 3 groups; 1 is a HPI intervention and the other 2 are Physical Activity interventions, ^a Pre to post intervention significance, ^b between groups significance.

(c) Study Limitations

Whilst this category was one of the most populated in the review, the types of exercise varied greatly between studies as did results, and it is possible that certain forms of exercise are more efficient for weight loss than others. Additionally, all the studies were of short durations and some were not specifically targeting weight loss as the main outcome. Weight loss interventions are recommended to be a minimum of 3-months duration with greater than 6-month interventions the ideal (NICE, 2014^b). Only four out of the nine studies exceeded 12 weeks duration. All studies had small sample sizes and only three studies had control groups to compare intervention effects.

2.2.4.2.4 *Behaviour Change Interventions (n=9)*

Nine studies were identified as Behaviour Change intervention (BCI) studies (see Table 2.5) and these incorporated specific behavioural strategies as outlined in NICE (2014^a), which are also listed under Research Question 1 above. Seven of the studies held weekly group HPI sessions about diet and exercise habits. During these sessions the participants also learnt behaviour change techniques that would assist them to stay on track to meet pre-determined goals for weight loss. Five of the studies utilised some or all of the Rotatori and Fox (1981) behavioural weight reduction program techniques. Durations ranged from 7 to 11 weeks, and the mean sample size was 12.22 (SD = 8.64), ranging from 1 to 29. Every study in this category aimed to reduce weight. The mean quality rating for BCIs was 57% (SD = 5.2, range 46 to 65%).

(a) Intervention Components

Except for Foreyt and Parks (1975) and Joachim (1977), all the interventions incorporated an HPI component with similar content which included nutrition, food types, portion sizes, meal planning, and exercise. Five of these studies followed the Rotatori and Fox (1981) behavioural weight reduction program or were adaptations of it such as the shortened version by Fox, Haniotes and Rotatori (1984). The main

behavioural change strategies used in these interventions were: goal setting, regular self-monitoring of weight, self-monitoring of food intake, negative self-talk used to avoid eating unhealthy foods, positive self-talk used to self-reinforce good choices, stimulus control strategies such as only eating in one designated place, chewing fully and swallowing before the next bite, self-monitoring of the frequency that eating behaviour techniques taught throughout the intervention were used each day, self-monitoring of daily exercise, external reinforcement for attendance, external reinforcement for each 1lb weight loss, and external reinforcement for adherence to behaviour change strategies taught. Parents and caregivers were essential partners in these studies to aid in the delivery of reinforcement in the home, and to help with self-monitoring. Of the other two studies that incorporate HPI, the Jones, Melville, Tobin and Gray (2015^a) study used the traffic light system for categorising foods (green for unlimited amounts of healthy foods and drinks, orange for healthy foods and drinks that had limited amounts, and red for unhealthy foods and drinks to be avoided). Self-monitoring was conducted using coloured stickers to signify foods eaten. Norvell and Ahern (1987) used their own custom HPI manual which included some of the same behavioural change techniques as Rotatori and Fox (1981), such as self-monitoring food intake, and stimulus control such as only eating in one designated place and not having food in view.

The oldest study by Foreyt and Parks (1975) used self-monitoring but with a colour coded token system to track food intake rather than a paper-based diary. Each colour represented a food type and each food type had its' own container for the day. Tokens were distributed to each container as a visual cue for how much of each food type the person could consume per day. When a food was consumed the participant had to move a coloured token to a different compartment therefore, visually demonstrating how much of each food type had been eaten that day and how much was left. At any point during the day participants could see what types and amounts of foods they could still consume.

Joachim (1977) used a multi-phase study design where components of the intervention were phased in and out to identify the effects on weight that different behavioural

strategies had. Components included self-monitoring of weight, self-monitoring of food and drink consumption, and weekly consultations.

(b) Study Outcomes

Table 2.5 shows the results for studies categorised as BCI. Mean weight changes were reported in all 9 studies with changes ranging from -2.2lbs in 8 weeks to -8.5lbs in 11 weeks (not including Joachim, 1977). Two studies reported statistically significant weight losses pre- to post- intervention (Jones et al., 2015^a; Norvell & Ahern, 1987). The only study reporting statistically significant between group results for weight loss was Fox, Rosenberg and Rotatori (1985) where the group that had active parental involvement outperformed the group completing the intervention without support from home. The Joachim (1977) multi-phase study produced a total weight change of -38lbs for the single participant, with the two instances of Phase B (self-monitoring of weight, self-monitoring of food and drink intake and weekly consultation) accounting for almost all the weight loss incurred. Only one study reported on BMI and waist circumference changes which were -0.65 kg/m² and -4.08cm reductions respectively in 7 weeks, both of which were statistically significant pre- to post- intervention (Jones et al., 2015^a).

(c) Study Limitations

Whilst there were many studies available that qualified for this category, the majority of the studies are variations of the same intervention by Rotatori and Fox (1981). Seven of the studies were also conducted prior to 1988 so may not satisfy all ethical criteria that current studies adhere to, which limits reproducibility. Small sample sizes and short durations are features of these studies, as are a lack of control groups to compare intervention effects.

Table 2.5: Behaviour Change Intervention (BCI) Studies

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Jones et al. (2015 ^a), UK, Pre- and post-intervention with no control group	<i>Participants:</i> n=29, (attn=0) <i>Weight Status:</i> Mean BMI=38.5kg/m ² (SD=6.8) Range (28.6-54.3) <i>ID:</i> mild/moderate <i>Females:</i> n=19 <i>Mean age:</i> 40.0 (SD=13.0) Range (19-66)	58%	7 weeks	Waist Winners Too (adapted from mainstream Waist Winners program). <i>HPI:</i> 8 x 1-hour sessions. Content included food and drink types, portion sizes, meal planning, and exercise. <i>Behaviour Change Strategies:</i> Goal setting and reviewing, daily food intake tracking using traffic light system for food categorisation, and daily exercise tracking.	Mean weight change: -3.7lbs, Range (-1.52 to -5.8), p = 0.002 ^a Mean BMI change: -0.65kg/m ² , Range (-0.27 to -1.03), p = 0.002 ^a Mean WC change: -4.08cm, Range (-1.97 to -6.21), p = 0.001 ^a	-	-	<i>Participants:</i> n=14 <i>Duration:</i> 6 weeks Baseline to Follow-up: Mean weight change: -5.5lbs, p = 0.032 ^a Mean BMI change: -0.65kg/m ² p = 0.027 ^a
Fox et al. (1984), US, Pre- and post-intervention with no control group (1) Behaviour Therapy Group [BT], & (2) Behaviour Therapy + Buddy Reinforcement Group [BTBR]	<i>Participants:</i> n=16, (attn=0), BT=8, BTBR=8 <i>Weight Status:</i> mean % overweight: BT=44.4% & BTBR=34.7% <i>ID:</i> moderate <i>Females:</i> n=9, BT=5, BTBR=4 <i>Mean age:</i> BT=29.5 (SD=7.2), BTBR=27.5 (SD=5.4)	65%	10 weeks	Streamlined version of the Rotatori and Fox (1981) curriculum described above, shortened from 14 weeks to 10 weeks duration. Parental training prior to program initiation. Session structure was: (i) review of homework and feedback, (ii) teaching of behavioural strategies, (iii) modelling of behaviour techniques, (iv) rehearsing techniques with feedback. BT + BTBR both received these interventions. BTBR had the addition of being split into buddy groups and the group with the most cumulative weight loss received additional reinforcement.	[BT] Mean weight change: -7.3lbs, Range (-1 to -16) [BTBR] Mean weight change: -8.2lbs, Range (-3 to -17) No significant weight losses between groups.	Weekly meetings where all behaviour strategies reviewed, and reinforcement was continued. Homework forms were gradually faded out.	<i>Participants:</i> n=16, (attn=0), BT=8, BTBR=8 <i>Duration:</i> 5 weeks [BT] Mean weight change: -2.13lbs, Range (+2 to -5) [BTBR] Mean weight change: -2.25lbs, Range (+1 to -6)	<i>Participants:</i> n=16, BT=8, BTBR=8 <i>Duration:</i> 12 months Post Intervention to Follow-up: [BT] Mean weight change: +6.63lbs, Range (+17 to -2) [BTBR] Mean weight change: -4.13lbs, Range (+18 to -16) Baseline to Follow-up: [BT] Mean weight change: -0.63lbs, Range (+5 to -8) [BTBR] Mean weight change: -4.13lbs, Range (+10 to -33)
Foreyt et al. (1975), US, Repeated measures with no control group	<i>Participants:</i> n=3, (attn=0) <i>Weight Status:</i> obese <i>ID:</i> severe <i>Females:</i> n=3 <i>Mean age:</i> 25.3 (SD=9.29) Range (19-36)	58%	11 weeks	A weight loss manual for parents ("A guide for parents of an overweight son or daughter" by Jim Parks). Self-monitoring by participants who used coloured tokens to track food intake. Daily weigh-ins. Reinforcement of 50c per week for weight loss of at least 1lb.	Mean weight change: -8.5lbs	-	-	-

Table 2.5: Behaviour Change Intervention (BCI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Fisher (1986)*, US, Pre- and post-intervention with no control group	<i>Participants:</i> n=9, (attn=0) <i>Weight Status:</i> 20% above desired weight <i>ID:</i> mild/moderate <i>Females:</i> n=9 <i>Mean age:</i> not given	54%	8 weeks	Rotatori and Fox (1981) procedures used for behavioural weight reduction as described above.	Mean weight change: -2.2lbs	-	-	Participants: n=9 Duration: 4 weeks Post Intervention to Follow-up: Mean weight change: +1.3lbs Baseline to Follow-up: Mean weight change: -0.9lbs
Saler et al. (2006), US, Multiple baseline across subjects	<i>Participants:</i> n=6, (attn=0) <i>Weight Status:</i> obese <i>ID:</i> mild <i>Females:</i> n=4 <i>Mean age:</i> 46 (SD=7.7) Range (34-54)	58%	10 weeks	Fox, Haniotes and Rotatori (1984) procedures used for behavioural weight reduction as described above. Reinforcement differed in that weight losses received ribbons and verbal praise by the group for weight losses of 1lb or more. Tangible reinforcers were also provided for completed self-monitoring sheets each week. A mid-week phone call was provided as additional support.	Mean weight change: -5.5lbs, Range (+1lb to -18lb)	-	-	Participants: n=5 Duration: 4 weeks Post Intervention to Follow-up: Mean weight change: -0.4lbs, Range (+4lb to -5lb) Baseline to Follow-up: Mean weight change: -3.4lbs, Range (+5lb to -8lb)
Rotatori et al. (1980), US, Pre- and post-intervention with control group	<i>Participants:</i> n=18, IG=10 (attn=0), CG=8 (attn=0) <i>Weight Status:</i> not stated <i>ID:</i> mild <i>Females:</i> not given <i>Mean age:</i> not given	46%	7 weeks	Intervention Group: 1-hour once per week meetings with content including (i) the manipulation of emotional responses, (ii) food-cue elimination, (iii) changing the act of eating, (iv) burning up calories, (v) finding other activities. Meeting structure was verbally defining the behavioural technique, peer video modelling, researcher modelling, practicing the technique. Reinforcement: money provided for weight loss and for completed self-monitoring. Control Group: were told that the weight loss group was full and they should try to lose weight on their own.	IG Mean weight change: -3.6lbs CG Mean weight change: +1.6lbs	The intervention group was split into two groups of 5, and each group had a weekly meeting. IG-A received fixed monetary reinforcement and IG-B received intermittent monetary reinforcement for weight loss and completed homework.	Participants: n=18, IG=10, CG=8 Duration: 6 weeks IG-A Mean weight change: -1.1lbs IG-B Mean weight change: +0.1lbs CG Mean weight change: +0.3lbs	Participants: n=18, IG=10, CG=8 Duration: 10 weeks Post Intervention to Follow-up: IG Mean weight change: -1lbs CG Mean weight change: +1lbs Baseline to Follow-up: IG Mean weight change: -3.6lbs CG Mean weight change: +2.6lbs

Table 2.5: Behaviour Change Intervention (BCI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Fox et al. (1985), US, Pre- and post-intervention with no control group	Participants: n=15, PI=8 (attn=0), SO=7 (attn=0), Weight Status: both groups were obese ID: mild/moderate Females: n=4 (all in PI) Mean age: PI 27 (SD=2.7), SO 29 (SD=2.2)	58%	10 weeks	Fox, Haniotes and Rotatori (1984) procedures used for behavioural weight reduction as described above. PI Group: The parents received specific training on how to assist in the program and how to provide reinforcement for weight loss at home. SO Group: Parents were provided with a verbal definition no instructions about weekly reward procedure. PI group could trade weight loss certificates for a reinforcer delivered at home by parents. SO received a weight loss card which stars were added for each 1lb lost and participants encouraged to show for verbal reinforcement. They could not trade certificates for reinforcers at home but at the end of 2 weeks the most stars received a trophy. Both groups provided self-reinforcement for completed self-monitoring.	PI Mean weight change: -7.4lbs, Range (-4 to -11) PI Mean % weight change: -4.75%, Range (-3 to -6%) SO Mean weight change: -2.4lbs, Range (+5 to -8) SO Mean % weight change: -1.86%, Range (+2 to -5%) Between-group differences were significant on both weight loss and % weight loss $p < 0.05^b$	3 monthly meetings. Behaviour strategies were reviewed, and reinforcement was still provided for completed homework and weight loss.	Participants: n=15, PI=8, SO=7 Duration: 3 months Mean weight change: +1.5lbs, Range (+8 to -6) Mean % weight change from baseline: -3.7%, Mean weight change: +0.3lbs, Range (+7 to -12) Mean % weight change from baseline: -1.3%, No significant between-group differences for both weight change and % weight change	Participants: n=15, PI=8, SO=7 Duration: 6 months Post Intervention to Follow-up: PI Mean weight change: +3.9lbs, Range (+12 to -7) SO Mean weight change: +6.3lbs, Range (+15 to 0) No significant between-group differences both weight change and % weight change Baseline to Follow-up: PI Mean weight change: -3.5lbs, Range (+4 to -13) PI Mean % weight change from baseline: -2.2% SO Mean weight change: +3.9lbs, Range (+17 to -8) SO Mean % weight change from baseline: +1.7%, No significant between-group differences both weight change and % weight change
Joachim (1977), Australia, Multi-phase design	Participants: n=1, (attn=0) Weight Status: overweight ID: mild Females: n=1 Mean age: 32	58%	Phase A: 3 weeks Phase B: 10 weeks Phase C: 5 weeks Phase D: 4 weeks Phase E: 5 weeks	Phase A Baseline: daily weigh for 3 wks Phase B Intervention: (i) self-monitoring weight 4 times per day, (ii) self-monitoring food and drink daily intake, (iii) weekly consultation for feedback. Phase C Intervention: no longer self-monitoring food and drink intake, (i) and (iii) remain. Phase D intervention: continued weighing 4 times per day but did not keep self-monitoring records, (iii) remained. Phase E: no procedures used Phase D reintroduced Phase C reintroduced Phase B reintroduced for 5 weeks	B: Weight change: -23lbs C: Weight change: -2lbs D: Weight change: +2lbs E: Weight change: -3lbs D: Weight change: +2lbs C: Weight change: -1lbs B: Weight change: -13lbs Total weight loss: -38lbs	-	-	-

Table 2.5: Behaviour Change Intervention (BCI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Norvell et al. (1987), US, Pre- and post-intervention with control group	<p>Participants: n=13, IG=6 (attn=0), CG=7 (attn=0)</p> <p>Weight Status: obese</p> <p>ID: mild/moderate</p> <p>Females: 8, IG=2, CG=6</p> <p>Mean age: IG=30.2 (SD=3.9), CG=30.1 (SD=8.1)</p>	62%	10 weeks	<p>Intervention Group: 1-hour once per week following a manual specific to this study.</p> <p>Structure was (i) review self-monitoring sheets from previous week, (ii) didactic, (iii) problem solving group discussion.</p> <p>Didactic section included nutrition, exercise and behavioural techniques.</p> <p>Weekly weigh ins and feedback provided.</p> <p>Wait List Control Group: Weekly weigh ins with feedback on gains or losses.</p> <p>Control Group started the intervention when the first group finished (IG2).</p>	<p>IG Mean weight change: -4.4lbs (SD=6)</p> <p>IG Mean % weight change: -2.5% (SD=3.5)</p> <p>CG Mean weight change: -0.33lbs (SD=0.51)</p> <p>CG Mean % weight change: -0.2% (SD=0.3)</p> <p>IG2 Mean weight change: -6.0lbs (SD=3.7)</p> <p>IG2 Mean % weight change: -3.4% (SD=2.1)</p> <p>No significant between-group differences, $p > 0.05^b$</p> <p>Significant differences pre to post for IG2, $p < 0.05^a$</p>	-	-	<p>Participants: n=13, IG=6, CG=7</p> <p>Duration: 6 months and 3 months for CG when they become IG2</p> <p>Post Intervention to Follow-up:</p> <p>IG Mean weight change: -0.9lbs</p> <p>IG2 Mean weight change: -1.5lbs</p> <p>Baseline to Follow-up:</p> <p>IG Mean weight change: -5.3lbs</p> <p>IG2 Mean weight change: -7.5lbs</p>

Fisher (1986) has two groups in the same study: one group is Behaviour Change intervention and the other is a Physical Activity + Behaviour Change intervention, ^a Pre to post intervention significance, ^b between groups significance

2.2.4.2.5 *Physical Activity and Behaviour Change Interventions (n=3)*

Three studies each incorporating two components: (1) a physical activity component which involved increasing the amount of physical activity engaged in regularly by participants, and (2) behaviour change strategies to support the changes in diet and/or exercise, were identified as Physical Activity + Behaviour Change interventions (PA+BCI) studies (see Table 2.6). All three studies performed the exercise component as a group, however, some of the behavioural strategies such as self-monitoring were performed individually throughout the day and across service and home environments. Intervention durations ranged from 8 weeks to 7 months, and the mean participant sample size was 32 (SD=46) ranging from 3 to 85. Both the Fisher (1986) and Bazzano et al. (2009) studies aimed to reduce weight, but Croce and Horvat (1992) targeted measures of physical fitness as the primary aim with body composition of secondary concern. The mean quality rating for PA+BCIs was 59% (SD = 4.4, range 54 to 62%).

(a) Intervention Components

The second group in the Fisher (1986) study used the same behavioural weight reduction strategies by Rotatori and Fox (1981) as did the other group (see Table 1.6) but it also incorporated a walking program with an incremental increase in duration as it's physical activity component. Bazzano et al. (2009) used community-based participatory research (CBPR) to develop the Healthy Lifestyle Change Program (HLCP) and included 11 adults with ID as a peer support network for participants. The HP covered six areas: (1) general health and self-care, (2) nutrition, (3) exercise, (4) medical conditions related to obesity, (5) medications, and (6) behaviour change strategies, over the 7-month intervention period. Physical activities were performed in local outdoor parks, a local exercise facility, and an exercise video that was made by the peer mentors. Participants received incentives for attending sessions, losing weight, and finishing the intervention. The Croce and Horvat (1992) physical activity component included both aerobic and strength training with increasing durations and intensities built into the program. Tokens were given to participants if they met the pre-set durations or distances decided for each session, and extra tokens were available

for durations or distances exceeded. Tokens could be traded at the end of the week for small prizes.

(b) Study Outcomes

Table 2.6 shows the results for studies categorised as PA+BCI. Weight changes were reported in all 3 studies with changes ranging from -1.3lbs in 8 weeks to -2.6lbs over 7 months. One of the 3 participants in the Croce and Horvat (1992) study gained +5.2lbs over 8 weeks, but the other 2 participants lost -6.4lbs in 14 weeks, and -6.8lbs in 11 weeks. Statistically significant weight losses pre- to post- intervention were achieved by the participants in Bazzano et al. (2009) study, and by the first two participants in the Croce and Horvat (1992) study. Only Bazzano et al. (2009) reported BMI changes and demonstrated statistically significant changes pre- to post-intervention, with the number of participants reducing their BMI category also achieving significance. Reductions in % body fat were only reported in participants in the Croce and Horvat (1992) study and only one subject achieved statistical significance pre- to post- intervention.

(c) Study Limitations

Since there are only three studies available in this category it is difficult to form an overall view of efficacy. Durations are shorter than the recommended 3 months for weight loss in two of the studies, sample sizes are small and a lack of control groups for comparison further cloud judgement. As with the PAI, this category is complicated by the fact that the physical activity component differs for each study in type, duration, and intensity.

Table 2.6: Physical Activity and Behaviour Change Intervention (PA + BCI) Studies

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Fisher (1986)*, US, Pre- and post-intervention with no control group	Participants: n=8, (attm=0) Weight Status: 20% above desired weight ID: mild/moderate Females: n=8 Mean age: not given	54%	8 weeks	<i>Physical Activity Component:</i> Walking for a set duration each day, which increased by 5 minutes every 2 weeks going from a total of 10 mins up to 30 mins by end of intervention. <i>Behaviour Change Strategies:</i> Strategies based on those used in the behavioural weight reduction program by Rotatori and Fox (1981). No detail on which strategies were used over the 8 weeks except self-monitoring.	Mean weight change: -1.3lbs	-	-	Participants: n=8 Duration: 4 weeks Post Intervention to Follow-up: Mean weight change: +1.36lbs Baseline to Follow-up: Mean weight change: 0lbs
Bazzano et al. (2009), US, Pre- and post-intervention with no control group	Participants: n=85, (attm=41) Weight Status: Mean BMI=33.3kg/m ² ID: not given Females: n=27 after attrition Age: 18-29 (11.4%), 30-39 (20.5%), 40-49 (43.2%), and 50-59 (25%)	62%	7 months	The Healthy Lifestyle Change Program (HLCP) <i>Physical Activity Component:</i> 2-hour sessions twice weekly with 50-mins Health Promotion, 10-mins healthy snack break, and 1-hour physical activity program in local amenities. <i>Behaviour Change Strategies:</i> Incentives provided for attendance, weight loss, and program completion. <i>Peer mentoring:</i> 11 adults with ID.	Mean weight change: -2.6lbs, p = 0.03 ^a Mean BMI change: -0.5kg/m ² , p = 0.04 ^a Significant shift from obese to overweight, or overweight to normal p < 0.0001 ^a	-	-	-

Table 2.6: Physical Activity and Behaviour Change Intervention (PA + BCI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Croce et al. (1992), US, Multiple baseline across subjects	Participants: n=3, (attn=0) Weight Status: obese ID: mild/moderate Females: n=0 Mean age: 24.66 (SD=3.5) Range (21-28)	62%	Subject 1 =14 weeks Subject 2 =11 weeks Subject 3 =8 weeks	<i>Physical Activity Component:</i> 1-hour session x three days each week + one 40-min session one day each week. 10 min warm-up of stretches, 20-min isotonic strength resistance training (not done on the 4 th day), 20-min aerobic exercise with intensity based on individual heart rates (either walking, jogging or pedalling a cycle ergometer), and a 10-min cool down. <i>Behaviour Change Component:</i> Verbal praise contingent upon time on task & Token Economy system for duration of exercise and intensity of exercise engaged in. Tokens traded at the end of each week for tangible rewards.	Subject 1: Weight change: -6.4lbs, $p < 0.05^a$ % Body Fat reduction: -8.42%, non-significant Subject 2: Weight change: -6.8lbs, non-significant, % Body Fat reduction: -10%, $p < 0.05^a$ Subject 3: Weight change: +5.2lbs, non-significant % Body Fat reduction: +3.84%, non-significant	-	-	Participants: n=3 Duration: 5 weeks Post Intervention to Follow-up: [S1] Weight change: +2.4lbs [S1] % Body Fat reduction: +0.7% [S2] Weight change: +3.3lbs [S2] % Body Fat reduction: 0% [S3] Weight change: +0.9lbs [S3] % Body Fat reduction: +0.7% Baseline to Follow-up: [S1] Weight change: -4.1lbs, $p < 0.05^a$ [S1] % Body Fat reduction: -6.21%, $p < 0.05^a$ [S2] Weight change: -4.0lbs, $p < 0.05^a$ [S2] % Body Fat reduction: -10%, $p < 0.05^a$ [S3] Weight change: +6.0lbs, non-significant [S3] % Body Fat reduction: +6.5%, non-significant

*Fisher (1986) has two groups in the same study: one group is Behaviour Change intervention and the other is a Physical Activity + Behaviour Change intervention, ^a Pre to post intervention significance, ^b between groups significance.

2.2.4.2.6 Multi-component Interventions (n=6)

Six studies fulfilled the NICE (2014^a) criteria of a targeted dietary deficit component, increased physical activity component, and behaviour change strategies necessary to qualify as an MCI (see Table 2.7). Four of the studies had durations of 6 months, the ideal duration for weight loss interventions, and the other studies had durations from 14 weeks to 20 weeks, still satisfying the minimum recommended duration for weight loss interventions (NICE, 2014^a). The mean participant sample size was 67 (SD=48.1) and ranged from 3 to 150, however, five out of the six studies had sample sizes greater than 50. All six studies specifically aimed to reduce weight. The mean quality rating for MCIs was 68% (SD = 11.1, range 54 to 77%).

(a) Interventions

Two studies used the *Take 5* program from Scotland, a program for adults with intellectual disabilities that was adapted from the Glasgow and Clyde Weight Management Service (GCWMS) intervention for the general population. *Take 5* consisted of nine sessions of approximately 1-hour duration provided to each individual participant in their home over a 6-month period. Personalised energy deficient diets were prescribed for each participant by a dietician with a -600kcal deficit per day, and portion sizes followed the *EatWell Plate* model (Food Standards Agency, 2009). Specific physical activity goals were set for each participant in-line with current activity levels and were reviewed at each meeting and incrementally increased towards recommended exercise guidelines. Participants set goals for their diet and exercise at each meeting and between meetings they recorded their daily food intake and exercise engagement in paper-based diaries. Carers were involved in assisting with the goal setting and self-monitoring activities where needed. The Harris et al. (2017) study included a control group that used the *Waist Winners Too* BCI detailed in the Jones et al. (2015^a) study, whereas the Melville et al. (2011) study had no control group.

Saunders et al. (2011) and Ptomey et al. (2018) both used variations of the *Enhanced Stop Light Diet (eSLD)* coupled with specific step count targets. Monetary incentives were provided for weight loss, completed self-monitoring and meeting physical activity goals. In the Saunders et al. (2011) study the eSLD consisted of: (1) a minimum of 5 portions of fruit and vegetables, (2) up to 3 low-calorie shakes, (3) 2 entrees that were less than 300kcal each, (4) other low-calorie items, and (5) all other foods eaten were to be recorded and categorised as per the traffic light system (described previously in Jones et al., 2015^a). The physical activity component involved a game board with milestone markers of 10,000's, 100,000's and 1,000,000 steps. Daily self-monitoring of food intake and exercise engagement were requirements and monetary incentives were provided for completion of these tracking sheets. Monetary incentives were also provided for reaching physical activity milestones and BMI reduction. Researcher consultations and goal setting meetings occurred monthly for each individual participant. The eSLD in the Ptomey et al. (2018) study consisted of: (1) 5 x 1-cup portions of fruit and vegetables, (2) 2 x low-calorie shakes, (3) 2 entrees that were less than 300kcal each, (4) non-caloric drinks, and (5) all other foods eaten were to be recorded and categorised as per the traffic light system (described previously in Jones et al., 2015^a). The physical activity component targeted 30-minutes per day of exercise with pedometers provided and a game board to track every 100,000 steps. Like the Saunders et al. (2011) study, daily self-monitoring of food intake and exercise engagement were requirements and monetary incentives were provided for completion of these tracking sheets. Monetary incentives were also provided for reaching physical activity milestones, but not for any improvements in body composition. Consultations and goal setting meetings with the researchers were monthly. This study included a control group who followed the *MyPlate* (US Department of Agriculture, 2019) approach to a daily dietary deficit of -500 to -700kcal with sample menu plans, and taught sessions for portion sizes and nutrition.

Croce (1990) was the oldest study in this category, however the components involved in the intervention are similar. The dietary component consisted of a strictly monitored diet with a -500kcal daily deficit. The physical exercise component was a

1-hour vigorous intensity exercise program performed 5 days of the week. Behaviour change strategies employed involved verbal reinforcement for meeting exercise durations, and a token economy system for achieving pre-set physical activity goals, with extra tokens given for exceeding these goals.

Martínez-Zaragoza et al. (2016) provided service centres and families with weekly menus that incorporated 1800kcal per day for meals and snacks as the dietary component. Five days per week a 1-hour aerobic and strength exercise session was held with participants for the physical activity component. Token economy systems were in place as motivators for weight loss and physical activity. Tokens earned for engagement in the physical activity sessions could be traded for small prizes, and tokens earned for weight loss could be traded for outings.

(b) Study Outcomes

Table 2.7 shows the results for studies categorised as MCI. Mean weight changes were reported in all six studies with changes ranging from -6.5lbs over 6 months to -21.4lbs over 20 weeks. Two studies reported mean weight losses as statistically significant pre- to post- intervention (Harris et al., 2017; Melville et al., 2011) and two studies reported statistically significant between group differences (Martínez-Zaragoza, Campillo-Martínez & Ato-García, 2016; Ptomey et al., 2018). BMI changes were reported in 4 studies with changes ranging from -1.19 kg/m² in 6 months to -2.7 kg/m² in 6 months. Two studies demonstrated statistically significant changes in BMI pre- to post- intervention (Harris et al., 2017; Melville et al., 2011), and one study reported statistically significant between group differences (Ptomey et al., 2018). Percentage body fat reductions were reported in 2 studies with changes ranging from -1.79% in 6 months to -8.55% in 20 weeks. Only one study reported statistically significant change pre- to post- intervention (Harris et al., 2017), with no studies showing statistically significant between group differences. Mean waist circumference changes were reported by three studies with changes ranging from -3.15cm in 6 months to -6.29cm in 6 months. One study demonstrated statistically significant

change pre- to post- intervention (Harris et al., 2017), and one study reported a statistically significant between group difference (Ptomey et al., 2018).

(c) Study Limitations

Three of the studies in this category did not have control groups, however, one of these studies employed a multiple baseline across subjects' design in which each subsequent subject acted as a control for the previous subject. One study had a small sample size of only 3, however, this study used single-subject design methodology to demonstrate intervention effects. Differences in the details of the components of each intervention could be viewed as limiting, however, the components were similar over most of the studies; five of the studies included energy deficient diets of approximately -600kcal per day, 4 of the studies used walking programs as their structured increase in physical activity, and all utilised similar behaviour change techniques such as goal setting, self-monitoring, feedback and incentives.

Table 2.7: Multi-component Intervention (MCI) Studies

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Harris et al. (2017), UK, Cluster RCT	<p><i>Participants:</i> n=50, IG=26 (attn=2), CG=24 (attn=3)</p> <p><i>Weight Status:</i> IG mean BMI=40.2kg/m² (SD=6.8), CG mean BMI=41.2kg/m² (SD=8.1)</p> <p><i>ID:</i> mild to profound</p> <p><i>Females:</i> n=32, IG=18, CG=14</p> <p><i>Mean age:</i> IG=40.6 (SD=15.0), CG=43.6 (SD=14.0)</p>	77%	6 months	<p>Intervention Group used the TAKE 5 program as described above.</p> <p>Control Group used the Behaviour Change intervention Waist Winners Too described in (Jones et al., 2015^a)</p>	<p>Mean weight change: IG -6.5lbs (p < 0.001^a), CG -2.8lbs, (p = 0.110), Between group difference p = 0.126</p> <p>Mean % change in weight: IG -3.25% (p < 0.001^a), CG -0.98% (p = 0.231), Between group difference p = 0.05^b</p> <p>Mean BMI change: IG -1.19kg/m² (p < 0.001^a), CG -0.46kg/m² (p = 0.133), Between group difference p = 0.085</p> <p>Mean % Body Fat change: IG -1.79% (p = 0.008^a), CG -1.02% (p = 0.155), Between group difference p = 0.430</p> <p>Mean WC change: IG -3.15cm (p = 0.001^a), CG -1.45cm (p = 0.120), Between group difference p = 0.186</p>	-	-	<p>Participants: n=50, IG=26, CG=24</p> <p>Duration: 6 months</p> <p>Post Intervention to Follow-up:</p> <p>Mean weight change: IG -1.4lbs, CG -0.4lbs</p> <p>Mean % change in weight: IG -0.55%, CG -0.24%</p> <p>Mean BMI change: IG -0.29kg/m², CG -0.13kg/m²</p> <p>Mean % Body Fat change: IG -0.44%, CG -1.02%</p> <p>Mean WC change: IG -0.45, CG -0.38cm</p> <p>Baseline to Follow-up:</p> <p>Mean weight change: IG -7.8lbs (p=0.001^a), CG -3.7lbs, (p = 0.108), between group p = 0.195</p> <p>Mean % change in weight: IG -3.8% (p = 0.001^a), CG -1.22% (p = 0.237), between group p = 0.084</p> <p>Mean BMI change: IG -1.48kg/m² (p = 0.001^a), CG -0.59kg/m² (p = 0.154), between group p = 0.134</p> <p>Mean % Body Fat change: IG -2.23% (p = 0.013^a), CG -0.65% (p = 0.495), between group p = 0.231</p> <p>Mean WC change: IG -3.6cm (p = 0.004^a), CG -1.83cm (p = 0.132), between group p = 0.304</p>

Table 2.7: Multi-component Intervention (MCI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Melville et al. (2011), UK, Pre- and post-intervention with no control group Maintenance Study is Spanos et al. (2016)	<i>Participants:</i> n=54, (attn=7) <i>Weight Status:</i> Mean BMI=40kg/m ² (SD=8.03) <i>ID:</i> not given <i>Females:</i> n=32 <i>Mean age:</i> 48.3 (SD=12.01) Range (23-71)	73%	6 months	The intervention was the TAKE 5 program as described above.	Mean weight change: -9.9lbs (p < 0.0001 ^a) Mean BMI change: -1.82kg/m ² (p < 0.0001 ^a) Mean WC change: -6.29cm (p < 0.0001 ^a)	Monthly meetings. Diet Prescribed diet with no calorie deficit, but balance intake with estimated energy output. Physical Activity remained as increasing towards recommended weekly engagement of 150 mins. Behaviour Change Weekly self-monitoring of weight, goal setting, self-monitoring of food and exercise, relapse prevention, stimulus control, assertiveness and problem solving.	Participants: 28 Duration: 12 months Mean weight change: -1.3lbs (p = 0.5) Mean BMI change: -0.06kg/m ² (p = 0.7) Mean WC change: -0.4cm (p = 0.8)	-
Croce (1990), US, Multiple baseline across subjects	<i>Participants:</i> n=3, (attn=0) <i>Weight Status:</i> Subject 1=129% of ideal weight (slightly obese), Subject 2=127% of ideal weight (slightly obese), Subject 3=125% of ideal weight (slightly obese) <i>ID:</i> severe <i>Females:</i> n=0 <i>Mean age:</i> 27.3 Range (24-30)	54%	Subject 1 20 weeks Subject 2 17 weeks Subject 3 14 weeks	Diet Component: -500kcal daily reduction. Physical Activity Component: 1-hour vigorous exercise 5 days/week. 15-min stretching warm-up. 30 mins of vigorous exercise (15-min on bike and 15-min on treadmill), 15-min cool-down. Behaviour Change Strategies: Verbal reinforcement contingent upon time on task for exercise. Token reinforcement for reaching set goals for exercise, and extra tokens given for exceeding goals.	Subject 1: Weight change: -21.4lbs % Body Fat reduction: -8.55% Subject 2: Weight change: -16.5lbs, % Body Fat reduction: -7.25 Subject 3: Weight change: -13.1lbs % Body Fat reduction: -4.93%	-	-	-

Table 2.7: Multi-component Intervention (MCI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Martínez-Zaragoza et al. (2016), Spain, Repeated measures with control group	<p><i>Participants:</i> n=66, IG=35 (attn=2), CG=31 (attn=0)</p> <p><i>Weight Status:</i> (Mean BMI) IG 31.76kg/m², CG 34.71kg/m²</p> <p><i>ID:</i> mild/moderate</p> <p><i>Females:</i> n=26, IG=15, CG=11</p> <p><i>Mean age:</i> IG=34 (SD=5.71), CG=34.71 (SD=5.84)</p>	73%	17 weeks (after the education section)	<p>1-month HPI phase.</p> <p>Diet Component: 1800kcal per day, weekly menus provided to service centre and to families.</p> <p>Physical Activity Component: 1-hour per day group sessions for 5 days Monday-Friday. Warm-up, sub-aerobic or aerobic activity, strength and power, then recovery.</p> <p>Behaviour Change Strategies: Token economy system for weight loss and physical activity (PA). PA tokens traded for prizes and weight loss tokens traded for outings.</p>	<p>Mean change in weight: IG -18lbs (SD=9.3)</p> <p>Between group difference for weight loss: $p = 0.048^b$</p>	-	-	<p>Participants: n=66, IG=35, CG=31</p> <p>Duration: 6 months</p> <p>Post Intervention to Follow-up: Mean change in weight: IG +0.24lbs (SD=14.6)</p>
Saunders et al. (2011), US, Pre- and post-intervention with no control group	<p><i>Participants:</i> n=79, (attn=6)</p> <p><i>Weight Status:</i> Mean BMI=38.0kg/m²</p> <p><i>ID:</i> varied</p> <p><i>Females:</i> n=3</p> <p><i>Mean age:</i> 25.2 (SD=5.9)</p> <p><i>Note: only 47 participants took part in the physical activity component</i></p>	54%	6 months	<p>Monthly consultations.</p> <p>Diet component: Enhance Stop Light Diet (eSLD) as described above.</p> <p>Physical Activity Component: Step counter and a game board with pathways of circles for every 10,000 steps towards islands of 100,000 steps, and the final island at 1,000,000 steps.</p> <p>Behaviour Change Strategies: (i) self-monitoring of weight, (ii) self-monitoring food and drink intake, (iii) monetary reinforcement for completed self-monitoring, (iv) monetary reinforcement for reduction in BMI, and (v) monetary reinforcement for physical activity goals.</p>	<p>Mean weight change: -13.12lbs</p> <p>Mean % weight change: -6.3%</p> <p>Mean BMI change: -2.7kg/m²</p>	<p>Monthly consultations.</p> <p>Diet: Advised calorie increases for those who were maintaining weight only, those continuing to lose weight were advised to keep going. No shakes provided.</p> <p>Physical activity no longer received sticker rewards or incentives.</p> <p>Behaviour Change: Incentives only provided for attendance and not for self-monitoring. Star cards still available for those losing weight.</p>	<p>Participants: 43</p> <p>Duration: 6 months (baseline to end maintenance)</p> <p>Mean weight change: -19.4lbs range +12.7 to -51.15</p> <p>Mean % weight change: Range +8.73 to -28.1%</p> <p>Mean BMI change: -2.7kg/m²</p>	-

Table 2.7: Multi-component Intervention (MCI) Studies (cont' d)

Study / Location / Type	Participants	Quality Rating	Duration	Intervention Description	Results	Maintenance Conditions	Post Intervention to Maintenance Results	Follow-up
Pomey et al. (2018), US, RCT	<p><i>Participants:</i> n=150, IG=78 (attn=11), CG=72 (attn=20)</p> <p><i>Weight Status:</i> oIG mean BMI=37.5kg/m² (SD=7.6), CG=36.4kg/m² (SD=8.1)</p> <p><i>ID:</i> mild/moderate</p> <p><i>Females:</i> n=85, IG=46, CG=39</p> <p><i>Mean age:</i> IG=36.1 (SD=12.0), CG=37.0 (SD=12.5)</p>	77%	6 months	<p>Monthly consultations.</p> <p>Intervention Group Diet Component: Enhanced Stop Light Diet (eSLD) as described above.</p> <p>Control Group Diet Component: MyPlate approach towards a -500 to -700kcal deficit per day. Taught on nutrition and portion size and example menu plans provided.</p> <p>Physical Activity Component for both groups: Target of 30mins per day advised and pedometers provided. Game board to track every 100,000 steps.</p> <p>Behaviour Change Strategies for both groups: Self-monitoring of dietary intake and physical exercise. Monetary incentives for self-monitoring, and for steps completed. Feedback on self-monitoring at each meeting.</p>	<p>Mean weight change: IG -15lbs, CG -7.9, p = 0.001^b</p> <p>Mean % weight change: IG -7%, CG -3.8%, p = 0.001^b</p> <p>Mean BMI change: IG -2.4kg/m², CG -1.4kg/m², p = 0.015^b</p> <p>Mean WC change: IG -5.2cm, CG -1.8cm, p = 0.001^b</p>	<p>Intervention Group continued with low-calorie pre-packaged meals and shakes and were encouraged to increase number of yellow foods eaten.</p> <p>Control Group given energy intake requirements for weight maintenance and provided with sample meal plans</p> <p>Physical activity remained the same.</p>	<p>Participants: n=150, IG=78, CG=72 Duration: 12 months</p> <p>Mean weight change: IG +0.7lbs, CG -5.5lbs, Between groups p = 0.052</p> <p>Mean % weight change: IG +0.3%, CG -2.2%,</p> <p>Mean BMI change: IG -0.02kg/m², CG -0.8kg/m²</p> <p>Mean WC change: IG +0.5cm, CG -1.7cm</p>	-

^a Pre to post intervention significance, ^b between groups significance.

2.2.4.2.7 *Family and Paid Carer Involvement (n=13)*

A further component worth exploring is the impact that family and paid carer involvement may have on the outcomes of weight loss interventions for adults with ID. The PAI and PA+BCI categories were removed from this analysis since all physical activity interventions were run by the intervention team and no carer involvement outside of the intervention time was required. Of the 24 studies remaining, 8 involved family carers, 3 involved paid carers and 2 involved either family or paid carers, as is shown in Table 2.8 below. When looking at HPI it appears that providing health education to carers as well as participants makes little or no difference to weight changes. With DI it is clear that carer involvement in diet plays an instrumental role in reducing weight, however, the high level of carer control and lack of choice around food consumption in these studies would be ethically inappropriate in today's research and practice. The BCI that incorporate family carer involvement appear to produce better results than those with paid carer input, and those without any carer involvement. The exception in this group is the Joachim (1977) study, however, this study duration was at least 3 times longer than any of the others. In the MCI category all except the Saunders et al. (2011) study included carers involvement. The Martinez-Zaragoza et al. (2016) and Ptomey et al. (2018) studies specifically recruited either a family or paid carer to support each participant. The Croce (1990) study involved paid carers at the centre overseeing and manipulating food consumption levels to ensure an EDD. The Harris et al. (2017) and Melville et al. (2011) studies made carer involvement an optional feature but did not provide details on the level of involvement that occurred. The MCI studies that specifically involved family or paid carers in their interventions produced larger weight losses, indicating that this may be an important component to add, where possible, to weight loss interventions for adults with ID.

Table 2.8: Carer Involvement

Type	Authors	Dur'n	Family Carer	Paid Carer	No Carer	Weight Loss/Gain	Mean Weight Change	Statistically Significant (pre to post)
HPI	Bergstrom et al. (2013)	16 m		√		WL	-	No
	Geller et al. (2009)	24 m			√	WL	-2.6lbs	No
	Pett et al. (2013)	12 w	√			WL	-4lbs	No
	Ewing et al. (2004)	8 w			√	-	-	-
	Chapman et al. (2005)	12 m			√	WL	-3.3lbs	Yes
	Mann et al. (2006)	8 w			√	-	-	-
	Marshall et al., (2003)	8 w			√	WL	-7.5lbs	Yes
DI	Antal et al. (1988)	4 w		√		WL	-33.1lbs	-
	Zoppo et al. (2008)*	9 m	√			WL	-30.9lbs	Yes
	Zoppo et al. (2008)*	9 m			√	WG	-	No
BCI	Jones et al. (2015)	7 w	√	√		WL	-3.7lbs	Yes
	Fox et al. (1984)	10 w	√			WL	-8.2lbs	-
	Foreyt et al. (1975)	11 w	√			WL	-8.5lbs	-
	Fisher (1986)	8 w			√	WL	-2.2lbs	-
	Sailer et al. (2006)	10 w			√	WL	-5.5lbs	-
	Rotatori et al. (1980)	7 w			√	WL	-3.6lbs	-
	Fox et al. (1985)	10 w	√			WL	-7.4lbs	Yes
	Joachim (1977)	27 w			√	WL	-38lbs	-
	Norvell et al. (1987)	10 w			√	WL	-4.4lbs	Yes
MCI	Harris et al. (2017)	6 m	√			WL	-6.5lbs	Yes
	Melville et al. (2011)	6 m	√			WL	-9.9lbs	Yes
	Croce (1990)	20 w		√		WL	-21.4lbs	-
	Martinez-Zaragoza et al. (2016)	17 w	√			WL	-18lbs	-
	Saunders et al. (2011)	6 m			√	WL	-13.1lbs	-
	Ptomey et al. (2018)	6 m	√	√		WL	-15lbs	Yes

WL = weight loss, WG = weight gain. Dur'n = Duration, m = month, w = weeks.

*Two separate groups in one study.

2.2.4.3 Research Question 4

Is there is a longer-term weight maintenance and/or follow-up component included and what are the reported effects?

The criteria for maintaining weight is unclear in the literature and the NICE (2014^a) guidelines do not provide specific figures to compare to. However, some studies suggest that a less than $\pm 3\%$ change in body weight immediately after a weight loss program dictates success in maintaining weight (Spanos, Hankey & Melville, 2016; Stevens, Truesdale, McClain & Cai, 2006). NICE (2014^b) provide clearer information for follow-up measures stating that follow-up should occur no sooner than 12 months after cessation of a weight loss program.

2.2.4.3.1 Health Promotion Interventions (n=2)

None of the studies included a component for weight maintenance, however, two studies reported follow-up measures (see Table 2.2). The participants in the Pett et al. (2013) group continued to lose weight after the intervention ceased and managed to reach a mean weight loss of greater than -3% by the 3-month follow-up. All participants were available for the follow-up measures. The Chapman, Craven & Chadwick (2008) study showed a small weight loss for the intervention group compared with a small increase for the control group at the 6-year follow-up.

2.2.4.3.2 Dietary Interventions (n=0)

Neither of the dietary intervention studies reported maintenance or follow-up measures.

2.2.4.3.3 Physical Activity Interventions (n=2)

None of the studies included a component for weight maintenance, however, two studies reported follow-up measures (see Table 2.4). The Rosety-Rodriguez et al. (2014) study contained the follow-up measures for the Ordonez et al. (2014) study. When comparing follow-up results to baseline the mean % body fat showed pre- to post- intervention significance, however, from post intervention to follow-up the mean % body fat had in fact increased, and a similar pattern existed for waist circumference

changes. Therefore, gains made during intervention were negligible 6 months later. Both groups in the Pett et al. (2013) study demonstrated a reduction in weight and BMI when comparing baseline to follow-up, however, from post- intervention to follow-up both show increases, as was the case with Rosety-Rodriguez et al. (2014).

2.2.4.3.4 *Behaviour Change Interventions (n=7)*

Three studies included a component for weight maintenance (see Table 2.5). Only the participants in the Fox et al. (1984) study, and the group in the Rotatori et al. (1980) study that received fixed monetary reinforcement continued to lose weight during maintenance conditions. For the groups that gained weight all of them demonstrated $< +3\%$ gain, therefore, meeting the weight maintenance criteria above.

Seven studies included follow-up measures (see Table 2.5), which ranged from 4 weeks to 12 months in duration. All studies still reported mean weight losses at follow-up measures when comparing to baseline. However, four out of the seven studies showed weight gains between post- intervention and follow-up measures with three groups regaining approximately 50% of their weight loss, one group approaching baseline weight again, and two groups exceeding baseline weights.

2.2.4.3.5 *Physical Activity and Behaviour Change Interventions (n=2)*

No studies in this category reported weight maintenance figures, however, two did report on follow-up measures (see Table 2.6). Follow-up durations were short at 4 and 5 weeks, respectively. The participants in Fisher (1986) study gained weight and returned to baseline measures within the 4 weeks. All 3 participants in the Croce and Horvat (1992) study also showed increases in weight from post- intervention to follow-up, however, both participants that had lost weight at the end of the intervention still retained statistically significant weight loss from baseline to follow-up.

2.2.4.3.6 *Multi-component Interventions (n=5)*

Three studies included weight maintenance components, and two studies included follow-up measures (see Table 2.7). Only one study showed weight gains after a 12-month maintenance intervention (Ptomey et al., 2018), however, gains remained less than +3% which is acceptable for weight maintenance. In contrast, the control group in this study, who were following a conventional -500kcal diet during the MCI, continued to lose weight during the maintenance period, which may be due to the provision of suggested meal plans that these participants were provided with as their maintenance component. One study continued to show weight losses at follow-up measures 6 months post- intervention (Harris et al., 2017) and the other study demonstrated a small mean weight regain of < +3% over the 6 months between post-intervention and follow-up (Martínez-Zaragoza et al., 2016).

2.2.5 Discussion

2.2.5.1 Research Question 1

What are the components present within lifestyle interventions for adults with intellectual disabilities?

Six intervention categories were defined from the components incorporated into lifestyle intervention studies found for this review. Defining interventions based on whether SMART goals are present for diet, exercise or behaviour change strategies allows distinction between interventions that are educational in nature or those that involve specific changes in one or more of these dimensions. This also allows for scrutiny of interventions claiming to be multi-component weight management interventions by insisting that the three distinct and measurable components of diet, physical activity and behaviour change are present, thus aligning with NICE (2014^a) recommendations for MCIs. Previous reviews have found the cross-over in components between different intervention categories to be confusing when trying to compare results (Hamilton et al., 2007; Spanos et al., 2013^a; Doherty et al., 2018;

Harris et al., 2018^a). Using the category definitions described in Table 2.1 above will reduce this confusion by ensuring comparisons are made between like interventions and analysis of the efficacy of intervention types based on their components can subsequently occur. One category that did not arise in any of the studies included in this review, but that could feasibly be included in an overall ‘Component Guideline’ is ‘Diet + Behaviour Change’.

2.2.5.2 Research Question 2

What are the effects of each type of intervention on body composition?

All the interventions included in this review resulted in reduced weight, reduced BMI, reduced % body fat, or reduced waist circumference, except for Pérez et al. (2018). The largest weight losses were produced by studies in the DI or MCI categories with some substantial weight losses demonstrated in relatively short durations (-30.9lbs in 1 month for DI, and -21.4lbs in 20 weeks for MCI). The PA+BCI category produced the lowest results for positive body composition changes. This may be as a result of having no health education or behaviour change techniques that focused on diet included in the intervention. The addition of dietary change, whether through health education only or as a targeted change, may greatly influence results. When analysing the results of the PAI or BCI categories alone the positive change on body composition is higher which may be due to the addition of dietary information included in the health promotion part of these studies. This further points to the addition of the dietary component to be of high value to any intervention program as is supported in the review by SIGN (2010). The results from the DI category would support the importance of a targeted dietary change more so than an educational component, however, controlled restrictive diets imposed by service centres, such as was done in the Antal et al. (1988) study, could not be reproduced due to ethical concerns that would be raised today. Behaviour change techniques alone which support better diet and exercise habits produce encouraging results, however, the addition of targeted SMART goals for both diet and exercise that MCI incorporate appear to enhance results. Considering all these factors and comparing anthropometric outcomes, MCIs appear to provide the most effective way forward for lifestyle interventions to manage

weight for adults with ID, mirroring recommendations for the general population (NICE, 2014^a; SIGN, 2010).

2.2.5.3 Research Question 3

How do the outcomes for each intervention category compare to the [NICE] (2014^a) guidelines for effective interventions for the General Population?

Not all the studies reported measures necessary to compare to the NICE (2014^a) guidelines for effective lifestyle interventions for overweight adults. All studies reported completion rates and except for three studies, all had > 60% of participants complete the program. Reasons provided for those that did not were high levels of missing data (Mann et al., 2006), and lack of parental support (Zoppo & Asteria, 2008). Every study in the PAI category, BCI category and MCI category achieved greater than 60% completion rates indicating that these types of interventions were highly acceptable to those participating.

Most studies reported mean weight loss figures (n=33), however, only 14 of these achieved $\geq -3\%$ mean weight loss as is recommended by NICE (2014^a). Of those 14 studies both the DI category and the MCI category demonstrated the best results with 100% (n=2) of the DI studies and 83% (n=5) of the MCI studies achieving criteria, suggesting that these types of interventions may be more successful for weight loss. However, whilst the DI category shows that both studies greatly exceeded the -3% mean weight loss target, there is inadequate evidence of success in only two studies. Additionally, ethical issues arise in the reproducibility of the Antal et al. (1988) study, and the results for Zoppo and Asteria (2008) are only for the 40% of participants who had parental support. There is more evidence associated with the six studies in the MCI category where five of these met criteria. However, it may be that these types of interventions produce large weight losses for some participants, therefore, increasing the overall mean or it may be that most of the participants achieve near this level of weight loss and that variability is low. Without individual weight losses reported this information is unknown.

The final criteria of *more than 30% of participants achieving $\geq -5\%$ weight loss* was reported in less than half of the available studies (n=14). Of those 14 studies only 8 met criteria, again with the MCI category appearing to produce the best results. Three out of the four studies reporting in the MCI category met this recommendation, indicating that a higher percentage of participants achieve clinically significant weight loss from this type of intervention and that MCIs may be the *treatment of choice* for weight loss interventions for adults with ID. However as is echoed in the Spanos et al. (2013^a) review, without across the board reporting of this variable within all studies, regardless of intervention type, this result remains questionable and would benefit from further research.

2.2.5.4 Research Question 4

Is there is a longer-term weight maintenance and/or follow-up component included and what are the reported effects?

Very few studies include a weight maintenance phase to their intervention, possibly due to most participants not having reached a normal BMI of less than 25kg/m² by the time that the lifestyle intervention ends. In theory most participants would be continuing to try to lose weight rather than maintain weight. Of the six studies that did include weight maintenance phases, four continued to demonstrate weight losses and two had increases in weight less than the +3%. However, the recommended duration for weight maintenance is suggested as 6 to 12 months (NICE, 2014^a; Spanos et al., 2016) which only three of the studies achieved (Spanos et al., 2016; Saunders et al., 2011; Ptomey et al., 2018). The literature would benefit from weight maintenance interventions of at least 6 months duration provided to participants who achieved their targeted weight loss or a BMI<25kg/m², for each type of lifestyle intervention. At present there are not enough studies reporting this measure across categories to evaluate efficacy between categories.

Approximately half (n=15) of the studies had follow-up measures, and most of these were in the BCI category (n=7). Only two studies achieved or exceeded the recommended 12 months, with the others ranging from 4 weeks to 6 months. Whilst

all 15 studies continued to show weight loss from baseline to follow-up measures, only 7 showed decreases in weight between post- intervention and follow-up. Many of the remaining studies reported weight regains that brought the mean weight close to baseline, meaning gains made were almost negligible at follow-up. Both studies in the HPI category continued to show weight loss from post intervention to follow-up indicating that the health education provided may have positive longer-term influence on weight management. The weight losses for the intervention group in the Chapman et al. (2005) study were small when considering the 6-year timeline, however, compared to the increasing trend in the control group these results were favourable. The continued weight loss in the Pett et al. (2013) study may be as a result of targeting parental education to influence longer term lifestyle changes within the home environment. All studies involved in the PAI and PA+BCI categories showed weight regain post- intervention to follow-up indicating that when the exercise intervention ceased that weight increases occurred. BCI category had a mixture of both continued weight losses and weight regains from post- intervention to follow-up. Most of the studies that had short follow-up durations of less than 6 months (range 4 to 10 weeks) appeared to continue with weight loss, whereas those studies with durations greater than 6 months predominantly showed weight regains. If this trend continues then gains made will also be lost without continued intervention. MCIs show the most beneficial effects on weight over the course of the intervention, and the results for follow-up are positive too. Whilst one study reports a small gain at 6 months of +1.3% (< +3%), the other reports continued weight losses. However, without standardised 12-month follow-up measures over all studies this is again difficult to evaluate and compare. Weight regain post- intervention is something the general population struggle with, and most of the research available suggests that maintaining weight losses over long-term durations has little success to date (Anastasiou, Karfopoulou & Yannakoulia, 2015). This will therefore be a challenge for interventions tasked with weight management for adults with ID, but one that needs to be recognised and prioritised within the research.

2.2.6 Limitations

Lifestyle interventions for weight management cover a broad variety of intervention components, making comparisons between studies complicated. However, by utilising defined categories aligned with the NICE (2014^a) component descriptions to group studies into categories of similar components, this reduces the overall variability to allow for comparison. The inclusion of studies that do not specifically aim to reduce weight as their primary outcome could be said to cloud the outcomes of this review. However, any study that aims to improve health outcomes for overweight adults with ID should be scrutinised as to its benefits on weight since overweight is one of the most prevalent health conditions of people with ID and since so many comorbid health issues are as a result of being overweight.

2.2.7 Conclusion

Lifestyle interventions targeting weight management for adults with ID need to be standardised in their reporting format due to the variability of components included. The suggested set of component definitions (devised to align with current guidelines) that are provided in this review could provide a structured ‘Component Guideline’ from which future research could draw. Utilising these suggested categories to compare intervention types for efficacy leads us towards the conclusion that MCIs produce the best results for weight loss for adults with ID during treatment and should therefore be considered as the *treatment of choice* for this population. As for maintaining weight loss on a long-term basis, there remains too little research available in the literature for the adult ID population to evaluate. There may be value in the addition of health promotion information for parents and/or caregivers to support longer term benefits and this area is worthy of further exploration.

Chapter 3

Supporting healthier lifestyle habits for adults with intellectual disabilities: recommendations from focus groups

3.1 Introduction

As the first two Chapters have shown, overweight is a major health concern for adults with ID, and the proportion of adults suffering from this condition is even higher than in the general population (Hsieh et al., 2014; Melville et al., 2008; Stedman & Leland, 2010). Other comorbid diseases are associated with being overweight further limiting physical and mental well-being, and in some cases life expectancy, for this population (World Health Organisation, 2018). In addition to reduced individual health outcomes, the economy bears the brunt of the substantial costs needed to manage the many problems caused by overweight (Centers for Disease Control and Prevention [CDC], 2010). On a positive note, a body of research exists examining how best to manage weight for adults with ID, concluding that multi-component interventions incorporating a specific dietary change component, an increase in physical activity, and behaviour change strategies produce the best outcomes (Spanos et al., 2013^a; Harris et al., 2018^a). The systematic review conducted in Chapter 2 further supports the conclusion, also adding that the inclusion of a comprehensive health education program may be advantageous to longer-term weight maintenance; however, this area is under researched at present.

Although MCIs produce the best results for weight loss in adults with ID, the percentage of participants who achieve clinically significant weight loss of –5 to -10% remains low and variability between participants can be high. Therefore, in addition to identifying the most effective type of intervention to reduce weight for adults with ID, it is pertinent to understand the factors that stop them from engaging in healthy practices (barriers) and those that aid healthy choices (facilitators). Such consideration will aim to ensure maximum uptake, minimise the variability in outcomes, and embed the intervention in a supportive environment so that lifestyle change occurs for the long-term rather than just during the intervention phase. The most informative way to access this information is by asking the adults themselves. Only by allowing adults with ID to speak for themselves and express their own opinions and feelings in relation to their lifestyle choices, can research claim to be inclusive. Inclusive research has also been found to positively affect the design of interventions (Cambridge &

McCarthy, 2001; Puyalto, Pallisera, Fullana & Vila, 2016). In fact, not only has it become ethically sound to include adults with ID in research that proposes to serve their needs, it has become a policy driven requirement (McDonald & Kidney, 2012; Department of Health, 2005; Gilbert, 2004). Several studies now exist in the literature that utilise qualitative research methods to elicit the views and experiences of adults with ID in terms of issues that affect their lives directly.

There are many different types of inclusive qualitative research methods that have proven effective in eliciting information from adults with ID: such as individual interviews, questionnaires, photographic research, ethnography, and focus groups. The two most common methods used are interviews and focus groups, and each methodology has benefits and limitations with respect to the implementation process and information outcomes. For example, whilst interviews have the potential to provide a vast amount of information for each individual these can be time consuming and rely on the interviewee having sufficient self-esteem to feel comfortable in expressing their views and ideas without the support and validation of others. Often in one-to-one interview situations the researcher plays a more dominant role and participants can feel pressurised into providing the “correct” learned response rather than a response that truly reflects their experiences or feelings. Additionally, individual participants often have a limited amount of responses that can be given to each interview question. In contrast, the group dynamics of focus groups allow comradeship in ideas and beliefs to flourish, and insightful debates to occur through the interaction and support of others, as long as participants feel comfortable in each other’s company. However, managing full representative participation in the interactions can be challenging and eliciting individual experiences and feelings that contradict the group may only occur if the person is confident enough in their self (Nind, 2008; Owen, 2001). The majority of the studies available in the literature have utilised focus groups to examine aspects of health for adults with ID and this has been demonstrated as a successful method to glean a large range of information on their lived experiences, thoughts and feelings (Cambridge & McCarthy, 2001; Puyalto et al., 2016; Kuijken et al., 2016; Lorentzen, & Wikstrom, 2012; Cartwright et al., 2015;

Kaehne & O'Connell, 2010; Bollard, 2003; Gibbs et al., 2008; Temple & Walkley, 2007; Lorentzen & Wilkstrom, 2012; Bennett & Cunningham, 2014).

3.1.1 Focus Group Methodology

For a group discussion to qualify as a focus group discussion it must involve a small group of participants who share commonality in certain characteristics that are of relevance to the topic in question. The discussion itself involves a number of pre-determined, open-ended questions that are focussed on a particular topic. Focus groups are appropriate to use when seeking to establish the full range of opinions, feelings and experiences in relation to a topic without the need for determining a majority point of view. The nature of the interactions in group discussions lead to variety in responses as participant interactions often remind or activate dormant thoughts. Furthermore, the back and forth flow of conversational debate allows the researcher to develop a sense of the general agreement or disagreement around different factors, and the strength of emotion involved. Focus groups are useful when researchers are trying to establish a range of views rather than a consensus of opinion, when the issue at hand affects behaviours or motivation, when looking for ideas or critique in order to effectively design a quantitative study, or when pilot testing a product or service (Kruegar & Casey, 2015; Curry, 2015; Asbury, 1995). Focus groups have been conducted with adults with ID for a range of health-related topics including accessing healthcare services (Bollard, 2003; Gibbs, Brown & Muir, 2008), social inclusion (Abbott & McConkey, 2006), and healthy living (Kuijken, Naaldenberg, Nijhuis-van der Sander & van Schrojenstein-Lantman de Valk, 2016). There are practical difficulties in conducting focus groups with the ID population due to issues such as recruiting enough participants in each area that share commonality with the topic, maintaining attendance if there is more than one focus group occurring, ensuring informed consent is obtained, allowing for cognitive and language difficulties, and ensuring discussion between participants occurs rather than just with the facilitator. However, these issues can be overcome with creativity and flexibility in the approaches used and the assistance of caregivers where necessary (Gates & Waight, 2007; Fraser & Fraser, 2001).

3.1.2 Barriers and Facilitators of Diet and Exercise

A moderate amount of focus group research has been conducted with adults with ID on the barriers and facilitators surrounding physical activity, and the preference for sedentary or active leisure activities. Barriers similar to the general population included lack of social support, medical issues, poor weather, lack of time, personal safety concerns, being too tired, and not motivated. However, some additional barriers such as the reliance on others for transport, the expense of exercise facilities, and the types of exercise available to them were also present for adults with ID (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent, Cooke & Long, 1999; Frey, Buchanan & Rosser-Sandt, 2005; NHS, 2019). Additionally, the positive or negative influence that both medical professionals and carers can have on exercise engagement is a contributing factor. For example, Frey et al. (2005) found that some adults with ID perceived themselves to be unable of moderate-vigorous exercise due to their Doctor or carer advising them not to overdo things, even when there was no medical issue actually constraining exercise. An additional factor that hampers physical activity engagement is the preference for sedentary leisure activities particularly watching TV, or gaming (Frey et al., 2005; Temple, 2007). However, many enjoy physical activity and are supported by both family and organisations like day service centres or Special Olympics to engage more in regular physical activity (Beart, Hawkins, Stenfort Kroese, Smithson & Tolosa, 2001; Frey et al., 2005, Temple, 2007). Additionally, many recognise some of the benefits of exercise such as emotional well-being and looking good (Heller, Hsieh & Rimmer, 2008). As with the general population, facilitators to exercising included the socialising element of joint exercise activities, motivation, access to facilities, and if the exercise is fun. Routine, belonging to a group, and receiving medals and awards were also cited as facilitators for adults with ID (Mahy, Shields, Taylor & Dodd, 2010; Temple & Walkey, 2007).

Less research is available in relation to healthy eating with adults with ID. Some studies demonstrate that basic knowledge around healthy eating exists, such as too much salt is not good for you, cutting down on fizzy drinks is healthier, fruit and vegetables should be eaten every day, and brown bread is better for you (Lorentzen &

Wikström, 2012; Bennett & Cunningham, 2014; Kuijken et al., 2016), however, there remains a lack of healthy eating knowledge when it comes to making good, functional, healthy choices. Further obstacles to healthy eating revolve around access to food as many adults with ID lack independence in food choices due to living within the family home or limited by residential menus, and poor knowledge of carers in relation to healthy eating (Kuijken et al., 2016; Bergström, Elinder & Wihlman, 2014; Melville et al., 2009). In addition to these barriers, for many adults with ID physical issues that affect sensory systems, oral motor abilities, or set off allergies can play a part in reducing food choices (Bergström et al., 2014). The most important facilitator to healthy eating was support from carers. This support was required for both sourcing and preparing healthy foods for consumption if living independently, or by providing healthy meals if living in a home or shared environment. Inclusion in choosing and preparing healthy meals and upskilling participants in cooking independently were also seen to facilitate better choices. Information and advice from suitable professionals or healthy peers were also acknowledged as encouraging healthier diets (Bennett & Cunningham, 2014; Kuijken et al., 2016).

Interventions that include structured carer supports appear to produce better results than those that do not (Fox et al., 1985; Hamilton et al., 2007; Hithersay, Strydom, Moulster & Buszewicz, 2014). However, fidelity in implementation can be variable and what supports work best have not yet been objectively examined. In exploring the difficulties that may jeopardise effective support from carers during a weight loss intervention, Spanos et al. (2013^b) found that staff systems played a major role. Where there were regular staff changes, higher staff turnovers, and a lack of staff numbers, consistency in delivery of the weight loss program, and effectiveness of communication systems were reduced. Differences in opinions amongst carers on how adults with ID make decisions that affect their health was also noted to be a barrier due to inconsistency and contradiction between practices. In another study, Melville et al. (2009) found that paid carers demonstrated poor knowledge in relation to recommended dietary and physical activity guidelines, which fosters doubt in the ability of some carers to provide correct information, guidance and support. Even when carers have the competency and skills to provide the correct support, their

guidance was often impeded by the cognitive ability and low motivation of the adults with ID who they care for (Spanos et al., 2013^b; Melville et al., 2009).

Differences in perspectives between carers and the adults they care for present another set of complications in terms of providing effective supports. For example, most carers identify, and highly rate, the physical and mental health benefits that adults with ID receive as a result of healthier diets and increased exercise. However, carers place little emphasis on the improvements to physical appearance that occur (Melville et al., 2009; Jones, Melville, Harris, Bleazard & Hankey, 2015^b). Improved physical appearance has been shown to be the most frequently quoted reason for wanting to lose weight by adults with ID, therefore, carers need to understand the importance of this factor to ensure continued motivation (Jones et al., 2015^b). Carers also rate lack of knowledge and ability, internal motivation, and the impact of other people's choices as the biggest barriers for both healthier diets and increased exercise for adults with ID. Carers did not seem to think that a lack of support from others, a lack of personal choices, issues of cost, or lack of transport greatly impacted adults with ID (Melville et al., 2009). Many of these perceptions are in direct contradiction to perceived barriers listed by adults with ID themselves such as the need for support from others, associated costs of exercise and healthy foods, inability to access facilities due to transport issues, medical reasons, poor weather conditions, lack of time, personal safety concerns, not enough information on healthy eating to make functional decisions, and food choices controlled by others (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005; Kuijken et al., 2016). Why carers perceive the majority of barriers to be within the person with ID rather than those presented by the environment, requires more investigation. However, since general stigma about overweight people includes labelling such as "lazy" and "stupid" (Puhl & Brownell, 2001), it may be that this attitude is present in carers and influences their perceptions that the barriers are down to the individual rather than the supports available.

Increases in carer knowledge of international guidelines for healthy diets and physical activity, and alignment of both motivating factors and perceptions of barriers will certainly increase the likelihood of more consistent and effective supports for weight loss interventions. Added to this, an understanding of factors that facilitate healthy lifestyle choices will also increase the efficiency of built-in carer supports. Spanos et al. (2013^b) found that carers reported more positive outcomes in terms of participation when service centres included physical activity and healthy eating programs, and when participants were part of the process for making choices relating to shopping and cooking. Motivation was also found to be positively influenced by the provision of verbal praise by carers. Other studies quote the importance of routine and creating a sociable, fun environment for exercising. Rewards and belonging to a group were also rated highly as motivators for exercising (Mahy et al., 2010; Temple & Walkey, 2007).

Whilst a moderate to large amount of research exists with respect to the barriers and facilitators for adults with ID trying to lead a healthy life, the majority concentrate on exercise engagement (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005). Studies that include information relating to healthy eating, as part of the overall picture to health, demonstrate that adults with ID, their families and their paid carers appear to place more emphasis on exercise as the main component needed for weight loss (Kuijken et al., 2016; Lorentzen, & Wikstrom, 2012; Cartwright, Reid, Hammersley, Blackburn & Glover, 2015). There are some studies available that examine food intake patterns for adults with ID (Ptomey, Herrmann, Lee, Sullivan, Rondon & Donnelly, 2013; Humphries, Traci & Seekins, 2007; Draheim, Stanish, Williams & McCubbins, 2007), however, these do not provide insight into the decision-making processes that overweight adults with ID engage in with respect to food choices, and only a few studies have touched on the knowledge base and current habits that exist around healthy eating and exercising for adults with ID (Kuijken et al., 2016; Lorentzen, & Wikstrom, 2012; Cartwright, et al., 2015). A more balanced understanding of the factors influencing both dietary and exercise choices for overweight adults with ID, may aid the design of future weight loss

interventions. For this particular population, it is important that future weight loss interventions should strive to incorporate effective support systems to overcome known barriers, whilst also including elements known to facilitate success. Additionally, insight into the level of knowledge that adults with ID have on how to create and maintain a healthy lifestyle, paying particular attention to diet, and how this knowledge compares to their current lifestyle practices is worthy of exploration to ensure health education programs include the necessary structures to aid change.

Therefore, this study aimed to add to the current literature by identifying themes relating to the following four domains of interest in relation to healthy eating and physical activity for overweight adults with ID in Ireland:

- 1) Facilitators
- 2) Barriers
- 3) Knowledge Base
- 4) Current Habits

3.2 Method

3.2.1 Rationale & Aims

Focus groups utilising the theoretical underpinnings of phenomenology methodology (Guest, MacQueen & Namey, 2012) were chosen as the best fit for the starting point of this project to allow inclusion of Irish adults with ID in research that would directly inform the design of an ID specific health promotion education series, and a multi-component weight loss intervention. Firstly, insights into the perceived barriers and facilitators of healthy behaviours for adults with ID in Ireland, was expected to provide information on issues that may affect success rates, possible motivators, and existing supports that work. Secondly, gaining an understanding of the present levels of knowledge in relation to healthy eating and exercise was expected to identify common deficits that would inform the design of the health promotion education series. Lastly, awareness of current habits was predicted to assist in both the development of the

health promotion education series and in identifying common areas where behaviour change support systems were needed most.

3.2.2 Recruitment Process

The researchers approached local service centres by emailing the managers with an outline of the full project to gauge potential interest. Interested service centres were then provided with a phone or face-to-face meeting with one of the researchers to describe the project in more detail, and easy access descriptions of the project and consent forms were provided to the managers to distribute, if interest held. Service centre managers were then asked to approach service users that were overweight, and that satisfied the inclusion criteria for the project. No information was provided by the managers on whether all service users satisfying the study criteria had been informed of the study and invited to participate, or whether particular people had been targeted for invite. Local Down Syndrome charity branches were also approached by emailing the Secretaries, who then emailed all their adult members to gauge interest. A face-to-face meeting with parents and adults with Down Syndrome, who expressed interest in the project, was organised by one branch's Adult Liaison Officer (a parent volunteer responsible for coordinating all of the branch's adult activities). Participants from both service centres and the Down Syndrome charity that wanted to lose weight, were interested in taking part in the project, and provided consent were recruited to form groups of between 6 and 10 people.

3.2.3 Participants

Commonality between the participants in this study was that they were all overweight adults with an ID residing in Ireland, who were interested in losing weight. Fifty-two participants were recruited to join one of 8 focus groups. Assignment to a focus group was based on geographical area and attendance at particular service centres or charity run groups. Group 1 participants were a parent-led group who were invited to join the study via their local charity's adult liaison officer (n=8), and participants from Groups 2 to 8 (n=44) were service-led groups who were invited to join the study via each of their service centre managers. Interested participants were eligible to join the study if

they met the following criteria: aged 18 or over, mild or moderate ID, and BMI > 25 kg/m². Participants were excluded if they showed any challenging behaviours or mental health issues that would unduly jeopardise participation in the study. The transcript for Group 8 (n=7) was corrupt on retrieval therefore, these participants were removed from the analysis, leaving a total of forty-five participants assigned to one of seven focus groups. Participants received an easy read demographic questionnaire one week before the focus groups began. Participants were asked to complete this questionnaire, with a support person if required, and submit it on the day of the focus group. The demographics for each group are shown in Table 3.2 below.

3.2.4 Procedure

3.2.4.1 Setting and Structure

Group 1's focus group took place in a designated room in the charity's educational centre, and the focus groups for Groups 2 to 7 took place in a designated room within each of their Service centres. Each session lasted approximately 1 ½ hours with a 15-minute break which included healthy refreshments, provided by the researchers. The author and a second researcher attended the focus groups; one as lead moderator and the other as assistant moderator. The lead moderator was responsible for delivery of questions, introducing any prompts, encouraging conversation between participants, and re-aligning the conversation towards the goals of the study where necessary. The assistant moderator was responsible for note taking, dispensing and collection of self-report checklists, and additional prompts where necessary. Each adult was invited to bring a support person if they wished, however, all attended independently. The discussions were audio-recorded to allow transcripts to be developed and analysed.

3.2.4.2 Anthropometric Measures

Participants heights and weights were collected by two researchers at the end of each focus group discussion. Participants were measured wearing a t-shirt, light trousers, and no socks or shoes. Measures were conducted by one of the researchers whilst the second researcher observed, and agreement was reached. A Stadiometer, Charder HM200P, was used to measure height in feet and inches to the nearest 0.5 inch. The

height of each participant was then programmed into the Smart Weigh SW-SBS500 Digital Body Fat Scale to allow automatic calculation of BMI, and participants were instructed to stand on the scale barefoot until both weight in lbs, to the nearest 0.1 lbs, % body fat, and BMI were recorded.

3.2.4.3 Materials

The framework of questions devised followed the 5-question framework outlined by Kruegar & Casey (2015). This framework is a series of open-ended questions; (1) opening question, (2) introductory question, (3) transition questions, (4) a set of key questions, and (5) conclusion questions. The 5-question framework creates a logically sequenced series of open-ended questions where the beginning questions are more general, then subsequent questions become more focussed to elicit more specific information. Table 3.1 details the questions devised by two researchers who acted as facilitator and assistant facilitator for all focus groups. Since the proposed weight loss intervention was intended to operate as the “Action” phase of the Transtheoretical Model (TTM), the Introduction and Transition questions were designed to try to establish what stage of change each participant may currently be operating at, and the influence this may have on individual results: (1) Pre-contemplation, (2) Contemplation, (3) Action, (4) Maintenance, or (5) Process Complete / Relapse (Marks, Murray & Estacio, 2018). This may provide insight into the influences affecting attitudes and opinions provided by participants during the Key questions. Additionally, these questions were designed to establish whether participants understood the need to eat healthy foods and exercise in order to lose weight. The Key questions were aimed at eliciting whether participants could identify factors present in their own lives that aided or hampered healthy choices. These questions were influenced by current research with the adult ID population which examines levels of autonomy, opportunity and ability to eat healthy diets and exercise (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005; Kuijken et al., 2016). Information relating to current knowledge and habits was also sought.

Table 3.1: *Question structure for Focus Groups*

Question Type	Details
Opening	Can you tell us your name and something about yourself?
Introduction	Can you tell us about your experiences of managing your weight, so it does not get too big or too high?
Transition	How long have you been aware that you need to lose weight?
Key 1 *	How do you plan and make your meals? (supporting visuals used)
Key 2	Do you do your own shopping, or does someone help you?
Key 3 *	What foods do you like or dislike? (supporting visuals used)
Key 4	How do you fill your free time in the evenings and at weekends?
Key 5 *	What kinds of exercise do you do each week? (supporting visuals used)
Key 6	What activities do you not like doing? (supporting visuals used)
Conclusion	Summary of topics discussed. “Of all the things we have talked about, which ones are really important?” “Is there anything else about health or losing weight that you want to talk about?”

**Self-report data sheets were used to enhance the information relating to autonomy in food choice and preparation, dietary preferences, and exercise engagement and preferences.*

Self-report data sheets: Participants were given the first data sheet (see Appendix B) after the discussion for question Key 1, shown in Table 3.1 above. The lead facilitator read the first question and participants were instructed to choose as many options as they felt were relevant to their own situations by circling each picture. The second question was then read by the lead facilitator when all participants had completed the first question. The same procedure was then followed for the final question on this data sheet. The second data sheet (see Appendix C) was given to participants after the discussion for question Key 3, shown in Table 3.1 above. Participants were instructed to place a tick beside foods they liked and a cross beside foods they disliked. The assistant facilitator checked full completion of each participants’ data sheet on collection and approached individuals to complete answers that were missing. Appendix D shows the final data sheet given to participants after the discussion for question Key 5, shown in Table 3.1 above. Participants were asked to place a tick beside any exercise type they engaged in regularly (weekly or fortnightly as a minimum).

3.2.4.4 Consent and Ethical Approval

The study was approved by a University Ethics Committee and was conducted in full accordance with World Medical Association Declaration of Helsinki, (2002). Particular attention was given to issues of informed, voluntary consent, and ability to give consent was corroborated by a caregiver who knew them well. At the beginning of each focus group the researchers conversed with participants about confidentiality and respecting other's opinions. Participants were assured, and all agreed, that whatever was spoken about during the focus groups was to remain confidential within the group. Boundaries were also set in relation to taking turns to speak and letting everyone express their own opinions even if they differ to ours.

3.2.4.5 Data Analysis

Transcripts of the audio-recordings were produced and subsequently coded using Theoretical Thematic Analysis Methodology as described by Braun & Clarke (2006). Each line of the transcript was assessed to determine its relevance to each of the domains of interest (1) Facilitators, (2) Barriers, (3) Knowledge Base and (4) Current Habits. Only quotes that were relevant to the four domains were included and developed into themes under each domain. The initial coding was conducted by one of two researchers before being reviewed by the second researcher who co-facilitated the focus groups. Queries in the coding were discussed between the two researchers and agreement reached in all cases. A number of themes were developed from the transcripts with respect to the four domains of interest: (1) Facilitators, (2) Barriers, (3) Knowledge Base and (4) Current Habits.

The self-report data sheets completed during the focus groups were analysed with respect to levels of autonomy in food choice, dietary preferences, and exercise engagement. During the completion of the checklist, both researchers interacted with participants individually querying their choices to determine whether the answers reflected comprehension of the question being asked. For example, if a participant had answered that they regularly played GAA football on the exercise checklist (Appendix D), but when questioned it transpired that they spectate at games rather than train with a team each week, this would indicate a lack of comprehension of the

question. Additionally, the researchers evaluated the answers given on checklists with respect to the information each participant provided during the free-flowing discussion. For example, if participants ticked only healthy foods on the food preference checklist (Appendix C) but had spoken about eating treats during the conversation, this would indicate that they had not approached the questionnaire honestly. A discussion was held between the two researchers immediately after each focus group and each checklist for each participant was discussed with respect to comprehension and honesty. Participants who were considered to have comprehended what the task entailed and have approached the questionnaire honestly were rated as “high” reliability. Only participants with “high” ratings were included in the analysis, which amounted to approximately 66% of those who completed the checklists (n=43).

3.3 Results

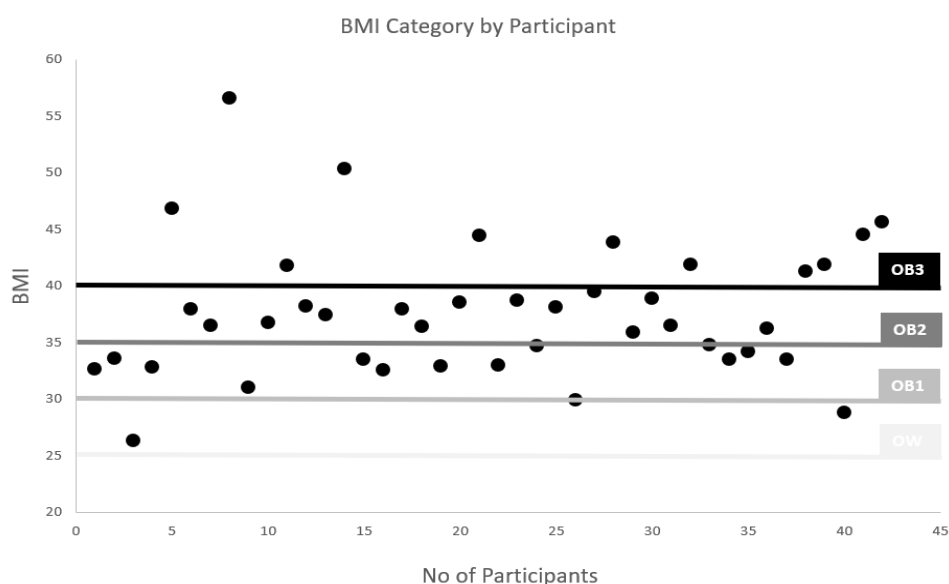
3.3.1 Participant Baseline Demographics

As is shown in Table 3.2, the focus groups ranged in size from 6 to 8 participants in each. More females (n=26) than males (n=19) participated in the study and the majority of participants resided at home with family members (69%). The mean age of participants was 40 (SD = 12.4, range 19 to 59), with Group 1 having the lowest mean age at 26 (SD = 5.9, range 21 to 39), and Group 3 having the highest mean age of 49 (SD = 8.1, range 38 to 59). Of the 42 participants who had BMI information available three participants were categorised as overweight (OW), thirteen were in the obese 1 category (OB1), 15 were in the obese 2 category (OB2) and 11 were categorised as obese 3 (OB3). The weight profile of the group was therefore 7% overweight and 93% obese, with the individual distributions detailed in Figure 3.1.

Table 3.2: Participant Demographics by Group

Demographic	All Groups	Group 1 KDS	Group 2 DHC	Group 3 RCC1	Group 4 RCM	Group 5 RCN	Group 6 RDC**	Group 7 RDQ***
Number of Participants	45	8	7	6	6	6	6	6
Males	19	2	2	3	3	3	3	3
Females	26	6	5	3	3	3	3	3
Mean Age	38.3***	26	32	49	38	46	32	32
Age Range	19-59***	21-39	21-44	38-59	25-52	26-57	22-46	19-45
Number of Participants in each Living Situation***:								
With family	31	7	4	3	5	3	5	4
Adjoined Apartment*	4	1	3					
Staff Supported Accommodation	3			1	1	1		
Own Home	6			2		2	1	1
Participants in each BMI Category:								
OW (25-29.9kg/m ²)	3	1			1			1
OB1 (30-34.9kg/m ²)	13	3	2	2	2	1	3	
OB2 (35-39.9kg/m ²)	15	2	3	3	3	3	1	
OB3 (>40kg/m ²)	11	2	2	1		2	1	3

*Adjoined Apartment is a separate independent living apartment within the grounds of the parental home, ** BMI for one participant was missing, *** missing information on living situation for one participant, age for two participants and BMI for two participants.

**Figure 3.1:** Scatterplot distribution of individual participant BMIs (n=42)

Participants interacted well with each other in all groups and all participants contributed to the overall conversation. A variety of themes emerged under each of the 4 domains of interest, all of which are shown in Figure 3.2 below.

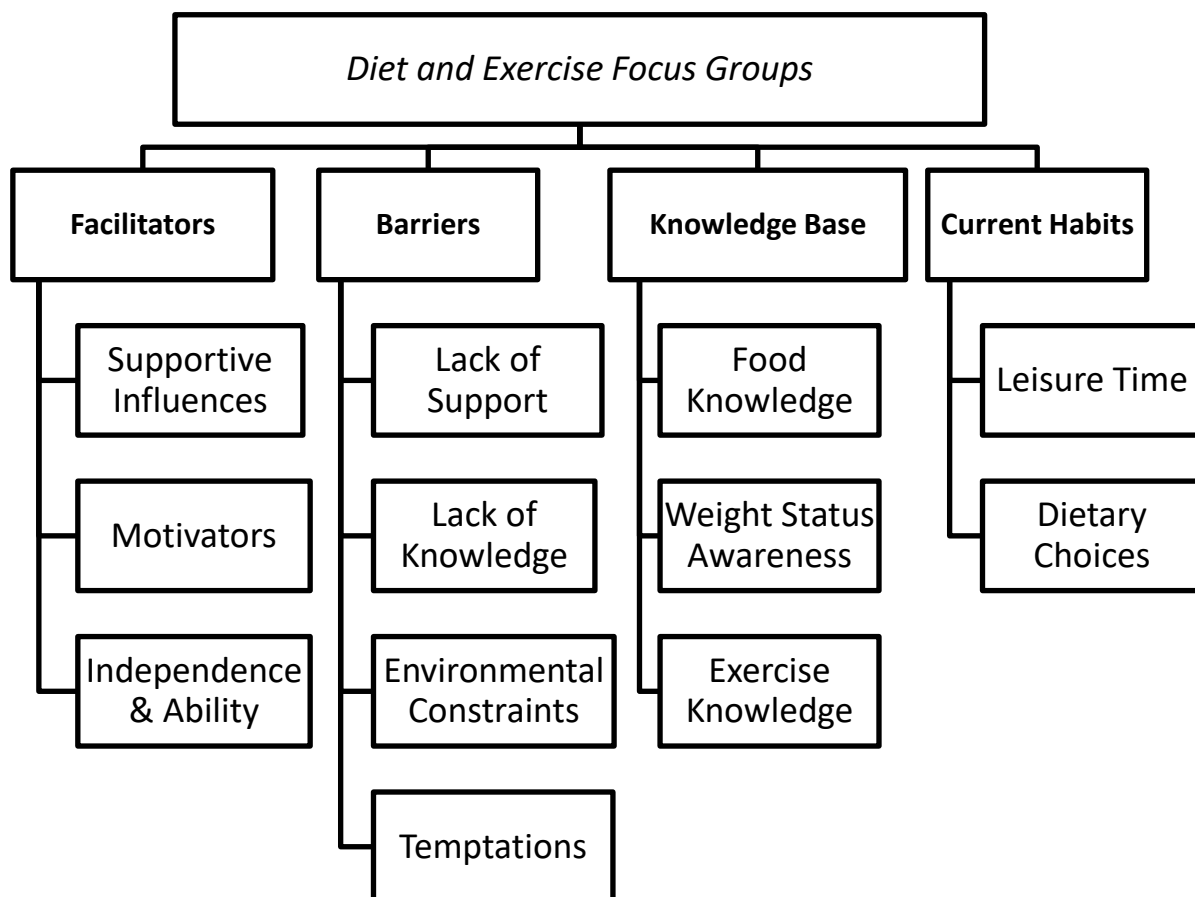


Figure 3.2: Thematic map of themes developed under each domain of interest

Facilitator themes consisted of people, places or events that participants identified as aiding them to engage in healthy eating or exercise. Three *Facilitator* themes emerged from the theoretical thematic analysis: (i) Supportive Influences, (ii) Motivators, and (iii) Independence & Ability. *Barrier* themes related to comments made about any aspect of their lives that prevented them from engaging in healthy eating or exercise. Four themes emerged under this domain: (i) Lack of Support, (ii) Lack of Knowledge,

(iii) Environmental Constraints, and (iv) Temptations. Demonstrations of knowledge relating to weight, health, foods or exercise by participants were captured under the domain of *Knowledge Base* and only 3 themes emerged under this domain: (i) Food Knowledge, (ii) Weight Status Awareness, and (iii) Exercise Knowledge. Two themes: (i) Leisure Time and (ii) Dietary Choices, were present for *Current Habits* which included any reference made to current eating or exercising habits. The number of quotes used to generate each theme are shown in Table 3.3.

Table 3.3: *Number of quotes used to generate each theme*

Domain	Theme	Number of Quotes
Facilitators	Supportive Influences	111
	Motivators	79
	Independence & Ability	54
	TOTAL	243
Barriers	Lack of Support	88
	Lack of Knowledge	82
	Environmental Constraints	57
	Temptations	40
	TOTAL	267
Knowledge Base	Food Knowledge	69
	Weight Status Awareness	33
	Exercise Knowledge	19
	TOTAL	121
Current Habits	Leisure Time	145
	Dietary Choices	115
	TOTAL	260
TOTAL NUMBER OF QUOTATIONS		891

3.3.2 Facilitator Themes

Table 3.4 details the emergent themes and sub-themes for each of the factors that facilitate healthy lifestyle choices.

Table 3.4: *Facilitator Themes and Sub-Themes*

Domain: Facilitators					
Themes	Sub-Themes	No of People Quoting	No of Groups Quoting	No of Quotes	Total Quotes
Supportive Influences	Service centres	15	6	39	
	Family members	18	7	30	
	Community organisations	11	6	19	
	Special Olympics	6	4	11	
	Working environments	6	4	8	
	Medical professionals	4	2	4	111
Motivators	Physical and mental health benefits	15	5	36	
	External reinforcement	10	4	19	
	Internal motivators	13	6	18	
	Positive role models	3	3	4	77
Independence & Ability	Freedom of choice	18	7	26	
	Walking as a mode of transport	12	4	20	
	Self-Management Aids	4	5	8	54
TOTAL NUMBER OF QUOTATIONS					242

3.3.2.1 Supportive Influences

The main source of support for healthier lifestyles was found in *service centres*, where a range of programs were available for healthy eating and exercise. One group spoke about how their service centre provided a healthy option at dinner time, for anyone who wished to purchase it. Another service centre ran a healthy eating program to educate on foods to eat or avoid and upskill independent cooking abilities. A third service centre organised and supported a group to go to Slimming World every week. All of the service centres provided a variety of exercise opportunities many of which were run by existing staff, with some run by qualified fitness instructors contracted in specifically. A number of the service centres also facilitated an optional weekly weigh-in service to help participants connect their lifestyle habits to their weekly weight gains or losses.

RDQ1.5: There is a group from here that does Slimming World on a Monday.

RCC1.1: Go for walks, do exercise in the centre. I go for walks, I walked around [place name] yesterday, we do that twice a week. And we do exercise here as well in the aging opportunity room.

RCM1.1: We actually get weighed by [staff member] every Friday.

Family members were also influential in helping to monitor food intake and keep eating on track. Dietary education was mainly provided by family, and some households opted for healthier options for the entire family to eat. Accessible exercise equipment was present in some homes (Wii for Wii Fit, a trampoline or a treadmill), and exercise partners for walks or the gym were most frequently parents and siblings. Transport to and from other exercise opportunities was predominantly provided by family members. Pets also played their part with dog walking quoted several times as a regular mode of exercise.

KDS1.4: My mum and dad says sugar is a no.

RCN1.0: We do get that butter [proactive] at home.

RDC1.3: Yes, my brother [helps me to exercise], my brother would walk, and he would say stop and go with the cars.

KDS1.6: Yeah, and we have a walking machine in the house. And I do like 30 and 40 minutes.

RCC1.0: My name is [person's name], and I have a dog and I walk him every day.

A number of *community organisations* also provided support in terms of healthy eating and exercise. Some participants had either tried or were engaged with community

groups like Weight Watchers, Slimming World or local equivalents, with varying rates of success, and some participants had joined community clubs for exercise such as martial arts, horse riding, soccer and grass bowling.

RDQ1.5: Do you know [person's name] she does all that nutrition up there? We went to her up there and oh my god she's mad she was showing us pictures of before and after and you wanna see the pictures I was like...ahhhhh. It's like wow, it's very good like you know she motivates everyone and tells you how to go about it.

RDC1.3: I am out because of the martial arts.

RCN1.5: Yeah it [horse riding] is near here and I've been going since I was like 4 years old.

More specialised organisations such as *Special Olympics* provided opportunities to exercise and socialise as part of a group, with sports such as bowling, basketball, bocce, and golf mentioned.

RDC1.4: Well I do, I do special Olympics. I'm getting ready now for the All Ireland games in Ten Pin bowling.

KDS1.0: I do bocce team.

For those participants who gained employment opportunities, the *working environment* often increased movement due to activities such as stacking shelves, serving customers, cleaning duties, dog walking and farming. One workplace also offered free access to an onsite gym.

RDC1.2: Oh, well em, I've got my job a place called the [place name]. Well I work very hard scrubbing the floors and cleaning the tables.

RCN1.5: Well I walk my neighbour's dog on my own every week and I get paid for it. Yeah, I've had that job for nearly four years now.

DHC1.4: On Saturdays I do a wee bit of farming.

RDQ1.3: You know what I get the gym for free. Yeah, that's 'cause I work with [company name].

In terms of educational support, *Medical professionals* like General Practitioners and dietitians, provided both general and individualised advice to influence both diet and exercise habits. Whilst most advice was helpful, one participant appeared to receive conflicting advice from different doctors leading to confusion in the message received.

RDC1.5: I've been at the doctors and I've been told all this. I was told by one of the men all of this before I started.

RCN1.3: I was told by the doctor that it [proactive spread] was good for the heart and things.

RCN1.4: Chicken and brown bread, no yogurts and no sweets [was what dietician said].

RCN1.2: Well I was told by the doctor to give up the fizzy drinks and that the amount of alcohol I was drinking could damage my liver and the doctor said your liver will be damaged, and another doctor said no cause if your liver was damaged you would be in the hospital wouldn't you. Yes one doctor said and the nurse said there at the ultrasound that I had no liver damage and another said that I had liver damage.

3.3.2.2 Motivators

The *physical and mental health benefits* gained from exercising and healthy eating were noted as important motivators. Physical exercise was noted to improve fitness and energy levels, and symptoms related to specific conditions such as high blood pressure, arthritis, high cholesterol, and psoriasis. Mobility issues like tying shoelaces or getting in and out of the bath were found to be difficult when carrying excess weight, and exercise was credited with improving this. Exercise was also found to be beneficial to mental health by enhancing mood, providing an activity to fill time, and facilitating access to social contact.

RCC1.1: And you're better for it when you walk, you're not as tired. You get more energy and you can do more things.

RCM1.2: I've psoriasis and the only way that I can be healthy is to lose the weight because I have skin conditions.

RCN1.3: It can be hard when you're tying your shoelace or something.

RCN1.0: But by the time you get your walk in and it helps you loosen up. You might not think it does, but it does.

RCN1.5: It brightens up your mood if you're in a bad mood or if you are feeling sad or that it helps make you feel happy again.

External reinforcers such as verbal praise, tangible rewards, and positive social interactions all motivated weight loss and engagement in physical activity. Most family members verbally encouraged and praised weight loss and exercise engagement. Medals and trophies provided by clubs and community organisations, were viewed as highly motivating to not only engage with exercise, but to encourage increased efforts. Other natural reinforcers identified were listening to music when you are exercising, enjoying the peace and quiet during a walk, admiring the scenery during particular walking routes, or the social reinforcement accessed during group experiences.

RDC1.3: [I like it] because I've won the trophies for martial arts.

KDS1.0: I had a medal, nine [medals for bocce].

RCN1.5: The scenic walk down near the river, that's a lovely walk so it is. Or in the woods if you are going for a walk around the woods there it is actually quite peaceful as well.

Being *internally motivated* was also important to encourage healthy choices, as people needed to be in the right mood to make the right decisions. Readiness to change was demonstrated by some participants who were dissatisfied with their personal appearance and so wanted to lose weight.

RDQ1.2: Yeah, because you just kind of have to be motivated. Motivated yeah. Yeah and you just kind of have to be in the mood for it, I mean if naturally if you're not in the mood you won't do it.

RDC1.4: Would you be able to help me? [lose weight].

RCN1.3: And then when you are buying clothes and its all the big sizes.

RCN1.5: Eh upset, the way you look in the mirror.

Positive role models inspired three participants and motivated them to either lose weight or become fitter. Whilst only three participants commented, the majority in each of the groups agreed.

RCN1.3: Or when you see other people very thin and you like that.

RCC1.0: If you see someone healthy eating and you'd have to do it too.

RDQ1.0: Yeah then fitter than [soccer team] I wanna be fitter than them.

3.3.2.3 Independence and Ability

Many participants reported having the freedom to choose their own foods, whether they lived independently, lived in assisted accommodation or even lived at home with family. Some wrote their own shopping lists, did their own shopping, and cooked their own meals, but these were mainly living independently. Even if the majority of meals were provided by others most participants felt they had the *freedom to choose* healthier foods to eat if they wished to.

RDC1.5: I do, I do the shopping, but the girls [staff] give me a hand.

KDS1.4: I make a [shopping] list and I bring it. My mum would go and drop me off there [supermarket]. She goes with her dad [to do the shopping] and I do mine.

RCC1.1: I do it on my own. I don't even write a list I just think of the things I want. I don't do anything else I just pick up the groceries I want, whatever I want for the week. I say do I want that, or do I WANT that, you know that kind of a way and I make a decision there and then, nobody tells me what to do, I do my own shopping. I make my own decisions and mind my own money and the whole lot.

In order to get to the Service centre or to community facilities in the locality, many participants *walked as their form of transport*. The ability to independently access facilities such as the library, gyms or exercise clubs was important to participants and walking was seen to be the easiest way to do this whilst also providing exercise in its own right.

RCN1.2: When I get up in the morning and I get the bus and get off I walk all the way from the shopping centre to up here. Even if it's a frosty morning or a wet morning. I still enjoy it. I don't like paying for a taxi, but I enjoy the walk it's a nice walk.

RDC1.3: Yeah, and I walk to my martial arts, myself I'll walk down.

KDS1.1: I go to walk to go place and bowling.

Self-management aids such as the Slimming World guidelines to pre-plan meals and track food intake, daily food diaries to track food intake, a Fitbit to track and target exercise, and the routine of doing exercises at the same time every night, were all methods used to facilitate independent management of healthier habits.

RDQ1.5: I look at my slimming world book [to plan my meals]. I count [the sins] as its better than when I'm not counting it. Cause then you know then how many calories. [I plan for] the whole week.

RDQ1.2: I would try and do it [my exercises] kind of in the evening about, about half eight to half nine you know. Because when I'm, if I don't do it at that time I kind of say to myself ahh sure I won't bother.

KDS1.0: [I have a Fitbit] Watch.

3.3.3 Barrier Themes

Table 3.5 details the emergent themes and sub-themes for barriers towards healthy lifestyle choices.

Table 3.5: *Barrier Themes and Sub-Themes*

Domain: Barriers					
Themes	Sub-Themes	No of People	No of Groups	No of Quotes	Total Quotes
Lack of Support	Meal choices controlled	29	7	60	85
	Accessibility issues	4	2	14	
	Modelling unhealthy habits	5	3	6	
	Long-term supports	3	3	5	
Lack of Knowledge	Food knowledge	17	6	55	85
	Planning and accountability	9	6	13	
	No time	6	2	8	
	Health issues	6	3	9	
Environmental Constraints	Cost	9	5	21	57
	Safety	13	4	20	
	Weather	12	5	16	
Temptations	Environmental triggers	13	7	19	40
	Current strategies	5	2	14	
	Specific foods	6	4	7	
TOTAL NUMBER OF QUOTATIONS					267

3.3.3.1 Lack of Support

Since many of the participants lived at home or with family members, they stated that *meal choices were controlled* by others and their food choices were restricted by this factor. For many, meal decisions were made at the time of planning and shopping for foods, which many participants were either not involved in at all, or at least not at an influential level.

RDQ1.3: My mum would always do the shopping. My mother would normally cook, or sometimes my brother would. They normally cook something that I would eat.

RCC1.4: Well I put away the groceries and that for her. No, she goes [shopping] on her own.

RCM1.3: Someone makes the decisions [for what I eat]. Who you live with, my mother.

KDS1.6: I go with family to do the shopping and stuff. Yeah, my mum does a list.

Many of the participants found that accessing exercise was dependent upon the level of support they had, with some having no supports available outside of the service centres. Since none of the participants were able to drive themselves, *accessibility issues* arose when trying to get to clubs or facilities for independent exercise opportunities. Opportunities existed when facilities were within walking distance, or if participants had family members or staff to transport them, however, some felt that at times people were too busy, and they sometimes felt like a liability. Accessibility was also hampered by not knowing what clubs or facilities would be inclusive and suitable, and often a lack of social skills would make participants reluctant to go themselves.

KDS1.2: Well I don't drive so usually I ask my parents and it's only the driving that would be a bit tight for me. Like I am doing the Olympics here in [place name] but like I would have to travel and I also engage with adults with special needs as well but then I have to commute if I am doing stuff. There is a bit of liability on me [to run me places for exercise].

RDC1.0: People can be busy.

RDC1.4: Yes, and you are shy [to go to new places].

Other people in the participants' environments were noted as *modelling unhealthy habits* such as buying and eating unhealthy foods, drinking alcohol, and regularly getting take-aways or going to restaurants.

DHC1.0: He would be putting it [treats] in [the shopping trolley].

KDS1.7: Well there is something that I did the other night when I saw my mam having a bit of chocolate, and I was looking forward to it and she ate the whole bar to herself.

RCM1.4: Well usually we have a treat on a Saturday night instead of my family cooking, we would have a Chinese, most Saturday nights and the family would have a bottle of wine, but I just drink water cause I can't have wine cause it gives me rotten headaches.

Even when weight loss has been achieved there was a lack of support when it came to maintaining losses over time. Participants lacked continued *long-term support* to keep them motivated to keep up the healthy habits. One participant referred to their memory being the issue for long-term change, as they kept forgetting to make the right choices.

RDQ1.3: I have done something like this in the past, and I have lost weight and then unfortunately I put it back on. Problem is, when the thing was over.

RCN1.4: I try losing weight, but it goes up and down all the time. I try but I forget about it and stop doing it.

3.3.3.2 Lack of Knowledge

Another of the main barriers to healthy eating was a deficit in *food knowledge* which resulted in poor choices. Most participants did not feel they possessed enough knowledge to understand what the right foods to eat were. A lot of confusion existed around low-fat options, correct portion sizes, and what calories were. Even when some knowledge was present such as “fish is a healthy food to eat”, the fish actually being consumed were frozen fish in batter which are not the best option for weight loss. Some participants were also unwilling to try new foods which meant their diets were restricted by routine and familiarity.

RDC1.5: Taste them [to know if they are healthy or not healthy], so there is a banana, and you can't taste a banana, but you can taste an orange.

RCN1.0: I think the doughnuts in Marks & Spencers are a lot better, I think they are low fat, but I don't know if that's right.

RCN1.5: In a dinner it should be between 90 and 100 calories. If you go over that it wouldn't satisfy you it would make you feel a bit sick.

RCN1.2: Yes, I just buy what I like to eat but I don't buy Chinese food or foreign food, I'm Irish remember that. Oh yes, I just buy what I like to eat and that's it. I wouldn't [try other food], I like good Irish food. No, no, no I wouldn't, I just stick to what I like eating.

Most participants did not possess the knowledge or skills to manage *planning and accountability* of their food intake. Because a lack of food planning existed, most participants purchased foods daily and in situ without understanding their overall food intake over the week and would claim to eat very little. Most did not have adequate recall skills to analyse their weekly intake for accountability of consumption.

- DHC1.4: Just pick up what I want. I look at the prices first. Whatever I see in front of me [is what I buy].
- RCC1.0: I buy the first thing that comes into my head, Mammy gives out to me. I'm not good at shopping.
- RDQ1.4: I do it, I can, I have shepherd's pie, just, then another week I plan like emm spaghetti hoops and all that.
- RCN1.2: If I was at home, I'd only eat once a day. I'd get a big dinner at 1 o'clock that would do me to the next day. So, I wouldn't have anything to eat in between that.

Whilst many of the participants spoke about the exercise they do when they are in the Service centre, most stated that they had little or *no time* to exercise at other times. Since the Service centres included in this study mainly finished around 4 o'clock and only opened from Monday to Friday, it is more likely that participants did not understand the options available to them at other times. *Health issues* were used to excuse a lack of participation in exercise however, no effort was made to clarify whether health was indeed a limiting factor and participants possibly limited themselves needlessly. Medication was also blamed for weight gain, and participants lacked the knowledge on how to make changes to diet to reverse the effects.

- RDQ1.3: I was going to say about exercise that I used to do. Oh, I haven't got time. When I'm working its hard.
- RDQ1.2: And you're trying to prepare the dinner you know so when you're trying to prepare the dinner you don't like being out of the house.
- RDQ1.3: I wanna, I have to find out from my doctor, if I can go to the gym. The problem is, it's just ahh the way my heart is.

RCC1.4: They put me on a lot of medication that's why I put it on the weight, medication was doing it.

3.3.3.3 Environmental Constraints

Eating healthy was seen to *cost* more since healthy foods were thought to be more expensive and many participants are limited to a budget for their weekly shopping. Comments were also made on how cheap some unhealthy foods were in comparison. When it came to private payment for exercise facilities or clubs most were aware of the high costs involved, however, the majority would be willing to pay up to €20 per month for membership, providing they got value out of it by using it regularly.

RCC1.3: Healthy food is dearer.

RCC1.1: The money you get you have to pay for the ESB bill, pay for the bins, pay for your oil.

RCN1.4: And chocolate is only €1.50, I noticed that myself. You can get apple tart in [place name] for €1.

RDQ1.2: There's no, there's no point in forking whatever amount of money it is, and not being able to get up the benefit of it you know. When it got up to fifty euro [it would be too much to pay each week].

Personal *safety* became an issue for exercising during winter months or on dark evenings, and some people still avoided night-time walking when accompanied due to the fear of being attacked in some way. Road *safety* was also mentioned as reducing the ability to exercise, due to no footpaths, the danger of passing cars, and a lack of streetlights and pedestrian crossings making it difficult to judge when to cross safely.

RCC1.3: I don't want to get mugged around [place name], because you could.

KDS1.6: You have to watch for cars and not walk on the road because that is dangerous.

RCN1.5: No there should be more pedestrian crossings and traffic lights. Yeah 'cause you can't really judge if it's safe or not?

Adverse *weather* conditions such as rain, snow, ice or just being too cold were all seen to stop participants from walking in their free time, therefore reducing exercise opportunities.

RDC1.4: Well it's hard in winter with the cold nights.

RCC1.0: The weather puts you down, you can't do much in the snow.

KDS1.7: You can only go out and start doing stuff if the rain stops.

3.3.3.4 Temptations

Certain *environmental triggers* were noted to be particularly tempting such as trying to resist treats on offer at events or resisting cake when buying a coffee in cafes. Succumbing to temptation was particularly difficult at times when they were surrounded by unhealthy choices in shops. Resisting the smell of fried foods often proved too difficult for people who regularly walked home past fast food outlets, and when habits had formed it became more difficult to avoid consuming the unhealthy option.

RDQ1.5: Mmm very bad, especially when you go to a wedding and there's a sweet trolley and you think I'll have some of them.

RCM1.4: When you're in a shop if you see buns or cakes it's just hard situation.

RCN1.2: The hardest part of it is having to walk past the chipper.

KDS1.2: I would have a habit for soft drinks it's more appealing where I would have the vision and see what I don't have. Like say if I don't want it like the other day, I had a chocolate and it was addictive and it's very appealing.

RCC1.1: Or you go in to get tea, that's the hard time. Will I have something with that tea or will I have tea on its own?

Some *current strategies* suggested were to not buy treats in the first place, to avoid the treats aisle, to avoid restaurants or cafes, to hide the goodies at home, or to use self-talk to avoid buying the foods. *Specific foods* noted as particularly tempting were white bread, pizza, chocolate, crisps, minerals and chips.

RDQ1.2: You try and avoid em looking at junk. Yeah, or hide it in the fridge.

RCM1.2: Yeah, I try to avoid restaurants and cafes and stuff.

RDC1.5: You know the crisp is very hard [to resist].

3.3.4 Knowledge Base Themes

Table 3.6 details the emergent themes and sub-themes with respect to knowledge base around health.

Table 3.6: *Knowledge Base Themes and Sub-Themes*

Domain: Knowledge Base					
Themes	Sub-Themes	No of People	No of Groups	No of Quotes	Total Quotes
Food Knowledge	General Food Knowledge	15	6	37	69
	Specific Food Knowledge	19	7	32	
Weight Status Awareness	Aware of being overweight	10	6	12	33
	How long they have been overweight	13	4	15	
	Historical weight losses	5	4	6	
Exercise Knowledge	To Lose Weight	11	6	12	19
	Health Benefits	4	7	7	
TOTAL NUMBER OF QUOTATIONS					121

3.3.4.1 Food Knowledge

Participants demonstrated some *general food knowledge* such as not eating junk, or rubbish when you are trying to lose weight. Others provided suggestions on healthier habits such as sticking to 3 meals per day with no snacks, eating smaller amounts of food, and not eating after 6 o'clock. There was some awareness around the fact that calories are important to look at and how you find them, however, there was also a lot of confusion and incorrect knowledge around how many calories are ok. Similarly, participants were aware of the fact that sugar, salt and fat contents should be low but again there was no concrete idea of what low constitutes.

RDC1.0: Stop eating junk food.

RCN1.5: I stick to three meals a day and I don't snack in between.

RCN1.3: I don't eat after six o'clock cause you're going to bed and you don't want a sick stomach.

RCN1.3: Look at where the calories are on the packet, about 4 or 5 [calories should be in a dinner or lunch].

RCN1.5: Yeah and how much sugar or salt is in it.

Several incidences demonstrating *specific food knowledge* of both healthy and unhealthy foods were also present. Proactive spreads were identified as healthy and linked to lower cholesterol. Fruit, vegetables, nuts and water were also identified as healthy foods to eat, with white bread, Chinese food, alcohol, fizzy drinks, crisps, cheesecake, chips, chocolate and cheese identified as unhealthy. Eating some unhealthy foods now and again was thought to be ok, but no concrete frequency of what is ok was given.

RCN1.5: It [proactive spread] lowers your cholesterol as well.

DHC1.5: Fruits and vegetable [when I am trying to lose weight].

RCC1.2: Yeah, drink plenty of water [is healthy].

RDQ1.5: Stop eating chocolate and crisps, and stop the fizzy drinks.

DHC1.1: Yeah white bread is bad.

DHC1.4: Chinese is not good for you.

3.3.4.2 Weight Status Awareness

Most participants were *aware that they were overweight*, and most could describe signs of weight gain, but no one had a clear idea of how much weight they needed to lose to be healthy.

RDC1.4: Well I know I need to lose weight when it's coming up to the Special Olympics. I don't know what weight is best so I'm finding it a bit hard.

RCM1.1: Well, I'm trying to lose weight and I am a heavy person, so I can watch for myself what to eat but I'm going to try to keep healthy and to not be eating any of the bad stuff.

RDQ1.0: Well every time I put on a pair of trousers, they're too tight for me and my t-shirts and trousers don't fit me anymore.

Some participants had an idea of when they started to become overweight and *how long they have been overweight* for, with some thinking they had always been overweight even in school, some linking their weight gain to eating habits, and some linking their weight gain to increasing age. Many participants were aware of *historical weight losses* but very few had an idea of the timescale it had taken to lose the weight or what changes they had made in order to lose weight.

RCC1.1: I was always thin when I was growing up, until lately. Until I started to eat sweet things until they come out my eyes.

RCM1.4: I think it's when you grow up [you get overweight].

RCN1.5: Yeah, 3 years ago I started losing weight. I was 18st 2lb and now I'm down to 15st 12lb.

RCC1.4: I lost a stone weight since I came here, I was 17 stone and now I'm 16 stone.

When talking about exercise most people referred to walking as the main form of exercise to help you get healthy and *to lose weight*. Some people also identified specific exercises of horse riding, football, riding a bike, using an exercise bike, aqua-

aerobics and swimming as ways to get fit. A number of participants understood that increasing physical activity was *beneficial to health*.

RDQ1.5: Go for a nice long walk [to lose weight].

RCN1.2: I think the walking now well hopefully, and I'm eating a lot less.

KDS1.4: written message by participant to researcher - [I go for walks and go swimming to lose weight].

RCM1.3: To get fit and lose weight.

3.3.5 Current Habits Themes

Table 3.7 details the emergent themes and sub-themes with respect to current eating and leisure habits engaged in.

Table 3.7: *Current Habits Themes and Sub-Themes*

Domain: Current Habits					
Themes	Sub-Themes	No of People	No of Groups	No of Quotes	Total Quotes
Leisure Time	General Perspectives	17	5	19	
	Preferred Activities	16	6	23	
	Household Chores	10	5	13	
	Physical Activities	27	7	55	
	Sedentary Activities	22	7	35	145
Dietary Choices	Food Preferences	15	5	32	
	Healthy Habits	22	5	42	
	Unhealthy Habits	20	6	41	115
TOTAL NUMBER OF QUOTATIONS					260

3.3.5.1 Leisure Time

The general perspective from most participants was that they were busy enough with work and household chores in the evenings and at weekends, so they did not get bored. A few felt they did not have enough options available to them during their free time, but they kept themselves busy anyway. Three people also noted their preference to be busy, with only one person stating they preferred just to relax.

RCN1.3: Yeah sometimes you do find it hard to find things to do, but when you are busy at home and you've the cooking and all you've got to do you don't find the time going. Then you have time to sit down and watch the programmes you know and get a shower and get ready for bed.

KDS1.3: I don't get bored, I'm always working.

KDS1.6: No, I've got work and tech so no [I don't get bored].

RCC1.0: You couldn't cope if you had nothing to do, you'd crack up.

DHC1.1: No, I don't [like being busy]. Yeah [I like to relax].

Preferred activities were a mixture of active and sedentary type activities, with almost equal reference made to both. Active preferences included walking, going to the gym, horse riding, bowling, golf and football. Sedentary preferences involved music, cinema, TV, DVDs, computer, watching football matches and going to the pub.

KDS1.1: I like playing golf.

RCM1.5: Yeah, I'd rather do the gym.

RCM1.2: I like going to the cinema.

DHC1.3: [I like] TV.

Active *household chores* such as cleaning and tidying the house, chopping sticks, gardening, and walking dogs were all listed as regular activities engaged in at the weekends or in the evenings.

RCN1.2: I'll tell you what I do, I would be cleaning the house, cleaning out the cooker and cutting sticks. Yeah, my favourite job at home is cutting sticks.

RCC1.1: Wash the windows that's right, pass my time and do my gardening.

Physical activities engaged in during leisure time included a mixture of community clubs, Special Olympics clubs and independent personal exercise. Community clubs such as martial arts, horse riding, Zumba dancing, line dancing, and using the gym were accessed regularly by some participants. Special Olympics clubs for bowling, basketball, swimming, and golf were also attended weekly by some participants. Personal exercise involved activities like walking, using a Wii for Wii fit or dancing games, using a treadmill, cycling, bowling or personalised physiotherapy exercises. The most common form of exercise referred to throughout was walking.

RDC1.3: [I do] martial arts.

RCN1.5: Yeah, I do Zumba every Tuesday in [place name].

KDS1.3: I go line dancing.

RDC1.4: I do sometimes the Special Olympics for fun on the Saturday and play basketball.

RCN1.3: Yeah, I walk every morning.

KDS1.6: I do exercises on the walking machine.

Thirteen different types of *sedentary activities* were regularly engaged in. Three of these activities involved different community groups: singing with a local choir, regularly supporting a local sports team, and attending a local bingo club. Outings with friends or family to the cinema, the pub or restaurants accounted for three more types of sedentary activities. And the other seven types of sedentary activities were individual activities of which 6 were engaged in at home; playing the Xbox or Playstation or iPad, watching TV, knitting, listening to music, doing puzzles, and relaxing; and one was going to the local library.

KDS1.7: I'm in a choir.

DHC1.5: Yeah, I do I go to the cinema.

RCM1.1: Ehh well, I like going to the pub. I go to the Irish pub in [place name], and I go to the clubhouse and to [pub name].

DHC1.4: I'd go on my Xbox.

RDQ1.0: I just play PlayStation a lot of the time.

RCN1.3: Watching the soaps yeah. I watch Fair City and then on Thursday the whole lot are on.

RDC1.4: And I do knitting and crocheting.

RCN1.3: Eh sometimes I like doing puzzles. And crosswords.

3.3.5.2 Dietary Choices

When discussing current *healthy and unhealthy dietary habits*, people spoke more about the foods they liked than disliked. Peoples preferences were more towards unhealthy foods such as chocolate, crisps, cakes, pizza, chips, cheese and curry, than

healthy foods, with only water, brown bread, vegetables, fish and fruit mentioned. Foods that were disliked were mainly foods that could be classified as healthy, or healthier alternatives such as red meats, tomatoes, rice, popcorn, coke zero and orange juice. The only unhealthy foods that were disliked were white bread, red bull and alcohol.

RCC1.0: Yeah. And chocolate, I love chocolate and buns.

DHC1.6: And [I like] pringles.

RCC1.2: I like pizza too.

RCN1.0: Well I love my donuts I have to admit that. And I love my apple tart too.

KDS1.1: I love bananas.

RDQ1.0: I tell you what I don't take, i don't take red bull.

RDQ1.5: I don't eat red meat either.

RCN1.0: Like I've said there I don't eat rice and stuff like that.

Participants were already engaging in many *healthy eating habits* such as just eating breakfast, lunch and dinner with no snacking, or eating smaller portions, or using steaming as a cooking process. One person also stated that they used to skip lunch but have now started to bring in a packed lunch. Regular consumption of foods such as fruit, vegetables, fish, soup, brown bread, and ham were spoken about in relation to lunches and dinners, and low fat or diet options were sometimes chosen over the full fat or full sugar options such as slimming world chips, proactive butter, and diet drinks. Some people also spoke about healthier dietary changes they have already made such as taking no extra salt, cutting down on sugar, cutting down on fizzy drinks,

drinking more water, not eating Chinese or chippers or cakes or cheese or chocolate, and not drinking alcohol or fizzy drinks.

RDQ1.2: Sometimes with chips, sometimes potatoes, if its salmon I tend to steam it.

KDS1.5: And I don't drink coke or 7UP. Yeah, I just like drink blackcurrant and water and that's it.

RCN1.0: I used to take 3 [spoons of sugar] but I've cut down to one.

RCN1.3: No, I don't have salt on anything either.

RCC1.3: I cut out all the..... I don't go to the chipper every day.

RCC1.4: I cut out coke, I cut it out altogether. I'm taking water now, and Mi Wadi. I don't take any fizzy drinks anymore. I don't eat too much at home either. I eat my dinner here every day and that does me. I don't eat chips either, I eat mashed potatoes instead.

KDS1.2: Yes I've been cutting down like I used to have 2 cans of coke and I force myself to only have one.

However, many more *unhealthy dietary habits* were present for most participants such as occasionally skipping meals, eating large amounts, frying foods as a means of cooking, eating late after 10pm, regularly eating out, frequently getting take-aways, eating multiple treats every day, and having a treat with a cup of tea every evening. Specific unhealthy foods referred to consisted of sweet treats (chocolate, ice-cream, buns & cakes, crisps, sweet popcorn, and biscuits), alcohol, take-aways, pizza, milky coffees, readymade meals, burgers, chips, coleslaw and mayo.

- KDS1.2: I tell myself if I'm hungry or not and I tend to eat late as well. And that's like after 10 or 11[pm]. I know if I feel hungry for it or not. I think it's a habit.
- RCC1.3: There's eggs at home and all I do is boxty. Put that on the pan, flip it over a few times until it browns and have boxty and eggs, that's my tea. And then my brother gets Chinese on Saturday, I love Chinese he gets Chinese for the two of us and we share.
- RCC1.4: I treat myself every Friday, once a week to a small cup of cappuccino coffee in the [Café name].
- KDS1.5: I was eating burger and chips and my class in college went out in [place name] and we were having our lunch and we had burger and chips.
- RCC1.3: I went to a band last Friday night and I had too much juice, Guinness. The following morning, I had a hangover. I felt the bad of it the following morning. I lost count, I lost count. Yeah, and I got a free one from someone and I said thanks. I should have said no, I should have left it where it was, I'd be better off.

3.3.6 Data Sheet Analysis

The three data sheets given to participants during the focus group discussion allowed additional information to be gathered in relation to independence and preferences around foods, and exercise habits.

3.3.6.1 Data Sheet 1

The first data sheet (see Appendix B) gleaned information about autonomy in planning and making meals, and what is important in relation to food choices. Categories were combined to reflect levels of autonomy with “on my own” rated as “independently”, “with my family” or “with staff” combined to make “with support”, and “in a group” or “I don’t” combined to make “no choice”.

Twenty-eight participants completed the first data sheet with “high” confidence, see Table 3.8. As Figures 3.3 and 3.4 show, the results were mixed and differed between groups for both planning and making meals. Almost half of the participants (46%) felt they had the ability to independently plan meals, with more claiming independence in the making of their meals (61%). Slightly larger numbers reported regularly planning and making meals (54% and 68% respectively) with the support of family or staff members. However, the overall numbers claiming to have no choice in the planning or making of meals (43% and 54% respectively) were also high and were similar to the numbers stating independence.

Table 3.8: *Number of participants per group with rated as “high” for data sheet 1*

Group	ALL	Group 1 KDS	Group 2 DHC	Group 3 RCC1	Group 4 RCM	Group 5 RCN	Group 6 RDC	Group 7 RDQ
Total in group	45	8	7	6	6	6	6	6
Total rated “high”	28	6	7	3	2	6	3	1

Seventeen participants (61%) chose only 1 option for planning meals, with 4 reporting they plan meals independently, 4 reporting they planned meals with support of family or staff, and the remaining 9 stating that they had no input or choice in the planning of meals. Ten participants (36%) chose 2 options for planning meals, with eight people reporting that they planned meals either independently or with support from family or

staff, and the remaining two participants stating that they had input in to the planning as part of the family unit or that they had no choice in what was planned for meals. Only 1 participant (3%) chose all three options for planning meals as this was the mix that reflected their life.

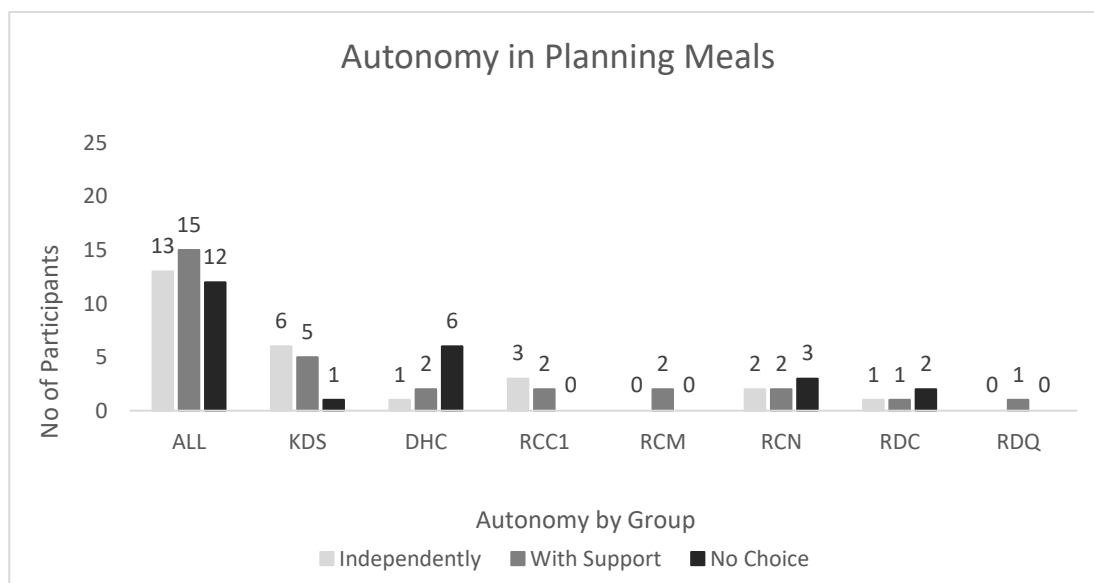


Figure 3.3: Level of support per group for how meals were planned.

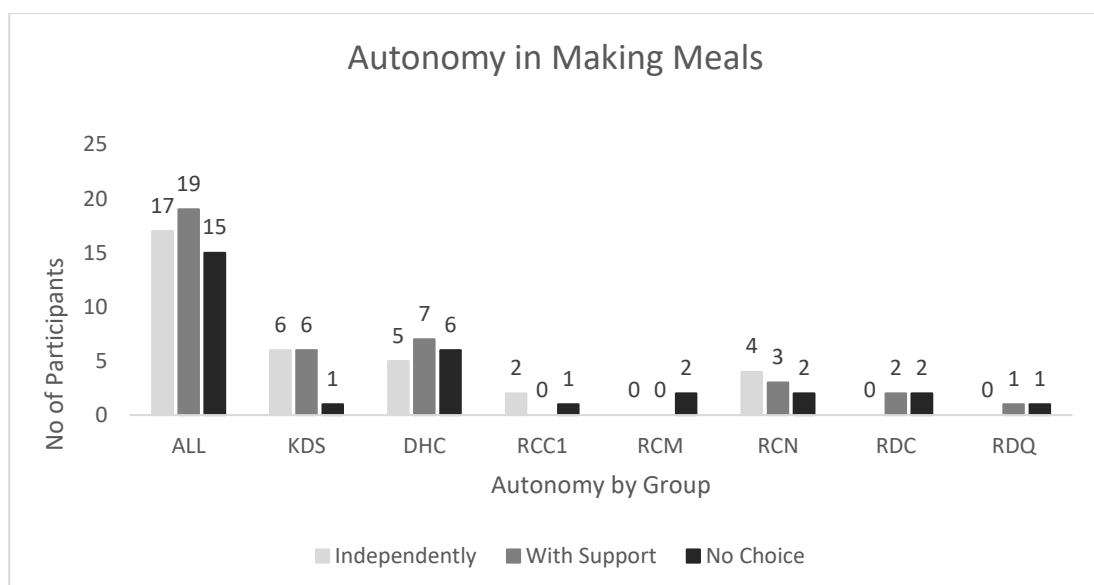


Figure 3.4: Level of support per group for how meals were made

When it came to making meals eleven participants (39%) chose only 1 option, with four people stating that they make their meals independently, 3 people made their meals with support from family or staff, and 4 people stated that they do not make any contribution to making meals. Eleven participants (39%) chose 2 options, with one person alternating between making meals independently and having no choice in what was made, six participants either making their own meals independently or with support, and four people either making meals with support or having no choice in what was made for them. Six participants (22%) chose all 3 options to reflect the mix in their lives.

As one participant had to leave early, 27 participants completed the final section on the first data sheet relating to what is important in food choices, as one participant had to leave early. As Figure 3.5 shows, the results were mixed and differed between groups in what was seen as important in food choices. Overall the most important aspect considered was the taste of the food (26%), with health (21%), the ability to fill you up (21%) and cost (20%) coming close. The lowest importance was placed on how easy the food was to make (11%). However, these results varied between groups.

The number of options chosen varied, with 6 participants (22%) choosing only 1 option, 5 participants (19%) choosing 2 options, 10 participants (37%) choosing 3 options, and 6 participants (22%) choosing 4 options. No participant chose all 5 options. The groups varied in what they deemed to be the most important factor in food choices, but Taste, Cost and Health were predominantly the most important across the groups.

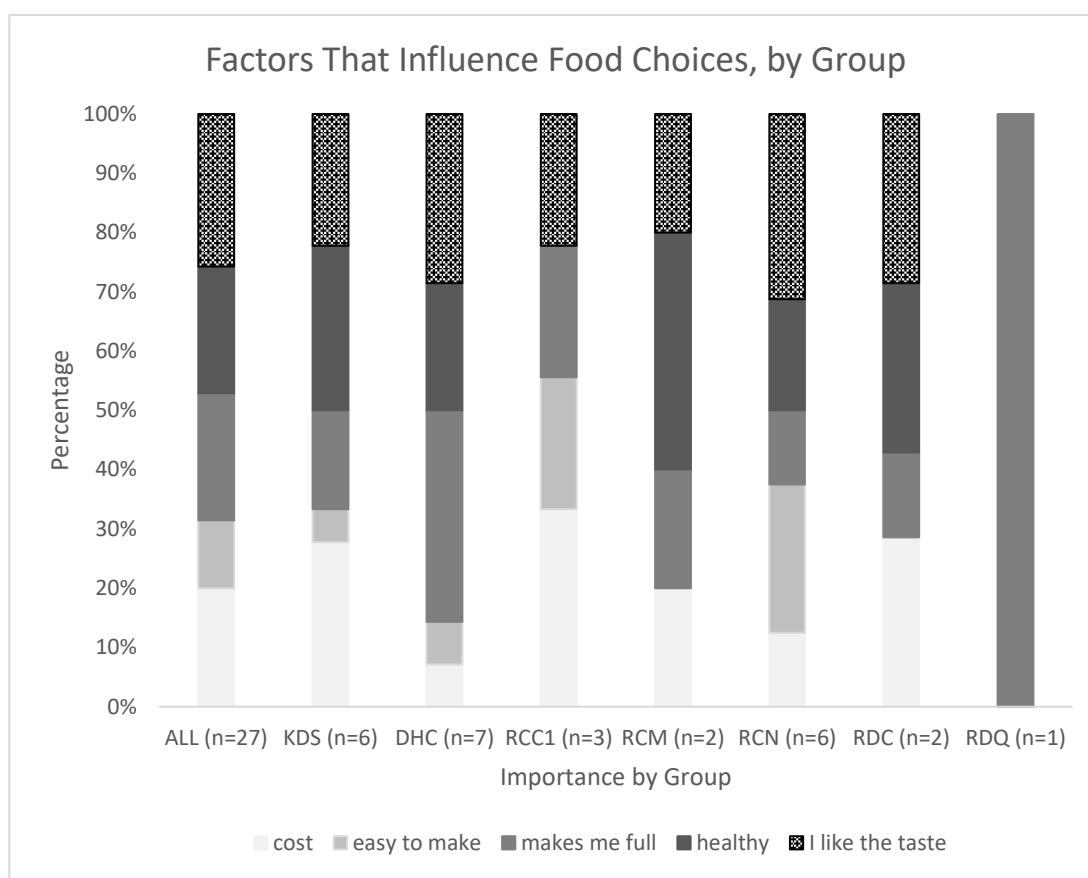


Figure 3.5: Factors of importance for meal choices.

3.3.6.2 Data Sheet 2

The second data sheet provided an insight into preferences towards types of foods, based on their categorisation of GREEN (*healthy foods*), YELLOW (*healthy foods providing quantities are controlled*) or RED (*unhealthy foods*) as per State of Victoria (2015) guidelines and the input of a qualified dietician. Both the data sheet and the food categorisation list can be found in Appendix C.

Thirty-five (78%) participants achieved a “high” rating for the completion of the second data sheet and are included in the results shown in Table 3.9. Mean % preferences were high for all three food categories for all groups, with the red foods rated as the most preferred foods overall at 84% (SD=5.96, range 76% to 91%). The

number of people stating a preference of greater than 70% for a particular food category was also highest for the red foods (97%), meaning that almost all of the participants liked the majority of foods in this category. In comparison, only 68% of participants liked the majority of foods in the green category, and 65% of participants liked the majority of foods in the yellow category.

Table 3.9: *Percentage Preferences by Food Category for “High” Rated Participants*

Group	No of “high” Participants	Mean % Preference			No of People >70% Preference		
		Green	Yellow	Red	Green	Yellow	Red
Group 1 KDS	6	72%	78%	80%	3	4	6
Group 2 DHC	7	79%	81%	91%	5	4	7
Group 3 RCC1	6	85%	79%	91%	4	3	6
Group 4 RCM	5	85%	80%	87%	5	3	5
Group 5 RCN	6	68%	78%	79%	3	4	4
Group 6 RDC	3	82%	82%	83%	2	3	3
Group 7 RDQ	2	75%	58%	76%	1	1	2
Totals/Mean	35	78%	77%	84%	23	22	33

When comparing food type preferences for each BMI category, as shown in Figure 3.6, the main difference between overweight and obese participants is that overweight participants demonstrated a higher preference for Green category foods (95% for overweight BMI versus between 74% and 79% for obese BMIs), and lower preferences for both Yellow (62% for overweight BMI versus between 76% and 83% for obese BMIs) and Red (71% for overweight BMI versus between 83% and 88% for obese BMIs) category foods. Additionally, overweight participants rated Green foods as their most preferred foods, whereas obese participants rated Red foods as their most preferred foods.

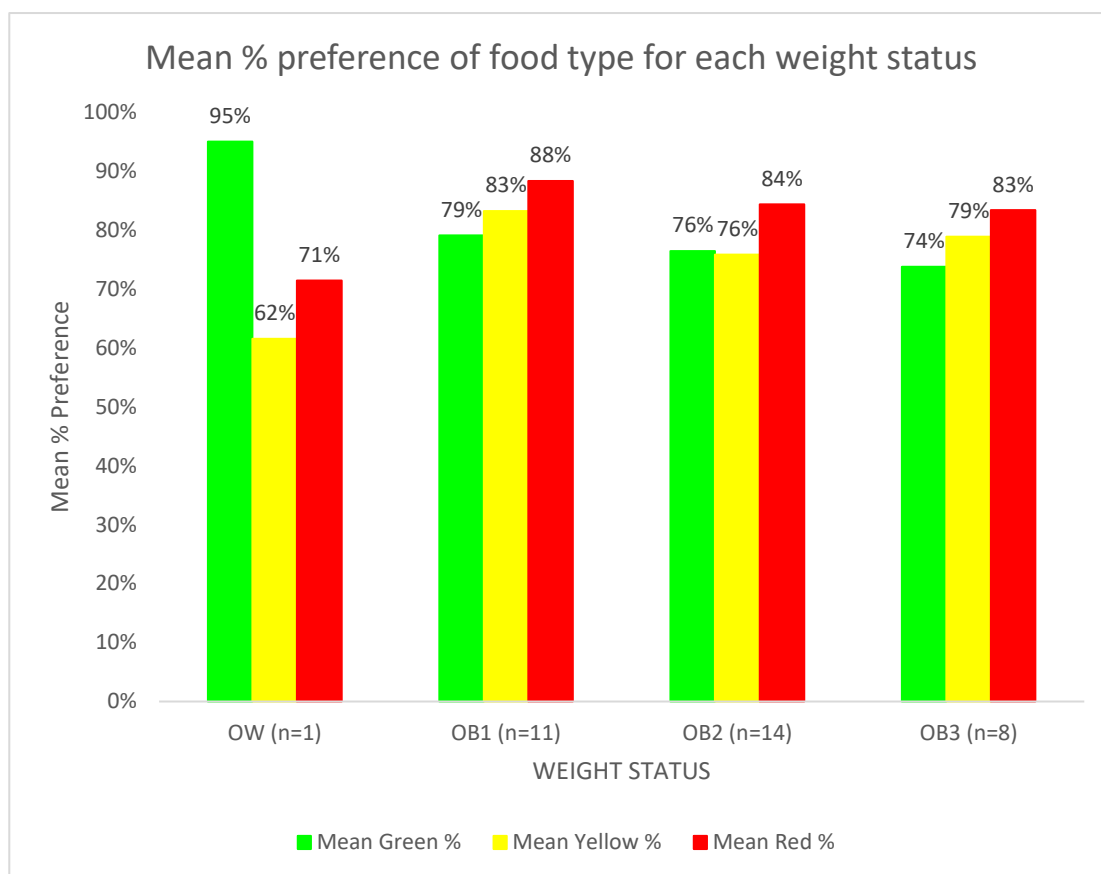


Figure 3.6: Mean % preference by food type for each BMI category

3.3.6.3 Data Sheet 3

The third data sheet provided information on types of regular exercise engagement. Twenty-one (47%) participants were rated as “high” confidence and were included in the analysis. Figure 3.7 shows that walking was the most common form of exercise with 90% of participants engaging in this activity regularly. Bowling (52%), swimming (43%), dancing (33%) and exercising on gym equipment (between 20% and 43%) were also cited as commonly accessed activities. Most activities identified were facilitated by the Service centre or organised through Special Olympics. Self-inclusion in community exercise programs or venues did not appear to be present for many participants.

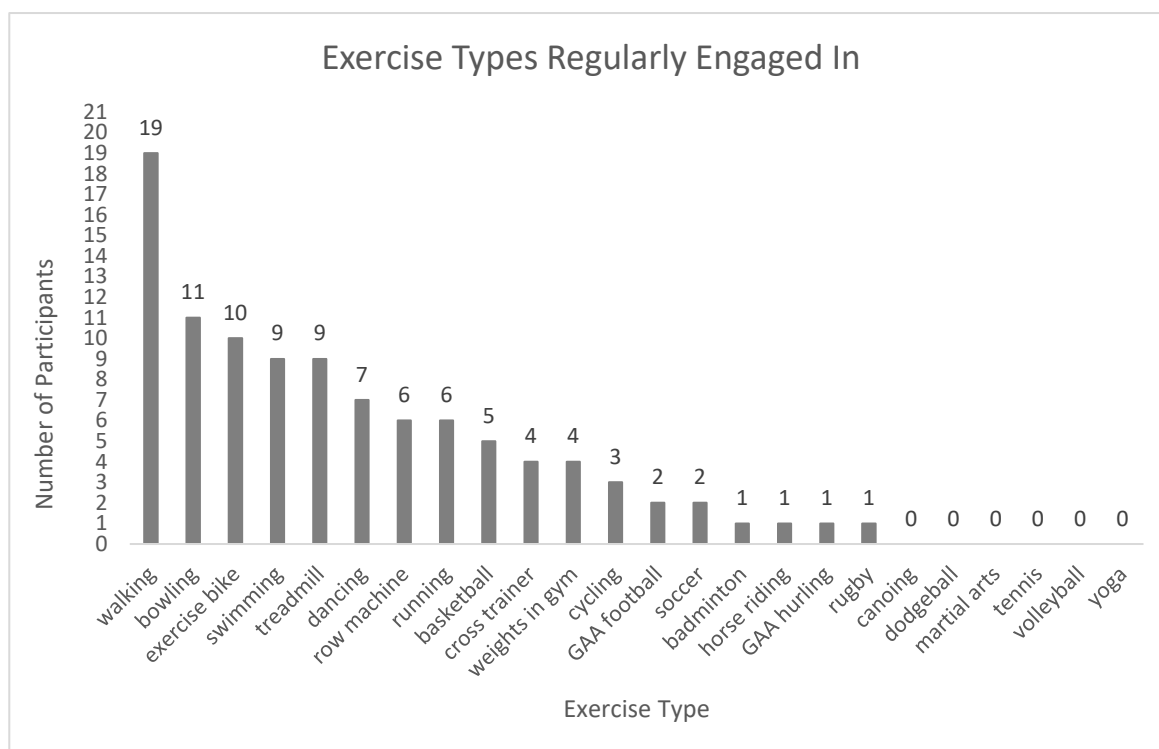


Figure 3.7: *Number of people who engage in each type of exercise on a regular basis, by group*

3.4 Discussion

The focus groups generated a wealth of information in relation to all four domains of interest: facilitators, barriers, knowledge base and current habits. Knowledge base generated the lowest number of quotes (approximately half of the other domains), possibly since the questions were geared towards life experiences and personal preferences, rather than knowledge levels. Participants' responses to items in all four domains identified existing supports that are effective, areas that may jeopardize success, current knowledge deficits and existing behaviours of concern. This provided important information, informing the development of a health promotion education series, and a multi-component weight loss intervention.

3.4.1 Facilitators

Many supports were already available to participants to encourage both healthy eating and exercising. The majority of existing supports were aimed at increasing exercise engagement, which was seen as the main intervention for weight loss by participants, care staff and families. Service centres provided a variety of exercise programs in-house, family members were often exercise partners or provided transportation to other exercise opportunities, community clubs were available if participants were cognitively and socially able to join in, Special Olympics clubs were available in most localities, and a few participants were in paid employment in manual jobs that increased physical activity. Despite these opportunities and supports existing they are not without difficulties, since providing opportunities does not automatically mean engagement. Service centres may facilitate exercise programs, but they cannot force people to engage in them (National Disability Strategy Implementation Group, 2013-2015). Family members must be available, able and motivated to accompany exercising or provide transport to facilities, which may not often be the case since lack of support has been listed as a barrier by adults with ID in previous research (Bodde & Seo, 2009; Messent et al., 1999). Accessing community clubs involves many skills, and poor social skills and lack of independent travel have been shown to reduce the ability of adults with ID to participate in mainstream community groups (Wilson, Jaques, Johnson & Brotherton, 2017). Local Special Olympics clubs are more accessible in terms of physical abilities and social comfort, but these are reliant on parents and volunteers to run (Special Olympics Ireland, 2019). Whilst working environments have the potential to provide increased exercise for adults with ID, jobs are few and far between. The rates of employment for adults with ID are low and estimated at 44%, which is approximately half the figure of the general population (Siperstein, Parker & Drascher, 2013).

Even when support is available, being motivated to exercise is essential to actually engaging in it. Whilst internal motivation was noted as a driver for exercising, it is unlikely that this was motivation enough since so many adults with ID lead sedentary lives (Frey, 2004). Providing incentives to exercise has however, been shown to

increase exercise engagement (Strohacker, Galarraga & Williams, 2014), and external reinforcement strategies have been successfully used in many weight reduction interventions with adults with ID (Foreyt and Parks, 1975; Rotatori et al., 1980; Fox et al., 1984; Fox et al., 1985; Fisher, 1986; Croce, 1990; Croce & Horvat, 1992; Sailer et al., 2006; Bazzano et al., 2009; Saunders et al., 2011; Martinez-Zaragoza et al., 2016; Ptomey et al., 2018). Families and service centres should consider employing these strategies to increase the number of adults who participate in exercise, and also the regularity of participation. Training carers on effective use of reinforcement should be part of every health promotion program and should be used in weight loss interventions.

Identification of naturally occurring positive consequences that may sustain weight losses for the longer term, is an under researched area worthy of exploration. Some natural consequences like increased mobility, increased energy levels, improved appearance and improved mood were acknowledged by participants as the physical and mental health benefits of exercising. Previous research has found that even one instance of exercise can improve mental health and brain functioning, and regular exercising can improve physical functioning, energy levels and quality of sleep, all of which directly reduce feelings of depression and anxiety (US Department of Health and Human Services, 2018). Additionally, improved personal appearance is rated as the most motivating factor for weight loss by adults with ID (Jones et al., 2015^b). However, for these consequences to be utilised effectively, participants must be able to connect their exercise engagement to actual improvements in physical functioning, well-being and physical appearance. By defining and measuring these dimensions and comparing them to weekly exercise engagement, feedback sessions could provide this link and increase the reinforcing value of these natural consequences.

In addition to positive consequences for engaging in exercise, adults with ID must begin to take responsibility for their own health outcomes. The ability to take responsibility for your own health grows from experiences of independence and choice, and this is no different for people with an ID (Stokes, Turnbull & Wyn, 2013). Allowing choice in the types of exercise each individual engages in may determine

whether exercise habits continue post-intervention or not. This is also true for dietary choices and people with ID should be educated and supported to make more of their own choices in relation to what they eat. Since dietary interventions, or combined dietary and exercise interventions, have been shown to have larger effects on weight loss than exercise interventions alone (Foster-Schubert et al., 2012), more emphasis must be placed on supporting this component. Current support for diet appears to be limited to basic advice and skill building by some service centres and families. However, as carer knowledge on healthy eating guidelines was found to be lacking (Melville et al., 2009), standardised, relevant and accessible dietary information and easy-make healthy meal options need to be readily available for both service centres and families.

Self-management of both physical activity and diet is essential to increasing independence and choice. Many paper-based tracking systems have been utilised for self-management in previous weight loss interventions with success (Foreyt & Parks, 1975; Joachim, 1977; Norvell & Ahern, 1987; Melville et al., 2011; Saunders et al., 2011; Jones et al., 2015^a; Harris et al., 2017; Ptomey et al., 2018). However, for tracking to be effective it must also be timely. Some of the participants in this study who used food diaries completed them at the end of the day relying on recall skills. In a study by Ptomey et al. (2013), food intake comparisons were made between 24-hour recall methods versus photo-assisted recall methods for adults with ID. Twenty-four-hour recall methods recorded less caloric intake than photo-assisted recall methods, demonstrating that memory recall alone is unreliable and tends to underestimate. Creating a simple tracking system that can be accessed easily at the time of eating or exercising, and that provides instantaneous feedback would benefit weight management interventions and support self-management of lifestyle choices.

3.4.2 Barriers

Whilst most of the facilitators in this study were about supporting exercise, in contrast most of the barriers involved diet. Lack of support and lack of knowledge were the main reasons identified as limiting healthy food choices. Approximately 70% of participants lived at home with family members and whilst many reported

independence in planning and preparing meals in the checklist (Appendix B), and some report helping with grocery shopping in the discussion, the majority of food purchased was usually pre-determined by parents or siblings. Previous research exploring choice-making for people with ID has shown that often food choices are controlled by carers. Lack of resources, lack of feasible options available, misconceptions about the long-term consequences of poor choices, and a lack of food knowledge are all listed as reasons for carers to control choices (Smyth & Bell, 2006; Jenkinson, 1993; Jackson & Jackson, 1998). However, as emphasised before, increased autonomy leads to higher levels of motivation and engagement (Jenkinson, 1993). At present, it has not been explored whether increasing autonomy in food choices will lead to healthier diets and indeed weight loss for adults with ID. Since lack of food knowledge has also been listed as a barrier by both carers and adults with ID, it is likely that if choice is not accompanied by a practical choice system then this impact will be minimal. Since making choices is a basic human right that is legislated for adults with ID (National Disability Strategy Implementation Group, 2013-2015), education must accompany experience to aid informed choice making, especially with regards to food since so many adults with ID are overweight.

Current education on foods was hampered by not knowing where to access reliable information or by receiving conflicting advice, factors also identified by Smyth and Bell (2006). Planning meals and accounting for foods consumed were other skills that were not present, therefore understanding and reflecting on overall weekly consumption was impossible. In a study by Hollis et al. (2008), participants who used food diaries to track their intake lost double the amount of weight than those who did not. Indeed, research shows that by just recording our food intake, we tend to reduce the amount we consume (Crone-Todd, 2012). Increasing food knowledge to empower decision-making coupled with support for meal planning and food intake tracking, will add value to weight loss interventions by supporting independence, choice and accountability.

However, even if people with ID are supported and educated to make better choices, other environmental characteristics jeopardise success. If the people around them are modelling unhealthy food choices, then this behaviour becomes the norm. Cartwright et al. (2015) found that unless lifestyle changes were made within the home for the entire family, then weight losses as a result of short term “diets” were not maintained. Environmental temptations also posed threat to the ability to continually make good choices, and though some strategies were referred to for avoiding temptation the need to allow for some flexibility as part of an overall healthy diet will have more success at long-term lifestyle change. Tracking unhealthy food choices will allow adults with ID to consume some foods regarded as temptations whilst ensuring they reduce and control the amounts of these foods to within healthy limits.

Barriers to exercise participation were similar to those already stated in the literature such as lack of support, costs, poor weather, safety concerns, and health concerns (Bodde & Seo, 2009; Messent et al., 1999; Temple & Walkley, 2007). Low motivation to exercise and a preference for sedentary activities are well versed in the literature (Frey et al., 2005; Temple, 2007) and may provide reasons as to why alternative activities are not looked for, but a learned dependence on others to provide and support exercise choices may play a larger part (Caton, Chadwick, Chapman, Turnbull, Mitchell & Stansfield, 2012). No solutions regarding alternative activities were given, which indicates a possible lack of knowledge in what alternatives are out there, possible rigidity in the routines of exercise, a lack of willingness to try other activities, or a lack of accessible alternatives. Broadening knowledge on the variety of choices available in accessible exercise would benefit health promotion programs. Weight loss interventions should also incorporate daily targets and incentives for exercises that have been selected by each individual’s preference.

3.4.3 Knowledge Base

All of the adults in this study were aware that they were overweight, but none referred to themselves as obese. Perceptions of weight are distorted in society with overweight becoming more normalised and a greater prevalence of clinically overweight people perceiving themselves as normal weight (Johnson-Taylor, Fisher, Hubbard, Starke-

Reed & Eggers, 2008; Howard, Hugo, Taylor & Wilson, 2008). This is also the case for adults with ID (Eden & Randle-Phillips, 2017), which means they may underestimate the need to lose significant amounts of weight. This will affect the emphasis they place on making dietary changes and increasing exercise.

Basic knowledge on healthy and unhealthy foods was present, which reflects previous research (Kuijken et al., 2016), however what is of note is that there was far more knowledge on foods to avoid eating than there was on foods that are good to eat. This type of knowledge appeared to breed feelings of deprivation in the participants when discussing healthy eating as there are more foods to avoid than eat. Additionally, if fruits and vegetables are the only known replacement, they lack the protein to fill you, again fostering feelings of deprivation. To make sustainable lifestyle changes to diet, the balance of foods to eat and foods to avoid must be achieved, and both health promotion programs, and weight loss interventions should focus more attention on the healthy foods that can be eaten.

Most participants had the basic understanding that exercise increased fitness and helped you lose weight. However, no participant demonstrated an understanding of how much exercise you should engage in daily, or the range of exercises that might be options available to them. Any exercise component of weight loss interventions should ensure that participants understand the difference between easy, moderate and vigorous types of exercise and also the recommended daily time associated with each (U.S. Department of Health and Human Services, 2018). Additionally, since carers also demonstrated that they did not know the guidelines for exercising (Melville et al., 2009) educating carers would benefit structured supports. Tailoring exercise to individual preference would also increase engagement.

3.4.4 Current Habits

Most participants felt they were occupied enough during leisure hours, with both sedentary and active leisure activities almost equally preferred. Actual activities engaged in formed three distinct categories: household chores, physical activities and

sedentary activities. The majority of participants stated that they spent time doing household chores in the evenings and at weekends, with these often quoted as the reason why they had no time to exercise. The majority of sedentary activities were individual activities engaged in at home, with games consoles and TV being the most popular. Even though this study did not measure actual levels of physical and sedentary behaviours, sedentary activities appeared to be the most common type of activity in the evenings. This reflects previous research findings that adults with ID lead more sedentary lives and fall short of recommended daily physical activity guidelines (Frey, 2004; Dairo, Collette, Dawes & Oskrochi, 2016; Melville et al., 2017). Physical activities during leisure time mainly involved walking with family members, or exercise orchestrated through Special Olympics clubs. Walking is known to be the most common form of exercise for adults with ID (Heller et al., 2008) and this may be the easiest type of exercise to promote for weight loss interventions, however, alternatives should be suggested to overcome barriers such as safety concerns, poor weather conditions, and lack of an exercise partner. Exercise engagement has also been shown to be influenced by social engagement (Mahy et al., 2010) which Special Olympics clubs provide, and these readymade options should be promoted and supported for weight loss interventions. Taking advantage of existing exercise habits for individual participants will increase the likelihood that physical activity targets will be met in any weight loss intervention.

In terms of dietary habits participants spoke more about their food preferences rather than foods they disliked. Preferred food statements included more unhealthy than healthy foods, and foods they disliked included more healthy than unhealthy foods. Studies analysing food intake for adults with ID have shown poor nutritional intake with many unhealthy foods consumed (Bergström et al., 2013; Mann et al., 2006; Ptomey et al., 2013), so increasing the range and preference for healthy foods is paramount to lifestyle change for diet. Self-reported claims about current healthy and unhealthy dietary habits demonstrated a grasp of the basic information that many health promotion programs cover (McDermott et al., 2012; Geller & Crowley, 2009; Ewing et al., 2004). However, being able to make healthier eating decisions at a

functional level when only basic dietary information is present, is not possible. More knowledge along with a support system to aid decision-making for a wider variety of food choices is essential for self-management of diet. Even though participants claimed to eat healthy foods, one important factor missing from this analysis is the frequency of this in comparison to unhealthy food intake. The fact that the majority of these adults were obese suggests that the balance of frequency lies more towards unhealthy foods and habits. The more frequently we engage in a behaviour the more habitual it becomes (Chance, 2014, Chapter 12), therefore, changing any behaviour that has a long history is challenging. It is likely that obese adults with ID have a long history of eating unhealthy foods that have also been reinforced by both the natural physical effects of consuming tasty or sugary foods, and also by the social reinforcement of “treating ourselves”. Future weight loss interventions will need to incorporate behaviour change strategies at a group level, such as self-monitoring techniques and group contingencies, but goal setting should be individualised to target specific behaviours for each individual. Differential reinforcement strategies such as DRL (differential reinforcement of low rates of behaviour) where gradual reductions of specific foods are reinforced, or DRA (differential reinforcement of alternative behaviours) where reinforcement is provided for abstaining from specific unhealthy foods whilst consuming alternative healthy options, could be explored as individualised strategies.

3.4.5 Limitations

The majority of adults with ID included in this study were living at home with parents or siblings, therefore, generalisability of these findings to adults living independently is limited. However, this demographic reflects the fact that the majority of adults with ID in Ireland currently live with family members. Additionally, the findings reported in this study are qualitative and self-reported and are not objectively validated. That said, the findings provide useful direction for the design of future health promotion programs and weight loss interventions for the adult ID population by understanding the perceptions that this population has towards supports and obstacles for achieving healthier lifestyles.

3.4.6 Conclusion

The majority of studies in the literature have looked at the barriers and facilitators for exercise for adults with ID, and a smaller number have examined barriers and facilitators to both diet and exercise for adults with ID. This study was novel, in that it adds and extends the current literature by examining the barriers and facilitators for both diet and exercise, whilst also looking at the knowledge of participants with respect to diet and exercise, and what current habits they report to have for both. The results are significant in that they provide key information on how to best support healthier lifestyles for this population. Since diet plays a larger role in weight gain or weight loss, service centres should incorporate adapted and standardised programs for adults with ID on food knowledge, meal planning and cooking skills. Families should also be provided with information and training to provide consistent support at home. Increasing family members knowledge may also influence healthier family meals where choice is limited or restricted. Whilst freedom of choice in food consumption can facilitate a healthy diet, sufficient knowledge and self-management techniques must be available to support healthy choices, or this could easily become a barrier to healthy eating. Current eating habits discussed in this study seemed to include more unhealthy food choices, so this would suggest poor choices are being made most often. Since knowledge appeared to be basic and was often confused, devising ways to teach foods for functional decision-making is essential for health promotion programs. Meal planning and food intake tracking tools would capitalise on supporting freedom of choice whilst ensuring choices do not jeopardize healthy diet, and these should be considered for future weight loss interventions.

Knowledge and support go hand-in-hand, and it remains a balancing act between encouraging independence and providing background support to inform choices. Increasing carer knowledge to improve dietary support tackles two of the main areas seen to jeopardise success. Flexibility in the foods available and inclusion in food choices will also increase responsibility for what is consumed. An understanding of the variety and accessibility of independent exercise options would also benefit adults with ID, their paid carers and their family carers as it may reduce the dependency that

adults with ID have on others to engage in exercise. Health promotion programs should include these aspects, and weight loss programs should incorporate accessible independent forms of exercise or ensure structured carer supports are part of the intervention.

Chapter 4

Factors that potentially influence successful weight loss for adults with intellectual disabilities: a qualitative comparison between two groups

4.1 Introduction

Adults with intellectual disabilities (ID) have been identified as a high-risk population for developing obesity (Fox & Rotatori, 1982; Stedman & Leland, 2010). Health complications arising from obesity not only reduce the quality of life for individuals, but they increase the load on health care providers (Kushner & Foster, 2000; Katz et al., 2000; Wang et al., 2011). The current economic burden that health care providers are faced with is driving efforts to reduce obesity on government agendas worldwide. However, until governments make dramatic policy changes to tackle the causes of obesity at a population level (Swinburn et al., 2011), overweight individuals must continue to moderate the drivers of obesity at a personal level for now. Whilst many predictors of obesity are known for the ID population, such as age, gender, level of ID, Down Syndrome, and living arrangements (Melville, et al., 2008; Ranjan, Nasser & Fisher, 2017), these do not explain the variability between individual achievements after participation in weight management interventions. More knowledge is required on factors that influence individual change and success.

Effecting change at an individual level is complex and involves many stages of change. The Transtheoretical Model (TTM) of behaviour change has been used as the theoretical underpinning for many health interventions and describes 5 main stages of change: (1) pre-contemplation, (2) contemplation, (3) action, (4) maintenance and (5) relapse/process complete (Marks et al., 2018). In the initial stages of weight change people must be aware that they need to lose weight (pre-contemplation), be dissatisfied with their body image or health (pre-contemplation/contemplation stages), and actually want to lose weight (contemplation stage). These factors must be present before they will actively and independently engage with any weight loss program (action stage). Research with the general population has identified that a large percentage of adults that are overweight perceive themselves as “normal weight” or “a little overweight”. In a study by Chang & Christakis (2001) where a sample of 41,676 American adults self-reported their weight, height and weight perception, 27.4% of the overweight adults rated their weight status as “just right”. Howard, Hugo, Taylor & Wilson (2008) quoted higher figures for a sample of 2,381 Australian

adults, with 39.2% of overweight adults categorising themselves as “normal weight”. Of even more concern in this study was the fact that 59.6% of medically obese participants in this study rated themselves as only “a little overweight”. Johnson-Taylor, Fisher, Hubbard, Starke-Reed & Eggers (2008) compared the results from two national studies conducted in the US, the NHANES III (1988-1994) and 1999-2004 NHANES, to assess whether peoples’ views of overweight were changing as prevalence increases and the overweight body image becomes more normalised. They found that fewer overweight people identified themselves as overweight in the more recent study, indicating that perceptions of an overweight body image are becoming skewed, and the perception of normal weight now lies more within the overweight medical model. Seeing yourself as overweight increases body dissatisfaction which is a key motivator in driving weight loss (Stice & Shaw, 2002; Johnson & Wardle, 2005), so accurate perception of weight status is an important starting point for any weight management intervention, and is required at the initial pre-contemplation stage of change.

A number of studies have examined body perceptions and body dissatisfaction for overweight adults with ID (Ayaso-Maneiro, Dominguez-Prado & Garcia-Soidan, 2014; Eden & Randle-Phillips, 2017; Pan, Maiano & Morin, 2018; Reel, Bucciere & SooHoo, 2013). In a study comparing weight perceptions to actual BMI, Ayaso-Maneiro et al. (2014) found that between 25% and 42.9% of participants underestimated their BMI classification. After completing a 10-week weight loss program this figure rose to between 42.9% and 88.9%. Whilst this increase shows the positive effect that participating in weight loss interventions may have on satisfaction with physical appearance and self-esteem, it also means that perceptions of the need to lose weight decrease. Additionally, there is a potential issue that the longevity needed for weight loss may be difficult to achieve if adults with ID expect such drastic changes in short durations for minimal effort. Eden & Randle-Phillips (2017) examined body perceptions in a group of younger adults with ID and found that only a marginal difference existed between perceived body size and actual body size. When females were examined separately however, they tended to rate themselves as significantly smaller than actual size. When ideal body sizes and perceived body sizes

were compared there was no significant difference, again demonstrating a lack of body dissatisfaction. These findings may also indicate that the overweight body size has become more normalised for the ID population. When examining body image in Special Olympics athletes, both Reel, et al. (2013) and Pan et al. (2018) found that as BMI increased so did body dissatisfaction. This is an encouraging finding as it may point to potential differences that can be harnessed to influence weight loss. However, at present there is no information examining levels of body dissatisfaction and subsequent achievement in weight loss interventions for adults with ID. There is also no research exploring whether adults with ID have a concrete understanding of the amount of weight they need to lose in order to achieve a medically healthy weight, or whether they understand the difference between BMI categories and what this means to their health. The beginning of any weight management intervention would benefit from educating each participant on their individual targets towards healthy weight to aid the move from the contemplation stage towards the action stage.

Even when the drive to lose weight is established, actually losing weight involves changing lifestyle habits (action stage). Whilst the particulars of change are individualised, the recommended composition for weight loss interventions for both the general population and the ID population are multi-component type interventions. These interventions utilise behaviour change strategies to reduce calorie intake and increase physical activity (NICE, 2014a; SIGN, 2010; Spanos et al., 2013^a; Harris, et al., 2018^a). However, effecting dietary and exercise change with the ID population is again more challenging than with the general population for a number of reasons. Adults with ID tend to consume more high-energy dense foods lacking in nutritional content. In a study examining food intake with Swedish adults with ID, Adolfsson, Sydner, Fjelstrom, Lewin & Andersson (2008) calculated the observed daily energy intake as between 1100 to 3300 kcal. Recommended daily intakes range from 1600kcal to 2600kcal depending on sex and physical activity level (Office of Disease Prevention and Health Promotion, 2015), and this study showed that both extremes of eating were present in adults with ID. Of concern was that for 9 out of the 32 participants the majority of their energy intake was consumed between meals, and when types of foods were analysed for the full group the majority of consumption was

milk-based foods, breads, meats, buns and cakes. Fruits and vegetables were one of the fewest food types eaten. Bertoli, Battezzati, Merati, Margonato, Maggioni, Testolin & Veicsteinas (2006) found that whilst energy intake was lower for adults with ID when compared to those without an ID, the daily intake was still +300kcal per day in excess of energy expenditure, and nutritional balance also did not meet recommendations.

Food knowledge, preferences and autonomy of choice may also affect each individual's dietary intake. A number of studies have shown that adults with a mild or moderate ID are more obese than those with a severe or profound ID (Fox & Rotatori, 1982; Robertson et al., 2000; Hove, 2004; Melville et al., 2008), possibly because they have more freedom to choose the foods they consume and are making poorer choices (Draheim et al., 2007). Whilst some studies have shown that interventions targeting an increase in dietary knowledge can have a positive effect on weight (Ewing et al., 2004; Mann et al., 2006), a study by Golden and Hatcher (1997) found that obese participants possessed more nutritional knowledge than their non-obese counterparts. However, in the Golden and Hatcher (1997) study 23% of the obese participants had received prior instruction in nutrition, compared with 16% of non-obese participants. Since no baseline weights were available in this study prior to previous dietary instruction, it is difficult to assess these results without knowing if knowledge had been increased and whether this had positively impacted weight prior to this study. It is therefore difficult to gain an overall understanding of whether increasing food knowledge is effective for weight loss or not. The relationship between food knowledge and weight remains debatable but could be a factor that influences individual differences, particularly when thinking of knowledge in terms of how functional it is for each individual. A second area that remains unexamined is the relationship between individual food preferences and BMI, another factor that could provide insight into individual differences in dietary habits and weight loss.

The need to increase physical activity levels is something both the general population and ID population have in common. Currently only 24.3% of US adults in the general population achieve weekly recommended guidelines for both aerobic and resistance

training (US Department of Health and Human Services, 2018). Studies that compare physical activity levels between adults with ID and those without ID, have found the ID population to be more sedentary (Messent et al., 1999; Robertson et al., 2000; Frey, 2004; Stancliffe & Anderson; 2017). In a recent systematic review of physical activity levels for adults with ID, by Dairo et al. (2016), the number of participants that met physical activity guidelines (PAG) was approximately 9% across all 15 studies. Studies that use self-report measures for physical activity engagement have quoted between 8.3% and 39.7% of participants with ID achieving recommended PAG (Messent et al., 1999; Koritsas & Iacono, 2016; Stancliffe & Anderson; 2017), whereas studies utilising actual accelerometer data report lower numbers of participants achieving PAG, ranging from 0% to 10.7% (Frey, 2004; Oviedo, Travier & Guerra-Balic, 2017). Comparative figures quoted for the general population, range from approximately 18% to 50% (Messent et al., 1999; Robertson et al., 2000; Frey, 2004; Stancliffe & Anderson; 2017). When looking at figures for the ID population that relate to the percentage of time spent in sedentary activities per day, both Oviedo et al. (2017) and Harris, McGarty, Hilgenkamp, Mitchell & Melville (2018^b) reported over 70% of awake time as sedentary, based on actual data taken from accelerometer outputs. Studies reporting durations spent engaged in physical activity, show that very little of the time relates to exercise at either a moderate or vigorous physical activity (MVPA) intensity, of which up to 150 minutes per week is recommended to realise health benefits (U.S. Department of Health and Human Services, 2018). For example, Frey (2004) found that an average of less than 20 minutes per day was spent in MVPA for adults with ID, which was less than both a sedentary control group from the general population, and significantly less than an active control group from the general population. Finlayson et al. (2009) found that only 35% of men and 35% of women with ID self-reported engaging in MVPA for less than 2 hours per week. When compared with the general population 83% of men and 82% of women self-reported engaging in MVAP for between 4.9 and 7.4 hours per week, the ID population was significantly lower. Messent et al., (1999) & Bodde, Seo, Frey, Puymbroeck and Lohrmann (2013) found that approximately 50% of their participants with ID engaged in no MVPA at all.

The amount of time spent in physical activity and the intensity that exercise is engaged in will all be factors that influence each individual's weight loss, however, there are many common predictors known to influence physical activity engagement. Many studies are available that list the most common predictors of low engagement in physical activity which are; being an older adult, being female, having a severe or profound ID, a diagnosis of Down Syndrome, being non-ambulatory, inability to access community exercise opportunities alone, having poor physical health, having mental health issues, and being in the obese category for BMI (Stancliffe & Anderson, 2017; Oviedo et al., 2017; Robertson et al., 2000; Harris et al., 2018^b; Dairo et al., 2016; Finlayson et al., 2009; Bodde et al., 2013). How these factors combine and influence each individual's exercise regime may explain some of the variance for weight loss achievements, however, understanding what factors are common between adults that achieve weight loss and comparing them to the factors for those that don't may help to tailor exercise opportunities and reduce variance of engagement. Exercise alone has however, been demonstrated to be ineffective for weight loss with the adult ID population. Shin and Park (2012) reported a moderate overall effect size of Cohen's $d = .41$ for health benefits of exercise for adults with ID. However, when this effect size was calculated for body composition measures such as weight, percentage body fat and BMI the effect size was very small at Cohen's $d = .04$. Whilst increasing exercise boosts weight loss in a multi-component intervention, diet plays the larger role and it is likely that differences in dietary habits explain more of the variability between successful and non-successful weight losses.

Along with individual differences in body image perceptions, body dissatisfaction, dietary habits and exercise participation, differences in the barriers and supports that each individual will experience in their environment is also pertinent. Common barriers reported in the literature for adults with ID are; lack of support from others, high costs of exercise facilities and healthy food alternatives, difficulties in accessing opportunities for exercise, medical constraints, weather constraints, time constraints, personal safety concerns, lack of healthy eating knowledge, and lack of independence in food choices (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005; Kuijken et al., 2016). Common facilitators reported in the literature

emphasise the importance of; having adequate physical and emotional support, making exercise fun and sociable, embedding exercise in routine and familiarity, and having awards and team membership readily available (Mahy et al., 2010; Temple & Walkey, 2007). Whilst these are commonly reported barriers and facilitators, the extent that they are present in each individual's life may go some way to explain the variability in successful weight loss between participants. Differences between barriers and supports for individuals and how this affects healthy lifestyle choices and weight management are lacking in the literature. One notable difference found by Heller, Ying, Rimmer and Marks (2002) was the correlation between the success or failure of participants to exercise, and caregivers' personal beliefs on whether exercise would benefit the person they cared for or not. This may go some way to explain differences that exist in exercise engagement due to the support network around each adult with ID, however, this has not been studied with respect to its effects on healthy eating or weight loss. Temple (2007) also studied levels of physical activity by comparing the perceived barriers or activity preferences between groups of active and sedentary adults with ID. She found that participants who engaged in lower step counts listed a higher quantity of barriers of which some related more to low motivation than the active groups. This type of comparison adds further insight into possible reasons for variance in exercise engagement across this population, however, there remains a lack of evidence available to analyse differences in both dietary *and* exercise habits, between healthy weight and overweight adults with ID. Further research is warranted to understand factors that influence lifestyle differences between adults with ID who achieve weight loss and those who don't.

This study aims to add to the current literature by exploring the similarities and differences between two groups that differed in weight status and healthy lifestyle behaviours, across four domains of interest in relation to healthy eating and exercising:

1. Facilitators
2. Barriers
3. Knowledge Base
4. Current Habits

4.2 Method

4.2.1 Rationale

In recent years researchers have paid increasing attention to the active involvement of people with ID in the research process, and the inclusion of adults with ID in research that proposes to serve their needs has now become policy driven (Gilbert, 2004). Qualitative research utilising the theoretical underpinnings of phenomenology methodology was chosen as best fit for this study as it allows for conversation to develop freely in relation to the thoughts, feelings, opinions and experiences of adults with ID in relation to diet and exercise (Guest et al., 2012). Focus groups were chosen as the specific method to gain insight, as these have proven effective in eliciting information from adults with ID on matters that affect their lives (Gates & Waight, 2007; Kaehne & O'Connell, 2010). Focus groups are semi-structured interviews held with a group of people that aim to explore a topic by means of the interactions between participants (Kruegar & Casey, 2015). Multiple perspectives can be gathered at the same time with the social group setting often eliciting a variety of emotions otherwise not seen by individual interview processes (Gibbs, 1997). The social interaction aspect to focus groups was viewed as advantageous for this study to gain insight into both the shared *and* different perspectives, opinions, experiences and feelings of these adults in relation to exercise and healthy eating. For focus groups to be successful, it is anticipated that participants share some commonality in relation to the topic that researchers wish to explore (Asbury, 1995). All the participants in this study were adults with ID that attended the same Service centre, who share commonality in the similar opportunities available to them with respect to healthy eating and exercise.

4.2.2 Participants

Group A participants (n=6) were recruited as part of the larger project relating to weight management for adults with ID (Chapters 3, 5 and 6 of this thesis). Participants were invited to join the larger study via the Service Manager if they satisfied the following criteria: aged 18 or over, mild or moderate ID, and BMI > 25 kg/m². Group

A's focus group ran prior to any health promotion information or weight management intervention being conducted. Group B participants were a convenience sample recruited from the same service centre specifically to support commonality in the opportunities available to them with respect to healthy eating and exercise, and to highlight potential differences between individuals that achieve weight loss and those who don't. Group B participants (n=6) were invited to join *this* study via the Service Manager if they satisfied the following criteria: aged 18 or over, mild or moderate ID, and had achieved and maintained a substantial amount of weight loss over the previous 12 months ("substantial amount of weight" was a subjective measure determined by the Service Manager). Previous weights and actual weight loss had not been objectively measured by the service centre, however, Group B participants had been actively engaging in the service centre's exercise and healthy eating programme for the last 12 months, with the result of visibly noticeable weight loss. Participants were excluded from both groups if they showed any challenging behaviours or mental health issues that would unduly jeopardise participation in the study. Participants received an easy read demographic questionnaire one week before the focus groups began. Participants were asked to complete this questionnaire, with a support person if required, and submit it on the day of the focus group. The demographics for each group are shown in Table 4.2 in the results section below.

4.2.3 Procedure

4.2.3.1 Setting and Structure

Both focus groups took place on the same day within the service centre in a designated room, with Group A attending during the morning and Group B during the afternoon. Each session lasted approximately 1 ½ hours with a 15-minute break which included healthy refreshments, provided by the researchers. The main author and a second researcher attended the focus groups; one as lead moderator and the other as assistant moderator. The lead moderator was responsible for delivery of questions, introducing any prompts, encouraging conversation between participants, and re-aligning the

conversation towards the goals of the study where necessary. The assistant moderator was responsible for note taking, dispensing and collection of self-report checklists, and additional prompts where necessary. Each adult was invited to bring a support person if they wished, however, all attended independently. The discussions were audio-recorded to allow transcripts to be developed and analysed.

4.2.3.2 Anthropometric Measures

Participants heights and weights were collected by two researchers at the end of each focus group discussion. Participants were measured wearing a t-shirt, light trousers, and no socks or shoes. Measures were conducted by one of the researchers whilst the second researcher observed, and agreement was reached. A Stadiometer, Charder HM200P, was used to measure height in feet and inches to the nearest 0.5 inch. The height of each participant was then programmed into the Smart Weigh SW-SBS500 Digital Body Fat Scale to allow automatic calculation of BMI, and participants were instructed to stand on the scale barefoot until both weight in lbs, to the nearest 0.1 lbs, % body fat and BMI were recorded.

4.2.3.3 Materials

The framework of questions devised followed the 5-question framework outlined by Kruegar & Casey (2015). This framework is a series of open-ended questions; (1) opening question, (2) introductory question, (3) transition questions, (4) a set of key questions, and (5) conclusion questions. The 5-question framework creates a logically sequenced series of open-ended questions where the beginning questions are more general, then subsequent questions become more focussed to elicit more specific information. Table 4.1 details the questions devised by two researchers who acted as facilitator and assistant facilitator for both focus groups. Since the proposed weight loss intervention was intended to operate as the “Action” phase of the Transtheoretical Model (TTM), the Introduction and Transition questions were designed to try to establish what stage of change each participant may currently be operating at, and the influence this may have on individual results: (1) Pre-contemplation, (2) Contemplation, (3) Action, (4) Maintenance, or (5) Process Complete / Relapse

(Marks et al., 2018). This may provide insight into the influences affecting attitudes and opinions provided by participants during the Key questions. Additionally, these questions were designed to establish whether participants understood the need to eat healthy foods and exercise in order to lose weight. The Key questions were aimed at eliciting whether participants could identify factors present in their own lives that aided or hampered healthy choices. These questions were influenced by current research with the adult ID population which examines levels of autonomy, opportunity and ability to eat healthy diets and exercise (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005; Kuijken et al., 2016). Information relating to current knowledge and habits was also sought.

Table 4.1: *Question structure for Focus Groups*

Question Type	Details
Opening	Can you tell us your name and something about yourself?
Introduction	Can you tell us about your experiences of managing your weight, so it does not get too big or too high?
Transition	How long have you been aware that you need to lose weight?
Key 1 *	How do you plan and make your meals? (supporting visuals used)
Key 2	Do you do your own shopping or does someone help you?
Key 3 *	What foods do you like or dislike? (supporting visuals used)
Key 4 *	How do you fill your free time in the evenings and at weekends?
Key 5 *	What kinds of exercise do you do each week? (supporting visuals used)
Key 6	What activities do you not like doing? (supporting visuals used)
Conclusion	Summary of topics discussed. “Of all the things we have talked about which ones are really important?” Is there anything else about health or losing weight that you want to talk about?”

**Self-report data sheets were used to enhance the information relating to autonomy in food choice and preparation, dietary preferences, and exercise engagement and preferences.*

Self-report data sheets: Participants were given the first data sheet (see Appendix B) after the discussion for question Key 1, shown in Table 4.1 above. The lead facilitator read the first question and participants were instructed to choose as many options as they felt were relevant to their own situations by circling each picture. The second question was then read by the lead facilitator when all participants had completed the first question. The same procedure was then followed for the final question on this

data sheet. The second data sheet (see Appendix C) was given to participants after the discussion for question Key 3, shown in Table 4.1 above. Participants were instructed to place a tick beside foods they liked and a cross beside foods they disliked. The assistant facilitator checked full completion of each participants' data sheet on collection and approached individuals to complete answers that were missing. Appendix D shows the final data sheet given to participants after the discussion for question Key 5, shown in Table 4.1 above. Participants were asked to place a tick beside any exercise type they engaged in regularly (weekly or fortnightly as a minimum).

4.2.3.4 Consent and Ethical Approval

The study was approved by a University Ethics Committee and was conducted in full accordance with World Medical Association Declaration of Helsinki, (2002). Particular attention was given to issues of informed, voluntary consent, and ability to give consent was corroborated by a caregiver who knew them well. At the beginning of each focus group the researchers conversed with participants about confidentiality and respecting other's opinions. Participants were assured, and all agreed, that whatever was spoken about during the focus groups was to remain confidential within the group. Boundaries were also set in relation to taking turns to speak and letting everyone express their own opinions even if they differ to ours.

4.2.3.5 Data Analysis

Transcripts of the audio-recordings were produced and subsequently coded using Theoretical Thematic Analysis as described by Braun & Clarke (2006). Each line of the transcript was assessed to determine its relevance to each of the domains of interest (1) Facilitators, (2) Barriers, (3) Knowledge Base and (4) Current Habits. Only quotes that were relevant to the four domains were included and developed into themes under each domain. Once the initial coding was complete a second researcher who co-facilitated the focus groups reviewed the themes and sub-themes devised. Queries in the coding were discussed between the two researchers and agreement reached in all cases. Common themes were developed from the transcripts with respect to the four domains of interest: (1) Facilitators, (2) Barriers, (3) Knowledge Base and (4) Current

Habits. The themes for each group were then compared to highlight possible differences between adults with ID that achieve and maintain weight loss, against adults with ID that are overweight.

Self-report checklists completed during the focus groups were analysed to determine any possible differences between groups in relation to autonomy in food choice, dietary preferences, and exercise engagement. During the completion of the checklist, both researchers interacted with participants individually querying their choices to determine whether the answers reflected comprehension of the question being asked. For example, if a participant had answered that they regularly played GAA football on the exercise checklist (Appendix D), but when questioned it transpired that they spectate at games rather than train with a team each week, this would indicate a lack of comprehension of the question. Additionally, the researchers evaluated the answers given on checklists with respect to the information each participant provided during the free-flowing discussion. For example, if participants ticked only healthy foods on the food preference checklist (Appendix C) but had spoken about eating treats during the conversation, this would indicate that they had not approached the questionnaire honestly. A discussion was held between the two researchers immediately after each focus group and each checklist for each participant was discussed with respect to comprehension and honesty. Participants that were considered to have comprehended what the task entailed and have approached the questionnaire honestly were rated as “high” reliability. Only participants with “high” ratings were included in the analysis, which amounted to approximately 75% of the data for Group A and 72% of the data for Group B.

4.3 Results

4.3.1 Participant Baseline Demographics

As is shown in Table 4.2, the groups were similar except for differences in their living arrangements and BMI scores prior to the study. Independent samples t-tests were conducted to compare age, gender, living arrangements and BMI between groups. There were no significant differences found between groups for age, gender or living arrangements, however, as was expected there was a significant difference in BMI ($t(10) = 4.171$, $p = .002$) with Group A (mean = 37.1, SD = 4.36) having a higher mean BMI than Group B (mean = 27.4, SD = 3.65). The magnitude of the differences in the means (mean difference = 9.70, 95% CI: 4.51 – 14.86) was small (Cohen's $d = .41$).

Table 4.2: Participant Demographics by Group

Demographic	Group A	Group B
Number of Participants:	6	6
Males	2	2
Females	4	4
Mean Age	49	45
Age Range	38-59	25-73
Number of Participants in each Living Situation:		
With family	3	5
Supported Accommodation	1	1
Own Home	2	0
Number of Participants in each BMI Category:		
Normal Weight (18-24.9kg/m ²)	0	2
Overweight (25-29.9kg/m ²)	0	3
Obese 1 (30-34.9kg/m ²)	2	1
Obese 2 (35-39.9kg/m ²)	3	0
Obese 3 (>40kg/m ²)	1	0

4.3.2 Themes and Sub-Themes Developed

Participants interacted well with each other in both groups and all participants contributed to the overall conversation. A variety of themes emerged under each of the 4 domains of interest, all of which are shown in Figure 4.1 below.

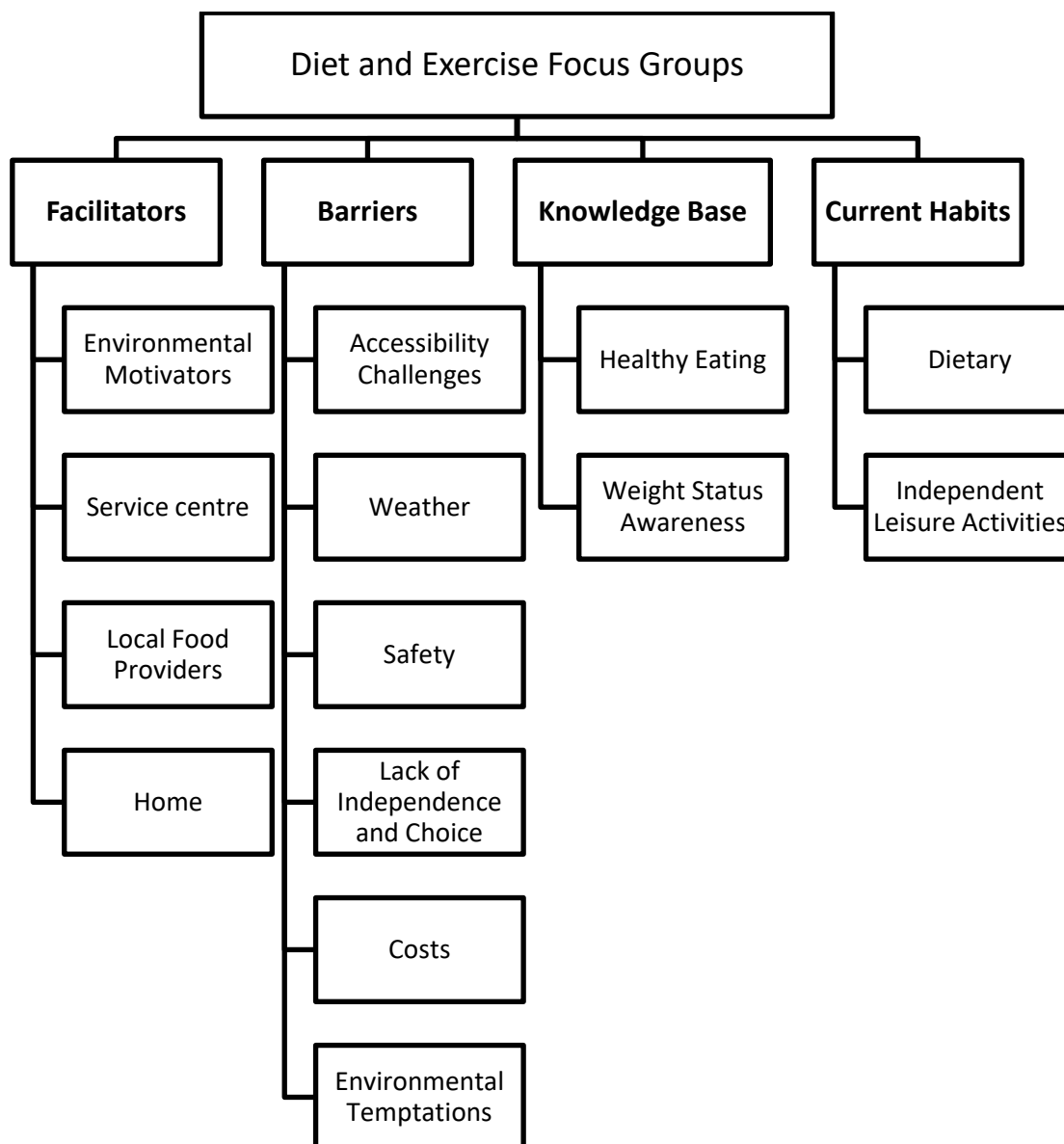


Figure 4.1: Thematic map of themes developed under each domain of interest

Facilitator themes consisted of people, places or events that participants identified as aiding them to engage in healthy eating or exercise. Four main *Facilitator* themes emerged from the theoretical thematic analysis: (i) Environmental Motivators, (ii) Service centre, (iii) Local Food Providers, and (iv) Home. *Barrier* themes related to comments made about any aspect of their lives that prevented them from engaging in healthy eating or exercise. Six themes emerged under this domain: (i) Accessibility Challenges, (ii) Weather, (iii) Safety, (iv) Lack of Independence and Choice, (v) Costs, and (vi) Environmental Temptations. Demonstrations of knowledge relating to weight, health, foods or exercise by participants were captured under the domain of *Knowledge Base* and only 2 themes emerged under this domain: (i) Healthy Eating, and (ii) Weight Status Awareness. Likewise, only 2 themes; (i) Dietary and (ii) Independent Leisure Activities, were present for *Current Habits* which included any reference made to current eating or exercising habits. The total number of quotations coded from each focus group were 85 for Group A and 101 for Group B, with the number of quotations used to develop each of the themes for each of the groups detailed in Table 3.3.

Table 4.3: Number of quotes used to generate each theme by group

Domain	Theme	Group A	Group B
Facilitators	Environmental Motivators	4	23
	Service centre	3	16
	Local Food Providers	0	3
	Home	2	2
	TOTAL	9	44
Barriers	Accessibility Challenges	0	5
	Weather	5	2
	Safety	2	4
	Lack of Independence & Choice	5	2
	Costs	3	3
	Environmental Temptations	3	2
	TOTAL	18	18
Knowledge Base	Healthy Eating	3	11
	Weight Status Awareness	5	4
	TOTAL	8	15
Current Habits	Dietary	26	6
	Independent Leisure Activities	24	18
	TOTAL	50	24
TOTAL NUMBER OF QUOTATIONS		85	101

A comparison between the theoretical thematic analyses of the two groups identified similarities and differences in these themes for each domain.

4.3.3 Facilitators

Table 4.4 details the emergent themes and sub-themes for each group with respect to factors that facilitate healthy lifestyle choices.

Table 4.4: *Facilitator Themes and Sub-Themes by Group*

Domain: Facilitators			
Themes	Sub-Themes	Group A	Group B
Environmental	External Reinforcement Programmes		✓
Motivators	Positive Feedback		✓
	Mental Health & Well-Being	✓	✓
	Positive Influence of Role Models	✓	✓
	Awareness of Overweight Status	✓	✓
Service Centre	Facilitating Exercise Engagement	✓	✓
	Facilitating Healthy Eating		✓
	Health Promotion Messages		✓
Local Food Providers	Solutions for Healthy Eating		✓
Home	Facilitating Exercise Engagement	✓	✓

4.3.3.1 Environmental Motivators

Both groups emphasised the benefits of exercise on *mental health and well-being* in their own lives. The *positive influence of role models* with regards to eating habits and physical appearance, and an *awareness of their overweight status* were also noted as powerful motivators towards a healthier lifestyle for both groups.

Group A: PARTICIPANT 1.1 And you are better for it when you walk, you're not as tired. You get more energy and you can do more things.

Group A: PARTICIPANT 1.0 If you see someone healthy eating and you'd have to do it too.

- Group A: PARTICIPANT 1.0 Every time I eat I get bigger and I have to go for walks.
- Group B: PARTICIPANT 2.0 I walk, if I don't I get annoyed. Otherwise I'd be anxious, so I go for my walk.
- Group B: PARTICIPANT 2.4 Well what was happening to me going out to buy clothes and see somebody there in a smaller size.
- Group B: PARTICIPANT 2.5 I said that when you go to try on your clothes [and they don't fit] and then I had to do something about it.

Two further motivating sub-themes that emerged solely for Group B were: engagement in *external reinforcement programmes* run by the Service centre, and the presence of *positive feedback* from others with respect to weight lost. Group contingency initiatives run by the service centre that concentrated on providing reinforcement for engaging in healthy eating or exercise were referred to many times during Group B's conversation. The availability and conditions of reinforcement were the same for participants in both groups, however, for Group A participants' things like tickets and medals did not function as reinforcers whereas for Group B they did. Additionally, the reaction and positive feedback of others in relation to weight lost was stated as an influential motivator to maintain lifestyle changes by Group B.

- Group B: PARTICIPANT 2.4 Em it was the year 2013 and we started to work for a gold medal.

- Group B: PARTICIPANT 2.4 If we go out walking, we have these tickets and we get one. If we go out walking, relaxation, eat fruit and veg, and what's the other one?
- Group B: PARTICIPANT 2.1 And now people are saying to me I'm losing weight and I'm so happy about that.
- Group B: PARTICIPANT 2.2 And when mam started saying "[name] *you are losing weight*", wow.

4.3.3.2 Service Centre

Exercising opportunities provided by the service centre were spoken about by both Groups, with Group B providing more volume of discussion (see Table 4.3) and more variety about the exercises available that they take part in. Both groups are provided with the same opportunities for exercising, however, Group B availed of these opportunities more than Group A and therefore added more to the discussion for this. A specific exercise group existed for over 50s, however, both groups had 3 participants who satisfied this criterion, so the opportunity to engage with this would have been the same for both groups.

- Group A: PARTICIPANT 1.1 We do exercise in the centre. I walked around [park name] yesterday, we do that twice a week, and we do exercise here as well as in the aging opportunity room.
- Group B: PARTICIPANT 2.3 I love doing the walking program twice a week.

Group B: PARTICIPANT 2.5 We do circuits here every morning.

Group B: PARTICIPANT 2.1 Dancing we do it.

The service centre was also credited by Group B for *facilitating healthy eating* by providing healthy meal alternatives for anyone wishing to avail of them. Health risks associated with overweight were highlighted in *health promotion messages* by the service centre manager and served as a motivator to exercise for Group B.

Group B: PARTICIPANT 2.5 [the dinners that get delivered to the centre] they are beautiful dinners. They are healthy.

Group B: PARTICIPANT 2.1 [Centre manager] said that we weren't getting healthy. [She said] you's will get heart attacks and stroke and everybody has thought about that and I think it's the walking and the running that. I think the staff should get praise for that.

4.3.3.3 Local Food Providers

Group B were the only group that provided possible *solutions for healthy eating* by stating local healthy food providers that were not too expensive.

Group B: PARTICIPANT 2.2 If you buy it [healthy food] in Aldi it's less than the price it is in Tesco, Dunnes Stores or Supervalu.

Group B: PARTICIPANT 2.1 If you went to the college you could get healthy options, better value.

Group B: PARTICIPANT 2.1 If you watched Operation Transformation, Tesco have done a lot for it and they have a lot of healthy options in there.

4.3.3.4 Home

Group A noted that the presence of pet dogs *facilitated exercise* in the form of walking in the evenings and at weekends, and Group B reported that family members encouraged exercise outside of service centre hours.

Group A: PARTICIPANT 1.5 I have a dog and I walk him every day.

Group B: PARTICIPANT 2.4 Exercise bike, I do it with my sister.

4.3.4 Barriers

Table 4.5 details the emergent themes and sub-themes for each group with respect to barriers towards healthy lifestyle choices.

Table 4.5: *Barrier Themes and Sub-Themes by Group*

Domain: Barriers			
Themes	Sub-Themes	Group A	Group B
Accessibility Challenges	Accessing community exercise facilities		√
Weather	Poor weather conditions	√	√
Safety	Road safety	√	√
	Personal safety	√	√
Lack of Independence & Choice	Independent opportunities	√	√
Environmental Temptations	Difficulty in avoiding temptations	√	√
Cost	Expense of healthy food	√	√
	Expense of community exercise facilities		√

4.3.4.1 Accessibility Challenges

Group B were the only group to discuss the accessibility challenges involved in using *community exercise facilities*. The physical act of getting to the facility posed numerous difficulties such as the distance of travel to the facility, the terrain around the facility, a lack of transport to the facility, and the cost of transport to the facility if needed.

Group B: PARTICIPANT 2.1	I don't like hills, walking on hills. [it is hard to get to the bowling] there are steps there and they can be steep and that.
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Group B: PARTICIPANT 2.1	I can't nearly walk right and the gym, I know my friend could walk up to it but I can't and it's €5 for a taxi up.
--------------------------	--

4.3.4.2 Weather & Safety

All participants agreed that *poor weather conditions*, *road safety* concerns, and *personal safety* concerns were barriers to exercising as they reduced both their motivation and ability to exercise independently.

Group A: PARTICIPANT 1.0	The weather puts you down, you can't do much in the snow. You can't go out in it.
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Group A: PARTICIPANT 1.1	You can't go out when it's raining.
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Group B: PARTICIPANT 2.2	Did you ever notice when it's raining and the walk isn't on, everybody is disappointed.
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Group B: PARTICIPANT 2.5	[you don't feel like going out walking] if it's winter and it's cold.
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4.3.4.3 Lack of Independence and Choice

Most participants in both groups lived at home with family members. For these participants family-based shopping and cooking were raised as barriers to healthy eating as participants often felt they *lacked independence and choice* around the foods purchased and essentially then the foods they ate.

Group A: PARTICIPANT 1.2	Your mother [decides on the food when you live with your family].
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Group B: PARTICIPANT 2.2	My mam does the shopping sometimes but if there is anything I need like, or if I'm in the house on my own I would see how much money I have and I'd go down the town and get what I need.
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4.3.4.4 Cost

Since healthy foods were thought of as more expensive by both groups, justifying the added expense was difficult, therefore, *cost of healthy food* became a noted barrier by both groups. Group B also noted the expense involved in community exercise facilities.

Group B: PARTICIPANT 1.3	Healthy food is dearer.
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Group B: PARTICIPANT 2.4	Cost [of healthy food is very important].
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Group B: PARTICIPANT 2.2	[It would be easier to exercise if] there is somewhere you can go that is free and you don't need to pay.
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4.3.4.5 Environmental Temptations

When faced with independent food choices in the community, both groups admitted to *struggling to avoid temptations* in cafes or shops.

Group A: PARTICIPANT 1.1 Or you go in to get tea [in a café] that's the hard time. Will I have something with that tea or will I have tea on its own?

Group B: PARTICIPANT 2.2 When the coffee shop used to be open over there, there was only, well there was healthy options like salad but in the other, over in the hot there was just temptation. Do I go to this or do I go to that? What do I do?

4.3.5 Knowledge Base

Table 4.6 details the emergent themes and sub-themes for each group with respect to knowledge base around health.

Table 4.6: *Knowledge Base Themes and Sub-Themes by Group*

Domain: Knowledge Base			
Themes	Sub-Themes	Group A	Group B
Healthy Eating	Types of healthy foods	√	√
	Types of unhealthy foods	√	√
	Portion size		√
Weight Status	Awareness of being overweight	√	√
	Association between overweight and reduced health		√

4.3.5.1 Healthy Eating

Both groups demonstrated knowledge in relation to commonly known *healthy and unhealthy foods*, but Group B were the only group to mention the importance of *small portions* for healthy eating habits.

Group A: PARTICIPANT 1.3	Because the chocolate would be all fattening and the apples would have nutrition or whatever you call it.
Group A: PARTICIPANT 1.1	Drink plenty of water.
Group A: PARTICIPANT 1.3	And eat lots of fruit.
Group B: PARTICIPANT 2.5	I think I was eating too much sweets that was why.
Group B: PARTICIPANT 2.3	Fruit I suppose. Healthy breads like wholegrain breads and stuff like that.
Group B: PARTICIPANT 2.1	And as I said before the lighter, like if you are buying a packet of crisps, don't buy the cheese and onion, buy the light crisps.
Group B: PARTICIPANT 2.2	Small portions.

4.3.5.2 Weight Status

Overweight participants in both groups *acknowledged that they were overweight* and made references to the past when they hadn't been overweight. Some participants also provided possible reasons for becoming overweight.

Group A: PARTICIPANT 1.1 I was always thin when I was growing up, until lately. Until I started to eat sweet things until they come out of my eyes. And I put on weight.

Group A: PARTICIPANT 1.3 I used to be very thin at one time, I was like a rake, but I went out like a bush. I said enough is enough I'm going to try to get back to where I was.

Group B: PARTICIPANT 2.5 Coming up to my cholesterol test I discovered I was a diabetic. I have to watch what I eat. [The dietician] she put me on a diet.

Group B: PARTICIPANT 2.2 When I was living in [place name] I used to come out from school and go in to McDonalds nearly every day of the week. That's when I started to get bigger.

The link between being *overweight and reduced health outcomes* was only referred to during Group B's discussion.

Group B: PARTICIPANT 2.2 [when I started putting on weight] I would be all out of breath whenever I walked up the steps or run really fast.

4.3.6 Current Habits

Table 4.7 details the emergent themes and sub-themes for each group with respect to current eating and leisure habits engaged in.

Table 4.7: *Current Habits Themes and Sub-Themes by Group*

Domain: Current Habits			
Themes	Sub-Themes	Group A	Group B
Dietary Habits	Healthy habits	√	√
	Unhealthy habits	√	√
Leisure Time	Physical activities	√	√
	Sedentary activities	√	√

4.3.6.1 Dietary Habits

Both groups spoke about *healthy eating habits* by claiming to drink more water, eat more fruit and vegetables and eat smaller amounts of food. Group B discussed these as general topics and Group A provided detail about actual changes that they have made to support healthier eating habits. Participants from both groups confessed to consuming the occasional treat when they visit coffee shops as *unhealthy eating habits*.

Group A: PARTICIPANT 1.3	I drank 6 beakers of water yesterday to get my weight off.
Group A: PARTICIPANT 1.1	I go for the healthy food.
Group A: PARTICIPANT 1.4	I don't eat too much at home either. I eat my dinner here every day and that does me.
Group A: PARTICIPANT 1.3	I cut out the cheese, that's fattening.

- Group A: PARTICIPANT 1.4 I treat myself every Friday, once a week to a small cup of cappuccino coffee in the [café name].
- Group B: PARTICIPANT 2.5 I'm very fond of a lot of fruit, and I buy a lot of fruit.
- Group B: PARTICIPANT 2.2 I don't eat when I go home, only sometimes I eat when I go home.....I have dinner.
- Group B: PARTICIPANT 2.4 [in the coffee shop I] normally [have] a treat.

Numerous additional *unhealthy eating habits* were stated by Group A. Discussions relating to regularly eating treats, drinking fizzy drinks and alcohol, and consuming take-away foods occurred with great frequency throughout Group A's conversation. These habits were not referred to in Group B's conversation.

- Group A: PARTICIPANT 1.3 I might have a biscuit after [dinner] every night.
- Group A: PARTICIPANT 1.0 I only have coke [at the weekends].
- Group A: PARTICIPANT 1.2 I do [have a drink when I am out], I do, I do. I'd have three, aye, that's the whole.
- Group A: PARTICIPANT 1.3 I'll tell you the truth on a Wednesday I do [go to the chipper].

- Group A: PARTICIPANT 1.3 I went to a band last Friday night and I had too much juice, Guinness. The following morning I had a hangover. I felt the bad of it the following morning. I lost count [of how many drinks I had], I lost count! Yeah, and I got a free one from someone and I said thanks. I should have said no, I should have left it where it was, I'd be better off.
- Group A: PARTICIPANT 1.3 My brother gets Chinese on a Saturday, I love Chinese yeah, he gets Chinese for the two of us and we share.

4.3.6.2 Leisure Time

Independent leisure time activities were similar for both groups with walking being the main form of *physical activity* and watching TV being the main *sedentary activity* for both groups. Both groups also helped with household chores which provided another form of *physical activity*.

- Group A: PARTICIPANT 1.4 I go for walks.
- Group A: PARTICIPANT 1.2 Run the park yesterday. Running for exercise. Go for a walk.
- Group A: PARTICIPANT 1.1 Watch television, sitting down.
- Group B: PARTICIPANT 2.5 I walk at home and I walk here as well.
- Group B: PARTICIPANT 2.1 I'd sometimes go for a walk.

Group B: PARTICIPANT 2.2	I am either watching TV or listening to my headphones, or if my room becomes a little bit messy I am always tidying it up.
Group A: PARTICIPANT 1.5	I just clean my house, water my flowers then.

4.3.7 Data Sheet Analysis

The three data sheets given to participants during the focus group discussion allowed additional information to be gathered in relation to differences in independence and preferences around foods, and exercise habits.

4.3.7.1 Data Sheet 1

The first data sheet (see Appendix B) gleaned information about autonomy in planning and making meals, and what is important in relation to food choices. Categories were combined to reflect levels of autonomy with “on my own” rated as “independently”, “with my family” or “with staff” combined to make “with support”, and “in a group” or “I don’t” combined to make “no choice”.

Group A had 3 (50%) participants and Group B had 4 (67%) participants rated as “high” reliability for data sheet 1. In both the planning and making of meals (see Figures 4.2 and 4.3) Group B reported less autonomy and more dependence on family, however, all members included in the analysis from Group B lived at home whereas only 1 member from the Group A analysis lived at home. With respect to factors that are important in meals (see Figure 4.4) the main difference between groups was that Group B identified *healthy* as important in food choices whereas Group A didn’t, and Group B seemed unconcerned with meals *making them full* which Group A identified as important to them.

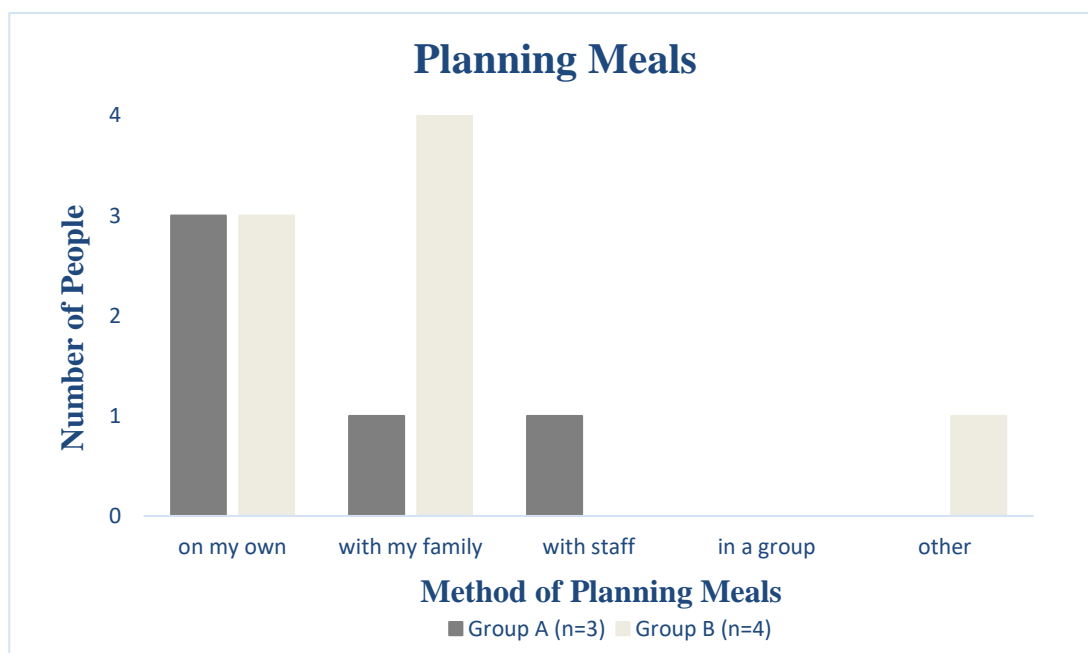


Figure 4.2: *The method and support for how meals were planned.*

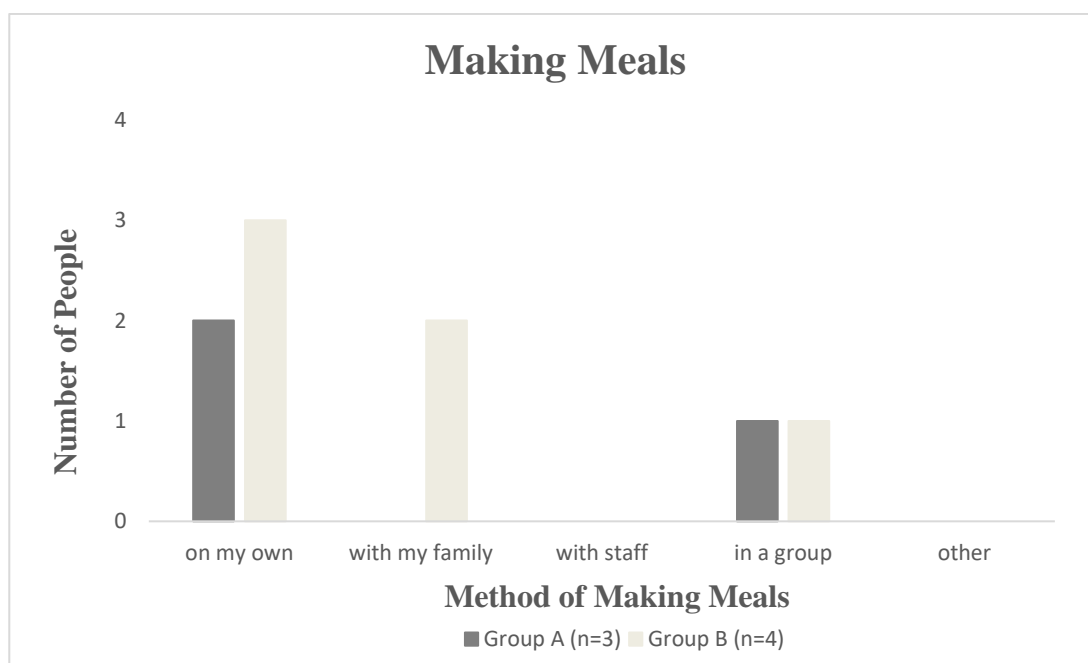


Figure 4.3: *The method and support for how meals were made*

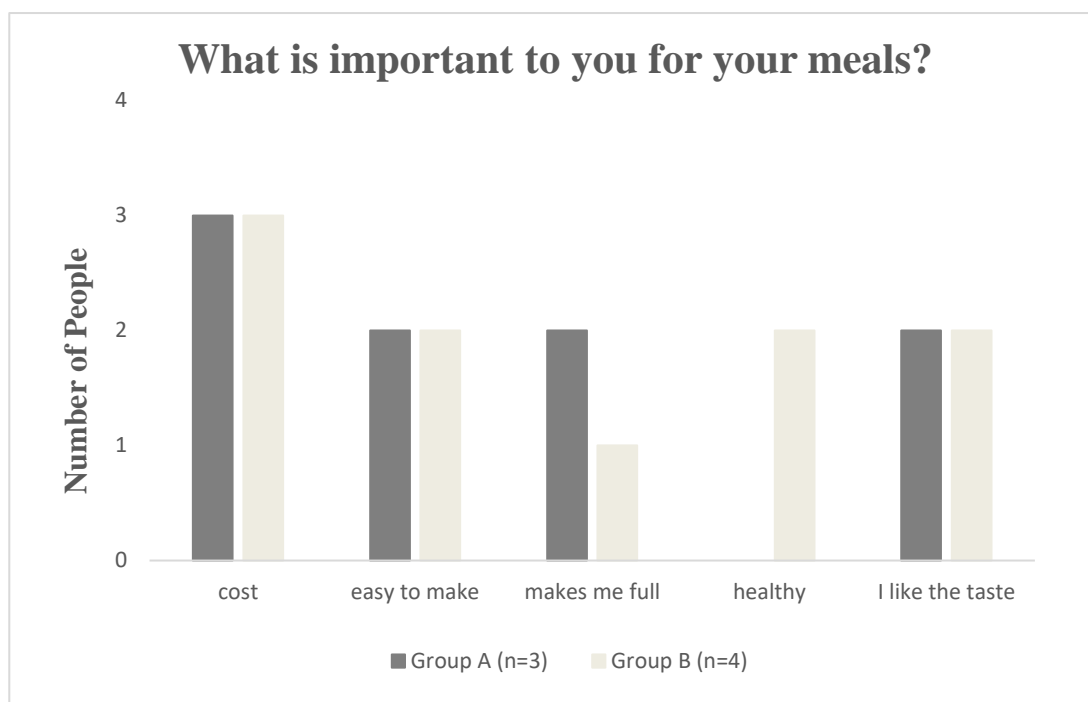


Figure 4.4: Factors that hold importance for meals.

4.3.7.2 Data Sheet 2

The second data sheet provided an insight into differences in preferences towards types of foods, based on their categorisation of GREEN (*healthy foods*), YELLOW (*healthy foods providing quantities are controlled*) or RED (*unhealthy foods*) as per State of Victoria (2015) guidelines and the input of a qualified dietician. Both the data sheet and the food categorisation list can be found in Appendix C.

Mean % preferences were high for both groups for all three food categories, with RED foods rated highest for Group A, 94% (SD=10.8, range 72% to 100%) and YELLOW foods rated highest for Group B, 79% (SD=13.1, range 65% to 90%), as shown in Figure 4.5 below. The number of people stating a preference of greater than 70% for a particular food category was also highest for the red foods for Group A (n=6, 100%), and highest in both yellow and red foods for Group B (n=3, 75% for both), as is shown in Table 4.8 below.

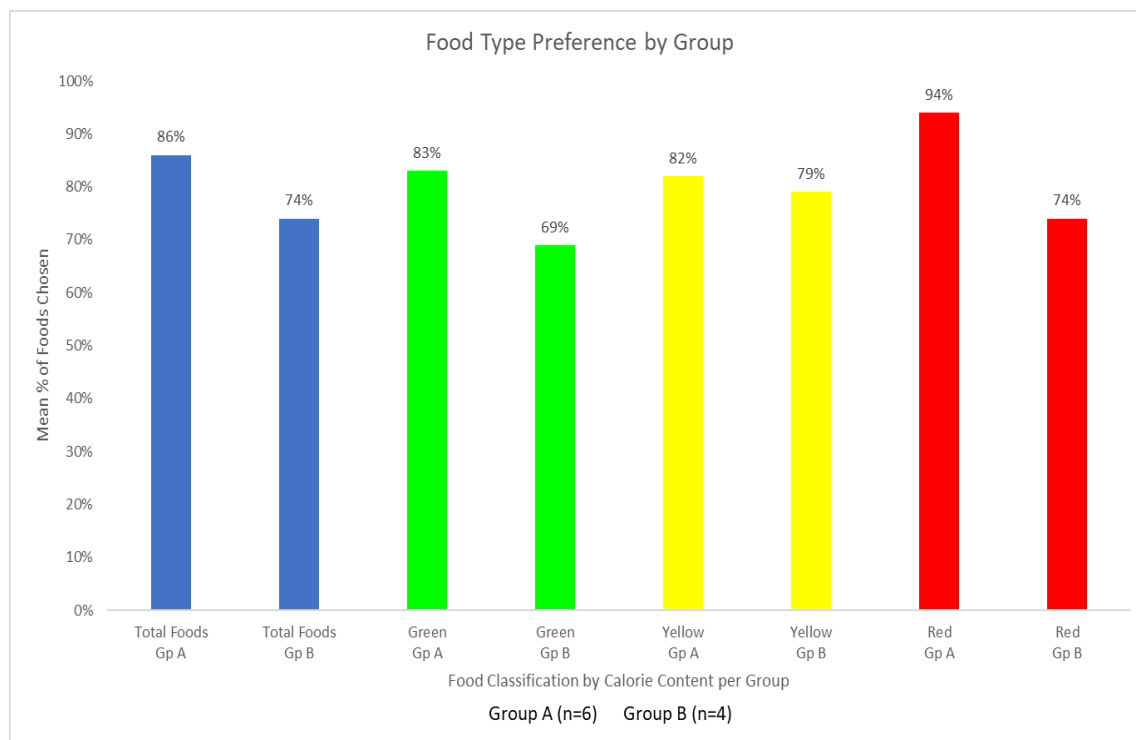


Figure 4.5: Mean number of foods preferred split by group and by food category

Table 4.8: Percentage Preferences by Food Category for “High” Rated Participants

Group	No of “high” Participants	Mean % Preference			No of People >70% Preference		
		Green	Yellow	Red	Green	Yellow	Red
Group A	6	83%	82%	94%	5	4	6
Group B	4	69%	79%	74%	2	3	3

4.3.7.2 Data Sheet 3

Figure 4.6 shows that *walking* was the most common form of exercise for both groups, with *running*, *bowling* and *dancing* also cited as common activities between Groups. Most activities identified were facilitated by the Service centre or organised through Special Olympics. Self-inclusion in community exercise programs or venues did not appear to be present for any participants regardless of group.

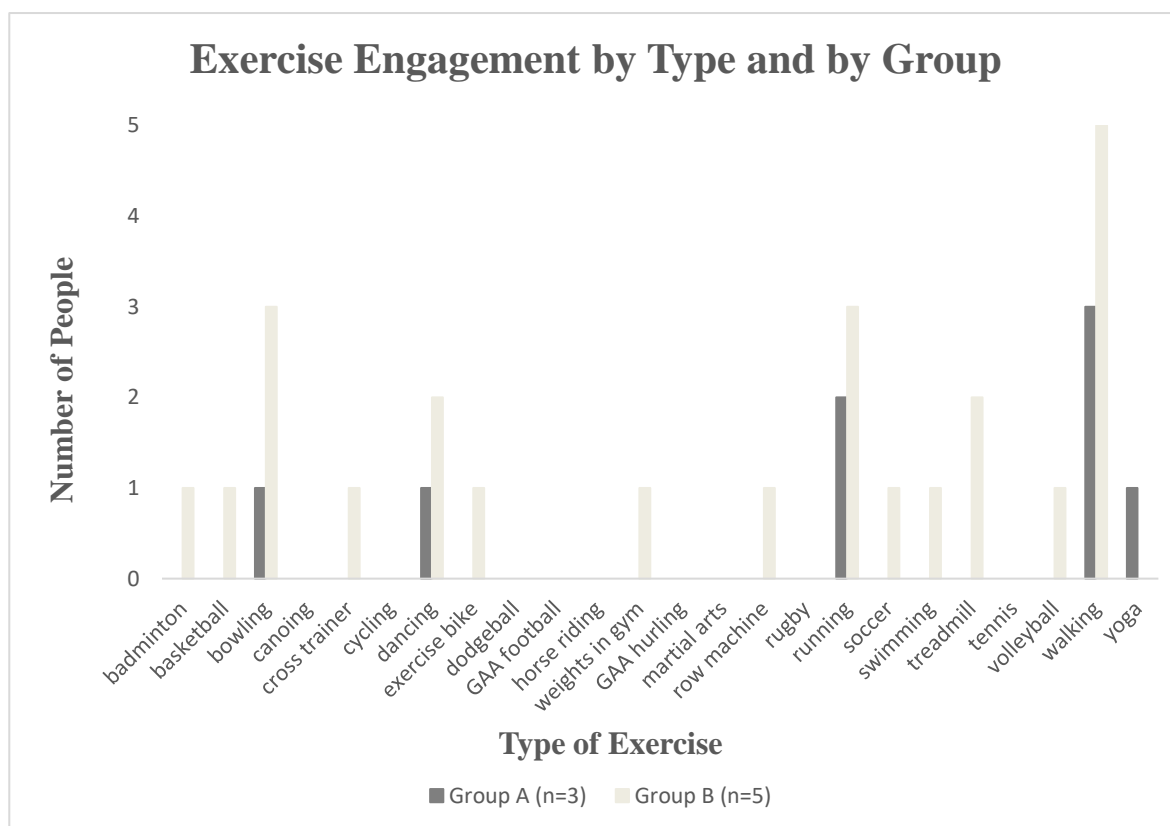


Figure 4.6: Number of people who engage in each type of exercise on a regular basis, by group

4.4 Discussion

The comparison of sub-themes between groups showed numerous similarities while also highlighting some important differences. Similar themes emerged for both groups under all four domains, however, knowledge of healthy options, increased practices of healthy behaviours, and higher levels of motivation towards weight loss differed, with Group B demonstrating wider awareness of these factors.

4.4.1 Facilitators

All the overweight adults in this study were aware of being overweight and quoted their weight status as a motivator to lose weight. However, weight status was spoken of in terms of actual weight (stones and lbs) with no comprehension of how this relates

to a healthy weight or to BMI category. Without the ability to compare actual weight to a specific target it was impossible for participants to understand the amount of weight they needed to lose to satisfy healthy weight criteria of a BMI < 25 kg/m². In fact, many of the studies available suggest that self-perceptions of weight status are distorted in adults with ID, with a tendency more towards underestimation, particularly in females (Eden & Randle-Phillips, 2017; Ayaso-Maneiro et al., 2014). Whilst holding a more positive perception of your weight may have advantages for self-esteem, it may reduce the motivating drive required to achieve and sustain weight loss. Body dissatisfaction is well documented in the literature as a driver for weight loss (Stice & Shaw, 2002; Johnson & Wardle, 2005), but since the prevalence of overweight and obesity is so high in both the general and ID populations (World Health Organisation, 2019) it is unlikely that weight status alone provides enough influence for sustained weight loss.

Perceptions of others, however, may influence weight loss since both groups were motivated to lose weight after observing the behaviour of others around them, a phenomenon well-known in behavioural literature as *Social Observational Learning* (Chance, 2014). If someone else's behaviour results in positive consequences whilst you are observing them then you are more likely to imitate their behaviour, often referred to as *vicarious reinforcement* (Cooper, Heron & Heward, 2014). Whether increased motivation in Groups A and B was as a result of observing someone's example of healthy eating or by observing someone fitting on an outfit in a small size and looking great is unimportant. What we can't underestimate is the importance of providing role models in the environments of adults with ID, who engage in healthy eating and exercise with the resulting effects of looking and feeling good.

Alongside positive role models, opportunities for health-related behaviours must be readily available. Both home and service centres were noted by the two groups as providing opportunities that aid exercise engagement, which is consistent with recognised facilitators found in the existing literature (Mahy et al., 2010; Temple & Walkey, 2007). In addition to the benefits for weight loss, exercise has long been established as beneficial to mental health and well-being with both the general and ID

populations (Callaghan, 2004; Jones et al., 2007), and these benefits were also echoed by both groups as motivating for exercise. However, providing opportunities does not assume engagement. The first glaring difference between the two groups occurs when analysing the volume of quotes in Table 4.3, the detail of quotes, and Figure 4.6. Group B discusses a much larger volume and variety of exercise that they regularly engage in when compared to Group A. To facilitate increased uptake of exercise for adults with ID that do not partake, it is important to explore further how to support families and service centres in enhancing the exercise opportunities available and tailoring these to service users' needs and interests.

Another glaring difference between the two groups is the larger volume of environmental motivators that facilitate healthier lifestyles for Group B (see Table 4.3). Two unique examples of environmental motivators provided by Group B were “external reinforcement programmes” and “positive feedback”. At the heart of both is *Positive Reinforcement*, a proven behavioural technique used to affect behaviour change (Leslie & O'Reilly, 2003; Cooper et al., 2014). Group B emphasised these influences on motivating them to lose weight and maintain weight loss. In contrast, for Group A, it may be that unhealthy foods and sedentary lifestyles hold more reinforcing value to them than the external reinforcement programmes and positive feedback provided for more healthy choices. Positive reinforcement has been used successfully in many weight loss interventions with the ID population (Fox et al., 1984; Sailer et al., 2006; Bazzano et al., 2009; Martinez-Zaragoza et al., 2016; Saunders et al., 2011). However, the incentives provided were pre-determined for the group and did not account for individual preferences and motivations, which may account for the variability in individual success. Reinforcement functions most effectively when individual preferences are considered (Cooper et al., 2014), therefore, promoting the implementation of individualised reinforcement options that can compete with unhealthy lifestyle choices is something that should be explored for individuals prior to any weight loss intervention. The practicalities and costs of providing this level of service are, however, fraught with difficulties and rely not only on funding but on high levels of commitment from family members and staff who support the adults with ID.

Health promotion interventions are common within the literature for weight loss with adults with ID, but these have had mixed impact (Marshall et al., 2003; Mann et al., 2006; Geller & Crowley, 2009). By citing health risks associated with being overweight and discussing ways to source healthy meal alternatives Group B demonstrated internalisation of health promotion messages delivered by staff. The impact that this internalisation has had on weight loss for this group is hard to quantify, however, this internalisation may be one aspect of facilitation in the process. In a study promoting exercise engagement for middle-aged women, Lenneis and Pfister (2017) credited internalisation of government health messages, relating to the health benefits of exercise for middle-aged females, as a catalyst for exercise engagement. The onset of middle age and the associated health risks prompted the women to take part in the intervention. A similar effect is noted by McDermott (2011) and Dallaire, Lemyre, Krewski, & Gibbs (2012) in relation to health behaviours, demonstrating that knowledge of health risks associated with poor lifestyle choices can increase physical exercise and alter dietary habits. Whilst health promotion interventions are common in the weight loss literature for adults with ID (Bergström et al., 2013; Geller & Crowley, 2009; Pett et al., 2013; Marshall et al., 2003; Ewing et al., 2004; Chapman et al., 2005; Mann et al., 2006), the main outcome measure is either anthropometric changes or improvements in health behaviours. It would be useful to measure the level of internalisation of health messages for each individual and compare this measure to the weight loss achieved to evaluate individual differences and determine the effect of internalisation. At present though, we note that internalisation of health promotion messages may add value and reduce variability if included in the overall framework of a multi-component intervention for weight loss.

4.4.2 Barriers

Many of the barriers to successful weight loss quoted by both groups state difficulties such as; a lack of support from others, a lack of choice in accessing healthy foods (also verified by the information collated in Data Sheet 1), perceived high costs associated with healthy eating and exercise options, poor weather conditions, road safety, personal safety and the difficulty of avoiding temptations in the environment, most of

which have been found in other studies (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005). The main difference in barriers between the groups involved the difficulties in accessing community exercise facilities and the expense it incurs. Because very few adults with ID have their own method of transport, accessing community facilities can be challenging. It is possible that Group B has more insight into these challenges due to participants engaging in or seeking exercise opportunities from sources other than those provided by the service centre, a barrier unique to active adults with ID that was also noted by Temple (2007). This may be an important difference between groups that relates to higher levels of internal motivation for exercise and therefore increased health. Whilst both groups discussed the expense of eating healthy foods another difference arose between the groups when Group B added potential solutions to the discussion demonstrating ways to problem solve around additional expense within their own environment.

4.4.3 Knowledge Base

Kuijken et al., (2016) demonstrated that most adults with a mild/moderate ID have grasped the basic themes of healthy living. In support of this, the current study found that both groups were able to identify healthy and unhealthy foods and recognise the need to drink plenty of water. However, according to Golden & Hatcher, (1997), knowledge alone does not appear to influence successful weight loss. Of note, however, Group B were the only group to discuss the link between being overweight and reduced health. Group B were also the only group conscious of the effect of portion size on weight and as Wansink, Painter & North (2005) discovered, the act of providing larger portions leads to the consumption of more food. Portion sizes appear to be growing and exceeding recommendations both at home and in the food industry (Kairey et al., 2018; Condrasky, Ledikwe, Flood & Rolls, 2012). As larger portion sizes become the norm the quantification of *how much* should be eaten becomes more difficult for all of us and particularly so for adults with ID. Knowing that eating less aids weight loss is a step in the right direction, however, it would be interesting to see whether actual portion sizes are less for adults with ID that manage weight loss, and of how close to the recommended portion sizes they are. Portion size education would

be a useful addition to any weight loss intervention for adults with ID with the inclusion of education for those persons that support or control their meals too.

4.4.4 Current Habits

Current eating habits of participants reflected the knowledge they displayed with both groups reporting that they eat fruit and vegetables, drink lots of water, and have the occasional sweet treat when they were out. Studies that have tried to document actual food intake for adults with ID but have found this to be a challenging task, however, most report a lack of fruit and vegetables, and a non-balanced diet biased toward high energy dense foods (Melville, Hamilton, Hankey, Miller & Boyle, 2007). Both groups in this study had a mixture of control over their food choices, however, the most notable difference in current habits related to Group A participants who indicated eating treats in the evenings, regularly drinking alcohol or fizzy drinks and regularly eating take away foods. Both groups reported high preferences for unhealthy foods, as seen in Figure 4.5, however, Group A was 20% higher and Group B did not report these preferences as habits during the discussion.

With respect to leisure habits both groups spoke about engaging in similar types of physical (walking) and sedentary (watching TV) activities, akin to those also reported in the literature (Finlayson et al., 2009; Frey et al., 2005). It is possible that Group B may engage in more exercise as a leisure activity since they appear more motivated, however, without an actual measure this is not possible to ascertain. Whilst some differences were noted between the groups with respect to leisure activities these were not dramatically different.

4.4.5 Limitations

This study involved a small convenience sample of participants which limits generalisation of the results however, the main findings of the study warrant future exploration on a larger scale. Since both groups were recruited from the same service centre, were provided with the same opportunities for healthier choices within the service centre, and since the service centre's culture was one of increasing healthier behaviours for all Service Users, the ability to directly compare two groups based on

those that engage with healthier practices and those that don't was a strength of this study. The recruitment of Group B participants was based on subjective weight losses identified by the Service Manager which lacks rigour however, since significant weight loss is difficult to achieve for this population gaining insight into the perspectives of those who have achieved noticeable weight loss is still worthy of examining. Since this sample involved adults with a mild or moderate ID, the results may not be applicable to those with a severe or profound ID. However, since adults with a mild or moderate ID are seen to be the most at-risk for obesity, pinpointing factors that aid weight loss for this population is paramount. Lastly, the findings reported in this study are qualitative and self-reported and are not objectively validated. That said, the findings provide useful recommendations for both families and service centres and can be viewed as a helpful beginning to more research where comparisons between the knowledge, motivation and habits of normal weight and overweight adults with ID can be explored further.

4.4.6 Conclusion

To conclude, the two groups encountered many similar experiences across the four domains which is in line with findings from other research in the area (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005; Kuijken et al., 2016; Mahy et al., 2010). However, the findings of this study identify key differences between groups that may strongly influence weight loss, and which have the potential to increase the number of people achieving successful weight loss by reducing the variability across participants. These differences were; internalisation of *health promotion messages* which make the link between overweight and reduced health, motivated by effective *external reinforcement programmes* and *positive feedback*, and the presence of *healthier dietary habits* that lack regular consumption of treats, alcohol, fizzy drinks and take-away foods. Ensuring internalisation of health messages and increasing knowledge around the health value of food would be a worthwhile addition to any weight loss intervention. Providing suggestions of healthy substitutes or alternatives to treats, alcohol, fizzy drinks and take-away foods, whilst supporting adoption of these new habits through effective and individualised

reinforcement systems and positive feedback appears to be paramount to successful and sustainable weight loss for adults with ID.

Chapter 5

Managing Weight: What do people with an intellectual disability want from mobile technology?

5.1 Introduction

The word technology refers to the practical applications created from scientific knowledge, that are designed to manipulate environments (Buchanan, 2019; Dictionary.com, 2020). The emergence of electronic technology began in the 20th Century with the invention of the computer. Electronic technologies grew rapidly in response to increasing pressure for more efficient production to generate greater volumes to satisfy growing demands. Solutions to many of westernised society's issues have been realised through the introduction of electronic technology, and many areas of life are supported by such technologies, including the food industry, transport, communications, engineering, space exploration, the military, and health (Buchanan, 2019).

The World Health Organisation commissioned a report by the Global Observatory for eHealth (GOe) in 2015, to outline an international electronic strategy to respond to increasing global health concerns arising from aging populations and growing incidence of chronic diseases. This strategy recommended many electronic solutions to be introduced at National level for each of the World Health Organisation's 194 member states. These suggestions were collated under the umbrella of eHealth, defined as “the cost-effective and secure use of information communication technologies (ICT) in support of health and health related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research” (World Health Organisation, 2016, page 11). In addition to creating a national database for individual electronic health records, the strategy outlined the importance of supporting healthcare through teleHealth initiatives, which involve remote consultation between patients and healthcare providers, and mHealth initiatives which utilise mobile technologies to support clinicians and patients in monitoring and managing health needs (World Health Organisation, 2016). One of the main contributors increasing chronic diseases is the rise in obesity prevalence observed globally (National Institute of Diabetes and Digestive and Kidney Diseases, 2012). In Ireland and Northern Ireland, approximately 60% of adults are either overweight or obese (Safe Food Ireland, 2012), and this figure is predicted to reach

around 70% by 2030 (Divajeve, Retat, Shaw, Brown & Webber, 2014). At a societal level, the direct costs to healthcare providers caused by obesity are significant, often amounting to billions of euro (Safe Food Ireland, 2012). TeleHealth and mHealth solutions have the capacity to increase access to more cost-effective healthcare and promote self-management of lifestyle choices to prevent or reduce obesity. Many weight loss and healthy lifestyle management technologies proliferate modern society such as ‘Fitbit’ by Fitbit Inc. (2019), ‘MyFitnessPal’ by Under Armour Inc. (2020), and ‘Noom’ by Noom Inc., (2020). These take the form of mobile applications (apps) that integrate with wearable devices and are designed to promote changes in diet and activity levels while providing individualised feedback on progress and performance. Research has indicated that the use of mobile technology in the form of apps for weight loss is not a universally successful intervention, however, it can be a useful addition to weight loss interventions for certain individuals (Laing et al., 2014). The potential utility of mobile app technology for weight management is, however, of particular interest as there exists within this format the possibility of providing cost-effective, accessible support on an on-going basis (Carter, Burley, Nykjaer, Cade, 2013). In particular, investigating the potential of apps as an assistive technology to support weight management for individuals with intellectual disabilities (ID) underpins this thesis.

Reducing obesity for individuals with ID is paramount since this population is particularly at-risk from developing this disease (Melville et al., 2008; Hsieh et al., 2014). Many key organisations urge increased efforts in promoting a healthy lifestyle and weight management in people with ID to decrease incidence within this population (Carmona, Giannini, Bergmark, & Cabe, 2013), however, traditional approaches such as educational initiatives, offering walks or activities, and participation in general population programmes such as Weight Watchers™, Slimming World™ or Dietician developed menu plans, have had limited success (Spanos et al., 2013^a). Research also shows that adults with ID access primary healthcare providers less than adults from the general population (Krahn et al., 2015), and so require innovative alternatives to support healthier lifestyle habits.

To date, attempts to incorporate technology into interventions for the management of a healthy weight and lifestyle for people with ID have been limited (Ptomey et al., 2015; Neumeier et al., 2017; Pérez-Cruzado & Cuesta-Vargas, 2013), and only one appears to utilise mobile app technology (Ptomey et al., 2015). As has previously been stated mobile technology, in the form of apps delivered via smart phone or tablet, has been developed to support weight reduction amongst the general population (Crone-Todd, 2012). In effect, these apps help manage weight control interventions through the use of behavioural antecedent and consequence strategies (Carter et al., 2013), that have a proven track record in supporting behaviour change with people with an ID (Rehfeldt, Dahman, Young, Cherry & Davis, 2003). The functionality of existing off-the-shelf weight management mobile technology and apps for people with an ID is currently an unanswered question. The complexity, however, of the input modes limit functionality as their design does not take into account the cognitive impairment associated with an ID, a consideration that is essential in promoting use and functionality of technology for people with an ID (Dawe, 2006). As a result, they currently do not provide a suitable user interface to allow them to be utilised as a self-management tool within the ID population. Technology nevertheless does have the potential to broaden access to behavioural health interventions and reduce health disparity in disadvantaged populations including people with an ID (Gibbons, Fleisher, Slamon, Bass, Kandadai, & Beck, 2011), but only if cognitive complexity and access are considered in the design (Wehmeyer, 1998).

The current study aimed to determine how people with an ID interacted and used portable technology, and their opinions on a proposed mobile app design for weight management. As such the study was conducted in two parts: Part 1 involved utilising qualitative research methodology to gain insight into the lived experiences of people with ID in relation to technology use, and Part 2 involved the evaluation of a proposed design for a mobile app to be used in a multi-component weight management program for adults with ID.

Part 1 aimed to identify:

- (i) comfort levels with smartphones, tablets, and associated app technology,
- (ii) opinions on what contributes to the functionality of apps in terms of utility and ease of access,
- (iii) opinions on how technology could help with weight loss.

Part 2 aimed to identify:

- (i) potential interface and usability issues relating to a proposed mobile app design, prior to development.

5.2 Method

5.2.1 Rationale

Whilst some basic guidelines for technology interface design in ID applications can be found in the literature (W3C, 2019; Haymes, Storey, Maldonado, Post & Montgomery, 2015), one potential solution to increasing the functionality of mobile technology is to provide opportunities for people with ID to contribute to the design process. This allows designers to gain a better understanding of their needs and desires with regard to interface and usability. Indeed the “increased participation of end users in the design process can reduce frustrations in use of technologies” (Rajapakse, Brereton, Roe & Sitbon, 2014, page 522). Qualitative research utilising the theoretical underpinnings of phenomenology methodology was chosen as best fit for this study as it allows for conversation to develop freely in relation to the lived experiences of adults with ID in relation to technology (Guest et al., 2012), and provides the opportunity for people to contribute to and shape the agenda of research that is relevant to them and their needs. Focus groups were conducted to explore the experiences of people with an ID in terms of experience and challenges relating to technology use. Focus groups are discussion-based sessions focused on a particular topic or subject matter that can be delivered within naturalistic settings promoting comfort and open

discourse when facilitated by a skilled moderator (Millword, 2008). Focus groups allow participants to impart “a broader as well as a more in-depth understanding on an issue or topic” (Millword, 2008, page 279). Additionally, the interactive nature of focus groups allows for the development of organic discourse between participants. Focus groups have become a valuable tool for gathering insights and information from the ID population on a range of topics (Kaehne & O’Connell, 2010).

5.2.2 Participants

Thirty adults with ID were invited to join one of five focus groups via each of their service centre managers. Assignment to a focus group was based on geographical area and attendance at particular service centres. Interested participants were eligible to join the study if they met the following criteria: aged 18 or over, mild or moderate ID, and BMI > 25 kg/m². Participants were excluded if they showed any challenging behaviours or mental health issues that would unduly jeopardise participation in the study. Participants received an easy read demographic questionnaire one week before the focus groups began. Participants were asked to complete this questionnaire, with a support person if required, and submit it on the day of the focus group. A total of 26 (87%) of the adults invited took part in the study, the particulars of which can be found in Table 5.2 in the results section below.

5.2.3 Procedure

5.2.3.1 Setting and Structure

The five focus groups took place in a designated room within each of their service centres. Each session lasted approximately 1 hour with a 15-minute break which included healthy refreshments, provided by the researchers. The author and a second researcher attended the focus groups; one as lead moderator and the other as assistant moderator. The lead moderator was responsible for delivery of questions, introducing

any prompts, encouraging conversation between participants, and re-aligning the conversation towards the goals of the study where necessary. The assistant moderator was responsible for note taking, dispensing and collection of self-report checklists, and additional prompts where necessary. Each adult was invited to bring a support person if they wished, however, all attended independently. The discussions were audio-recorded to allow transcripts to be developed and analysed.

5.2.3.2 Anthropometric Measures

The majority of participants heights and weights had been collected by the two researchers in focus groups relating to diet and exercise that had taken place the previous day. Participants had been measured wearing a t-shirt, light trousers, and no socks or shoes. Measures were conducted by one of the researchers whilst the second researcher observed, and agreement was reached. A Stadiometer, Charder HM200P, was used to measure height in feet and inches to the nearest 0.5 inch. The height of each participant was then programmed into the Smart Weigh SW-SBS500 Digital Body Fat Scale to allow automatic calculation of BMI, and participants were instructed to stand on the scale barefoot until both weight in lbs, to the nearest 0.1 lbs, % body fat and BMI were recorded. No weight could be taken for one participant in Group 7 RDQ who was a wheelchair user, since no specific measurement equipment was available. Any participant whose body composition measures had not been taken at the diet and exercise focus groups was measured in the same way at the end of the technology focus group.

5.2.3.3 Materials

An interview protocol utilising a series of open-ended questions was developed by the two researchers. The questions were developed within the 5-question framework for focus groups (Kruegar & Casey, 2015). This framework incorporates an opening question, an introductory question, transition questions, key questions and concluding questions. Participants received visual supports for each question, where necessary. Variations of questions were pre-planned to ensure any required rephrasing of questions was in plain English and consistent with the meaning and intent of the

original question. Table 5.1 details the questions devised by the two researchers who acted as facilitator and assistant facilitator for all 5 focus groups.

Table 5.1: *Question structure for Technology Focus Groups*

Question Type	Details
Opening	We are going to talk about technology. Can you give us examples of technology?
Introduction*	What kinds of technology do you own, or have you used?
Transition	How long have you had a smartphone or tablet or computer for, and do you use it a lot?
Key 1	What kinds of things have you used technology for?
Key 2	What things make them easy or hard to use?
Key 3 *	If you wanted to use technology to lose weight could you pick the things that you would want it to do for you?
Conclusion	Summary of topics discussed. “Of all the things we have talked about, which ones are really important?” “Is there anything else about technology that you want to talk about?”

**Data sheets were used to identify the types of technology owned/used by participants, and to provide opinions on the most important uses of technology for weight loss.*

Data sheets: Participants were given Data Sheet 1 (see Appendix E) during the introduction question, see Table 5.1 above. The data sheet showed 10 types of commonly used technologies and a “?” symbol for “something else”. Participants were instructed to choose all of the types of technology that they owned by circling each picture. If they owned any other technologies that were not shown, they were asked to circle the “? - something else” option and where possible list the other technology types. Data Sheet 2 (see Appendix F) was issued to participants during Key Question 3, as shown in Table 5.1 above. This checklist provided participants with 8 options relating to what aspects of health they might like technology to help them with. The 8 options provided were based on components known to influence weight loss such as increasing exercise, increasing food knowledge, food intake tracking, the effect of immediate feedback, increasing fluids and getting enough sleep (Healthline, 2020). Participants were instructed to put a tick in any of the boxes they

thought were appropriate to their needs and to add their own ideas in the “*Anything else*” space provided.

5.2.3.4 Consent and Ethical Approval

The study was approved by a University Ethics Committee and was conducted in full accordance with World Medical Association Declaration of Helsinki, (2002). Particular attention was given to issues of informed, voluntary consent, and ability to give consent was corroborated by a caregiver who knew them well. At the beginning of each focus group the researchers conversed with participants about confidentiality and respecting other’s opinions. Participants were assured, and all agreed, that whatever was spoken about during the focus groups was to remain confidential within the group. Boundaries were also set in relation to taking turns to speak and letting everyone express their own opinions even if they differ to ours.

5.2.3.5 Data Analysis

Transcripts of the audio-recordings were produced and subsequently coded using Theoretical Thematic Analysis Methodology as described by Braun & Clarke (2006). Each line of the transcript was assessed and codes were developed with respect to the type of information in each quote, i.e, was it about ownership, or usage, or was it a particular aspect about technology that made it easy or hard to use, etc. Only quotes that were relevant to the aims of the study were included and developed into themes. The initial coding was conducted by one of the two researchers before being reviewed by the second researcher who co-facilitated the focus groups. Queries in the coding were discussed between the two researchers and agreement reached in all cases and a number of themes were developed from the transcripts.

Data Sheet 1, completed during the focus groups, was analysed with respect to age specific differences in technology ownership. The results from Data Sheet 2 were collated to assess what areas of health participants were particularly interested in having technological solutions available to aid self-management.

5.3 Results

5.3.1 Participant Baseline Demographics

As is shown in Table 5.2, the focus groups ranged in size from 4 to 6 participants in each. Equal numbers of females (n=13) and males (n=13) participated in the study and the majority of participants resided at home with family members (70%). The mean age of participants was 39.6 (SD=12.2, range 19 to 59). Of the 25 participants who had BMI information available two participants were categorised as overweight (OW), 7 were in the obese 1 category (OB1), 9 were in the obese 2 category (OB2) and 7 were categorised as obese 3 (OB3). The weight profile of the group was therefore 8% overweight and 92% obese, with the individual distributions detailed in Figure 5.1.

Table 5.2: Participant Demographics by Group

Demographic	All Groups	Group 3 RCC1	Group 4 RCM	Group 5 RCN	Group 6 RDC	Group 7 RDQ**
Number of Participants	26	6	6	5	4	5
Males	13	3	3	2	2	3
Females	13	3	3	3	2	2
Mean Age	39.6	49	38	37	32	32
Age Range	19-59	38-59	25-52	26-57	22-46	19-45
Number of Participants in each Living Situation:						
With family	18	3	5	3	3	4
Adjoined Apartment*						
Staff Supported Accommodation	3	1	1	1		
Own Home	5	2		1	1	1
Participants in each BMI Category:	**					
OW (25-29.9kg/m ²)	2		1			1
OB1 (30-34.9kg/m ²)	7	2	2	1	2	
OB2 (35-39.9kg/m ²)	9	3	3	2	1	
OB3 (>40kg/m ²)	7	1		2	1	3

*Adjoined Apartment is a separate independent living apartment within the grounds of the parental home, ** missing information on BMI for one participant.

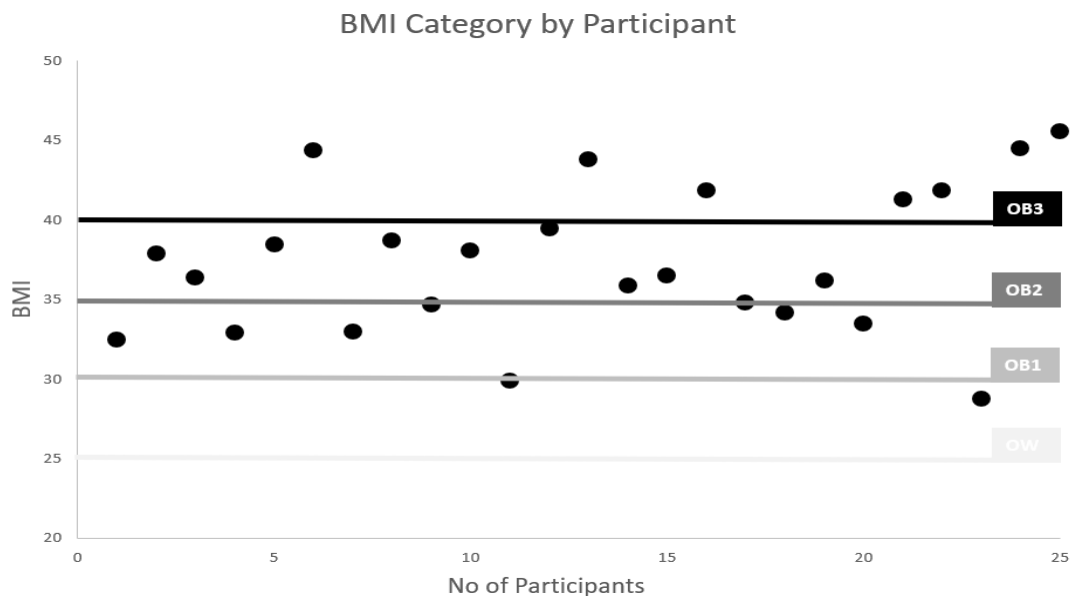


Figure 5.1: Scatterplot distribution of individual participant BMIs ($n=25$)
Note: BMI not available for one participant due to lack of suitable equipment to take weight.

5.3.2 Part 1: Technology Focus Groups

Participants interacted well with each other in all groups and all participants contributed to the overall discussion. A variety of themes were developed, all of which are shown in Figure 5.2 below.

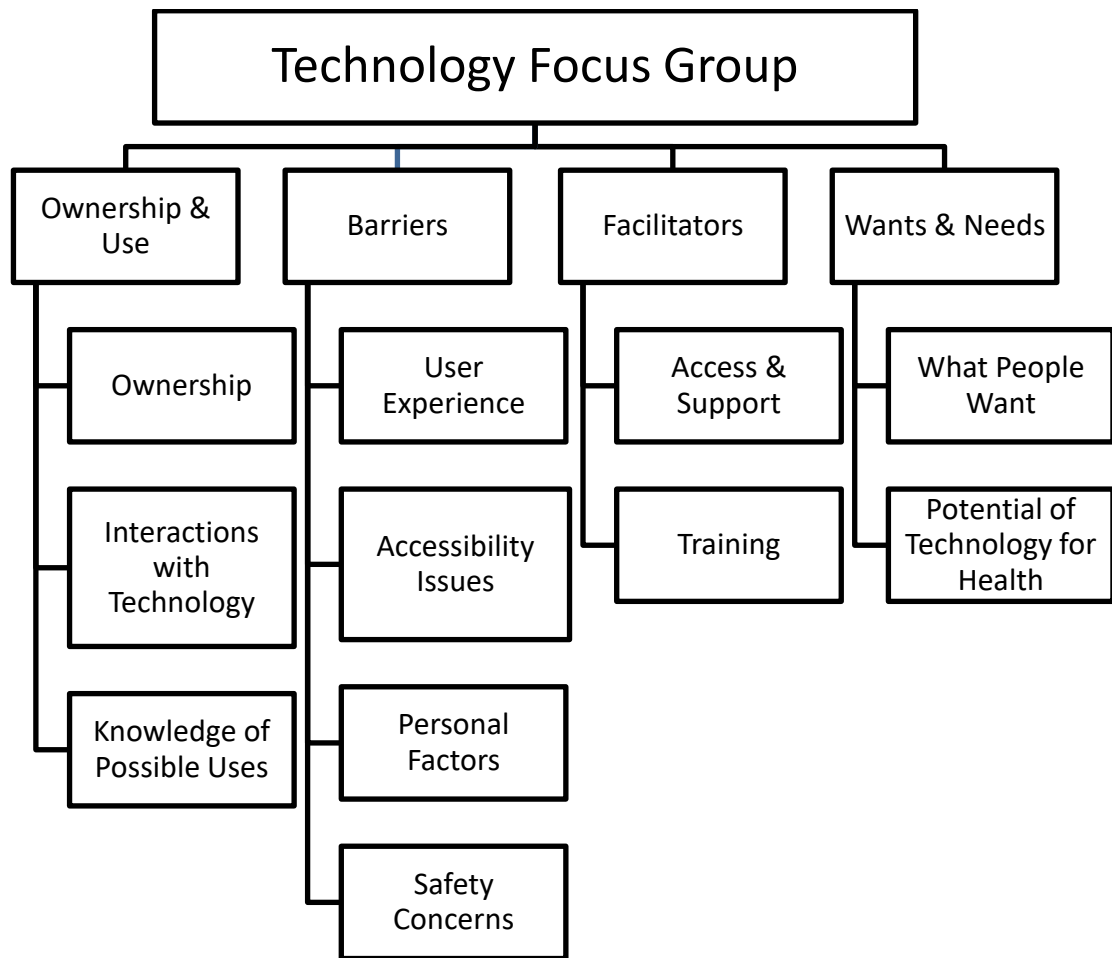


Figure 5.2: Thematic map of main themes and sub-themes developed

Ownership & Use referred to any mention of the types of technologies that people owned or what purposes they used technology for. Three sub-themes were determined under this main theme during the theoretical thematic analysis: (i) Ownership, (ii) Interactions with Technology, and (iii) Knowledge of Possible Uses. *Barriers* related to comments made about any aspect of their lives that prevented them from fully engaging with technology. Four sub-themes emerged under this main theme: (i) User Experience, (ii) Accessibility Issues, (iii) Personal Factors, and (vi) Safety Concerns. *Facilitators* consisted of people, places, design elements or skills that participants identified as aiding them to engage with technology. Two sub-themes were developed under this main theme: (i) Access & Support, and (ii) Training. Two sub-themes were also devised in relation to the main theme *Wants & Needs*: (i) What People Want and (ii) Potential of Technology for Health. These incorporated comments made in

relation to future use and design of technologies for people with ID. The number of quotes captured from participants and used to generate each theme are shown in Table 5.3.

Table 5.3: Number of quotes used to generate each theme

Theme	Number of Quotes
Ownership & Use	113
Barriers	96
Facilitators	32
Wants & Needs	25
Total Quotes	266

5.3.2.1 Ownership & Use

Table 5.4 details the sub-themes relating to ownership and use of technology by people with ID.

Table 5.4: Ownership & Use Sub-Themes

Sub-Themes	No of People	No of Groups	No of Quotes
Ownership	20	5	30
Interactions with Technology	24	5	69
Knowledge of Possible Uses	5	1	14
Total Quotes			113

5.3.2.1.1 Ownership

The main types of technologies owned by participants were phones, iPads/tablets, and laptops. All except two participants had their own phones with a mixture of traditional feature phones utilising button input, and touchscreen-based smartphones present. When analysed by age there emerged a very definite division in mobile phone technologies. Of those younger adults (YA) who were less than 39 years of age (n=12), 10 (83%) owned a smartphone, with only two (17%) owning a traditional feature phone. For older adults (OA) who were greater than 40 years old (n=14), 5

(36%) owned a smartphone, 7 (50%) owned traditional feature phones and 2 (14%) reported no phone. Participants from both age groups reported owning iPads/tablets and laptops.

YA - Adults <39 years old:

RCM1.2: Touchscreen [phone], yeah, and I have the tablet and I have a laptop.

RCM1.1: I have an iPad and I have a phone [smartphone], and then I have the laptop.

RCM1.5: I use the iPad and the phone [smartphone].

RCN1.5: Well I've a phone [smartphone] and I've a laptop.

RDC1.5: [I have] phone [smartphone], laptop.

RDQ1.3: I have a mobile phone, flip up one, and I recently got an iPad, no, a laptop.

OA - Adults >40 years old:

RCC1.1: I use a phone, it's a Vodafone [not smartphone].

RCC1.5: It's a button one [phone].

RDC1.4: I have my iPod with me, touch phone, laptop.

Age and sex differences were noted in the ownership of games consoles with only three under 39-year old males referring to this type of technology.

RDC1.3: [I have a] PS4.

RDC1.5: I had a Gameboy.

RDC1.5: [I had] the PC and Atari.

RDQ1.1: I have an Xbox One.

RDQ1.1: I have a PlayStation 4, I think.

Twenty-five participants (96%) completed Data Sheet 1, issued to participants during the introduction question (see Table 5.1). Table 5.5 below shows that while participants aged 39 and younger (n=12) made up 48% of the participant group, they owned 60% of all technology within the group. Additionally, this group owned more than 50% more mobile smart technology (smartphones/iPhones and tablets/iPads) than the group aged 40 or older.

Table 5.5: *Technology owned and used by participants within age groups*

Participants	Total Tech	Old Style Phone	Smartphone / iPhone	Tablet / iPad	PC / Laptop	Other
Age 40+ (n=13) (52%)	23	6	5	8	2	2
Age 39- (n=12) (48%)	34	2	10	9	9	4
Totals	57	8	15	17	11	6

5.3.2.1.2 *Interactions with Technology*

Technology was used to occupy time, to communicate and connect socially, to find out information and in a few cases as a self-management tool. Using technology as a way to occupy yourself during leisure time was relevant to both smart technology owners, and those that had access to a laptop or PC either at home or in the Service centre. The main uses for leisure were accessing videos or music on YouTube, downloading music, taking photos or videos, and playing app-based games.

RCC1.3: Yeah games, some kinds of games to keep me occupied when I'm upstairs [in my apartment].

RCN1.0: I go looking up music things and all that. Yeah and they've different albums on it [internet] too. They've thousands on you know. And YouTube, stuff like that.

RCN1.3: Ahh there's crossword challenge, and then I do a word search. Aye I do word search and what else do I play on it..... I play one of the Mario games on it.

RCN1.1: I have one [tablet] I play games on and take photographs and videos. Sometimes I play games but not all the time.

RCM1.2: I use apps on my mobile and the laptop, and the tablet I use, sometimes I use the apps on it for videos and stuff like that, YouTube.

RDC1.2: I love YouTube put music on it and downloads.

RDC1.4: Yeah candy crush. I like to just use it for games when I'm out with my mum or that [I play games on it].

RDQ1.2: [I use my phone] for games and music, and my photos.

Age differences became apparent when looking at the ways in which technology was used for communication and social connectivity. All participants used their phones to communicate in the traditional manner of phone calls, however, this type of communication was the only method used by the OA, compared to the YA who used a combination of phone calls, texts, emails, Viber, WhatsApp and Facetime to communicate. A few of the YA also reported using some social media platforms as a means of connecting socially, whereas the OA did not.

YA - Adults <39 years old:

RCM1.6: Chats on that now, on the phone.

RCM1.2: I need the phone for the phone calls.

RCN1.5: I'm on Viber and WhatsApp.

RCM1.2: [I use] FaceTime.

RDC1.2: I send emails to my Dad.

RCC1.2: [I use] Snapchat.

RCM1.1: I use the Snapchat.

RDQ1.1: I have Facebook, twitter.

OA - Adults >40 years old:

RCM1.4: I just don't.... to be honest I don't bother just texting, I just use it for phone, and if I didn't feel well I phone home or if I'm out late or anything like that, tell them I'll be a bit later in case they'd be wondering where I was and stuff.

RCC1.1: No that's all, I only make a phone call.

RCC1.3: I have a phone upstairs [smartphone]. I phone different people on it and play games, but I can't text.

RCM1.3: Just phone calls, no text.

The main method used to source information, across age groups, was via the online search engine, Google. Searches appeared basic and were mainly focused on sporting scores or fixtures, specific routes to recipes, and information relating to upcoming events or outings.

RCC1.4: You type in and it brings it up, Google, I'd try and get Google, I find Google easy.

RDC1.5: [I Google] stuff like what's on.

RDQ1.1: I look up the [regional soccer] league, yes, I look up the league tables.

RDQ1.5: I use it for the weight watcher's things [recipes].

For a small number of participants technology was used as a scheduling tool to manage aspects of life such as a daily wake-up alarm or appointment reminders. A few participants had utilised remote on-line booking platforms for events and holidays and reported these as useful life management features of technology. One participant referred to how they relied on mobile technology to enable them to work.

RCM1.2: I do three alarms on my phone, because I have three connections to the alarm.

RDQ1.5: I put the alarm on for like say time to get up, on my phone.

- RCN1.3: Like say if I've an appointment or something, like on these something comes up and reminds you that you've an appointment.
- RDC1.5: Yeah and then I have DJ equipment as well so if you were out doing DJ and you're looking for stuff, go on the phone type in what you need.
- RDQ1.3: Looking up different things, I mean I'm going to a show, I don't know whether you've heard of the [hotel name] in [city name], I'm going to something in it on the [date], I booked it on the computer.
- RDQ1.4: I got the hotel booked through the internet and my flights.

5.3.2.1.3 *Knowledge of Possible Uses*

The current uses of technology were mainly for communication, leisure activity and basic knowledge acquisition, but interestingly, one group's discussion hit upon possible uses that technology could have. Some suggestions reflected actual uses quoted by other groups, such as looking up information or booking events, however, novel uses (accessing a map, accessing a Fanclub, getting local news, or buying goods) were also referred to which demonstrates that there is an understanding that technology can do more than what they currently use it for.

- RCC1.0: You could use it as a map, looking up things.
- RCC1.1: Ways to go for walks and everything like that.
- RCC1.2: Write to a certain wrestler, write to Hulk Hogan [Fanclub].

RCC1.4: Local news.

RCC1.3: See if there's any bikes for sale in the yoke.

5.3.2.2 Barriers

Table 5.6 details the sub-themes relating to the barriers that people with ID face in relation to accessing and using technology.

Table 5.6: Barriers Sub-Themes

Sub-Themes	No of People	No of Groups	No of Quotes
User Experience	16	5	47
Accessibility Issues	13	4	25
Personal Factors	6	3	11
Safety Concerns	8	4	13
Total Quotes			96

5.3.2.2.1 User Experience

Age and ownership differences affected user experiences. OA reported lower comfort and confidence levels with touchscreen technology, possibly due to inexperience since very few in this age group owned these types of devices.

RCC1.1: No, it's all in the one. I wouldn't be able to use one of them [smartphone].

RCC1.0: The one where you touch the screen [is my dad's phone]. He can look up things on the internet. He can press the button and talk into it and it shows up, what do you call that? [Siri] I wouldn't have a clue about these [technologies].

RCM1.4: Oh no, no, no, no. The screen was ok. The screen was big it was just when you were trying to get into somebody's number. Like say if I was ringing [person's name] saying I can't come in to work some day and stuff like that you'd be picking... you'd press the wrong number and then you'd be 'oh sorry, sorry wrong number'.

RDQ1.4: No, I don't use the iPads, no. The touchscreen wouldn't agree with me. I wouldn't..... I'd try it but I.....I just try it you know what I mean? I'd rather type something in.

Even participants that were comfortable with touchscreen technology reported difficulties with certain aspects of the interfaces. For example, passwords were an issue both to remember and to enter, small screen sizes or small writing sizes were difficult visually, and setups or apps that involved moving between pages were difficult to navigate. Searching Google and YouTube were common practice among the majority of participants and they reported a unique set of issues with regards to usage, mainly; knowing what to type in to the search, getting lost on the screen when scrolling, and only feeling confident with choosing the first answer that appears on the list.

RCN1.5: Yeah if you remember them [passwords] it's easy, if you don't then no.

RCM1.4: No, I just find it hard putting the passwords in. Yes, it's trying to remember what number you have to put in, I just don't like it.

RCC1.1: I had to change it to a bigger one [screen].

RDC1.4: Sometimes the writing can be small. That's why I have to wear these for reading and writing and stuff.

RDC1.5: No, I find that [moving between pages and setting up] hard.

RCC1.3: I find that [scrolling] frustrating. I've had enough of that.

RCC1.4: I get lost [in searches on google].

RCC1.4: The first result [is the one I use].

Another obstacle to technology use from a user experience perspective was the frustration and annoyance when technology did not function effectively. A lack of problem-solving skills when things went wrong provided a negative user experience which did not encourage future engagement or perseverance.

RCC1.3: When I want to get a programme like [programme name] I can't get it because it's stuck at times and I just leave it.

RCC1.3: Yeah, [when it's not working] I just let it go, I don't bother, yeah, I just get mad with it [tablet].

RCC1.3: I hate deleting, I like to get into the thing and be done.

RCN1.3: Same with the tablet and freezing [it's annoying].

RCN1.0: That's when you get the hardships in here [when the computer doesn't work].

RDC1.4: Sometimes you feel that angry with it [when it doesn't work], bang it round the room (laughs).

RDC1.5: Yeah and if that doesn't work [fix the issue] get a hammer.

RDQ1.3: Well sometimes it would annoy me [if it doesn't work]. Only because I'd be looking for the thing more than once.

5.3.2.2.2 *Accessibility Issues*

The high costs of purchasing technology reduced the choices available and the ability for ownership. Often the devices that were owned by participants were second-hand pieces donated by family members or neighbours. The cost of some apps was also a factor that limited use, and participants predominantly used free apps or services. One participant was so afraid of the cost of apps that they didn't use any, even if they stated that they were free. Running out of credit was referred to many times as a particular concern which often limited use to areas where participants could access WIFI instead of cellular data.

RCC1.5: Yeah, they are [expensive to get ipads/tablets].

RCM1.4: I'd love to have an iPhone 6 but firstly I need the money and my brother won't let me get one because they're just too complicated.

RCM1.1: My mother gave me the phone [second-hand], so that's why I got it.

RCC1.0: No, you'd be killed, the cost of it, you'd be killed.

RCM1.2: WhatsUp [WhatsApp] is another app, I use that, it's free calls.

RCM1.4: Some of them [apps] can be very complicated to try to get into them, because like some of them you have to like pay money for them. They say they're free, but I don't do that to be honest because they just... just rob you.

RCM1.1: You need to turn off your Vodaphone [cellular data]; you need to turn off your em [cellular data]. No before you go onto the internet you have to turn off your em...your Vodaphone before you connect it to the internet.

RCM1.2: I do that [use Wi-Fi] just in case my credit runs out.

Lack of regular use made it more difficult for technology to be used functionally and in any meaningful way for some participants. A lack of ownership meant that access was limited to borrowing family members technologies or availing of technology within the service centres. Even those that did own their own technology often did not have it charged and ready for use or did not carry it with them when they left the house. Restrictions enforced by carers or service centres also reduced access to certain packages, mainly social media platforms such as Snapchat and Facebook. However, one participant who lived independently also reported not being allowed to access the internet in their home environment.

RCC1.4: No, Mammy has a mobile and I use that.

RCC1.0: No, I don't use phones. I only see my Dad using them.

RCC1.3: I have a tablet too, but I didn't get it charged up yet, but I will, but I haven't used it yet, but I will sometime.

RCC1.3: No, I don't like that [carrying phone with me all the time]. If they want, I go up and get it, if not I just throw it there on the bed.

RDC1.2: Eh aha sometimes, sometimes yeah [I bring my phone with me].

RCN1.5: No wouldn't go near it [Snapchat], banned from them.

RDC1.4: Facebook is banned [in the centre] (laughs).

RDC1.2: Somebody was caught doing something [on Facebook in the centre].

RDC1.5: Yeah, gone blocked [Facebook from the centre]. Yeah head office blocked it completely.

RCN1.4: I use google in here but not allowed to at home.

Some participants reported taking part in training courses to use iPads and desktop computers, however, the lack of regular use and practice opportunities after these training courses were completed, rendered the training worthless in the long run.

RCC1.4: Years ago, I did a computer course, but I haven't done it for a long time.

5.3.2.2.3 *Personal Factors*

Poor literacy skills affected the level of engagement that users had with technology, in particular the ability to send and receive texts, and the ability to type information to email or internet searches. Additionally, the level of perseverance individuals had played a role in their ability to continue to interact with technology when difficulties arose.

RCC1.1: I get messages from other people yeah, I can read them a little bit; I'm not great at reading either.

RCC1.3: I can't text and it's just...that's why, I can't text. I'd love to text my sisters over in America, but I won't because they'll be in there bed now and it's early in the morning over there in America now and I don't want to ring them. I'd be in the doghouse, put it that way [laughs]

RCC1.4: I find texting very hard.

- RCC1.1: I don't find YouTube hard or the puzzles, the word searches. I don't find them hard at all. But writing stuff in is very hard.
- RCN1.0: I've never text in my life.
- RDC1.2: Its hard, it's hard to send a message I think sometimes, yeah, I find it difficult sometimes, spellings not great.
- RDC1.2: Em...I just look at pictures on my iPod.
- RCC1.4: What I find difficult is Gmail and all that, I find that very difficult.
- RDC1.4: I'm stuck on 104 now [candy crush], it's a curse.

5.3.2.2.4 *Safety Concerns*

People with ID were very concerned about the possibility of losing or damaging their phones, or the possibility of their phones being stolen. This made them reluctant to carry any technology around with them, which immediately reduced the amount of time that they had access to technology. Passwords were also spoken about with respect to their usefulness in keeping private data safe, but due to the difficulties in remembering and entering them, as mentioned before, people with ID felt their technologies were safer at home. Stranger danger was a concern when non-identifiable numbers called on phones, or in the possibility of bullying or connecting with strangers on social media platforms. These assumed dangers appeared to be derived from advice they were receiving from carers and staff.

- RCC1.3: No because it [phone] might fall out of my pocket.
- RDQ1.4: No, I think it's [a password] a good thing because at least nobody else knows your PIN number.

- RDQ1.3: You could actually remember it [password] and keep it in your head. I mean if you write it down the wrong person is going to get it, you know, God forbid.
- RDQ1.4: And whatever money you had in your account could be gone [if someone stole your technology and had your password].
- RDQ1.5: But I didn't want to be in it [Facebook] because I heard all kinds of things like Facebook can go into.
- RCN1.5: No, no I'm afraid to [go on social media].
- RDC1.4: No, I think some people, some people ring me, and I don't know who they are, no name or nothing. And my mother doesn't know why. I show my mother and she would tell me not to answer that.

5.3.2.3 Facilitators

Table 5.7 details the sub-themes relating to the facilitators that aid access to and use of technology for people with ID.

Table 5.7: Facilitator Sub-Themes

Sub-Themes	No of People	No of Groups	No of Quotes
Access & Support	12	4	23
Training	8	4	9
Total Quotes			32

5.3.2.3.1 Access & Support

All of the service centres provided access to desktop computers, and some also provided access to iPads. The ability to regularly access these technologies increased comfort and ability with their use. Staff and family members often assisted by personalising some of the settings or information contained on devices, providing visual prompts, or physically assisting in-situ. Software aids such as predictive text also assisted when using internet searches.

- RCC1.4: I like using the iPad here [in the centre].
- RCC1.5: I might have used some of them [tablets or iPads] in here all right.
- RDQ1.4: I go through the internet on the computer, but I use that in here [centre].
- RDQ1.3: This one [phone] is much easier and I'm able to make my own phone calls, most of the numbers that I would use and do use are actually saved in there.
- RCN1.0: Nah I don't mind cause all the words are written down for me so it's just looking it up.
- RCN1.0: If I have to do it and if I wasn't stuck or I'd ask some of the staff, they'd help with it.
- RCN1.3: Eh no I ask a staff member to show us, show it to me first.
- RDC1.2: An email, maybe mum helps send email. Em, I would get someone to help me. My niece [name], she presses it on the iPod.

RCN1.0: Ehh no it's handy, I'm alright, once I know what I'm at, I find them okay when I'm looking. Oh yeah, I find them easy enough, the correct spelling comes up on mine anyway, yeah so that's easy for me.

RDQ1.4: Ah that's a bit frustrating but once you're on the computer it'll find a word for you anyway.

5.3.2.3.2 *Training*

Some service centres provided training classes for iPads/tablets and computers to increase skillsets and confidence in using technology. Computer training incorporated the basics needed to use computers functionally, for example emailing. For some participants computer training was used to teach basic literacy skills, which not only increased these pre-requisite skills required to engage functionally with technology, but incorporated learning to use technology at the same time. Some participants reported that they enhanced their own learning of technology themselves by engaging with it regularly and practicing new skills.

RCC1.4: I did an iPad course and I found it very helpful.

RCM1.3: On Mondays there I do a class there with Gordon. I do computers.... I do a computer class, a laptop one.

RCN1.4: [I'm learning] reading and writing sort of things, passwords.

RDC1.5: We were doing them [emails] last week.

RCN1.0: Well I'm learning myself [computer].

RDC1.5: I get used to it this is my first touch phone.

RCN1.3: Getting to know it [makes it easier to use].

5.3.2.4 Wants & Needs

Table 5.8 details the sub-themes relating to what people with ID wanted and felt they needed in relation to technology.

Table 5.8: *Wants & Needs Sub-Themes*

Sub-Themes	No of People	No of Groups	No of Quotes
What People Want	11	5	16
Potential of Technology for Health	5	1	9
Total Quotes			25

5.3.2.4.1 What People Want

One of the main things that participants wanted was the ability to text. Owning their own technology and understanding how to use it was also a priority for some participants. From a design perspective larger screen sizes that were brighter, with pictures as well as text were identified as elements that would make using technology easier.

RCC1.5: No, I'd like to have one [a tablet] but sure I'll get one sometime.

RCN1.0: Ahh no, I'm thinking of getting one [computer] next year. I'm just learning at the moment.

RDQ1.4: Oh yeah, it would, in a way [be easier with a big screen].

RCM1.4: I would rather have it a wee bit brighter.

RCC1.4: A mixture of the two [pictures and text].

RCC1.1: Pictures would be better.

RDC1.4: I like pictures and a wee bit of writing.

5.3.2.4.2 *Potential of Technology for Health Management*

Although current use of technology mainly revolved around communication and leisure activities, some participants had reported using it for self-management too. The participants in one group took this part of the discussion one step further by expanding the idea of using technology to help manage their health. The participants demonstrated that they understood the ways that technology could enrich their lives and support change by referring to ways that technology could increase exercise, improve diet and to help them relax.

RCC1.0: [To make you] go for walks.

RCC1.4: Relaxation music, it could do it for your, for relaxation. Sleep and relax, yeah.

RCC1.1: Tell you the right food to eat.

RCC1.2: [Help you make choices] go for the apples.

RCC1.4: [To help you] to have a treat, just as a treat, once a week.

RCC1.3: [Compare foods] because the chocolate would be all fattening and the apples would have nutrition or whatever you call it. It would be a bit like scales.

RCC1.4: To show us the correct food.

Twenty-five participants (96%) completed Data Sheet 2, issued to participants during the Key Question 3 (see Table 5.1). Data Sheet 2 was used to determine aspects of health that people would like technology to help them with. The features participants identified that they would like to see in a mobile app specifically designed to help people with ID manage their health and weight, are shown in Table 5.9 below. There

were no significant differences between age groups and so results are presented as totals, with preferences listed in ascending order of importance.

Table 5.9: *Desired Features for an ID Specific App to Manage Health and Weight*

Feature	Totals
Remind you to exercise	20
Remind you to stay within the eating guidelines	18
Give you feedback if you are doing well	16
Show you a picture of how you are doing	12
Give you suggestions	10
Remind you to drink healthy fluids	10
Track how long you sleep	8
Give you feedback if you are not doing well	7
Other	4
Totals	105

The most desirable features related to reminders about exercising and eating habits. Positive feedback for good days was also highly preferred and whilst some were comfortable with receiving a realistic picture of how they were performing, most did not wish to receive feedback if they were not doing well. Other suggestions revolved around exercise with one participant suggesting a timer to indicate the length of time people should stay walking when they exercise.

5.3.3 Part 2: App Wireframe Mock-up

Three of the groups (Group 3 RCC1, Group 4 RCM and Group 7 RDQ) took part in an evaluation of a wireframe mock-up for the proposed mobile app, designed to be used in the multi-component weight management program under development for the intervention stage of this project. Wireframes are likened to blueprints of mobile apps and provide information on how the app will function. Mock-ups are visual

presentations of the user interface of the app (Mkrtchyan, 2018). The mock-ups were presented as a collection of laminated pages, bound together as a booklet, with each page designed to reflect a mobile phone screen size and shape. Every page of the booklet represented a page of the proposed app design, see Appendix G for page design details. The wireframe, or functionality, of the app was discussed during presentation of each of the mock-up pages.

The researchers described the colour coding adopted within the screen design; specifying what green, yellow, and red foods meant (healthy, a bit healthy as long as you don't eat too much, and unhealthy, respectively). Each page of the app was then shown one at a time and the participants discussed the functionality, design, and layout of each of the pages. Examples of different visual feedback scenarios were also presented for the Home Screen, to ascertain whether participants understood what the app was showing them in terms of feedback, and to assess whether this type of information was seen to be of use. As Table 5.10 shows, three themes were developed during the wireframe mock-up: (i) Comprehension of display and concepts, (ii) Usefulness for decision-making, and (iii) Interface Design.

Table 5.10: App Wireframe Mock-up Themes

Sub-Themes	No of Quotes
Comprehension of Display and Concepts	19
Usefulness for Decision-Making	25
Interface Design	46
Total Quotes	90

5.3.3.1 Comprehension of Display and Concepts

Participants in all three groups demonstrated an understanding of the concept of green, yellow, and red food types based on their health value.

RCC1.3: The green is better than the red because the red is more fattening than the green.

RDQ1.3: Yeah, because it gives you different colours and it goes through step by step this is the not so good food and this is the good food.

Both the daily and weekly visual feedback displays for food intake and exercise engagement were easily understood by participants who not only read the graphical displays correctly but provided judgements on whether the different scenarios presented were good or bad for health.

RCC1.3: Yeah, you ate the wrong food, it would be better to have the green sky high and the red down.

RDQ1.4: The red, the amber and the green are all the one level.

RCC1.4: It shows you the time you were able to do it [exercise] for. It shows you not too hard, or would it be alright or very difficult.

RDQ1.3: [the scenario of food intake shown is not good] because it's not a healthy choice, too many red foods.

RDQ1.4: Yeah but the next one [is not a good day because] there's only a little bit of green, amber is the bigger one and the red.....NO [is very high].

RDQ1.1: He got a thumbs down.

RDQ1.3: He got a thumbs down [for exercise] for some of the week, not all of the week. Well he did very well for himself.

5.3.3.2 Usefulness for Decision-Making

Participants felt that the information that the proposed app design presented would be helpful to them in terms of prompting them to make changes to their food intake across the day and also to the amount of exercise they engaged in. Whilst the majority of participants stated that they would not like to see feedback that was negative, they acknowledged that feedback would be a good motivator to eat healthier foods, resist unhealthy foods, and encourage more exercise.

RCM1.4: [If the app showed lots of thumbs down, I'd] probably try and be good for the rest of the week [with my food].

RCM1.4: Yes, very helpful [then you can] make a plan on what you want to do.

RCC1.3: If what I'm doing not so good [I could change it].

RCC1.1: Go for walks make it better [if I had a thumbs down at lunchtime]. Take a walk or eat something different, yeah.

RCC1.4: It would show that you didn't eat the right food, you'd change to the green.

RCC1.0: You be trying to eat the healthy food.

RCC1.1: You'd rather go and do the exercise.

RCC1.4: Well to stick to the food, the healthy food and not to go back on the bad food.

RDQ1.4: Yeah, I think it would, yeah [be helpful to know]. You'd change it [food intake, if you had the information].

RDQ1.3: Yeah, because you can make sure you have a good nourishing dinner. So, if you don't eat a good lunch, god forbid now I do, but if you don't eat a good breakfast well you kind of make up with the dinner.

5.3.3.3 Interface Design

The proposed interface was designed by the researchers as a starting point for discussion within the focus groups, prior to the development of the app. Input modes were designed to take the least amount of effort as possible by reducing steps to the minimum possible, as is recommended in app designs for people with cognitive impairments (W3C, 2019; Haymes, Storey, Maldonado, Post & Montgomery, 2015). Feedback screens were designed to provide cumulative data over the day for diet and exercise to allow participants to self-evaluate and re-adjust behaviours accordingly as is appropriate for a self-management programme (Cooper, Heron & Heward, 2014). The participants found the design acceptable and felt that the data entry would be easy to do. Topographical changes suggested were: using the lighter colours for the buttons (in particular removing the darker blue colour), using larger text, including pictures with the text, slightly increasing the size of the buttons, and making sure there is enough spacing between buttons on the page. A particular change suggested for the feedback system was to use “happy/sad faces” rather than “thumbs up/down” as participants found these images more acceptable. One functional change suggested was the addition of a step counter as participants already used pedometers and would find it useful to have all in the one place.

RCC1.3: Easy, easy [to enter data].

RCC1.1: Easy to do [enter data].

RCM1.4: No, I'd say it would be grand [not too many pages].

- RCC1.3: A lighter colour, [the coloured backgrounds are] way better than the blue.
- RCC1.4: Brighter colours, yeah. It's far better than the blue on the other one, blue is hard.
- RCC1.1: The writing could be a bit bigger. The writing is very small on it.
- RCC1.0: You'd be going like this [makes a face] looking at it [small writing] all the time.
- RDQ1.4: I'd have to put on my glasses probably to see it, because it's very small print.
- RCC1.2: And bigger circles [for the buttons].
- RDQ1.3: You see there is a big gap between [items on the screen], it so it's not squashed together on the [page] there's a big [space].
- RCC1.4: More pictures.
- RCM1.4: I would probably suggest if it's ok to do the faces with them, ones that you're happy or you're not, it's only a suggestion.
- RCM1.5: Ah no, I'd go with the happy faces.
- RCM1.1: I like the happy faces.
- RDQ1.5: I have a thing [pedometer] and it tells me how much I'm doing [I'd like that in it too].

5.4 Discussion

The focus groups captured a large and diverse amount of information in relation to technology ownership, use and knowledge for adults with ID. Responses highlighted the need to provide more access to technology, particularly for older age adults, and the need to expand the variety of activities that technology is used for. Knowledge of how technology could aid self-management was present but very little actual use in this area was demonstrated. Both parts of the focus group provided important information to inform the development of an ID specific mobile app designed to support self-management during a multi-component weight loss intervention.

5.4.1 Ownership & Use

Technology plays a large role in everyday life for the majority of adults in the Westernised world. However, there remains disparity between the ID population and the general population in the types of technologies owned and their uses. For example, approximately 96% of US adults own cell phones, with 81% owning a smartphone (Pew Research Center, 2019^a). In Ireland, this figure is higher with 95% of adults now owning a smartphone (Deloitte, 2019). When comparing these figures to the participants in this study we find that a similar percentage of the adults with ID owned cell phones (92%), however, only 58% owned smartphones. This 58% smartphone ownership is high in comparison to the 10% reported by Patrick, Obermeyer, Xenakis, Crocitto & O'Hara (2020) in their study with 370 adult participants with an ID. However, the participants in this study were all aged between 18 and 59 and were adults with a mild or moderate ID, whereas the Patrick et al. (2020) study included all adults aged 18+ (of which 17% were over 60 years) and all levels of ID. The higher percentage of smartphone ownership in this study may be more representative of a younger profile of adults with a mild or moderate ID.

Age differences in technology adoption are well documented in the literature for both the general population and the ID population. When looking at cell phone versus smartphone ownership for different age groups in the general population, Pew Research Center (2019^a) found that the figures dropped as age increased, 96%

ownership for 18-29 years old versus 53% for 65+ years. Olson, O'Brien, Rodgers and Charness (2011) also reported adults aged 18-28 years as having a significantly higher usage of cell phones than adults aged 65-90 years ($p < 0.008$). The Patrick et al. (2020) study with adults in the ID population reported a decline in smartphone ownership as age increased with 19.5% of those aged between 18-29 years owning a smartphone compared to only 4.7% of those aged between 50-59 years. The participants in this study were no different with 83% of the adults aged between 18-39 years owning a smartphone compared to only 36% of adults aged between 40-59 years. Ownership of all smart mobile technology was approximately 50% higher in the younger participants in this study when compared by age groups. Again, our figures are a great deal higher than the Patrick et al. (2020) study for both age profiles, indicating that level of ID may be a more significant barrier to owning smart technology than age.

Age and gender appeared to play a role in the ownership of games consoles with only three of the under 39-year-old males in this study referring to this type of technology. Within the general population ownership is higher in younger adults, with approximately half of all adults in the 18 to 50-year-old category owning consoles compared to only 19% for those over 50 years (Anderson, 2015). Figures reported in 2015 showed that more females than males owned games consoles in the US (Anderson, 2015), however, this figure did not provide information on the amount of use for each gender. Consumer insight figures showed engagement with consoles for men and women as approximately 37% of men compared to 23% of women playing at least monthly (newzoo, 2017), suggesting this type of technology is suited more towards young males. Figures from 2018 in the UK reflect this finding with 44% of males compared to 32% of females reporting regular use of games consoles, with the highest prevalence, 65%, reported in the 16 to 24-year old age category (Johnson, 2020). The young adult, male population is certainly seen as the stereotypical audience for games consoles, and game developers have targeted this population with highly focused marketing strategies to encourage this profile (GameSparks, 2020). The lack of games consoles owned by females and older males in this study may highlight the effectiveness of this marketing and indicates the relevance that people

with ID and their families may place on peer models for social inclusion (Wilson et al., 2017). If peer modelling is indeed an important factor, this highlights the need to create technological solutions that are socially acceptable to people with ID to encourage inclusion and allow them to align with general population trends and uses (European Parliamentary Research Service, 2018).

At a macro level participants' uses of technology were similar to those reported for the general population, in terms of communicating with family and friends, occupying leisure time, sourcing information and managing aspects of their lives (Olson et al., 2011; Patrick et al., 2020; Weafer, 2010). Increased age played a role in limiting the uses of technology across populations, with younger adults using technology more than older adults for social connectivity and streaming. However, when comparing this study's participants to the general population, the younger participants in this study utilised technology less than their peers and were more akin to older adults (65+ years) from the general population (Olson et al., 2011; Smith, 2014; Anderson & Perrin, 2017). One glaring difference was the lack of social media use by participants in this study. Only three of the younger participants stated using social media platforms such as Facebook, Snapchat, and Twitter. Whilst these particular platforms are in line with the most commonly used social networking sites, approximately 72% of US adults regularly use them (Pew Research Center, 2019^b), compared with only 12% in this study. None of the older adults in this study used any form of social media, and whilst prevalence of use also decreases with age in the general population, there remains over 50% of adults aged 50+ that access some form of social media (Pew Research Center, 2019^b). When comparing our participants' social media access to other adults with ID, comparable pictures are reported, with Weafer (2010) quoting no access to social media and Patrick et al. (2020) reporting only 13.2% accessing social media. Since social networking is the main form of online connection for most adults in the general population, it is imperative that this function be made safer and more accessible to adults with ID, if we are to achieve social inclusion and broaden the scope of communication and connectivity.

Very few participants reported using their technology to manage aspects of their lives, with basic alarms being the most common function used. Using mobile technologies to manage lives is commonplace in modern society with functions such as multiple schedules and alarms, on-line shopping, exercise tracking, dietary tracking, health checks, mental health checks, budgeting, and banking all regularly used (Reddy, 2020). Technology has been used to support self-management for a variety of skills in both children and adults with intellectual disabilities and has demonstrated effectiveness in doing so (Lai Cheng Chia, Anderson & McLean, 2018; Kim & Kimm, 2017). However, the amount of disability specific apps available that target health management are limited and can be difficult to use (Jones, Morris & Deruyter, 2018). One group in this study referred to other possibilities that technology could be used for in life, but only one participant referred to a health-related use. Mobile apps related to health management are plentiful with over 165,000 available to download, and approximately 26,000 regularly used, of which many lack informed research in their design. Health apps suitable for disabled users amount to just 2%, and many of these target specific groups or health conditions (Jones et al., 2018). Mobile apps to aid self-management of healthier lifestyle choices for people with ID are virtually non-existent, which is in stark contrast to the amount available for the general population. Since mobile technology ownership and use is increasing in the ID population, more development and research on how best to utilise these to improve health outcomes is needed, particularly since this is an at-risk group for chronic diseases and a group that access primary care facilities less.

5.4.2 Barriers

Increased age presented challenges in overcoming negative attitudes towards technology, with older adults reporting less confidence and comfort around smart technology. This lack of confidence acted as a barrier to exploring technology, as many felt they would not be able to understand how to use it before they had actually tried. These attitudes are also noted in older adults from the US, with only 18% reporting confidence in adopting new smart technologies (Smith, 2014). In the four focus groups that Weafer (2010) conducted with adults with ID across Ireland, higher

levels of computer literacy were found for the younger adults, however, the majority found using technology difficult regardless of age. Difficulties in remembering and entering passwords, understanding setup procedures, navigating through pages, knowing what to enter when searching in Google, and getting lost while scrolling through search lists, all contributed to negative user experiences. Further frustrations arose when technology did not perform as expected contributing to negative user experiences since problem-solving skills were also lacking. Increased knowledge in using assistive technologies was noted as one of the main facilitators in accessing technology in a systematic review of 27 studies by Boot, Owour, Dinsmore and MacLachlan (2018). Roberts and Hernandez (2018) suggest that sufficient digital literacy skills, along with the necessary self-efficacy to make effective use of technology, are two of the main contributing factors in the uptake of smart technology for minority groups. This highlights the importance of increasing knowledge and confidence in using smart technology. If technology is seen to be too difficult to adopt by adults with ID, this will limit use. Gaining confidence and comfort in the basic functions may be necessary as a pre-requisite to any mobile app intervention. Since mobile app technology use is increasingly being utilised as an assistive technology aid it is imperative that adults with ID are upskilled to increase confidence and comfort of use, to allow them to take advantage of the benefits that this technology can provide to their lives.

Use of smart technology is not only limited by lack of confidence and skills, but also through lack of access. Access was limited for a variety of reasons including cost and ownership issues, imposed restrictions on usage, and perceived risks associated with carrying smart technology around. All technologies were seen to be expensive to purchase and the majority relied on parental purchases or receiving second-hand goods. This immediately limited the amount and types of technology owned and available for use. Boot et al. (2018) mirrored this finding when they reported the most common barrier to accessing assistive technology as a lack of policy and funding. Whilst most service centres availed of funding opportunities to purchase technology, these remained in the Service centre and could only be accessed during daytime hours. Some service centres also imposed restrictions on what content could be accessed,

with one group reporting a service wide ban on Facebook. Whilst these restrictions may be due to the increased risks associated with on-line and social media use for those with intellectual disabilities (Jenaro et al. 2018; Buijs, Boot, Shugar, Fung & Bassett, 2017), they present yet another barrier to peer appropriate, smart technology use, and also highlight potential ethical issues in terms of restricted practice. Imposed restrictions on technology use should not be service wide but should instead be individually dictated through appropriate risk assessment procedures (Health Information and Quality Authority [HIQA], 2014). This would immediately remove this barrier for some participants and possibly highlight an educational plan for others. Other limitations restricting the range of uses of smart technologies for participants were the purchasing cost of apps, and the fear of using up credit when WIFI was unavailable. Many limited themselves to free apps, which is contradictory to the rising revenue figures reported for app purchases (Statistica, 2020). Many only accessed on-line applications when they could avail of WiFi in their home environments. Some participants chose not to carry their smartphones or tablet/iPads with them on a daily basis due to concerns about losing or damaging their technologies, or the risk of theft, again reducing accessibility. Whilst these concerns are reasonable considering the heightened risks of personal and property crimes against people with intellectual disabilities (Fisher, Baird, Currey & Hodapp, 2016), it again sets this population apart in terms of the continual access to technology that their peers engage in. If mobile app technology is to be promoted for mHealth solutions for the ID population, the ability to purchase the necessary hardware and software is essential. Additionally, the design of apps should ensure that mobile credit and real-time connectivity are not required to execute an app or to store information, and any upload of information to remote databases or repositories should only occur when WiFi becomes available. Improved education and creative solutions around keeping personal property safe may also alleviate fears of technology being stolen which would allow for ready access in all environments.

Even when technology was available and unrestricted, many participants struggled to use it due to poor literacy skills. Basic skills like sending and receiving text messages were compromised due to difficulties with reading and spelling. The more advanced literacy skills required to make full use of internet searches, apps and social media sites proved out of reach for the majority of participants in this study. Research conducted in the area of literacy with adults with ID has shown that whilst the majority demonstrate only emergent or primary school levels, they remain interested in literacy development and benefit from ongoing education in this area (Moni, Jobling, Morgan & Lloyd, 2011; van den Bos, Nakken, Nicolay & van Houten, 2007). Service centres have been found to be lacking in their provision of appropriate, concentrated literacy instruction (Moni et al, 2011) and the provision of such would certainly benefit the accessibility of technology. Increased literacy skills may improve accessibility for some users, but this will not meet the needs of all. It is vital that user interfaces adapt to serve those who have lower abilities in literacy and are designed specifically for those with ID if their applications propose to serve their needs.

When participants lack the education, skills, and experience necessary to access smart technology effectively it is easy to see why they receive messages of caution from those around them. The negative perceptions that these cautionary messages create often discourage use altogether, when a more productive approach would lie in training people to use applications safely and privately. Bespoke, standardised, and evidence-based training on commonly used applications should be accessible for staff, families, and service users to increase accessibility. Additionally, ID specific mobile apps with easy access interfaces, limited navigation requirements, high levels of personal data privacy, and affordable purchase and running costs need to be developed to increase use and diversity of technology for the ID population, particularly in areas of health management.

5.4.3 Facilitators

Service centres facilitated access to technologies such as iPads/tablets to access apps, and PCs to access the internet. This provision increased access for many of the participants but was limited to the hours that services operate. Some service centres also provided training sessions on how to use these technologies, however, the majority of training was conducted by staff members so relied on their availability and ability to teach the necessary skills. Predominantly those staff that provided structured training to groups, had an interest in the technology package they were teaching and displayed some proficiency in the area. However, the majority of Service centre staff that work directly with adults with IDs in Ireland require a QQI Level 5 qualification in Health & Social Care or equivalent. This type of qualification does not include any module focusing on technology (Liberties College, 2020) therefore, knowledge and experience of technology differs between services, and the subsequent training and support that can be offered to service users will be dependent upon the staff employed in each service rather than a standardised system. Ongoing support and assistance from staff when accessing technology was noted as facilitating use, but again this was limited by individual staff availability and computer literacy skills. Some staff members created written prompts to encourage independent internet searches for those with limited literacy and computer literacy skills. This allowed users to access the internet without waiting for staff to be available. If easy access step-by-step visual or video guides were developed and standardised for the most commonly used applications, this may increase independent usage and provide a visual trail for problem-solving when utilising technology. It would also alleviate the time pressures on staff to support these activities. Both picture activity schedules and video modelling techniques have been proven effective in teaching acquisition skills in many areas with adults with ID (Chan, Lambdin, Graham, Fragale & Davis, 2014; Kim & Kimm, 2017), and could be utilised to facilitate skill building in the area of technology use.

5.4.4 Wants & Needs

Participants were interested in technology and indicated that they would like the opportunity to own more smart technology themselves and learn how to use it properly. All 205 adults with ID that did not use technology in the Patrick et al. (2020) study, also stated an interest in owning technologies such as computers/laptops, iPads/tablets, and smartphones. The ability to send texts was raised on many occasions and appeared to be the main area of need for participants in this study. Again, this highlights the need for both literacy and digital literacy skills to be promoted, supported, and targeted more within Service centre programmes if people with ID are not to be left further behind in the advancement of technology. It also identifies the need for interfaces to be more user friendly for those with lower levels of literacy, particularly for apps that can be utilised in an assistive technology capacity. Other design elements that participants stated they would like were larger screen sizes, larger text sizes and more pictures to compliment the text. These design wishes underpin the need for simpler designs to accommodate those with lower literacy levels and cognitive impairments, to ensure accessibility to technological solutions. Many of these design elements are already listed as standards in web designs by the W3C (2019) in their Cognitive Accessibility section, and both Google (Material Design, 2020) and Apple Inc. (2020) have design guidelines with accessibility sections, however, these may not be fully utilised by many app developers prior to design.

Not only did participants demonstrate an understanding of how technology could help to improve health and reduce weight, but there was genuine interest in the possibility of this type of mobile app being available to them. While some studies have reported on the health benefits that technology could provide to adults with ID (Jones et al., 2018; Haymes et al., 2015; Sheehan & Hassiotis, 2017), to date only a few have been developed to facilitate increased exercise engagement and healthier diets (Peréz-Cruzado & Cuesta-Vargas, 2013; Ptomey et al., 2015; Neumeier et al., 2017). This is not only an area of need for the ID population, but an area of interest, and future research should incorporate accessible technological solutions into weight management interventions to aid choice and self-management.

5.4.5 App Wireframe Mock-up

The concept of the traffic light colours representing the health value of different foods was acceptable and understandable to participants, as was the graphical feedback display representing this (see Appendix G). The same view was expressed for the exercise visual feedback display (see Appendix G) and both the duration and intensity inputs were also acceptable and understandable. One aspect of slight confusion for the exercise display was when participants commented that if the symbol of the man was near the left-hand side of the display that this would be bad. Since any duration of exercise is seen to induce health benefits (US Department of Health and Human Services, 2018), participants would need to be educated to this effect. Participants felt that the type of information this app could provide them with would be beneficial to aid self-management of both diet and exercise. However, some design changes were suggested to increase accessibility, mainly: lighter colours, larger text sizes, larger buttons, more space between buttons on a page, pictures to supplement the text, and the use of happy/sad faces instead of thumbs up/down. Many of these design changes reflect the standards listed in Google (Material Design, 2020) and Apple Inc. (2020), and were used in the finished design for the app developed for the multi-component weight management intervention in Chapter 6 of this thesis.

5.4.6 Limitations

This study only included participants aged between 19-59 years, with a mild or moderate ID. Whilst this does not capture the views and experiences of older adults or those with severe and profound ID, it does capture the particular profile of this population that are most susceptible to obesity and that would most benefit from technology solutions that support self-management of health choices. The findings reported in this study are qualitative and self-reported and are not objectively validated. That said, the findings identify important pre-requisite skills and barriers that must be duly considered in the design of any smart technology solution for adults with ID. The design changes suggested are particular to the proposed app designed for the subsequent weight management intervention in this study, however, many of

the elements reflect generic design standards to increase accessibility for those with cognitive impairments.

5.4.7 Conclusion

Adults with ID are interested in using smart technology but experience many barriers when it comes to accessing it. High costs deter ownership in the first instance which immediately reduces accessibility to the necessary smart hardware. Cognitive impairments, poor literacy skills and fear of on-line social media sites limit use and reduce the possibilities for appropriate peer inclusion in this area. Lack of access, necessary education and supporting systems for smart technology has led to a lack of confidence and comfort in utilising this type of technology, meaning only basic functions are ever realised by people with an ID. Younger adults with ID are increasingly accessing more smart technology and utilising it for more variety of functions, however, their levels of ownership and use are equivalent to those of much older adults (60+ years) in the general population, and restrictions on use are still imposed by families and services for safeguarding purposes.

Many service centres and families provide access to different technologies and indeed provide a basic level of training and support, but more structured training and support mechanisms are needed to embed smart technology in the lives of adults with ID. Only with ownership, education, support, regular access, and regular use can people with ID develop the skills to utilise this type of technology for leisure and to fully assist them with self-managing aspects of their lives.

Chapter 6

The HealthyTaps Programme:

Utilising mobile app technology to support self-management during a multi-component weight management intervention for adults with ID

6.1 Introduction

Different types of health interventions have been tried and tested in the effort to reduce obesity within the adult ID population (Spanos et al., 2013^a). These can be categorised into either (1) health promotion interventions, (2) dietary interventions, (3) exercise interventions, (4) behaviour change interventions, (5) physical activity and behaviour change interventions, (6) or MCIs, as was demonstrated in the systematic review in Chapter 2. Whilst MCIs appear to be the most effective for both the general population and the ID population, they must comprise of three particular components: (1) a sufficient calorie deficit (approximately -500 to -600 kcal per day), (2) an increase in physical activity, and (3) proven behaviour change strategies (Spanos et al., 2013^a; Harris et al., 2017). Even with all three components present the outcomes for individuals with ID vary greatly and the percentages of participants achieving clinically significant weight losses of $\geq -5\%$ range from around 21% to 62% (Harris et al., 2017; Melville et al., 2011; Ptomey et al., 2018). Only one small MCI study available achieved 100% of participants with $\geq -5\%$ weight loss (Croce, 1990), however, the 3 participants involved in this study had severe IDs and lived in a residential setting where their diet and exercise conditions were more closely monitored and controlled than would be the case for those living more independent lives. With the move towards more community access, more autonomy, and more independent living for adults with ID (Inclusion Ireland, 2014), close monitoring and control of food intake is not appropriate nor an option. The current prevalence rates of obesity are highest in adults who have a mild or moderate ID and live independent lifestyles (Bhaumik et al., 2008; Melville et al., 2008; Hsieh et al., 2014). It is therefore, necessary for adults with ID to take more control and responsibility for their own choices in relation to diet and exercise, but this can only be achieved if the correct supports are in place to aid self-management and overcome existing barriers.

A lack of choice in mealtimes, poor functional knowledge of foods, and difficulties in avoiding temptations have all been identified as barriers to healthy eating by adults with ID (Kuijken et al., 2016; Lorentzen & Wikstrom, 2012). Accessibility issues due to lack of transport, high costs, poor weather and safety concerns have all been identified as barriers to exercising by adults with ID (Bodde & Seo, 2009; Temple &

Walkley, 2007; Messent et al., 1999; Frey et al., 2005). These barriers were also raised by the participants during the focus groups held at the start of this study (Chapters 3 and 4). In order to overcome as many of these barriers as possible, it is necessary to upskill, enable and motivate adults with ID to move towards healthier choices. Current policy directives support the involvement of adults with ID in choices that directly affect them, and the New Directions Report specifically advocates support for health and wellbeing (Inclusion Ireland, 2014). However, the ability to make good choices in relation to health is dependent upon adequate knowledge, the ability to have control of your own choices, and the presence of functional support systems.

Increasing knowledge of diet and exercise has been attempted in many weight management and health interventions for adults with ID (Bergström et al., 2013; Mann et al., 2006; Ewing et al., 2004). The dietary advice given to the general public for weight loss is to reduce daily calorie intake by approximately -500 to -600 kcal below energy expenditure (NICE, 2014^a). This method may prove difficult for adults with ID for a number of reasons. When eating take-away foods, deli-foods or meals in restaurants, there is often no information available on calorie content. Additionally, when meals are prepared by other family members, the person with ID may not include unseen calories such as the fats involved in the cooking process or the additions within sauces. Counting calories can be complex for many of us as it not only involves competence in addition and subtraction, but often involves multiplication or division in order to calculate the calories present in the particular portion you are eating. For many people with ID simple maths computational skills are often missing or delayed (Schnepel, Krähenmann, Dessemontet & Opitz, 2019) which makes calorie counting a bigger challenge for this population.

Many of the Health Promotion type interventions for adults with ID have provided simple dietary information in relation to good foods to eat, bad foods to avoid, and general portion sizes (Bergström et al., 2013; Mann et al., 2006). Whilst these are good starting points for any dietary change, if only the basic food information such as increasing fruits, vegetables and brown breads, and reducing treats, soft drinks, alcohol and white breads is covered, this does not provide enough information for functional decision-making to become a reality. For studies that have provided dietary

information only without any active dietary change component, the results have largely shown no significant effect on weight (Bergström et al., 2013; Mann et al., 2006; Ewing et al., 2004; Chapman et al., 2005; Geller & Crowley, 2009). Studies that went beyond dietary information to include prescribed diets or weekly menus that ensured reduced calorie intake of -500 to -600 kcal per day, if they were adhered to, demonstrated greater success (Harris et al., 2017; Antal et al., 1988; Zoppo & Asteria, 2008; Melville et al., 2011; Croce, 1990; Martinex-Zaragoza et al., 2016). Whilst the latter types of interventions resulted in clinically significant weight losses for a large proportion of the participants, they failed to adequately incorporate the aspect of choice and did not account for times when decisions outside of the plan were required.

Some studies (Saunders et al., 2011; Ptomey et al., 2018; Jones et al., 2015^a) incorporated choice into the dietary component by providing a food categorisation system based on the Traffic Light Diet by Epstein, Wing, Koeske, Andrasik & Ossip (1981). The Traffic Light Diet used by Epstein et al. (1981) colour-coded foods based on their calorific content, a concept which the authors successfully utilised in weight loss programmes for obese children. Foods were separated into 11 different food groups and then coded as Green, Yellow or Red depending on the calorie content in specific portion sizes. The diet consisted of two rules (1) keeping the daily calorie consumption under prescribed limits, and (2) not eating more than 4 Reds per week. As part of their dietary component Saunders et al. (2011), Ptomey et al. (2018) and Jones et al. (2015^a) created food lists that were categorised as Green, Yellow or Red based on calorie content, and provided daily consumption guides for each category. The main dietary interventions in all three studies comprised of prescribed elements of diet but then used the colour-coded food lists to support additional food choices that fell outside of the prescribed diet. This type of system allowed for flexibility and choice in some of the foods eaten, whilst encouraging participants to eat more of the healthier Green category foods and limit the unhealthy category Red foods. This type of system also increased food knowledge in a functional manner to support decision-making in food intake. Whilst temptations would remain difficult to avoid, the quantity guide provided in this type of dietary intervention may help to limit

consumption of unhealthy, high calorie Red foods. However, the main emphasis of the dietary component in all 3 studies remained as a prescription diet.

Many of the studies incorporating physical activity components consisted of exercise programs run within service centres (Croce & Horvat, 1992; Ordonez et al., 2014; Mendonca et al., 2011; Mendonca et al., 2009), or pedometers used to increase daily steps (Harris et al., 2017; Melville et al., 2011; Saunders et al., 2011; Ptomey et al., 2018). Exercise programs run through service centres provide routine, social activities that are at an acceptable physical level for adults with ID. These have all been identified as factors that facilitate engagement with physical activity by adults with ID (Mahy et al., 2010; Temple & Walkey, 2007). They are provided free of charge to Service Users and do not rely on external transport or good weather conditions to go ahead. However, again choice is compromised due to the ability of service centres to cater for all preferences. Additionally, ensuring that everyone engages with exercise at the intensity and duration required each day is impossible for service centre staff to manage, and will be influenced by each service centres culture towards exercising. This again is where personal choice and personal responsibility for daily exercise becomes necessary. The main form of exercise chosen by adults with ID appears to be walking (Heller et al., 2008), however, achieving the daily physical activity guidelines is lacking for the majority (Frey, 2004). Pedometers provide a monitoring system and a daily target which can motivate people to increase the amount of walking they take part in each day (Pal, Cheng, Egger, Binns & Donovan, 2009), and this has proven successful for adults with ID (Saunders et al., 2011; Ptomey et al., 2018). However, this does not translate to the target guidelines of a minimum of 150 minutes of moderate exercise per week. In fact, counting steps alone provides no measure of the intensity of exercise engaged in. Bearing in mind that for most adults with ID the guidelines are well beyond reach at present (Frey, 2004), and since exercise plays a smaller role in weight loss, any increase in physical activity must be seen to be beneficial to both health and weight loss.

Personal choice, personal responsibility and environments that support choice and change, are essential elements to achieving long-term changes in diet and exercise habits (Brownell et al., 2010), but managing choices and taking responsibility for healthier ones takes competent self-management skills. Self-management is defined as “a behaviour that a person emits to influence another behaviour” (Cooper, Heron & Heward, 2014, page 585). Self-management programmes often consist of goal setting, self-monitoring, reinforcement contingencies, evaluation of performance, and adjustment of goals where appropriate (Cooper, Heron & Heward, 2014). Many people in the general population utilise mobile apps and wearable technologies to aid them in self-managing both dietary choices and physical activity engagement (Jones et al., 2018). The majority of mobile apps available to aid self-management of diet provide a function for goal setting, a method of food intake tracking, and a system of feedback for evaluating progress (Under Armour, Inc., 2020; Fitbit, Inc., 2019; WW International, Inc., 2020). Goal setting may require an understanding of the guidelines around food intake and exercise engagement, or goals may be automatically generated depending on the information each individual inputs in the initial setup of the app. Additionally, the adjustment of goals is usually a process that occurs by manually inputting different parameters at different times, predominantly when weight changes occur. These initial set up processes and additional manual adjustments may prove too difficult for many adults with ID (Jones et al., 2018), and may reduce the ability to set reasonable goals. The process of recording food intake has been shown to decrease weight (Hollis et al., 2008; Crone-Todd, 2012), and this form of self-monitoring is one of the main behavioural strategies recommended for weight loss interventions (NICE, 2014^a). However, available mobile apps for self-monitoring food intake remain difficult for adults with ID as the majority rely on a system of calorie counting and use complex interfaces (Jones et al., 2018). Technological self-monitoring solutions for exercise, such as pedometers or Fitbit watches, may be more accessible to adults with ID as tracking is automated, however, accuracy varies from 52% to 100% (Vandelanotte et al., 2015), and many relate to step count targets but do not provide measures of intensity and duration to enable comparison to guidelines. In order to evaluate progress throughout the day and adjust eating and exercise patterns

accordingly, the feedback systems incorporated into apps must be simple enough for adults with ID to compare their progress against goals or guidelines set. Successful self-monitoring and successful behaviour changes towards healthier eating and increased exercise should also receive reinforcement to encourage future instances, however, the provision of reinforcement through apps is limited to accruing some form of token such as points or stars. For some people, these tokens will be reinforcement in themselves, however, for others this type of reinforcement falls short if there is no ability to trade these tokens for more meaningful tangible or sociable reinforcers.

At present MCIs targeting weight loss for adults with ID include (1) dietary components that incorporate prescribed diets, with some also including a system to manage additional choices, (2) specific exercise programmes, and (3) behavioural strategies such as goal setting, self-monitoring of food intake and exercise, and monetary incentives or tokens traded for tangible and social reinforcers (Harris et al., 2017; Melville et al., 2011; Croce, 1990; Martinez-Zaragoza et al., 2016; Saunders et al., 2011; Ptomey et al., 2018). Whilst these components have proven successful in reducing weight for adults with ID, they utilise prescribed diets and paper-based self-monitoring systems and rely on weekly feedback sessions with a consultant where reinforcement is then delivered. Mobile app technology has the potential to provide a platform for an easily accessible self-monitoring tool that can provide instantaneous visual feedback on performance to allow evaluation and real-time adjustment of food intake choices and exercise engagement. Reinforcement schedules can be programmed into the app as appropriate, to ensure regular and timely delivery of conditioned token reinforcers for self-monitoring. These tokens can then be traded at weekly goal setting consultations for more meaningful tangible or social reinforcers appropriate to the individual.

To date no MCI intervention has incorporated mobile app technology as a tool to aid self-management of diet and exercise for adults with ID. This pilot project aims to reduce overweight in adults with a mild/moderate ID, by means of a multi-component weight management intervention which uses the HealthyTaps app combined with a novel self-management approach.

The primary aims of this study were:

- 1) To assess the feasibility of running a larger scale randomised control trial (RCT) in terms of recruitment, attrition rates and attendance.
- 2) To assess the impact of an ID-specific Health Promotion Education Series (HPES) on weight related anthropometric measures.
- 3) To assess the impact of an ID-specific MCI utilising the HealthyTaps mobile app on weight related anthropometric measures.
- 4) To evaluate the efficacy of The HealthyTaps Programme (the HPES and the MCI) against the NICE (2014 ^a) guidelines for effective weight management lifestyle interventions for the General Population.
- 5) To assess the ability of adults with ID to continue to self-manage their healthy choices after intervention ceases.
- 6) To evaluate differences in sub-groups for gender, diagnosis and living arrangements.
- 7) To assess the social validity of The HealthyTaps Programme.

The secondary aims of this study were:

- 8) To gain insight into the types of foods commonly eaten by adults with ID through the use of food diaries.
- 9) To determine whether adults with ID understand and retain the core concepts delivered during the HPES.
- 10) To measure baseline food knowledge levels and food knowledge gains as a result of the HPES and the HealthyTaps app food game.
- 11) To evaluate correlations between attendance and weight losses, app usage and weight losses, and knowledge and weight losses.

6.2 Method

6.2.1 Rationale & Design

This study was designed as a pilot study to assess whether overweight adults with a mild or moderate ID could successfully self-manage their diet and exercise choices to affect clinically significant weight loss of $\geq -5\%$. This pilot study was also developed to assess the feasibility of running a larger scale randomised control trial (RCT) in the future. The NICE (2014^a) guidelines for effective weight management interventions advocate MCIs that incorporate (1) a dietary component that produces a calorie deficit, (2) an increase in physical activity levels, and (3) the use of proven behaviour change strategies to support changes in diet and exercise habits. The intervention designed for this pilot study comprised of a 10-week health promotion intervention followed by a 16-week MCI that incorporated the NICE (2014^a) guidelines, and that utilised the HealthyTaps app to support self-management of diet and exercise. Pre- and post-measures of body composition were examined and compared to the NICE (2014^a) outcome guidelines for effective weight loss interventions, and food knowledge gains were also evaluated. A second replication of the study was conducted to increase reliability of the results found. The original study and the replication study are both reported in this Chapter.

6.2.2 Research Team

Two researchers, Laura Skelly and Dr Philomena Smyth, qualified to Master's Degree and Doctoral Degree levels respectively in Applied Behaviour Analysis, were responsible for the design and implementation of this project. In Study 1 Laura Skelly was the lead researcher for Groups 1 to 3, and Dr Smyth was the lead researcher for Groups 4 and 5. In Study 2 Laura Skelly was the lead researcher for Group 6, and Dr Smyth was the lead researcher for Groups 7 and 8. Both researchers designed the content for the HPES, the MCI, the HealthyTaps app and the reinforcement contingencies, as detailed in the Intervention section below. A registered dietician, Patricia Cusick, consulted on the study to inform and validate the dietary information

to be used in the HPES, MCI and HealthyTaps app. An app developer, Phillip Hartin, was contracted to build the HealthyTaps app based on the design and functional requirements provided by the two main researchers. All app features were designed in consultation with the two main researchers, who provided final approval.

6.2.3 Participants

6.2.3.1 Study 1 Participants

Forty-one adults with ID were invited to take part in The HealthyTaps Programme. Participants were invited to join the study via their service centre manager (n=32) or their charity's adult liaison officer (n=9) if they satisfied the following criteria: aged 18 or over, mild or moderate ID, and BMI > 25 kg/m². Participants were excluded if they showed any challenging behaviours or mental health issues that would unduly jeopardise participation in the study. Participants were targeted for invite to this phase of the project if they had participated in the focus groups or if they had approached the service centre managers and expressed interest. Thirty-two (78%) of those invited were interested in participating and consented to join. Of the 32 participants that started Study 1, 28 (88%) had previously attended the focus groups during the initial phase of this project, and 4 (12%) were newly recruited from existing service centres after expressions of interest were made to the service centre managers. The 9 participants that were invited but chose not to participate, did so due to lack of interest (n=5), lack of support (n=3), and the inability to attend sessions on the chosen day due to prior commitments (n=1). The 32 consenting participants were assigned to one of five groups based on geographical area and attendance at particular service centres or charity run groups. Group 1 participants (n=5) were a parent-led group who were invited to join the study via their local charity's adult liaison officer, and participants from Groups 2 to 5 (n=27) were service-led groups who were invited to join the study via each of their service centre managers. Participants that did not previously take part in the focus groups received an easy read demographic questionnaire one week before the study began. Participants were asked to complete this questionnaire, with a support person if required, and submit it on the first day of the HPES. The

demographics for participants who had previously attended focus groups, were updated for age and weight but all other information remained as per the original form. The demographics for each group are shown in Table 6.2 in the Results section.

6.2.3.2 Study 2 Participants

Twenty-six adults with ID were invited to take part in Study 2 of The HealthyTaps Programme. Participants were invited to join Study 2 via their service centre manager (n=23) or their charity's adult liaison officer (n=3) if they satisfied the following criteria: aged 18 or over, mild or moderate ID, and BMI > 25 kg/m². Participants were excluded if they showed any challenging behaviours or mental health issues that would unduly jeopardise participation in the study. Participants were targeted for invite to this phase of the project if they had participated in the focus groups or if they had approached the service centre managers or adult liaison officer and expressed interest. Fifteen (58%) of those invited were interested in participating and consented to join. Of the 15 participants included in Study 2, 6 (40%) had previously attended the focus groups during the initial phase of this project, and 9 (60%) were newly recruited after expressions of interest to service centre managers or the charity adult liaison officer. The 11 participants that were invited but chose not to participate, did so due to lack of interest (n=5), and lack of support (n=6). The 15 consenting participants were assigned to one of three groups based on geographical area and attendance at particular service centres or charity run groups. Group 6 participants were a parent-led group who were invited to join the study via their local charity's adult liaison officer (n=3), and participants in Groups 7 and 8 (n=12) were service-led groups who were invited to join the study via each of their service centre managers. Participants that did not previously take part in the focus groups received an easy read demographic questionnaire one week before the study began. Participants were asked to complete this questionnaire, with a support person if required, and submit it on the first day of the HPES. The demographics for participants who had previously attended focus groups, were updated for age and weight but all other information remained as per the original form. The demographics for each group are shown in Table 6.3 in the Results section.

6.2.4 Procedure

6.2.4.1 Consent and Ethical Approval

The project was approved by a University Ethics Committee and was conducted in full accordance with World Medical Association Declaration of Helsinki (2002). Particular attention was given to issues of informed, voluntary consent, and ability to give consent was corroborated by a caregiver who knew them well. Consent was also gained from each participant's General Practitioner stating that they had no medical issues that would deter them from taking part in the study. Weekly body measures and the delivery of individual information were conducted in a private setting due to the sensitivity of the data being communicated. Participants who did not meet weekly goals set and who were not eligible for reinforcement were often disappointed in themselves. To counteract this and ensure continued motivation for the week ahead participants were provided with a detailed, easy-access, individual plan to problem-solve issues from the previous week, with structured steps that would ensure achievement for the upcoming week. The researchers also offered to discuss the proposed plan for the week ahead with support staff or family carers if the participants wanted this. Participants were also reassured that weight loss can be difficult and takes time for all of us.

6.2.4.2 Setting and Structure

6.2.4.2.1 *Food Diaries*

Participants were provided with 4 x 7-day weekly food diaries at the end of the focus groups and were asked to complete these prior to the HPES starting. Each page represented one day, as shown in Appendix H, and participants were instructed to place a tick for each food they consumed in the box that best represented that food. For example, if they ate a banana one tick was placed in the "fruit and veg" box, and if they ate 2 sausages then 2 ticks were placed in the "processed meat and fish" box. All completed diaries were collected and analysed by researchers prior to the HPES starting.

6.2.4.2.2 *Health Promotion Education Series (HPES)*

The HPES took different form for each of the study groups with Study 1 consisting of 10 weeks, and Study 2 consisting of 7 weeks, as detailed in Appendix K. On review of the HPES post Study 1, material deemed as adding no value to the practical workings of The HealthyTaps Programme was removed from the Study 2 HPES sessions. Additionally, Study 1 participants did not receive access to the app until week 8 of the HPES since the app was still under construction and testing before that time. Study 1 participants utilised food flashcards to learn about food categories from week 3 of the HPES until the app was available in week 8. In contrast, Study 2 participants gained access to the food game on the app from week 2 of the HPES to learn about food categorisations.

For Study 1 the ten HPES sessions for participants were held once per week for 10 consecutive weeks for Groups 1 and 2, and over 12 weeks for Groups 3 to 5 due to service centre closures. The sessions were held in a designated room in the charity's educational centre for Group 1, and a designated room within each of the service centres for Groups 2 to 5. Sessions were approximately 1½ hours in duration, with a 15-minute break in the middle, and consisted of both theoretical and practical elements. All HPES sessions were delivered by one of the main researchers.

For Study 2 the HPES was streamlined into 7 sessions, once per week for 7 consecutive weeks for Group 6, over 9 weeks for Group 7 and over 10 weeks for Group 8 due to varying participant availability issues. Group 6's sessions were held in a room within parental homes and sessions rotated weekly between the three homes. The sessions for Groups 7 & 8 took place in a designated room within each of the Service centres. Sessions were approximately 1½ hours in duration, with a 15-minute break in the middle, and consisted of both theoretical and practical elements. All HPES sessions were delivered by one of the main researchers.

In both studies, training was also provided for the people considered to be the “Circle of Support” (COS) surrounding the participant, i.e., parents, siblings, staff members, employers, etc. Attendance was voluntary and COS could either join the training

sessions that participants engaged in, or opt for a more detailed 3-session training designed specifically for COS. All COS HPES sessions were delivered by one of the main researchers.

6.2.4.2.3 *Multi-Component Intervention (MCI) using HealthyTaps*

Each participant downloaded the HealthyTaps app on to their own mobile smartphone, or a smartphone provided for the study. In Study 1 participants had access to the app under a training ID code from week 8 of the HPES which was the app training, until the start of the MCI. Delays of between 0 and 6 weeks occurred between the end of the HPES and the beginning of the MCI due to technical issues requiring de-bugging and updating of the app, and summer closures for some service centres. During these delays' participants continued to have access to the app under their training code but no consultations took place. Weight changes during this period are reported as part of the anthropometric measures in the Results section in Tables 6.6 to 6.11. In Study 2 participants had access to the app from week 2 of the HPES for the purpose of playing the food categorisation game (as described below).

At the start of the MCI in both studies, participants were transferred onto a live individualised ID code and had 24-hour access to the app for the duration of the MCI. Each participant attended a private one-to-one consultation with one of the main researchers, each week during the MCI, in the designated rooms provided by each of their settings. Individual consultations took around 15 to 20 minutes per person and involved the researcher in (a) taking all anthropometric measures, (b) reviewing and discussing the previous week's app usage, (c) discussing any difficulties that arose, (d) helping to set goals for the week ahead, (e) informing participants of what reinforcement they were eligible for that week, and (f) providing certificates for weight losses. When all individual consultations were completed each week, participants came together in their group for a revision of the general concepts for weight management, a review of the food and exercise guidelines, a discussion on the importance of using the app, and the presentation of reinforcers to those who were eligible.

6.2.4.3 Interventions

6.2.4.3.1 *Traffic Light Diet for Intellectual Disabilities (TLD-ID)*

The Traffic Light Diet for Intellectual Disabilities (TLD-ID) designed for use in this study, was based on the Epstein et al. (1981) idea of colour-coding foods based on their calorific content, a concept which had been used successfully in weight loss programmes for obese children. The Epstein et al. (1981) diet used Green, Yellow and Red colour coding to rate the calorie content in specific portion sizes of foods that had been separated into 11 food groups. The diet consisted of two rules: (1) keeping the daily calorie consumption under prescribed limits, and (2) not eating more than 4 Reds per week. Since the diet was designed for obese children, the responsibility for managing food intake and adhering to the rules predominantly lay with parents, therefore calculation of calorie intake over the day was feasible. Since this study involved self-management of food intake for cognitively impaired adults, the structure and rules surrounding the diet required simplification.

The TLD-ID used in this study still involved the categorisation of foods and drinks into either Green, Yellow or Red types. The main researchers made a list of 185 common foods and drinks, before categorising them into either Green, Yellow or Red type using the guidelines given in The Victorian Healthy Eating Enterprise's "Healthy Choices: Food and Drink Classification Guide" (2015). When the 185 foods had been allocated to a particular colour category the researchers reviewed the list and made changes that would encourage better choices from a behavioural perspective when eating for weight loss. For example, in The Victorian Healthy Eating Enterprise's (2015) guideline nuts and seeds are listed as Green category foods due to their nutritional health value, however, these foods are high in calories and were therefore changed to a Red category for this study. Diet soft drinks are listed as a Red category drink in The Victorian Healthy Eating Enterprise's (2015) guideline, however, this was changed to a Green category for this study. Regular consumption of full-sugar soft drinks has been noted to be high in adults with ID (Hsieh et al., 2014), and this was also reflected by participants in this study during the focus groups in Chapters 3 and 4 of this theses. Elimination of soft drinks was deemed unattainable for most

participants, therefore, providing encouragement to consume the lower calorie option was desirable from a behavioural perspective for weight loss. If both full-sugar and diet soft drinks were categorised as Red foods, then participants were more likely to continue consuming the more calorific choice if this was their current habit. When behavioural changes to the food and drinks list were complete, the qualified dietician reviewed the list to ensure the dietary information was appropriate for weight loss purposes. The Green category was made up of low-calorie healthy foods such as fruits, vegetables, wholemeal breads and grains, eggs (except fried), fresh fish (not fried or coated), and lean meats. The Yellow category was made up of medium calorie foods that required more stringent portion control such as white breads, low-fat dairies, low-fat sauces, stews, bolognese sauces, fish fingers, oven chips and better option treats (popcorn, baked crisps, chocolate rice cakes). The Red category consisted of foods that should be avoided or severely restricted when trying to lose weight such as treats (biscuits, cakes, crisps, chocolates), alcohol, full-sugar soft drinks, fried foods, take-away foods, full-fat dairies, full-fat sauces, and creamy foods. Samples of the food lists can be found in Appendix I.

When the 185 foods had been coded and approved by the dietician, a set of rules was derived to guide daily consumption levels for each food type. A number of realistic healthy eating plans were created by the main researchers to assess how many of each Green and Yellow food types were present. The daily eating plans consisted of (1) three healthy meals representing breakfast, lunch and dinner, (2) a low-fat snack for morning tea-break, (3) a low-fat snack for afternoon break, and (4) a low-fat snack for evening time. After analysis of 8 different healthy eating plans, the amount of Green and Yellow foods per day were decided as per Figure 6.1 below. Since participants would be managing their intake on a daily basis from visual feedback provided by the HealthyTaps app, the weekly rule for Red foods in the Epstein et al. (1981) study was deemed inappropriate. For the 20 participants that returned food diaries prior to the HPES, the average weekly consumption of Red foods was 16 (SD=6.9, range=7 to 29) which is on average four times the amount recommended by Epstein et al. (1981), but could be as high or higher than 7 times as many for some participants. The reality of participants being able to drop from 16 or 29 Red foods to 4 Red foods per week as

per the Epstein et al. (1981) were slim. Therefore, the researchers adjusted the Reds to a maximum of 7 per week or 1 per day as shown in Figure 6.1 below. These daily consumption levels were also approved by the consultant dietician.

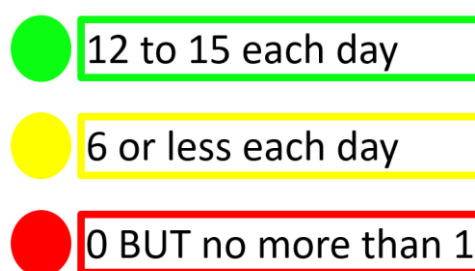


Figure 6.1: Daily Consumption Rules for the Traffic Light Diet During Weight Loss

If any participant reached their target healthy weight (BMI of approximately 23kg/m²) the daily consumption rules for Yellow and Red foods increased to the amounts shown in Figure 6.2 below for weight maintenance purposes. These amounts were again approved by the consultant dietician.

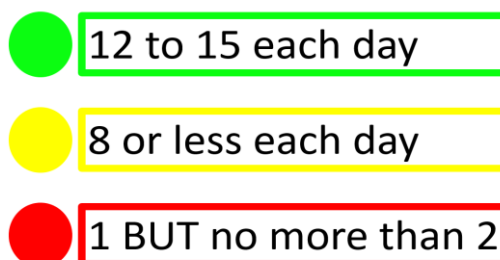


Figure 6.2: Daily Consumption Rules for the Traffic Light Diet During Weight Maintenance

Portion sizes based on parts of the hand (unlockfood.ca, 2018) were used to produce a measurement reference guide for portion sizes of particular foods. Different foods were categorised under 6 different hand shapes: fist, cupped handful, flat hand, palm, thumb and fingertip (see Appendix J). An easy reference guide was given to each participant on Week 4 of the HPES. Participants were taught how to shape their hands for each of the sizes, before using actual foods to practice measuring out different foods during the HPES. The consulting dietician approved the portion size guide prior to participants receiving the information.

6.2.4.3.2 *Exercise Guidelines*

Physical activity guidelines were based on The U.S. Department of Health and Human Service's 2018 version of Physical Activity Guidelines for Americans (2nd Edition). This guideline is recommended by the CDC (2019^b) for increasing physical activity in adults with disabilities. These guidelines recommend a combination of both cardio and resistance type exercises as described below.

For Cardio/Aerobic exercise:

- A minimum of 150 minutes per week of moderate-intensity aerobic exercise;
- or**
- A minimum of 75 minutes per week of vigorous-intensity aerobic exercise.

For Resistance/Muscle-Strengthening:

- Two or more days each week of activities that use all major muscle groups and are moderate or high intensity.

Since the majority of adults with ID engage in extremely low levels of physical activity with very few achieving moderate or vigorous intensity (Harris et al., 2018^b), reaching these levels each week would be very difficult to achieve. In acknowledging this the CDC (2019^b) also state that:

- Adults with disabilities that cannot reach guidelines should regularly exercise at their own level and avoid being sedentary.

Participants in this study were provided with daily guidelines that equated to the amounts shown in Figure 6.3, however, they were also advised that any amount of exercise at any intensity provided health benefits, and they were encouraged to move as often as possible. Since this study involved self-management of physical exercise for cognitively impaired adults that may not have the ability to access equipment or facilities for resistance training, the daily guidelines provided related to cardio type exercise only (see Figure 6.3).

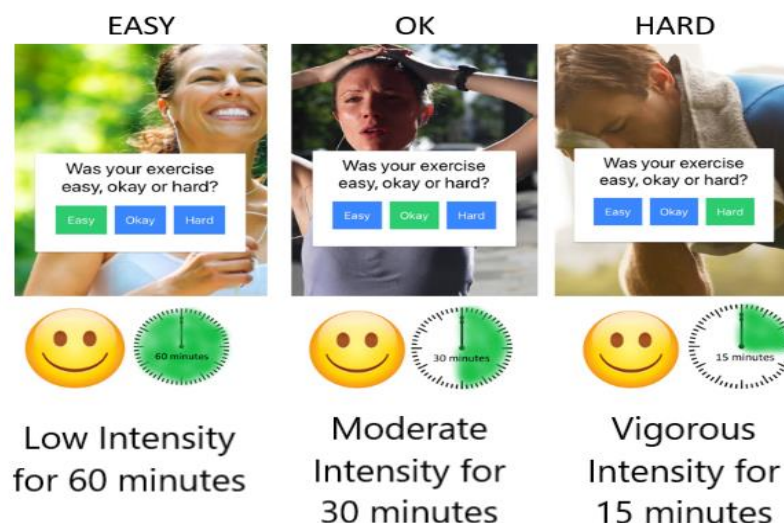


Figure 6.3: Daily Exercise Intensity and Duration Guidelines

6.2.4.3.3 Health Promotion Education Series (HPES)

The outline of topics covered in the HPES over the 10 weeks for Study 1, and the 7 weeks for Study 2, are listed in Appendix K along with the COS training. The series began by introducing the basic concept of eating healthier diets and increasing exercise as the way to lose weight. Subsequent sessions laid the groundwork for the TLD-ID, introduced the exercise guidelines, provided suggestions for changing eating behaviours, introduced the concept of self-managing choices, and trained participants on using the HealthyTaps app. Participants were also informed of the reinforcement contingencies that would be in place during the MCI phase of the project.

In Week 3 of the HPES each participant in Study 1 was given 185 flashcards of common food items and 3 coloured tubs: a green, a yellow and a red. Participants were given the instructions:

“A green food is healthy and good for us. We can eat lots of it. A yellow food is ok for us to eat but we wouldn’t want to eat too much of it. A red food is not healthy for us and we should try not to eat it. Put each food into the colour you think it should go into for these rules.”

Seventy-four (40%) of the food flashcards represented Green category foods, 38 (21%) represented Yellow category foods and 73 (39%) represented Red category foods, as per the TLD-ID described above. When participants had completed sorting the flashcards the boxes were sealed, and the participant's individual code referenced to the set number on the top of the boxes. Correct and incorrect choices were logged at a later date by the researchers. Each participant was then provided with a second set of the same flashcards, and a green, yellow, red and white set of A4 card. This set of flashcards not only showed a picture of the food on the front of the card but contained a green, yellow or red coloured dot on the back to depict the category that food was in. Participants were asked to shuffle the flashcards every day and then take a bundle of about 25-30 cards to practice. Practice involved looking at the food picture, verbally guessing the colour category, and turning the flashcard over to check if the colour guessed matches the coloured dot on the back. If they answered correctly, they placed the card on its corresponding A4 coloured card, however, incorrect answers were placed on the white A4 card. When the 25-30 flashcards were complete participants were advised to review all of the cards that had been placed on the white A4 card before returning all flashcards to the full bundle.

Participants in Study 2 were not given the flashcards but were given access to the food game in the HealthyTaps app (see the Food Game section under 6.2.4.3.4 *Multi-Component Intervention using HealthyTaps App* for details) from the end of Week 2 training and were instructed to play the game as many times as they could each day.

6.2.4.3.4 *Multi-Component Intervention Using HealthyTaps App*

The MCI was a 16-week intervention where participants used the HealthyTaps app to track and self-manage their food and exercise choices on a daily basis. Entries for each participant were saved under their individual code which had been pre-programmed on their mobile device. Participants also received a weekly, one-to-one consultation with one of the main researchers followed by a group consultation, as was described previously in the Setting and Structure section above. The details of the diet, exercise and behaviour change strategies are outlined below.

(1) *Dietary Component:* The TLD-ID described above formed the dietary component of the MCI. Participants were asked to track and manage their daily food intake using the HealthyTaps app, by entering the number of Green, Yellow or Red foods they ate as they ate them throughout the day. HealthyTaps provided immediate visual feedback to participants on the number of each type of food eaten at that time. Participants were taught how to interpret the feedback and alter eating habits if needed, based on the visual feedback they were receiving. Figure 6.4 and Figure 6.5 below are examples of the input mode and visual feedback interface for the food tracking component in the HealthyTaps app. A reference book incorporating the food intake rules, the foods listed under each of the colour categories, a variety of healthy meal suggestions with their respective colour coded tracking quantities, and information on the best options from different types of restaurants and take-aways was also provided to all participants. The colour category food lists were also available to access within the HealthyTaps app. For any foods that were not included in the lists provided, a general rule of Green < 60 kcal, 60 kcal < Yellow >100 kcal, and Red >100 kcal was given and participants were instructed to request help from staff or parents to identify the category based on these rules.

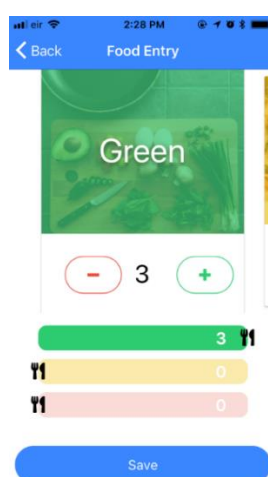


Figure 6.4: Input interface for entering the amount of green foods eaten.

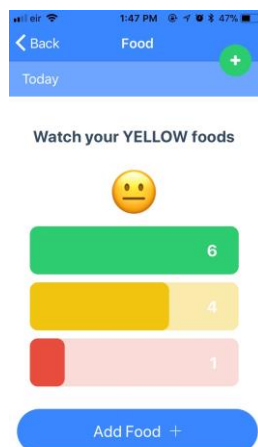


Figure 6.5: Visual Feedback display for foods eaten each day

During the feedback section on app usage at the weekly one-to-one consultation, visual feedback was provided by the researcher on the previous week's entries. The researcher discussed the accuracy of entries based on (1) the number of days food intake had been logged, (2) the overall amounts entered each day, and (3) the entry times of the data reflecting mealtimes. Advice and instructions were provided on how to increase accuracy in all three areas, with accuracy goals agreed for the week ahead. Discussions also focused on the amounts of foods entered and how this related to the guidelines. Goals were discussed and agreed for dietary changes for the week ahead.

Food Game: An additional dietary element available in the HealthyTaps app was a food categorisation game designed to teach the colour codes associated with the 185 common food items used in the HPES. The game presented 10 foods, one-at-a-time, and the participant pressed either the Green, Yellow or Red button to indicate their answer. If the answer was correct a tick in a white circle appeared over the food picture, and if incorrect an X the colour of the correct answer appeared over the picture. Pictures provided also represented appropriate portion sizes. At the end of the 10 foods presented, participants were automatically awarded points based on their performance, see Figure 6.6 below for examples. At each weekly one-to-one consultation with the

researcher, participants were encouraged to use the game and were provided with their overall stats for the previous week's game usage: (1) how many days the game was accessed, (2) how many days they had played more than 3 games, and (2) % correct over all games.

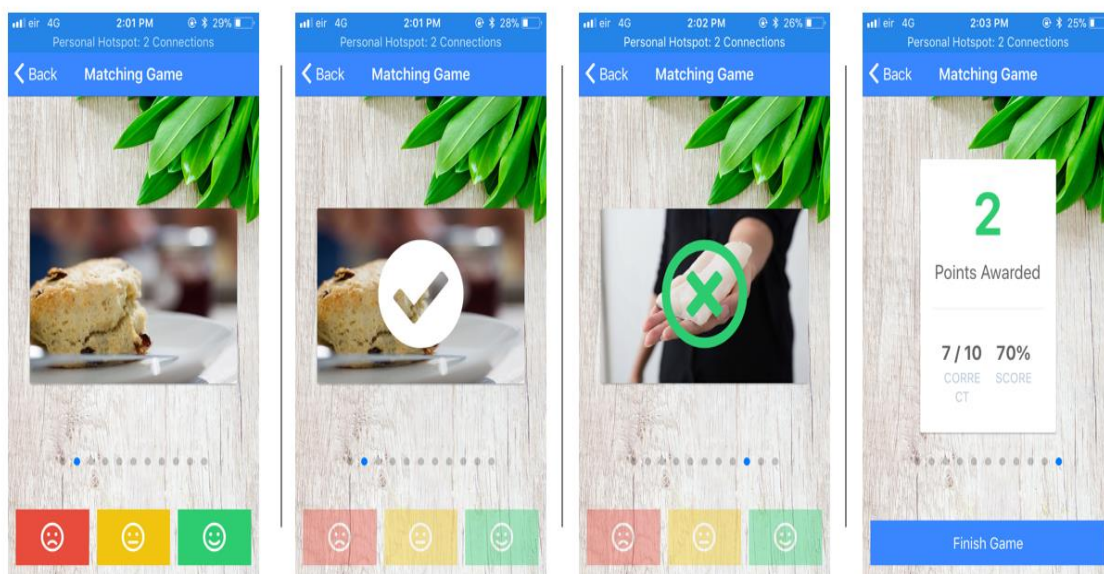


Figure 6.6: HealthyTaps Food Categorisation Game

(2) *Exercise Component:* For the exercise component of the MCI, 15 minutes of vigorous intensity exercise, or 30 minutes of moderate intensity exercise, or 60 minutes of low intensity exercise were set as the daily targets representing 100% within the HealthyTaps app. Participants were asked to track the intensity and duration (see Figure 6.7) of all bouts of exercise they engaged in at the time they completed them throughout the day. The HealthyTaps app provided immediate visual feedback to participants on the cumulative exercise for that day, as shown in Figure 6.8 below. Participants were instructed to try to achieve the daily guidelines given by reaching 100% each day.

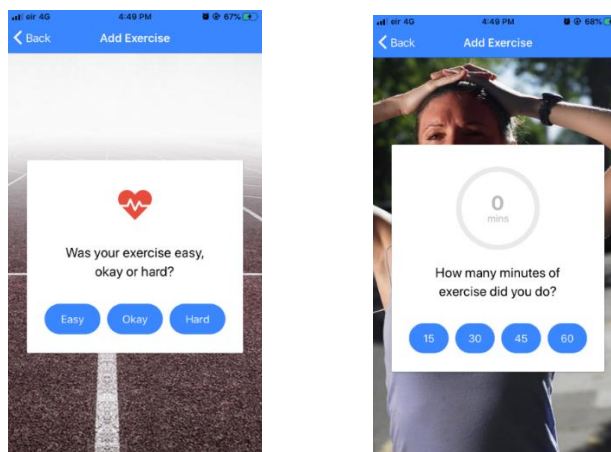


Figure 6.7: Input interfaces for intensity and duration logging for exercise

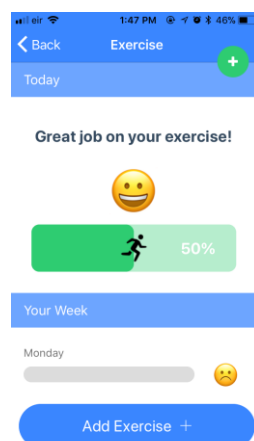


Figure 6.8: Visual Feedback display for daily exercise engagement

At the weekly one-to-one consultation visual feedback was given by the researcher on the previous week's entries. The researcher discussed the accuracy of entries based on (1) the number of days of exercise that had been logged, (2) the intensities and durations logged, and (3) the entry times of the data. Advice and instructions were provided on how to increase accuracy in all three areas, with accuracy goals set for the week ahead. Discussions also focused on how their exercise related to the guidelines, and exercise goals were set for the week ahead.

(3) *Behaviour Change Strategies:* A number of behaviour change strategies were used in the MCI: self-monitoring, self-evaluation, visual and verbal feedback, problem-solving, weekly goal setting, and reinforcement. *Self-monitoring* was conducted by entering food intake and exercise engagement into the HealthyTaps app on a daily basis. *Self-evaluation* involved reading and interpreting the visual feedback systems that the HealthyTaps app provided, then adjusting food intake and exercise engagement across the day to reach the weekly goals that had been set. *Visual and verbal feedback* during one-to-one consultations aimed to increase the accuracy of the self-monitoring by pinpointing potential areas where data was missing, i.e., food only logged for 3 out of the 7 days, or no food logged after 1 pm most days, etc. Feedback also compared performance against weekly goals and recommended guidelines. *Problem-solving* areas of difficulty involved the participants identifying any issue that occurred the previous week and working with the researcher to resolve these issues. *Weekly goal setting* was a joint process between the participant and the researcher where suggested changes for both food intake and exercise engagement were discussed before specific goals were agreed. Goals were designed to move participants towards the guidelines of the programme. Both food intake and exercise goals were individualised and were based on the previous week's goals and the data extracted from the HealthyTaps app. Additional goals were agreed with the purpose of increasing the accuracy of self-monitoring. For example, a participant who had managed to log 3 days of their food intake may set a goal to log 5 days of their food intake for the forthcoming week.

Reinforcement strategies: A token economy was used to encourage increased engagement with the HealthyTaps app. The HealthyTaps app incorporated a points system that was available to each individual user under their own user code. Points were awarded in the HealthyTaps app for playing the food knowledge game, with 1 point awarded for completing the game, a bonus 1 point awarded for achieving over 50% correct, and a further bonus 1 point awarded for achieving over 80% correct. Points were only awarded for the

CHAPTER 6 | The HealthyTaps Programme

first 5 games each day, but participants were free to play as many games each day as they liked. Points were also provided for food entries (1 point for every entry) and exercise entries (1 point for every entry). Participants who had earned 100 points or more each week were given the option to trade 100 points at the group consultation each week for small items such as toiletries, make-up, keyrings, pens, etc. Reinforcement was also available for weight losses and certificates were provided to participants during the one-to-one consultation for those who had lost 1 lbs or more from the previous week's weigh-in. For each 1 lb lost participants received a raffle ticket to enter a draw which took place during the group consultation. The draw consisted of one participant per group winning a choice of a larger item such as slippers, jewellery, socks, scarfs, gloves, etc.

6.2.4.3.5 Follow-up

When the 16-week MCI was finished, participants were encouraged to continue using the app on their own, but no weekly weigh-ins, consultations or reinforcement strategies were in place. A final one-to-one follow-up weigh-in and consultation followed by a group consultation with reinforcement provided, was held for each group between 12- and 14-weeks post- intervention.

6.2.4.4 Outcome Measures

6.2.4.4.1 Food Diaries

The number of ticks per week were calculated for each participant for each of the food categories: (1) lean meat and fish, (2) processed meat and fish, (3) breads, cereals and carbs, (4) fruit and vegetables, (5) lean dairy, (6) lean fluids, (7) fluids, and (8) treats. The average weekly amount was then computed for each category for each participant. The eight food categories from the food diaries were grouped together to best represent either Green, Yellow or Red foods. 'Lean Meat and Fish' + 'Fruit and Veg' + 'Lean Dairy' + 'Lean Fluids' were grouped as Green category foods. 'Breads, Cereals and

Carbs’ + ‘Dairy’ were grouped as Yellow category foods. ‘Processed Meat and Fish’ + ‘Fluids’ + ‘Treats’ were grouped as Red category foods. The average number of Green, Yellow and Red foods consumed per week were reported.

6.2.4.4.2 Schedule of Measures

Table 6.1 shows the types of measures that were taken at particular time points over the study. In addition to these measures the anthropometric measures were also taken at each weekly one-to-one consultation over the 16-week duration of the MCI i.e., weekly between T4 and T5.

Table 6.1: Measurement Types Taken at Each Timepoint

Measure	T1 Focus Groups	T2 Pre- HPES	T3 Post- HPES	T4 Week 1 MCI	T5 Post- MCI	T6 Follow- up
Weight (lbs)	√	√	√	√	√	√
BMI (kg/m2)	√	√	√	√	√	√
% Body Fat	√	√	√	√	√	√
Concept Acquisition			√			
Food Knowledge		√	√	√	√	
Social Validity					√	

6.2.4.4.3 Anthropometric Measures (Weight, % Body Fat, and BMI)

Participants were measured wearing a t-shirt, light trousers, and no socks or shoes. A Stadiometer, Charder HM200P, was used to measure height in feet and inches to the nearest 0.5 inch. The height of each participant was then programmed into the Smart Weigh SW-SBS500 Digital Body Fat Scale to allow automatic calculation of BMI and % body fat. Participants were instructed to stand on the scale barefoot until their weight in lbs, to the nearest 0.1 lbs, % body fat and BMI were recorded. Heights were measured firstly by the lead researcher of the group and subsequently by a second researcher for all participants in Study 1 and for 55% of the participants in Study 2. For the remaining 45% of participants in Study 2 heights were measured by the lead researcher only. Other anthropometric measures in both studies were conducted by the lead researcher for each group with a percentage of measures verified by either a

second researcher, the consultant dietician, staff or parents, see Tables 6.20 and 6.21 in the Results section for details of the inter-observer reliability (IOR) scores.

6.2.4.4.4 Concept Acquisition

A summative test was conducted at the end of the HPES for Study 1 participants and Group 6 CDS in Study 2, to test whether participants had understood and retained the main concepts of the training. A total of 46 points were available: 8 points relating to core concepts for weight loss, 18 points relating to categorisation of common foods and traffic light diet rules, 14 points relating to portion sizes, 3 points relating to exercise benefits, and 3 points relating to exercise rules. Participants were given a total % correct score, a % correct score for core concepts, a % correct score for food types and rules, a % correct score for portion sizes, a % correct score for exercise benefits, and a % correct score for exercise rules. Details of the summative test conducted can be found in Appendix L. Summative tests were conducted by one of the two main researchers whilst the other researcher observed for Group 2 DHC in Study 1. The two researchers alternated who delivered the test to ensure reliability between testers in delivery and marking. Testing for all other groups was conducted by the lead researcher for that group.

6.2.4.4.5 Food Knowledge

Baseline measures of food knowledge were calculated for participants in Study 1 using the data from the food flashcard sorting exercise that was conducted in Week 3 of the HPES. This measure was then repeated in Week 10, the final week of the HPES, to assess growth in functional food knowledge as a result of the HPES and daily flashcard practice. At both Week 3 (Baseline) and Week 10 (post-HPES) timepoints the % of foods correctly sorted was calculated for Green, Yellow and Red food categories separately, and as a total % correct for all foods for each participant. Additional analysis of the data provided both baseline and post- HPES results for (a) the percentage of foods that were under-estimated in their calorie content, and (b) the number of people who demonstrated greater than 70% knowledge in each of the food categories. Incorrectly categorised foods were analysed to determine whether participants tended to over-estimate or under-estimate their calorie content. Over-

estimation occurred when the flashcard had been placed in a category representing a higher calorie content, i.e., a Green food placed in a Red tub, and under-estimation occurred when the flashcard had been placed in a category representing a lower calorie content, i.e., Yellow food placed in a Green tub. The % of foods that had been under-estimated was calculated from the incorrect flashcards to determine whether under-estimation may also play a part in excess consumption and weight gain. Both baseline and post-HPES timelines were reported. Participants that possessed greater than 70% knowledge within each food category were considered to have enough knowledge of foods to enable functional decision-making in healthier food choices. A balance of knowledge across the food categories at this level would enable participants to understand the foods that they can eat regularly and in larger quantities (Green), the foods they can eat in moderation (Yellow), and the foods they should avoid (Red).

Knowledge gains were also calculated for Study 1 participants as a result of using the HealthyTaps app food game. The pre-App knowledge levels were calculated as the average % correct over the first 3 weeks of using the HealthyTaps app game, and were calculated for the total % correct, % correct Green foods, % correct Yellow foods and % correct Red foods. This period included some cross-over with the HPES since app training started in the final two weeks of the HPES training. A period of three weeks was chosen to reduce the effects of any initial issues caused by lack of experience in using technology rather than lack of food knowledge. The post-App average % correct measure was taken from the last three weeks of the HealthyTaps app game during the MCI, for the same four measures. This period was chosen for analysis to balance the effects of reduced usage from participants who had reached high levels of knowledge and who had begun to access the game less as a result. Presentation of the 185 foods contained in the app was randomised so three-weeks of data was also determined as a more reliable amount of time to cover responses on individual foods.

For Study 2 participants pre- and post- food knowledge measures were all taken from the HealthyTaps app food game. The pre- App measures for total % correct, % correct Green, % correct Yellow and % correct Red were taken from the first three weeks of

usage (start of Week 3 to end of Week 5 of the HPES), and the post- App measures were taken from the last three weeks of the HealthyTaps app game during the MCI.

6.2.4.4.6 Social Validity

Social validity questionnaires were completed by participants and parents/service centre staff at the end of The HealthyTaps Programme. The participant questionnaire was an easy access version of the parental/service centre staff questionnaire. Cumulative scores were calculated for each item and the total % of responses that agreed, disagreed or were unsure was reported.

6.2.4.5 Materials

- i. Food Diaries: Four x weekly food diaries for each participant (see Appendix H for diary format).
- ii. Stadiometer, Charder HM200P to measure height.
- iii. Smart Weigh SW-SBS500 Digital Body Fat Scale for body measures.
- iv. Epson EB SO4 portable projector and Epson ELPSC32 portable projector screen to host training presentation for HPES.
- v. Weekly PowerPoint slides and practical demonstration equipment for HPES.
- vi. 8 sets of testing flashcards and coloured tubs for food categorisation measures.
- vii. 41 sets of practice flashcards and coloured A4 card sets for food categorisation practice.
- viii. Reference manuals for diet and exercise guidelines, food categories, portion sizes, healthy meal suggestions and restaurant/take-away suggestions.
- ix. The HealthyTaps app and access codes for each participant.
- x. Standardised visual feedback forms for one-to-one consultations during MCI.
- xi. Tangible reinforcers for app usage and weight loss draw.
- xii. Weight loss certificates.
- xiii. Raffle tickets for weight loss draw.

6.2.4.6 Statistical Analysis

Age, being female, living independently and having Down Syndrome are all identified as confounding variables for weight in adults with ID (Rimmer et al., 1993; Bhaumik et al., 2009; Melville et al., 2008; Hsieh et al., 2014). Independent samples t-tests were conducted to compare means between the two studies for both age and BMI to ensure there were no significant differences between the samples. Two-sample Kolmogorov-Smirnov tests were conducted to compare distributions between the two studies for the categorical variables of gender, independence in living and diagnosis of Down Syndrome/other.

Separate one-way repeated measures ANOVAs were conducted for (i) weight, (ii) % body fat and (iii) BMI to compare the effects of time on each, using pre- HPES, post- HPES, pre- MCI and post- MCI as the time points. Where significant results were found, paired samples t-tests were conducted on pre- and post- measures where appropriate, as is described in the Statistical Analysis section of the Results. All tests were conducted for Study 1 participants, Study 2 participants, and for both Studies combined.

Independent t-tests were conducted to evaluate differences in weight changes between (a) gender (male versus female), (b) living conditions (independent living versus dependent living), and (c) diagnosis (Down Syndrome versus other).

Paired samples t-tests were conducted to compare pre- HPES to post- MCI food knowledge gains for (a) total food knowledge gains, (b) Green food knowledge gains, (c) Yellow food knowledge gains and (d) Red food knowledge gains.

Correlations were conducted for the two studies combined. Pearson's product-moment correlation coefficient was used to examine the relationship between the results of the HPES summative test and total weight losses. Due to non-normal distributions, Spearman's rank-order correlation was used to examine the relationships between: (a) attendance and weight losses, (b) app usage and weight losses, (c) food knowledge and weight losses, and (d) age and weight losses.

6.3 Results

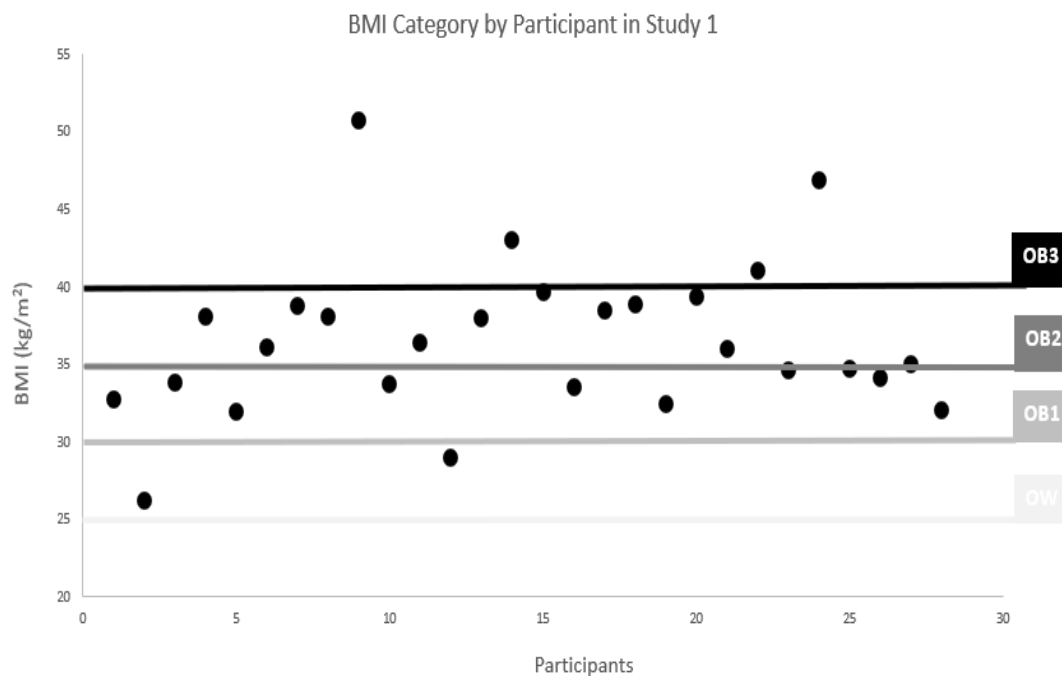
6.3.2 Participant Baseline Demographics

6.3.2.1 Study 1 Participants

Thirty-two participants started the intervention and 29 (91%) completed the full 26 weeks (10-week Health Promotion and 16-week MCI). The 3 participants who dropped out did so due to lack of interest (n=1), technology issues (n=1) and attending college on the same day (n=1). A further one participant from Group 4 RCC was removed from the results analysis as no pre- HPES measures were available. The final analysis consists of 28 (87.5%) out of the original 32 consenting participants. As is shown in Table 6.2, groups ranged in size from 4 to 8 participants in each. More females (n=21) than males (n=7) participated in the study and the majority of participants resided at home with family members (75%). The mean age of participants was 37 (SD=12.8, range 21-60), with Group 1 having the lowest mean age at 23 (SD=1.5, range 22-25), and Group 3 having the highest mean age of 47 (SD=8.8, range 31-55). Nine (32%) of the participants had a diagnosis of Down Syndrome. Two participants were categorised as overweight (OW), ten were in the obese 1 category (OB1), 12 were in the obese 2 category (OB2) and 4 were categorised as obese 3 (OB3). The weight profile of the group was therefore 7% overweight and 93% obese, with the individual distributions detailed in Figure 6.9.

Table 6.2: Study 1 Participant Demographics by Group

Demographic	All Groups	Group 1 KDS	Group 2 DHC	Group 3 RCK	Group 4 RCC	Group 5 RDC
Number of Participants	28	4	8	6	6	4
Males	7	1	2	3	0	1
Females	21	3	6	3	6	3
Mean Age	37	23	33	47	43	33
Age Range	21-60	22-25	21-44	31-55	23-60	23-46
Number of Participants in each Living Situation:						
Dependent Living	21	4	5	5	3	4
Independent Living	7		3	1	3	
Diagnosis:						
Down Syndrome	9	4	2		1	2
Other	19		6	6	5	2
Participants in each BMI Category:						
OW (25-29.9kg/m ²)	2	1	1			
OB1 (30-34.9kg/m ²)	10	2	2	1	2	3
OB2 (35-39.9kg/m ²)	12	1	4	4	2	1
OB3 (>40kg/m ²)	4		1	1	2	

**Figure 6.9:** Scatterplot distribution of Study 1 participant BMIs (n=28),

See Table 6.2 for definitions of OW, OB1, OB2 and OB3

6.3.2.2 Study 2 Participants

Fifteen participants started the intervention and 11 (73%) completed the full 23 weeks (7-week Health Promotion and 16-week MCI). The 4 participants who dropped out did so due to lack of interest (n=2) and technology issues (n=2). As is shown in Table 6.3, groups ranged in size from 3 to 5 participants in each. More females (n=6) than males (n=5) participated in the study and the majority of participants resided at home with family members (91%). The mean age of participants was 33 (SD=10.6, range 23-53), with Group 6 CDS having the lowest mean age at 24 (SD=1.5, range 23-26), and Group 8 RCM having the highest mean age of 39 (SD=12.4, range 26-53). Five (45%) participants had a diagnosis of Down Syndrome. Two participants were categorised as overweight (OW), 5 were in the obese 1 category (OB1), 3 were in the obese 2 category (OB2) and 1 were categorised as obese 3 (OB3). The weight profile of the group was therefore 18% overweight and 82% obese, with the individual distributions detailed in Figure 6.10.

Table 6.3: Study 2 Participant Demographics by Group

Demographic	All Groups	Group 6 CDS	Group 7 RDQ	Group 8 RCM
Number of Participants	11	3	3	5
Males	5	2	1	2
Females	6	1	2	3
Mean Age	34	24	33	39
Age Range	23-53	23-26	27-42	26-53
Number of Participants in each Living Situation:				
Dependent Living	10	3	3	4
Independent Living	1			1
Diagnosis:				
Down Syndrome	5	3	1	1
Other	6		2	4
Participants in each BMI Category:				
OW (25-29.9kg/m ²)	2		1	1
OB1 (30-34.9kg/m ²)	5	3	1	1
OB2 (35-39.9kg/m ²)	3			3
OB3 (>40kg/m ²)	1		1	

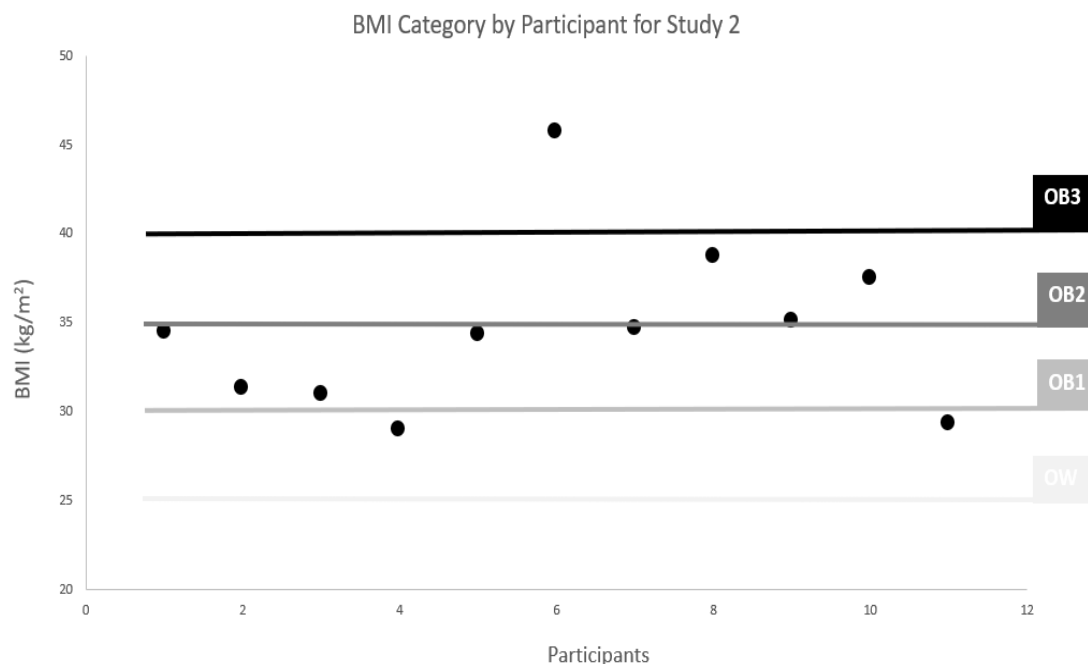


Figure 6.10: Scatterplot distribution of Study 2 participant BMIs ($n=11$)

See Table 6.3 for definitions of OW, OB1, OB2 and OB3

6.3.3 Food Diaries

Twenty-five participants from the original focus group studies were given 4 x weekly food diaries to complete prior to the HPES. Twenty (80%) participants returned food diaries of which a mean of 3.8 (SD=0.5) weeks were completed, with a mean of 6.1 (SD=1.3) days per week completed. The mean amount of Green category foods (Lean Meat and Fish + Fruit and Veg + Lean Dairy + Lean Fluids) reported as eaten each week was 40 (SD=16.0, range 18 to 74), approximately 6 per day. The mean amount of Yellow category foods (Breads, Cereals and Carbs + Dairy) reported as eaten each week was 22 (SD=10.1, range 8 to 45), approximately 3 per day. The mean amount of Red category foods (Processed Meat and Fish + Fluids + Treats) reported as eaten each week was 16 (SD=6.9, range 7 to 29), approximately 2 per day.

6.3.4 Attendance

Attendance was high in both Study 1 and Study 2 for the majority of participants during the HPES and the MCI, as is shown in Tables 6.4 and 6.5 below. Twenty-six (93%) of Study 1 participants attended 70% or more of the 10 x HPES sessions, and 21 (75%) of Study 1 participants attended 70% or more of the 16 x MCI weekly consultations. Ten (91%) participants from Study 2 attended over 70% of the 7 x HPES sessions (8 of whom attended 100% of the sessions), and 8 (73%) of Study 2 participants attended 70% or more of the 16 x MCI weekly consultations.

Table 6.4: *Percentage Attendance at HPES Sessions and MCI Consultations for Study 1*

Group	n	HPES % Attendance (SD)	MCI % Attendance (SD)
Group 1 KDS	4	90% (20)	95% (9.4)
Group 2 DHC	8	83% (19.1)	77% (10.4)
Group 3 RCK	6	85% (10.5)	69% (7.9)
Group 4 RCC	6	87% (12.1)	68% (9.2)
Group 5 RDC	4	88% (9.6)	77% (6.0)
Mean		86% (14.3)	76% (12.3)
Range		40% - 100%	56% - 100%

Table 6.5: *Percentage Attendance at HPES Sessions and MCI Consultations for Study 2*

Group	N	HPES % Attendance (SD)	MCI % Attendance (SD)
Group 6 CDS	3	100% (0)	94% (0)
Group 7 RDQ	3	67% (15.3)	60% (14.4)
Group 8 RCM	5	100% (0)	68% (8.1)
Mean		91% (17.0)	73% (16.1)
Range		50% - 100%	44% - 94%

In Group 1 KDS and Group 6 CDS each participant had one parent who attended 100% of the COS HPES training sessions. In Group 2 DHC one staff member attended 100% of the participant HPES training sessions, and 2 parents and 1 sibling attended

66% of the COS training sessions. In Groups 3, 4, 5, 7 and 8 one staff member attended 100% of the participant HPES training sessions, but no parents or siblings attended any training.

6.3.5 Anthropometric Measures

The mean weight (lbs), mean % body fat and mean BMI for each group is reported for each of the intervention timepoints T2, T3, T4 and T5. Weight, % body fat and BMI changes were calculated for each group to show the effect of the HPES (T3 [post-HPES] - T2 [pre-HPES]), and the effect of the MCI (T5 [post-MCI] - T4 [pre-MCI]) separately. To assess the effect of the full intervention, two different figures are shown for the changes in each of the anthropometric measures. The first figure is the combined result of direct intervention from the HPES and MCI phases. This figure was calculated by adding the change from the HPES (T3 – T2) and the change from the MCI (T5 – T4) together. The second figure is calculated by taking the difference between T5 [post-MCI] – T2 [pre-HPES], which also includes any changes that occurred in the time between the end of the HPES and the start of the MCI, durations of which varied between groups as is shown by the ‘No. of Weeks Delay’ column in the tables below.

6.3.5.1 Study 1

Tables 6.6, 6.7 and 6.8 detail the results for weight, % body fat and BMI respectively for the Groups involved in Study 1.

Table 6.6: *Pre- to Post- Weights (lbs) for Study 1 Participants*

Group (no of participants)	HPES (lbs)			MCI (lbs)			TOTAL HPES + MCI (lbs)	No WEEKS DELAY	Pre- HPES to Post- MCI (lbs)
	Pre	Post	Diff	Pre	Post	Diff			
Group 1 KDS (n=4)	165.6 (21.0)	159.5 (19.6)	-6.1 (6.9)	157.7 (18.6)	143.9 (18.3)	-13.8 (6.8)	-19.9 (13.1)	1	-21.7 (12.5)
Group 2 DHC (n=8)	203.1 (31.4)	203.6 (34.2)	0.5 (6.6)	202.0 (34.4)	197.8 (35.9)	-4.2 (3.6)	-3.7 (7.8)	6	-5.3 (8.1)
Group 3 RCK (n=6)	237.6 (44.7)	236.8 (47.4)	-0.8 (9.2)	236.4 (49.2)	233.3 (54.6)	-3.1 (6.2)	-3.9 (12.0)	6	-4.3 (13.1)
Group 4 RCC (n=6)	204.0 (24.8)	202.7 (24.9)	-1.3 (1.1)	202.1 (24.3)	201.4 (23.7)	-0.7 (5.3)	-2.0 (5.8)	5	-2.6 (5.1)
Group 5 RDC (n=4)	192.9 (25.0)	188.5 (27.8)	-4.4 (3.0)	188.5 (22.3)	181.1 (16.6)	-7.4 (8.2)	-11.8 (6.4)	3	-11.8 (10.1)
Mean	203.9 (36.7)	202.0 (39.1)	-1.9 (6.3)	201.1 (39.2)	196.1 (42.6)	-5.0 (6.7)	-6.9 (10.5)	4.2 (2.2)	-7.8 (11.1)
Range – Min to Max	137 309	132 322	-15.8 12.2	131 324	118 330	-23.2 6.4	-39.0 18.2	0 6	-40.2 20.8

Table 6.7: Pre- to Post- Body Fat (%) for Study 1 Participants

Group (no of participants)	HPES (%)			MCI (%)			TOTAL HPES + MCI (%)	No WEEKS DELAY	Pre- HPES to Post- MCI (%)
	Pre	Post	Diff	Pre	Post	Diff			
Group 1 KDS (n=4)	36.8 (9.2)	34.7 (10.0)	-2.1 (1.5)	34.3 (9.8)	30.3 (11.1)	-4.0 (1.5)	-6.1 (2.7)	1	-6.5 (2.6)
Group 2 DHC (n=8)	43.1 (10.1)	43.0 (10.5)	-0.1 (1.7)	42.8 (10.6)	41.6 (11.1)	-1.2 (0.9)	-1.3 (1.9)	6	-1.5 (2.3)
Group 3 RCK (n=6)	45.4 (6.5)	45.0 (6.7)	-0.4 (2.0)	45.1 (6.1)	44.2 (6.2)	-0.9 (1.6)	-1.3 (2.5)	6	-1.2 (2.9)
Group 4 RCC (n=6)	49.6 (7.5)	49.3 (7.8)	-0.3 (0.4)	49.4 (7.7)	49.3 (8.1)	-0.1 (1.3)	-0.4 (1.5)	5	-0.3 (1.2)
Group 5 RDC (n=4)	39.6 (5.1)	38.1 (4.3)	-1.5 (1.1)	38.3 (5.0)	36.7 (6.9)	-1.6 (2.0)	-3.1 (1.1)	3	-2.9 (2.5)
Mean	43.6 (8.7)	42.9 (9.2)	-0.7 (1.6)	42.8 (9.2)	41.5 (10.4)	-1.3 (1.8)	-2.0 (2.6)	4.2 (2.2)	-2.1 (2.9)
Range – Min to Max	24.4 60.0	24.9 60.0	-4.0 2.9	24.5 60.4	18.5 60.0	-6.0 1.4	-10.0 3.4	0 6	-10.4 4.2

Table 6.8: Pre- to Post- BMI (kg/m²) for Study 1 Participants

Group (no of participants)	HPES (kg/m ²)			MCI (kg/m ²)			TOTAL HPES + MCI (kg/m ²)	No WEEKS DELAY	Pre- HPES to Post- MCI (kg/m ²)
	Pre	Post	Diff	Pre	Post	Diff			
Group 1 KDS (n=4)	32.7 (4.9)	31.6 (5.1)	-1.1 (1.2)	31.2 (4.9)	28.6 (5.5)	-2.6 (1.1)	-3.7 (2.1)	1	-4.2 (2.0)
Group 2 DHC (n=8)	36.8 (6.5)	37.0 (7.0)	0.2 (1.2)	36.6 (6.9)	35.9 (7.2)	-0.7 (0.6)	-0.6 (1.4)	6	-1.0 (1.5)
Group 3 RCK (n=6)	38.6 (3.1)	38.4 (3.0)	-0.2 (1.4)	38.3 (2.7)	37.7 (3.6)	-0.6 (1.0)	-0.8 (1.7)	6	-0.9 (1.9)
Group 4 RCC (n=6)	38.4 (5.3)	38.2 (5.4)	-0.2 (0.3)	38.1 (5.3)	38.0 (5.3)	-0.1 (1.0)	-0.3 (1.1)	5	-0.5 (1.0)
Group 5 RDC (n=4)	34.0 (1.4)	33.2 (1.7)	-0.8 (0.7)	33.3 (1.5)	32.1 (2.2)	-1.2 (1.3)	-2.0 (1.0)	3	-1.9 (1.6)
Mean	36.6 (5.1)	36.2 (5.4)	-0.4 (1.1)	36.0 (5.3)	35.1 (6.0)	-0.9 (1.2)	-1.3 (1.8)	4.2 (2.2)	-1.4 (1.9)
Range – Min to Max	26.2 50.7	25.3 51.5	-2.7 2.1	25.1 50.8	22.7 50.9	-4.1 1.1	-6.8 2.4	0 6	-7.1 2.7

6.3.5.2 Study 2

Tables 6.9, 6.10 and 6.11 detail the results for weight, % body fat and BMI respectively for the Groups involved in Study 2.

Table 6.9: Pre- to Post- Weights (lbs) for Study 2 Participants

Group (no of participants)	HPES (lbs)			MCI (lbs)			TOTAL HPES + MCI (lbs)	No WEEKS DELAY	Pre- HPES to Post- MCI (lbs)
	Pre	Post	Diff	Pre	Post	Diff			
Group 6 CDS (n=3)	174.7 (15.4)	170.9 (8.7)	-3.8 (6.9)	170.1 (8.1)	157.3 (0.8)	-12.8 (7.8)	-16.6 (14.5)	0	-17.4 (15.0)
Group 7 RDQ (n=3)	210.1 (31.9)	205.3 (31.1)	-4.8 (1.8)	203.9 (31.9)	204.3 (34.6)	0.4 (3.7)	-4.4 (2.0)	1	-5.9 (3.8)
Group 8 RCM (n=5)	193.2 (41.0)	193.2 (42.3)	0.0 (1.9)	190.6 (42.8)	187.7 (43.5)	-2.9 (4.1)	-2.9 (5.8)	0	-5.5 (6.4)
Mean	192.8 (33.3)	190.4 (33.3)	-2.4 (4.1)	188.6 (33.5)	183.9 (36.6)	-4.7 (7.1)	-7.1 (9.7)	0.3 (0.6)	-8.9 (9.7)
Range – Min to Max	150.2	148.4	-11.8	143.8	139.4	-21.4	-33.2	0	-34.4
	243.8	240.6	1.8	237.8	239.4	3.6	5.4	1	4.2

Table 6.10: Pre- to Post- Body Fat (%) for Study 2 Participants

Group (no of participants)	HPES (%)			MCI (%)			TOTAL HPES + MCI (%)	No WEEKS DELAY	Pre- HPES to Post- MCI (%)
	Pre	Post	Diff	Pre	Post	Diff			
Group 6 CDS (n=3)	31.8 (5.1)	30.7 (5.2)	-1.1 (1.9)	30.5 (5.4)	27.0 (7.0)	-3.5 (2.1)	-4.6 (3.9)	0	-4.8 (3.9)
Group 7 RDQ (n=2)*	38.3 (5.2)	37.3 (4.7)	-1.0 (0.5)	37.0 (5.4)	36.8 (6.6)	-0.2 (1.1)	-1.2 (0.6)	1	-1.5 (1.4)
Group 8 RCM (n=5)	40.0 (10.5)	40.0 (10.8)	0.1 (0.5)	39.3 (10.8)	38.4 (11.7)	-0.8 (1.2)	-0.9 (1.6)	0	-1.6 (2.0)
Mean	37.2 (8.5)	36.7 (8.4)	-0.5 (1.1)	36.2 (8.8)	34.7 (10.2)	-1.5 (1.9)	-2.0 (2.7)	0.3 (0.6)	-2.5 (2.8)
Range – Min to Max	24.2	23.7	-3.2	23.2	21.3	-5.8	-9.0	0	-9.2
	49.1	49.6	0.5	49.4	50.4	1.0	1.5	1	1.3

*One participant was missing data for % Body Fat.

Table 6.11: Pre- to Post- BMI (kg/m²) for Study 2 Participants

Group (no of participants)	HPES (kg/m ²)			MCI (kg/m ²)			TOTAL HPES + MCI (kg/m ²)	No WEEKS DELAY	Pre- HPES to Post- MCI (kg/m ²)
	Pre	Post	Diff	Pre	Post	Diff			
Group 6 CDS (n=3)	32.3 (1.9)	31.6 (0.7)	-0.7 (1.2)	31.4 (0.7)	29.1 (1.0)	-2.3 (1.4)	-3.0 (2.6)	0	-3.2 (2.7)
Group 7 RDQ (n=3)	36.7 (9.1)	35.8 (8.9)	-0.9 (0.3)	35.6 (8.9)	35.7 (9.3)	0.1 (0.6)	-0.8 (0.3)	1	-1.0 (0.6)
Group 8 RCM (n=5)	35.1 (3.6)	35.0 (3.9)	-0.1 (0.4)	34.6 (4.0)	34.1 (4.7)	-0.5 (0.8)	-0.6 (1.1)	0	-1.0 (1.3)
Mean	34.8 (5.1)	34.3 (5.0)	-0.5 (0.7)	34.0 (5.0)	33.2 (5.8)	-0.8 (1.3)	-1.3 (1.8)	0.3 (0.6)	-1.6 (1.8)
Range – Min to Max	29.0	28.5	-2.1	28.0	27.3	-3.9	-6.0	0	-6.2
	46.8	45.7	0.3	45.4	45.8	0.8	1.1	1	0.9

6.3.5.3 BMI Category Changes

At the beginning of intervention (Pre- HPES), all participants were overweight, with the majority of participants (n=30) weighing within the Obese 1 and Obese 2 categories. By the end of the intervention (Post- MCI), 1 participant had reduced their weight sufficiently as to be categorised as a healthy weight (BMI < 25kg/m²). In total 8 (21%) participants had reduced their BMI category, 28 (72%) remained in the same BMI category and 3 (7%) had increased category moving from Obese 2 to Obese 3, as is shown in Table 6.12 below.

Table 6.12: BMI Category Changes for Study 1 + Study 2

	HW (18kg/m ² to 24.9kg/m ²)		OW (25kg/m ² to 29.9kg/m ²)		OB1 (30kg/m ² to 34.9kg/m ²)		OB2 (35kg/m ² to 39.9kg/m ²)		OB3 (40kg/m ² +)	
	Pre- HPES	Post- MCI	Pre- HPES	Post- MCI	Pre- HPES	Post- MCI	Pre- HPES	Post- MCI	Pre- HPES	Post- MCI
Study 1	0	1	2	3	10	10	12	7	4	7
Study 2	0	0	2	4	5	4	3	2	1	1
TOTAL	0	1	4	7	15	14	15	9	5	8

HW – healthy weight, OW – overweight, OB1 – obese category 1, OB2 – obese category 2, OB3 – obese category 3.

6.3.5.4 Follow-up

Thirty-two out of the 39 participants (82%) that took part in both of the studies had a follow-up measure (T6) taken between 12 and 14-weeks post- intervention. Table 6.13 shows the mean weight (lbs), mean % body fat and mean BMI results. Weight change, % body fat change and BMI change were calculated as the difference between the follow-up measure and the post- MCI measure (T6 – T5), and only participants that had both measures were compared in this analysis. Small increases in the mean weight (+0.4 lbs) and mean % body fat (+0.1%) were found from post- MCI to follow-up, however, BMI remained the same. Five out of the 7 groups that had participants

present at the follow-up measure showed increases across measures, however, 41% (n= 13) of participants continued to lose weight.

Table 6.13: Post-MCI to Follow-up Measure for all Participants

	N	Weight (lbs)	Weight Change (lbs)	n	% Body Fat	% Body Fat Change	n	BMI (kg/ m ²)	BMI Change (kg/m ²)
Group 1 KDS	4	139.2	-4.7	4	28.8	-1.5	4	27.6	-1.0
		17.7	5.1		10.6	1.8		4.9	1.2
Group 2 DHC	7	191.2	2.3	7	39.5	0.6	7	34.1	0.4
		28.8	1.9		9.0	0.6		4.2	0.3
Group 3 RCK	5	234.2	1.6	5	42.9	0.8	5	37.2	0.3
		62.4	5.7		4.0	0.7		3.9	0.9
Group 4 RCC	4	212.4	1.4	3	53.6	-0.1*	3	40.4	-0.3*
		19.6	8.0		3.9	2.0		3.5	1.2
Group 5 RDC	4	182.0	0.9	4	37.1	0.4	4	32.3	0.2
		18.4	3.3		7.1	0.9		2.4	0.5
Group 6 CDS	3	156.2	-1.1	3	26.7	-0.3	3	28.9	-0.2
		7.2	7.8		7.9	2.0		2.0	1.3
Group 8 RCM	5	188.4	0.7	5	38.8	0.4	5	34.2	0.1
		42.8	2.4		11.6	0.6		4.6	0.5
Mean	32	189.2	0.4	31	38.4	0.1	31	33.6	0.0
		42.8	4.9		10.5	1.3		5.2	0.9
Range – Min to Max		117.8	-10.4		16.5	-3.8		22.5	-2.5
		334.8	10.6		56.7	1.8		44.0	1.2

*One participant was missing from these results.

6.3.5.5 Sub-Group Analysis

Mean % weight losses for the sub-groups relating to the confounding variables of Down Syndrome diagnosis, independence in living, and gender are shown in Table 6.14 below. Table 6.15 details the number of participants losing or gaining weight for each variable. Those with a diagnosis of Down Syndrome performed better than those

with other diagnoses, males performed better than females, and those participants that lived at home with family members and were deemed to be dependent in their living situation performed better than those that lived independently.

Table 6.14: % Weight Losses for Confounding Variable Groupings

Comparison Groups	n	% Weight Loss		
		Pre- to post- HPES	Pre- to post- MCI	Pre- HPES to post- MCI
Down Syndrome Diagnosis	14	-2.2	-5.3	-7.4
Other Diagnosis	25	-0.5	-1.5	-2.0
Male	13	-1.8	-4.3	-6.1
Female	26	-0.8	-2.1	-2.8
Living Independently	8	0.1	-1.9	-1.8
Living Dependently	31	-1.4	-3.1	-4.5

Table 6.15: Number of participants losing or gaining weight in each sub-group

Comparison Groups	n	Number of Participants (%)	
		Gained Weight	Lost Weight
Down Syndrome Diagnosis	14	1 (7%)	13 (93%)
Other Diagnosis	25	6 (24%)	19 (76%)
Male	13	1 (8%)	12 (92%)
Female	26	6 (23%)	20 (77%)
Living Independently	8	3 (38%)	5 (62%)
Living Dependently	31	4 (13%)	27 (87%)

Two groups of adults with Down Syndrome (n=7) were supported solely by parents, and in isolating this group and comparing them to the other adults with Down Syndrome that were part of Service-led groups, the results show that parental input plays an important role in weight loss, see Table 6.16 below.

Table 6.16: Comparison of Results for Groups of Adults with Down Syndrome

Result	Parent-Led Group (n = 7)	Service -Led Group (n = 7)
No. participants losing weight	7	6
Mean weight loss (lbs)	-18.5	-6.6
Mean % weight loss	-11.1	-3.8
% participants achieving \geq -5% weight loss	86	29
% Attendance at MCI weekly consultations	95	73

6.3.5.6 Comparison of results with NICE (2014^a) guidelines

The percentage weight change was calculated for each participant for the HPES, the MCI and the combination of both. Mean % weight changes were also calculated for each group. The NICE (2014^a) guidelines for effective weight loss interventions for the general population state that:

1. Sixty percent or more of the participants must complete the intervention.
2. The mean % weight loss \geq -3%.
3. Thirty percent or more of the participants must achieve \geq -5% weight loss.

Tables 6.17 and 6.18 show that at the end of the HPES section of the intervention 92% of the participants in Study 1 and 100% of the participants in Study 2 remained and started the MCI section of the intervention. At the end of the full intervention (HPES + MCI) 90% of participants in Study 1 and 81% of participants in Study 2 achieved completion. These results exceed the NICE (2014^a) guideline of a minimum of 60% of participants achieving completion. However, Group 7 RDQ in Study 2 only managed a 43% completion rate. Two out of the 4 participants that dropped out had technical issues that prohibited them from downloading the app, unduly affecting the completion rate for this group.

Table 6.17: Intervention Completion Rates for Study 1 Participants

Group	Started HPES	% Completed 10-Week HPES	Finished MCI	% Completed Full 26-Week Intervention
Group 1 KDS	5	80%	4	80%
Group 2 DHC	8	100%	8	100%
Group 3 RCK	6	100%	6	100%
Group 4 RCC	7	100%	6	86%
Group 5 RDC	5	80%	4	80%
TOTAL	31	92%	28	90%

Table 6.18: Intervention Completion Rates for Study 2 Participants

Group	Started HPES	% Completed 10-Week HPES	Finished MCI	% Completed Full 26-Week Intervention
Group 6 CDS	3	100%	3	100%
Group 7 RDQ	7	100%	3	43%
Group 8 RCM	5	100%	5	100%
TOTAL	15	100%	11	81%

Tables 6.19 and 6.20 show that the total mean % weight losses were -3.9% for Study 1 and -4.0% for Study 2, both of which exceed the minimum required by NICE (2014^a) for a weight loss intervention to be found effective. The HPES phase alone produced mean % weight losses of -1.1% for Study 1 and -1.2% for Study 2, neither of which would satisfy the NICE (2014^a) criteria (see Tables 6.21 and 6.22). However, the MCI phase alone produced mean % weight losses of -2.8% for Study 1 and -2.8% for Study 2, both of which come close to NICE (2014^a) criteria (see Tables 6.23 and 6.24).

Thirty-two percent of participants in Study 1 achieved $\geq -5\%$ weight losses after participating in the full 26-week intervention combining the HPES and MCI, which again exceeded the NICE (2014^a) criteria for effective weight loss interventions. Study 2 also came close to criteria with 27% of participants achieving $\geq -5\%$ weight losses over the 23-weeks of the streamlined version of the full intervention. Only 7% of Study 1 participants and 10% of Study 2 participants achieved $\geq -5\%$ weight losses

after the HPES phase alone, which would not satisfy the NICE (2014^a) criteria. The MCI phase alone came close to criteria in Study 1 with 25% of participants achieving $\geq -5\%$ weight losses, however, only 18% of participants in Study 2 managed weight losses $\geq -5\%$ (see Tables 6.18, 6.19, 6.20, 6.21, 6.22 and 6.23 for details).

Table 6.19: % Weight changes for Study 1 participants as a result of the HPES + MCI

Group	Mean % Weight Change (SD)	Number of Participants (n / %)		
		Weight Gain > +0%	Weight Loss $\leq -5\%$	Weight Loss $\geq -5\%$
Group 1 KDS	-12.3 (7.3)	0 (0%)	0 (0%)	4 (100%)
Group 2 DHC	-2.2 (3.8)	2 (25%)	4 (50%)	2 (25%)
Group 3 RCK	-2.1 (4.4)	1 (17%)	4 (66%)	1 (17%)
Group 4 RCC	-1.0 (2.9)	3 (50%)	3 (50%)	0 (0%)
Group 5 RDC	-6.1 (3.0)	0 (0%)	2 (50%)	2 (50%)
TOTAL	-3.9 (5.5)	6 (21%)	13 (47%)	9 (32%)

Table 6.20: % Weight changes for Study 2 participants as a result of the HPES + MCI

Group	Mean % Weight Change (SD)	Number of Participants (n / %)		
		Weight Gain > +0%	Weight Loss $\leq -5\%$	Weight Loss $\geq -5\%$
Group 6 CDS	-9.4 (7.6)	0 (0%)	1 (33%)	2 (67%)
Group 7 RDQ	-2.3 (1.4)	0 (0%)	3 (100%)	0 (0%)
Group 8 RCM	-1.8 (3.5)	1 (20%)	3 (60%)	1 (20%)
TOTAL	-4.0 (5.4)	1 (10%)	7 (64%)	3 (27%)

Table 6.21: % Weight changes for Study 1 participants as a result of the HPES

Group	Mean % Weight Change (SD)	Number of Participants (n / %)		
		Weight Gain > +0%	Weight Loss ≤ -5%	Weight Loss ≥ -5%
Group 1 KDS	-3.6 (3.7)	1 (25%)	2 (50%)	1 (25%)
Group 2 DHC	+0.1 (3.2)	4 (50%)	4 (50%)	0 (0%)
Group 3 RCK	-0.4 (3.7)	2 (33%)	3 (50%)	1 (17%)
Group 4 RCC	-0.7 (0.6)	1 (17%)	5 (83%)	0 (0%)
Group 5 RDC	-2.5 (1.9)	0 (0%)	4 (100%)	0 (0%)
TOTAL	-1.1 (3.0)	8 (29%)	18 (64%)	2 (7%)

Table 6.22: % Weight changes for Study 2 participants as a result of the HPES

Group	Mean % Weight Change (SD)	Number of Participants (n / %)		
		Weight Gain > +0%	Weight Loss ≤ -5%	Weight Loss ≥ -5%
Group 6 CDS	-2.0 (3.6)	2 (67%)	0 (0%)	1 (33%)
Group 7 RDQ	-2.3 (0.8)	0 (0%)	3 (100%)	0 (0%)
Group 8 RCM	-0.1 (1.1)	3 (60%)	2 (40%)	0 (0%)
TOTAL	-1.2 (2.1)	5 (45%)	5 (45%)	1 (10%)

Table 6.23: % Weight changes for Study 1 participants as a result of the MCI

Group	Mean % Weight Change (SD)	Number of Participants (n / %)		
		Weight Gain > +0%	Weight Loss ≤ -5%	Weight Loss ≥ -5%
Group 1 KDS	-8.7 (4.0)	0 (0%)	1 (25%)	3 (75%)
Group 2 DHC	-2.2 (1.9)	2 (25%)	6 (75%)	0 (0%)
Group 3 RCK	-1.7 (2.9)	1 (17%)	4 (66%)	1 (17%)
Group 4 RCC	-0.3 (2.7)	3 (50%)	3 (50%)	0 (0%)
Group 5 RDC	-3.7 (3.9)	0 (0%)	2 (50%)	2 (50%)
TOTAL	-2.8 (3.8)	6 (21%)	15 (54%)	7 (25%)

Table 6.24: % Weight changes for Study 2 participants as a result of the MCI

Group	Mean % Weight Change (SD)	Number of Participants (n / %)		
		Weight Gain > +0%	Weight Loss ≤ -5%	Weight Loss ≥ -5%
Group 6 CDS	-7.4 (4.2)	0 (0%)	1 (33%)	2 (67%)
Group 7 RDQ	+0.1 (2.0)	2 (67%)	1 (33%)	0 (0%)
Group 8 RCM	-1.7 (2.5)	1 (20%)	4 (80%)	0 (0%)
TOTAL	-2.8 (4.0)	3 (27%)	6 (55%)	2 (18%)

6.3.5.7 Inter-Observer Reliability (IOR).

With the exception of the height measurement taken during focus groups, or at the beginning of the HPES for some participants, all other measures were automatically generated by the Smart Weigh SW-SBS500 Digital Body Fat Scale. The height measure was a manual measurement performed by the researchers, and so was subject to measurement discrepancy. The two researchers were present for this measure for 100% of the participants in Study 1, and 55% of the participants in Study 2. 100% of the height measures taken for Study 1 participants were the same for both researchers. Of the 6 participants in Study 2 who had 2 researchers present for height measurements, matching measurements occurred for 5 (83%). For the one participant where disagreement arose, the measurement was conducted again with both researchers present and agreement was reached. For all of the other anthropometric measures the IOR was calculated as the percentage of sessions that a second person was present to verify the digitally produced body measures provided by the Smart Weigh SW-SBS500 Digital Body Fat Scale. The accepted norm for this type of IOR is a minimum of 20%, with 25 to 33% seen as a more preferable level (Cooper, Heron, Heward, 2014).

Column two in Tables 6.25 and 6.26 below shows the total amount of measures taken for each group based on the number of participants per group and their attendance at the different measuring points from T1 to T6. Also included in this figure are the weekly measures conducted during one-to-one consultations during the MCI phase

between T4 and T5. Column three shows the number of these measures that were verified by a second party. The inter-observer reliability (IOR) is the percentage of the total measures that have been verified. Study 1 had an IOR of 34%, which is above the accepted amount. Study 2 had an IOR of 47% which is above the accepted norm.

Table 6.25: Inter-Observer Reliability for Study 1

Group	Total Measures Taken	Total Measures Verified	%IOR
Group 1 – KDS	85	19	22%
Group 2 – DHC	127	73	57%
Group 3 – RCK	83	20	24%
Group 4 – RCC	85	50	59%
Group 5 – RDC	66	4	6%
Mean			34%

Table 6.26: Inter-Observer Reliability for Study 2

Group	Total Measures Taken	Total Measures Verified	%IOR
Group 6 – CDS	58	13	22%
Group 7 – RDQ	35	17	49%
Group 8 – RCM	74	52	70%
Mean			47%

6.3.6 Concept Acquisition

The summative test was delivered on the final week of the HPES for four groups in Study 1 and for Group 6 CDS in Study 2. In Study 1 the Group 4 RCC participants (n=6) were excluded from the summative test due to their participation in a side study that involved additional weekly testing of fluency with the food flashcards. Four of the participants in the remaining groups in Study 1 had difficulty with the testing due to fatigue and so did not complete the test. The scheduled training times for Group 7 RDQ and Group 8 RCM from Study 2 did not allow for the additional duration that the summative testing would take due to service centre closing times, and so these groups were also excluded from the test (n=8). Therefore, only 21 (54%) participants from both Study 1 and Study 2 completed the summative test, the results of which are shown in Table 6.26 below.

Prior to the HPES the majority of participants stated that exercising more was the best way to lose weight. After 10 weeks in Study 1 or 7 weeks in Study 2 of consistently hearing the health promotion message that food intake plays a larger role in weight loss than exercise, more than half (57%) of the participants continued to identify exercise as the most effective way to lose weight. However, the majority of participants (86%) had grasped the concept of Green (healthy foods we can eat a lot of), Yellow (foods that are ok to eat but we must not eat too many), and Red (unhealthy foods that we need to avoid eating) food categorisation. Portion sizes and exercise guidelines were the two main areas of difficulty with the majority of participants (86%) getting less than half of the portion sizes correct, and only one participant demonstrating an understanding of the link between duration and intensity for exercise. Table 6.27 below details the mean % correct for each of the categories tested in the summative test.

Table 6.27: Mean % Correct Scores for the HPES Summative Test

Group (no of participants)	% Attendance	Mean % Correct (SD)					
		Total Score	Core Concepts	Food Types and Rules	Portion Size	Exercise Benefits	Exercise Rules
Group 1 KDS (n=4)	92.5 (9.6)	57.0 (14.9)	59.8 (32.8)	77.8 (11.7)	26.8 (19.8)	100.0 (0.0)	24.8 (16.5)
Group 2 DHC (n=7)	80.0 (23.1)	64.1 (10.7)	75.3 (17.7)	79.4 (19.8)	36.9 (18.5)	100.0 (0.0)	33.0 (0.0)
Group 3 RCK (n=5)	84.0 (11.4)	63.4 (14.7)	82.6 (24.3)	73.6 (16.7)	38.6 (17.1)	100.0 (0.0)	33.2 (40.8)
Group 5 RDC (n=2)	80.0 (0.0)	59.5 (0.7)	75.0 (0.0)	86.0 (4.2)	14.0 (0.0)	100.0 (0.0)	16.5 (23.3)
Group 6 CDS (n=3)	100.0 (0.0)	51.3 (10.0)	42.0 (25.9)	76.0 (14.1)	24.0 (15.1)	89.0 (19.1)	22.0 (19.1)
Mean	86.2 (16.0)	60.3 (12.0)	69.3 (25.1)	77.9 (15.1)	31.3 (17.6)	98.4 (7.2)	28.3 (21.8)
Minimum	40.0	41.0	13.0	44.0	7.0	67.0	0.0
Maximum	100.0	83.0	100.0	100.0	71.0	100.0	100.0

6.3.7 Food Knowledge

6.3.7.1 Flashcard Analysis

Only participants in Study 1 took part in the food flashcard intervention during the HPES. Group 4 RCC participants (n=6) were excluded from the flashcard analysis as they took part in an additional fluency study between Week 3 and Week 8. Remaining participants with both baseline and post- HPES measures for the flashcards were included in the analysis (n=18). As Table 6.28 shows, 83% (n=15) of participants in the flashcard analysis, made gains in knowledge, with the total mean % correct rising

from 52% (SD=11, range 26 to 66) to 61% (SD=16, range 24 to 89). At the baseline measure (Week 3 HPES) no participant demonstrated $\geq 70\%$ knowledge, however, at the post- HPES measure 5 (28%) participants achieved $\geq 70\%$ knowledge. For Green category foods, as shown in Table 6.29, 50% (n=9) of participants increased their knowledge, with the Green Foods mean % correct rising from 57% (SD=19, range 24 to 88) to 60% (SD=22, range 11 to 85). At the baseline measure 6 (33%) participants demonstrated $\geq 70\%$ knowledge, and at the post- HPES measure this remained at 6 (33%), however, only 4 of these were the same participants at baseline and post-HPES. Eighty-three percent (n=15) of participants, demonstrated gains in knowledge for Yellow Foods with the mean % correct rising from 29% (SD=17, range 0 to 61) to 43% (SD=22, range 5 to 79). At the baseline measure no participants demonstrated $\geq 70\%$ knowledge, however, by the post- HPES measure this had increased to 2 (11%) participants having achieved $\geq 70\%$ knowledge (see Table 6.30). Red category foods also increased with seventy-eight percent (n=14) of participants demonstrating gains at the post- HPES measure. The mean % correct increased from 59% (SD=21, range 15 to 93) to 71% (SD=24, range 1 to 97). Seven (39%) participants demonstrated $\geq 70\%$ knowledge at baseline, which increased to 11 (61%) at the post- HPES measure, however, 2 of the original count fell below 70% knowledge at the post- HPES measure (see Table 6.31).

Table 6.28: Total % Correct Scores for Study 1 Participants

Group and Participant	FLASHCARDS		APP GAME	
	Week 3	Week 10	First 3 Weeks	Last 3 Weeks of MCI
Group 1 KDS1.0	44	59	76	95
Group 1 KDS1.2	58	70	75	99
Group 1 KDS1.3	-	-	94	98
Group 1 KDS1.5	42	66	68	96
Group 1 DHC1.0	44	59	52	74
Group 2 DHC1.1	37	57	40	82
Group 2 DHC1.2	-	-	44	81
Group 2 DHC1.4	64	72	67	77
Group 2 DHC1.5	61	68	63	79
Group 2 DHC1.6	59	46	38	28
Group 2 DHC1.7	-	-	93	93
Group 2 DHC1.8	60	79	81	94
Group 3 RCK1.0	56	64	87	85
Group 3 RCK1.1	45	24	-	-
Group 3 RCK1.2	-	-	49	53
Group 3 RCK1.3	66	89	82	96
Group 3 RCK1.4	54	50	35	90
Group 3 RCK1.5	55	65	62	91
Group 5 RDC1.1	59	61	-	-
Group 5 RDC1.2	26	29	56	61
Group 5 RDC1.3	45	54	41	80
Group 5 RDC1.4	58	78	60	79
MEAN	52	61	63	82
SD	11	16	19	18
MINIMUM	26	24	35	28
MAXIMUM	66	89	94	99

Table 6.29: Green Foods % Correct Scores for Study 1 Participants

Group and Participant	FLASHCARDS		APP GAME	
	Week 3	Week 10	First 3 Weeks	Last 3 Weeks of MCI
Group 1 KDS1.0	32	70	88	97
Group 1 KDS1.2	88	73	80	100
Group 1 KDS1.3			94	98
Group 1 KDS1.5	24	54	61	97
Group 1 DHC1.0	46	61	60	70
Group 2 DHC1.1	57	69	42	87
Group 2 DHC1.2			92	92
Group 2 DHC1.4	78	61	69	88
Group 2 DHC1.5	74	68	65	79
Group 2 DHC1.6	50	11	67	4
Group 2 DHC1.7			100	93
Group 2 DHC1.8	86	85	88	98
Group 3 RCK1.0	43	62	82	79
Group 3 RCK1.1	45	57		
Group 3 RCK1.2			36	54
Group 3 RCK1.3	70	85	81	95
Group 3 RCK1.4	53	46	40	95
Group 3 RCK1.5	69	43	60	92
Group 5 RDC1.1	73	82		
Group 5 RDC1.2	31	15	61	50
Group 5 RDC1.3	58	50	50	85
Group 5 RDC1.4	51	85	75	85
MEAN	57	60	70	82
SD	19	22	19	23
MINIMUM	24	11	36	4
MAXIMUM	88	85	100	100

Table 6.30: *Yellow Foods % Correct Scores for Study 1 Participants*

Group and Participant	FLASHCARDS		APP GAME	
	Week 3	Week 10	First 3 Weeks	Last 3 Weeks of MCI
Group 1 KDS1.0	55	32	57	93
Group 1 KDS1.2	18	61	63	99
Group 1 KDS1.3			88	100
Group 1 KDS1.5	61	79	67	93
Group 1 DHC1.0	32	5	5	50
Group 2 DHC1.1	18	29	33	82
Group 2 DHC1.2			4	58
Group 2 DHC1.4	0	61	46	65
Group 2 DHC1.5	37	42	53	77
Group 2 DHC1.6	11	21	24	96
Group 2 DHC1.7			91	91
Group 2 DHC1.8	26	45	53	90
Group 3 RCK1.0	29	42	84	87
Group 3 RCK1.1	37	5		
Group 3 RCK1.2			26	22
Group 3 RCK1.3	37	79	73	94
Group 3 RCK1.4	18	47	29	84
Group 3 RCK1.5	47	50	62	83
Group 5 RDC1.1	5	18		
Group 5 RDC1.2	39	47	45	49
Group 5 RDC1.3	13	53	33	67
Group 5 RDC1.4	37	61	33	65
MEAN	29	43	48	77
SD	17	22	25	21
MINIMUM	0	5	4	22
MAXIMUM	61	79	91	100

Table 6.31: Red Foods % Correct Scores for Study 1 Participants

Group and Participant	FLASHCARDS		APP GAME	
	Week 3	Week 10	First 3 Weeks	Last 3 Weeks of MCI
Group 1 KDS1.0	51	63	80	94
Group 1 KDS1.2	49	73	80	100
Group 1 KDS1.3			97	98
Group 1 KDS1.5	51	71	76	97
Group 1 DHC1.0	48	86	78	81
Group 2 DHC1.1	26	59	44	76
Group 2 DHC1.2			22	76
Group 2 DHC1.4	84	89	80	82
Group 2 DHC1.5	59	82	70	82
Group 2 DHC1.6	93	95	18	6
Group 2 DHC1.7			85	95
Group 2 DHC1.8	51	92	93	94
Group 3 RCK1.0	82	77	94	89
Group 3 RCK1.1	49	1		
Group 3 RCK1.2			76	74
Group 3 RCK1.3	78	97	91	97
Group 3 RCK1.4	74	56	38	88
Group 3 RCK1.5	44	96	64	95
Group 5 RDC1.1	74	60		
Group 5 RDC1.2	15	34	60	80
Group 5 RDC1.3	49	59	33	84
Group 5 RDC1.4	77	81	67	84
MEAN	59	71	67	84
SD	21	24	24	20
MINIMUM	15	1	18	6
MAXIMUM	93	97	97	100

At the baseline measure, the main food types identified correctly by more than 70% of participants were (i) fruits, vegetables and brown bread in the Green category, and (ii) treats, take-aways and alcohol in the Red category. There were no Yellow category foods correctly identified by more than 70% of participants. At the post- HPES measure, the main foods identified correctly by more than 70% of participants were (i) fruits, vegetables, brown bread, and eggs in the Green category, (ii) and treats, take-aways, alcohol and processed foods in the Red category. Again, there were no Yellow category foods correctly identified by more than 70% of participants.

The number of foods where calorie content was under-estimated was calculated from the incorrect flashcards to determine whether under-estimation also played a part in over consumption. Table 6.32 shows that at baseline measures under-estimation (48%) and over-estimation (52%) of calorie content was almost equal. At the post-HPES measure not only had the number of incorrect categorisations reduced, but the majority of incorrect answers (65%) over-estimated the calorie content.

Table 6.32: Analysis of Under-Estimation of Food Categorisation Flashcards

Group (no of participants)	Mean % Under- estimated (% / SD)			
	Baseline		Post	
Group 1 KDS (n=3)	49.0	(20.8)	41.3	(7.1)
Group 2 DHC (n=6)	55.0	(21.1)	31.0	(17.9)
Group 3 RCK (n=5)	39.6	(15.2)	22.0	(14.4)
Group 5 RDC (n=4)	48.8	(7.9)	50.3	(7.4)
Mean	48.3	(16.9)	34.5	(16.6)
Minimum / Maximum	20.0	80.0	5.0	59.0

6.3.7.2 HealthyTaps Food Categorisation Game Analysis

The analysis of food knowledge from the HealthyTaps app game was conducted for both Study 1 and Study 2 participants, but Study 1 participants gained access to the game on Week 8 of the HPES and Study 2 participants gained access to the game on Week 2 of the HPES. Group 4 RCC (n=6) were again excluded from the analysis for

Study 1 due to the additional food knowledge fluency study that they took part in. Of the remaining 22 participants in Study 1, all participants that had both pre- and post-App measures were included (n=20), the results of which are shown in Tables 6.26 to 6.29 above. The two participants who were excluded had only played the food game in HealthyTaps for the first few weeks of access and so did not have adequate post-App usage data to include. Sixteen out of the 20 participants had also been included in the flashcard analysis. Only 1 participant from Group 6 CDS in Study 2 was excluded from the App game analysis as they stopped using the game prior to the last 3 weeks of the MCI, which again left inadequate data at the post-App measure for analysis. Ten participants were included in the analysis for Study 2, the results of which are shown in Table 6.33.

As Table 6.28 shows, 85% (n=17) of Study 1 participants made gains from pre- to post-App measures, with the total mean % correct rising from 63% (SD=19, range 35 to 94) to 82% (SD=18, range 28 to 99). At the pre-App measure 7 (35%) participants demonstrated $\geq 70\%$ knowledge, however, this rose substantially at the post-App measure with 17 (85%) participants achieving $\geq 70\%$ knowledge. The majority of Study 2 participants also made gains with 80% (n=8) increasing their scores from pre- to post-App measures, as is shown in Table 6.33. The total mean % correct rose from 64% (SD=14, range 41 to 90) to 80% (SD=14, range 58 to 100). At the pre-App measure 3 (30%) participants demonstrated $\geq 70\%$ knowledge, however, this rose substantially at the post-App measure with 8 (80%) participants achieving $\geq 70\%$ knowledge.

Seventy-five percent (n=15) of Study 1 participants made gains in their Green foods knowledge levels as a result of the HealthyTaps game, as Table 6.29 shows. The Green foods mean % correct rose from 70% (SD=19, range 36 to 100) to 82% (SD=23, range 4 to 100). Nine (45%) participants demonstrated $\geq 70\%$ knowledge at the pre-App measure, however, this increased to 17 (85%) participants at the post-App measure. Table 6.33 shows a similar story for Study 2 participants with 7 (70%) demonstrating gains in their Green Foods knowledge. The Green foods mean % correct rose from 69% (SD=20, range 24 to 95) to 81% (SD=16, range 58 to 100). In

Study 2, 6 (60%) participants demonstrated $\geq 70\%$ knowledge at the pre- App measure. At the post- App measure this remained at 6 (60%). however, only 4 of these were the same participants at pre- and post- App.

In Table 6.30, 90% (n=18) of Study 1 participants made gains in their Yellow food knowledge, with the mean % correct increasing from 48% (SD=25, range 4 to 91) to 77% (SD=21, range 22 to 100). Four (20%) participants demonstrated $\geq 70\%$ knowledge for the first 3 weeks of using the HealthyTaps game, however, this increased to 13 (65%) of the participants at the post- App measure. As Table 6.33 shows, increases were also found for 7 (70%) of Study 2 participants for the Yellow foods, with the mean % correct increasing from 46% (SD=18, range 17 to 76) to 69% (SD=19, range 42 to 99). Only 1 (10%) participant in Study 2 had achieved $\geq 70\%$ knowledge at the pre- App measure, however, at the post- App measure this had increased to 4 (40%) participants.

As Table 6.31 shows, 85% (n=17) of Study 1 participants made gains in their Red foods knowledge levels as a result of the HealthyTaps game. The Red foods mean % correct rose from 67% (SD=24, range 18 to 97) to 84% (SD=20, range 6 to 100). Twelve (60%) participants demonstrated $\geq 70\%$ knowledge at the pre- App measure, however, this increased to 19 (95%) of the participants at the post- App measure. Nine (90%) of Study 2 participants also made gains in Red foods knowledge, with the total mean % correct increasing from 70% (SD=13, range 55 to 95) to 86% (SD=14, range 57 to 100), as can be seen in Table 6.33. At the pre- App measure 5 (50%) participants demonstrated $\geq 70\%$ knowledge, and again this rose substantially at the post- App measure with 9 (90%) participants achieving $\geq 70\%$ knowledge.

Table 6.33: % Correct Scores for Study 2 Participants

	Total % Correct		Green % Correct		Yellow % Correct		Red % Correct	
Group and Participant	Pre-	Post-	Pre-	Post-	Pre-	Post-	Pre-	Post-
Group 6 CDS1.8	61	83	80	84	40	77	57	86
Group 6 CDS1.9	41	70	24	69	27	69	67	72
Group 7 RDQ1.0	90	89	95	95	76	76	95	93
Group 7 RDQ1.5	71	90	69	100	66	50	78	100
Group 7 RDQ1.6	68	96	70	95	58	94	73	98
Group 8 RCM1.1	71	100	81	100	45	99	79	100
Group 8 RCM1.2	44	58	50	67	17	46	55	57
Group 8 RCM1.3	64	63	75	58	55	42	59	84
Group 8 RCM1.4	65	73	88	61	40	66	57	90
Group 8 RCM1.5	63	80	62	85	38	67	82	84
MEAN	64	80	69	81	46	69	70	86
SD	14	14	20	16	18	19	13	14
MINIMUM	41	58	24	58	17	42	55	57
MAXIMUM	90	100	95	100	76	99	95	100

6.3.8 Social Validity

6.3.8.1 Participants

A total of 19 participants (49%) from the two studies returned the Social Validity questionnaires. Seven of the participants were from parent-led groups: Group 1 KDS (n=4) and Group 6 CDS (n=3), and the remaining participants were from Service-led groups: Group 2 DHC (n=6) and Group 3 RCK (n=6). The majority of participants rated the intervention positively with only one person disagreeing that the app was easy enough to use, and two people disagreeing that more information should be available about the program. The combined results for all groups are shown in Table 6.34 below.

Table 6.34: Social Validity Ratings by Participants

Question		Disagree	Not Sure	Agree
1	The information was easy to understand.			19
2	The program was worth the effort.		1	18
3	The diet and exercise goals set were at an achievable level.		2	17
4	The App was easy enough to use.	1	2	16
5	I found it enjoyable.			19
6	There would be more interest in this program if people knew more about it.		4	15
7	More information should be available about this program.	2		17
8	I am glad I had the opportunity to take part in this program.			19
9	I would recommend this program to other people trying to lose weight.		1	18
Total Responses		3	10	158
		1.7%	5.8%	92.5%

6.3.8.2 Caregivers

A total of 8 caregivers from the two studies returned the Social Validity questionnaires. Seven of the caregivers were parents who had participated as the support person in the two parent-led groups for adults with Down Syndrome: Group 1 KDS and Group 6 CDS. The other caregiver was a member of staff that had been assigned as the main support person for the study for Group 3 RCK. Every response except one rated the intervention positively, with the only question disagreed with by one caregiver being that ‘Service centres would have more interest in the program if they knew more about it’. The combined results for all caregivers are shown in Table 6.35 below.

Table 6.35: Social Validity Ratings by Caregivers

Question		SD	D	NS	A	SA
1	The education series provided was easy to understand.				1	7
2	The information we gained would be worth the extra effort of doing this training.				1	7
3	The education program promotes more positive attitudes to weight loss and health.				1	7
4	The diet and exercise goals set were at an achievable level.				3	5
5	The App was easy enough to use.				2	6
6	The people participating in the program found it enjoyable.				1	7
7	I have seen positive changes in healthy eating with my son/daughter or person I support professionally.				2	6
8	I have seen positive changes in exercising with my son/daughter or person I support professionally.				3	5
9	There would be more interest in this program if parents knew more about it.				2	6
10	There would be more interest in this program if Service centres knew more about it.	1			2	5
11	More information should be provided to parents and professionals about this program.					8
12	I am glad I had the opportunity to learn about this program.				1	7
13	I am glad my son/daughter or person I support professionally had the opportunity to take part in this program.				1	7
14	I would recommend this program to other parents and professionals.				1	7
Total Responses		1	0	0	21	90
		1%			19%	80%

SD = Strongly Disagree, D = Disagree, NS = Not Sure, A = Agree, SA = Strongly Agree

6.3.9 Statistical Analysis

6.3.9.1 Participant Demographics - Comparison Between Study Samples

Independent samples t-tests comparing means between studies for age and BMI showed no significant differences between the study samples on either variable: age ($t(37) = .9, p = .38$), and BMI ($t(37) = 1.0, p = .33$). Two-sample Kolmogorov-Smirnov tests were conducted to compare distributions between Study 1 and Study 2 participants on each of the categorical variables of gender, independence in living and diagnosis of Down Syndrome/other. Again, there were no significant differences found between study samples on any of these confounding variables: gender ($p = .50$), independence in living ($p = .99$), and diagnosis of Down Syndrome/other ($p = 1.0$).

6.3.9.2 One-Way Repeated Measures ANOVAs

One-way repeated measures ANOVAs were conducted to test the effects of time on (i) weight, (ii) % body fat, and (iii) BMI. Four timepoints for analysis were entered: pre- HPES, post- HPES, pre- MCI and post- MCI. Analyses were performed for Study 1, Study 2 and the combined samples of Study 1 + Study 2.

6.3.9.2.1 Study 1

- i. *Weight:* Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 43.0, p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .53$). There was a significant effect of time on weight, $F(1.6, 42.9) = 11.4, p < .01$.
- ii. *Body Fat:* Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 43.1, p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .53$). There was a significant effect of time on % body fat, $F(1.6, 42.9) = 10.9, p < .01$.

- iii. *BMI:* Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 36.8$, $p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .55$). There was a significant effect of time on BMI, $F(1.6, 44.6) = 12.6$, $p < .01$).

6.3.9.2.2 Study 2

- i. *Weight:* Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 26.5$, $p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .43$). There was a significant effect of time on weight, $F(1.3, 12.9) = 7.9$, $p = .01$).
- ii. *Body Fat:* From pre- to post- MCI, Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 25.1$, $p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .40$). There was a significant effect of time on % body fat, $F(1.2, 10.8) = 7.8$, $p = .02$).
- iii. *BMI:* Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 25.5$, $p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .43$). There was a significant effect of time on BMI, $F(1.3, 12.9) = 7.5$, $p = .01$).

6.3.9.2.3 Study 1 and Study 2 Together

- i. *Weight:* Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 64.9$, $p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .51$). There was a significant effect of time on weight, $F(1.5, 57.0) = 15.7$, $p < .01$).

- ii. *Body Fat:* Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 63.5$, $p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .50$). There was a significant effect of time on % body fat, $F(1.5, 54.0) = 15.3$, $p < .01$).
- iii. *BMI:* Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(5) = 57.4$, $p < .01$, and therefore, a Greenhouse-Geisser correction was used, with estimates of sphericity ($\epsilon = .53$). There was a significant effect of time on BMI, $F(1.6, 58.5) = 16.5$, $p < .01$).

6.3.9.3 Paired Samples T-Tests

Separate paired samples t-tests were conducted to compare the effects of each of the phases of the intervention (pre- to post- HPES, pre- to post- MCI, and pre- HPES to post- MCI) on (i) weight, (ii) % Body Fat and (iii) BMI to determine which particular phases were significant. Intervention effect sizes (Cohen's d) were calculated for the total intervention only (Pre- HPES to Post- MCI). Analyses were performed for Study 1, Study 2 and the combined samples of Study 1 + Study 2.

6.3.9.3.1 Study 1

- i. *Weight:* There was no significant difference in weight from pre- to post- HPES ($t(27) = 1.55$, $p = .13$), however, significant differences were found from pre- to post- MCI ($t(27) = 3.96$, $p < .01$), and from pre- HPES to post- MCI ($t(27) = 3.70$, $p < .01$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 7.78, 95% CI: 3.46 – 12.10) was small (Cohen's $d = .20$).
- ii. *Body Fat:* There were significant differences in % body fat from pre- to post- HPES ($t(27) = 2.30$, $p = .03$), pre- to post- MCI ($t(27) = 3.99$, $p < .01$), and pre- HPES to post- MCI ($t(27) = 3.73$, $p < .01$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 2.08, 95% CI: .93 – 3.21) was small (Cohen's $d = .22$).

- iii. *BMI*: There was no significant difference in BMI from pre- to post- HPES ($t(27) = 1.69, p = .10$), however, significant differences were found from pre- to post- MCI ($t(27) = 4.07, p < .01$), and from pre- HPES to post- MCI ($t(27) = 3.97, p < .01$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 1.44, 95% CI: .69 – 2.18) was small (Cohen's $d = .26$).

6.3.9.3.2 Study 2

- i. *Weight*: There was no significant difference in weight from pre- to post- HPES ($t(10) = 1.92, p = .08$) or pre- to post- MCI ($t(10) = 2.20, p = .05$), however, a significant difference was found from pre- HPES to post- MCI ($t(10) = 3.02, p = .01$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 8.85, 95% CI: 2.31 – 15.4) was small (Cohen's $d = .25$).
- ii. *Body Fat*: There was no significant difference in % body fat from pre- to post- HPES ($t(9) = 1.61, p = .14$), however there were significant differences found from pre- to post- MCI ($t(9) = 2.52, p = .03$), and pre- HPES to post- MCI ($t(9) = 2.87, p = .02$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 2.53, 95% CI: .54 – 4.52) was small (Cohen's $d = .27$).
- iii. *BMI*: There was no significant difference in BMI from pre- to post- HPES ($t(10) = 2.0, p = .07$) or pre- to post- MCI ($t(10) = 2.11, p = .06$), however, a significant difference was found from pre- HPES to post- MCI ($t(10) = 2.96, p = .01$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 1.6, 95% CI: .39 – 2.81) was small (Cohen's $d = .29$).

6.3.9.3.3 Studies 1 and 2 Combined

The same paired samples t-tests as above were conducted for both studies combined since the combined sample size ($n=39$) would provide more power for the statistical tests.

- i. *Weight:* Significant differences in weight were found for all three timepoints, from pre- to post- HPES ($t(38) = 2.19, p = .04$), pre- to post- MCI ($t(38) = 4.58, p < .01$), and pre- HPES to post- MCI ($t(38) = 4.74, p < .01$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 8.08, 95% CI: 4.63 – 11.53) was small (Cohen's $d = .21$).
- ii. *Body Fat:* Significant differences were also found for all three timepoints for % body fat, from pre- to post- HPES ($t(37) = 2.77, p = .01$), pre- to post- MCI ($t(37) = 4.79, p < .01$), and pre- HPES to post- MCI ($t(37) = 4.71, p < .01$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 2.19, 95% CI: 1.25 – 3.14) was small (Cohen's $d = .22$).
- iii. *BMI:* BMI changes also showed significant differences for all three timepoints, from pre- to post- HPES ($t(38) = 2.36, p = .02$), pre- to post- MCI ($t(38) = 4.61, p < .01$), and pre- HPES to post- MCI ($t(38) = 4.98, p < .01$). The magnitude of the differences in the means from pre- HPES to post- MCI (mean difference = 1.48, 95% CI: .88 – 2.08) was small (Cohen's $d = .27$).

6.3.9.3.4 Follow-up

No significant differences in weight, % body fat or BMI were found from post- MCI to follow-up. However, significance was retained from the pre- HPES measures to follow-up for weight, % body fat and BMI: weight ($t(31) = 3.18, p < .01$), % body fat ($t(30) = 3.35, p < .01$), and BMI ($t(30) = 3.29, p < .01$). The magnitude of the differences in the means from pre- HPES to follow-up remained small: weight (mean difference = 8.2, 95% CI: 2.94 – 13.46) and (Cohen's $d = .21$), % body fat (mean difference = 2.3, 95% CI: .89 – 3.7) and (Cohen's $d = .24$), and BMI (mean difference = 1.64, 95% CI: .71 – 2.58) and (Cohen's $d = .35$).

6.3.9.3.5 *Sub-Groups*

Significant differences in weight loss achievements were found between adults with a Diagnosis of Down Syndrome and adults with other diagnoses ($t(37) = -2.8, p < .01$). Whilst males outperformed females and those living dependently outperformed those living independently in weight loss achievements, neither factors were significantly different.

6.3.9.3.6 *Food Knowledge*

Gains in overall food knowledge reached statistical significance ($t(29) = 6.54, p < .01$). Statistically significant gains in food knowledge were achieved within all 3 food categories: Green ($t(29) = 2.9, p < .01$), Yellow ($t(29) = 6.9, p < .01$) and Red ($t(29) = 5.2, p < .01$).

6.3.9.4 *Correlations*

The relationship between the HPES summative test scores (the measure used to determine internalisation of health promotion messages delivered during the HPES) and total weight losses accrued as a result of the HPES and MCI combined, was investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was a large, positive correlation between the two variables ($r = .52, n = 21, p = .02$). This indicates that the two variables share approximately 27% of variance in common. Results indicate that higher levels of HPES summative test scores are associated with greater weight losses. Looking at the two phases of HPES and MCI separately showed that the correlation was significant for the HPES phase alone ($r = .55, n = 21, p < .01$), but not for the MCI phase alone ($r = .34, n = 21, p = .14$). No correlation was found between HPES summative scores and the duration of the HPES (10 weeks for Study 1 versus 7 weeks for Study 2) indicating that the information removed for Study 2 participants was indeed redundant.

Spearman's rank-order correlations were run to determine the relationships between (a) attendance and weight losses, (b) app usage and weight losses, (c) food knowledge level and weight losses, and (d) age and weight losses.

- (a) There was a strong, positive correlation between attendance over The HealthyTaps Programme and weight loss, which was statistically significant ($r_s(38) = -.53, p < .01$). This indicates that the two variables share approximately 28% of variance in common. Results indicate that higher levels of attendance are associated with larger weight losses. When attendance was separated for the HPES phase and the MCI phase, there was no significant correlation between attendance at the HPES sessions and weight losses, however, attendance at the MCI phase remained significant ($r_s(38) = -.50, p < .01$). Approximately 25% of variance was shared between the two variables with higher levels of attendance during the MCI phase resulting in larger weight losses.
- (b) There was no significant correlation between app usage and weight loss, ($r_s(38) = -.22, p = .17$).
- (c) There was no significant correlation between food knowledge level at the end of the intervention and weight loss, ($r_s(29) = -.19, p = .31$).
- (d) There was a strong, positive correlation between age and weight loss, which was statistically significant ($r_s(38) = -.51, p < .01$). This indicates that the two variables share approximately 26% of variance in common. Results indicate that younger age adults are associated with larger weight losses.

6.4 Discussion

The changes in body compositions as a result of The HealthyTaps Programme, were not only positive but exceeded the guidelines for effective weight management lifestyle interventions that are set by NICE (2014^a) for the general population.

6.4.1 Feasibility of a Randomised Control Trial (RCT)

To assess whether a larger scale RCT would be feasible, factors of recruitment, attrition and attendance were examined. The original target for recruitment for this pilot project was 4 groups of 6 participants (n=24), however, 8 groups of between 3 and 8 participants (n=39) were recruited between the two studies involved indicating that recruitment through service centres and parent-led Charitable groups is feasible. Seventy percent (n=47) of those invited to take part in the intervention (n=67), were interested in taking part in the project and consented to do so. Of those 47 participants that consented to take part, 40 (85%) completed both phases (one participant completed the intervention but did not have some body composition measures and so was excluded from the analysis). Attrition rates in other multi-component interventions with adults with ID, range from 6% (Martinez-Zaragoza et al., 2016) to 17% (Ptomey et al., 2018), compared with the 15% found in this study. Whilst the attrition rate in the Ptomey et al. (2018) study was similar to this project, their original sample size was nearly four times as large at n=150. Four of the participants in this project dropped out due to technology issues (mainly that their mobile technology did not have sufficient available storage on a continual basis to maintain download and use of the app), a factor which did not affect attrition in the other MCIs. If the technology had performed as planned for these four participants and they had been able to continue this may have decreased attrition to as low as 6%, equal to Martinez-Zaragoza et al. (2016). Lower attrition rates in the Martinez-Zaragoza et al. (2016) may have been as a result of the programme specifically enlisting family members as part of the support system for every participant, a factor that has been shown to increase success in weight loss interventions for adults with ID (Fox et al., 1985), and also for adults in the general population (Wang, Pbert & Lemon, 2014). With the exception of the 2 parent-led groups in this project, support was provided by one staff member in each of the service centres so did not expand to household changes. Interestingly, only one participant (12.5%) from the parent-led groups dropped out compared to 6 (19%) participants from the service centre led groups, indicating that family carer involvement may aid continued engagement in weight loss interventions.

Our attrition rate of 15% is also within the norm for MCIs and in fact far exceed the 60% completion rates deemed acceptable by NICE (2014^a).

Attendance was high for both studies during both the HPES phase and the MCI phase, which also suggests feasibility for running a larger scale RCT. Both of the parent-led groups demonstrated the highest attendances in both phases, again suggesting that family support increases engagement. A power analysis for a paired samples t-test (two tail) was conducted in G*Power to determine a sufficient sample size using an alpha of .05, a power of .80 and a small effect size of Cohen's $d = 0.21$, as was found for the weight losses in this project. Based on these assumptions the required sample size to power a large scale RCT sufficiently would be 180 participants. Allowing for a minimum of 15% attrition would bring the required recruitment to a minimum of 210 participants for a larger scale RCT.

6.4.2 Attendance

As was stated above, the attendance was high for both studies during both the HPES and the MCI. In fact, attendance over the 16-week MCI phase was significantly correlated with weight loss which indicates that regular consultation plays an important role in achieving weight losses. Both the NICE (2014^b) and SIGN (2010) guidelines acknowledge the benefits of regular consultations in weight management lifestyle interventions, with NICE (2014^b) going a step further by recommending that lifestyle interventions should “Last at least 3 months, and that sessions are offered at least weekly or fortnightly and include a ‘weigh-in’ at each session”. The importance of regular consultation is further emphasised in this project by the fact that mean weight changes at the follow-up measure had slightly increased. Between the end of the intervention and the 12 to 14-week follow-up measure all participants continued to have access to the app, but the researchers no longer provided weekly consultations with weekly weigh-ins or reinforcement. A longer-term follow-up measure was not possible for this project due to the time constraints for PhD completion. However, future research would benefit from longer-term follow-up measures at both 6 and 12-

months post- intervention. These measures would provide a more accurate picture of whether self-management was sustained without the addition of regular consultations.

6.4.3 Anthropometric Changes

Both Study 1 and the replica Study 2 demonstrated similar patterns of change for all anthropometric measures, illustrating that the replication study reliably produced the same effects as the original study. Mean % weight losses were almost identical at -3.9% for Study 1 and -4% for Study 2. Similar mean % weight losses were also observed at each of the different phases for both studies with the HPES phase demonstrating -1.1% for Study 1 and -1.2% in Study 2, and the MCI phase demonstrating -2.8% for both studies. The proportion of participants that achieved \geq -5% weight loss was also similar between the two studies at 32% for Study 1 and 27% for Study 2, again with the majority of participants achieving this in the MCI phase in both studies. The patterns in changes in % body fat and BMI means were also almost identical with both studies showing -2% change in % body fat and -1.3 kg/m² change in BMI, and similar losses occurring in each of the phases for both studies. The similarities in the results found between the studies demonstrates reliability in the findings of the effectiveness of the intervention, and the results achieved are comparable with other MCI studies available in the literature. For example, Harris et al. (2017) achieved a -3.25% mean weight change, a -1.79% reduction in % body fat and a -1.19 kg/m² reduction in BMI, over a 6-month MCI. Twenty-one percent of their participants achieved the \geq -5% weight loss that is seen to be clinically significant. Melville et al. (2011) reported a mean % weight loss of -4.4%, a reduction in BMI of -1.82 kg/m², and 36% of their participants achieving \geq -5% weight loss at the end of a 24-week MCI. Whilst the results of our project are similar to the above studies the components have some striking differences. Both of these studies delivered their interventions, every 2 to 3 weeks for between 4 and 6 months, on a one-to-one basis in each participant's home environment with a carer involved as individual support. Whilst our project incorporated one-to-one consultations weekly during the MCI, the participants attended these alone in line with the goal of self-management. In our project the main support and encouragement was provided by

the researchers in the one-to-one consultation, and peers during the group consultations each week. Participants were given the option to have a carer present in the consultations, but all chose to attend alone. Since many participants may not have adequate support from family carers and since lack of support has been highlighted as a barrier in previous research, including the focus group discussions in Chapter 3 of this thesis, the option to self-manage is an important one for some. However, when comparing the results of the parent-led groups in our studies to the Harris et al. (2017) and Melville et al. (2011), our results are better than both studies (-18.5lbs mean weight loss and 86% of participants achieving $\geq -5\%$ weight loss), which highlights the benefit of combining a self-management approach with carer input where possible. A further difference between our project and the Harris et al. (2017) and Melville et al. (2011) studies is in their dietary component as both studies incorporated an individually prescribed diet of -600 kcal per day, whereas our dietary component was designed to nudge eating towards healthier, low-calorie foods whilst reducing intake of unhealthy high-calorie foods. No definitive calorie deficit diet was prescribed in our project as the values of choice and self-management underpinned the dietary component, with the aim of achieving long-term behavioural change. Other MCI studies reported higher mean % weight losses ranging from -6.3% to -7.73%, greater reductions in BMI ranging from -2.4 to -2.7 kg/m², and up to 63% of participants achieving $\geq -5\%$ weight losses (Croce, 1990; Saunders et al., 2011; Ptomey et al., 2018). Again however, these studies all incorporated prescribed energy deficient diets that participants followed. Whilst the MCIs that incorporate an energy deficient diet demonstrate effectiveness in reducing weight for adults with ID, they do not focus on providing functional skills required to make food choices that will aid longer term self-management of healthy eating for overweight adults with ID. Food knowledge alone was not significantly correlated with weight losses in this study, but the combination of increased knowledge and the addition of a practical, functional system to aid decision-making around foods did prove to be an effective way to promote self-management and achieve clinical weight loss.

When looking at the HPES section alone our results, -1.2% weight change and -0.5 kg/m² BMI change, are comparable to most of the other health promotion interventions in the literature (Chapman et al., 2005; Mann et al., 2006; Pett et al., 2013). Mann et al. (2006) found the smallest change in BMI at -0.31 kg/m². However, they had a much larger sample size (n=192) and the training was delivered by trained service centre staff rather than the researchers. Chapman et al. (2005) and Pett et al. (2013) had BMI changes of -0.61 and -0.7 kg/m² respectively which were both slightly higher than this project's HPES results. However, the Chapman et al. (2005) had an intervention duration of 12-months compared to our 10-weeks, and the Pett et al., (2013) specifically targeted parental training to instigate changes within the home environment rather than directly training adults with ID themselves. All three of these health promotion studies report statistically significant reductions in BMI though, whereas this project only reports statistical significance for the HPES when the combined sample size of 39 is used. In the case of this project the 7 to 10-week HPES did result in reductions of weight, % body fat and BMI for 26 (67%) participants and paved the way for a good start to the MCI.

The repeated measures ANOVAs showed that the intervention produced statistically significant reductions in weight, % body fat and BMI for both studies alone and as a combined sample. When paired t-tests were conducted to analyse the effects of the different phases both studies met significance from pre- HPES to post- MCI. In Study 1 the HPES phase alone only met significance for % body fat changes, however, the MCI phase alone met significance for all three body measures. In Study 2 neither the HPES or the MCI phases alone achieved significance for weight or BMI, and only the MCI phase met significance for % body fat. When the two study samples were combined, however, all three body measures reached significance in both the HPES and the MCI phases alone. It may be that the small sample sizes in both studies on their own do not adequately power the statistical analyses to detect significance, but the combined sample size does. What is of note though is that when the study samples are combined the MCI phase shows greater significance than the HPES phase across all three body measures. This reflects the consensus in the literature that MCIs are the

most effective type of intervention for weight loss in adults with ID (Spanos, 2013^a; Harris et al., 2018^a). However, in The HealthyTaps Programme it is to be noted that there is a confounding effect of the HPES on the results of the MCI. Effect sizes for weight changes, % body fat changes and BMI from pre- HPES to post- MCI, were all small, ranging from Cohen's $d = .20$ to Cohen's $d = .29$, however, this effect size would be expected for weight loss interventions (Harris et al., 2018^a).

Eighteen (56%) of the 32 participants measured at follow-up re-gained weight, 1 (3%) participant remained the same, and 13 (41%) continued to lose weight. Of the 18 that re-gained weight only 7 of these exceeded their initial baseline measure at pre- HPES, and 5 of these were participants that had not achieved weight loss at all during the intervention. Weight regain is a common issue after weight management interventions (Mann, Tomiyama, Westling, Lew, Samuels & Chatman, 2007) and as such some MCI studies have incorporated specific weight maintenance phases into their interventions to counteract this. Maintaining weight is said to occur when weight remains $\pm 3\%$ of the weight measured at the end of the weight loss intervention (Stevens et al., 2006). Almost 65% of people who diet, in the general population, regain the weight they lost, and changing eating habits rather than short-term restrictive diets are seen to be better for longer-term maintenance of weight loss (O'Meara, 2020). In the Harris et al. (2017) study a 6-month weight maintenance phase was conducted, with participants encouraged to continue to increase exercise and use behavioural techniques such as self-monitoring and relapse prevention. The main differences between the maintenance phase and the intervention phase was the change from an energy deficient diet to a balanced energy diet, and consultations were conducted once per month instead of fortnightly. Twenty-nine percent of the participants lost $> -3\%$ weight during the maintenance phase, 58% remained within the $\pm 3\%$ of post- intervention weight, and 13% re-gained $> +3\%$ of post- intervention weight. The Melville et al. (2011) study followed the same maintenance procedures as the Harris et al. (2017) study, however, the duration of the maintenance phase lasted 12-months. Twenty-one percent of participants lost $> -3\%$ weight, 50% remained within the $\pm 3\%$ of post- intervention weight, and 29% re-gained $> +3\%$ of post- intervention weight. It is

encouraging that 41% of the participants in this project continued to lose weight over the 12 to 14-week follow-up period without any specific maintenance program in place except the expectation of continued self-management using the HealthyTaps app. Using the same criteria as the Harris et al. (2017) and Melville et al. (2011) studies, 16% of our participants lost $> -3\%$ during follow-up, 44% remained within the $\pm 3\%$ of post- intervention weight, and 40% re-gained $> +3\%$ of post- intervention weight. The thirteen participants that had gained +3 lbs or more at follow-up had all still been overweight at the end of the MCI, with 1 categorised as overweight, 5 categorised as Obese 1, 4 categorised as Obese 2 and 3 categorised as Obese 3. Since this is a substantial proportion of participants that still needed to reduce their weight, the importance of some form of continuous support cannot be underestimated, and embedding this support in both service centres and homes could possibly aid longer-term changes and further weight losses for those that are still overweight at the end of the intervention, and to prevent $> +3\%$ weight regain.

The effects of this intervention on reducing weight in adults with ID is extremely positive but what may be of greater value is the results achieved for those adults with a diagnosis of Down Syndrome, a particularly high-risk group. Two MCIs in the literature specifically report on the results for those participants who have Down Syndrome. In the Melville et al. (2011) study adults with Down Syndrome approached significance ($p = .07$) for weight loss in the Take 5 intervention. In the Saunders et al. (2011) study participants with Down Syndrome achieved mean weight loss of -5.3% which exceeds the NICE (2014^a) guideline. In this project, not only did participants with Down Syndrome achieve a mean weight loss of -7.4% exceeding that of the Saunders et al. (2011) study and the NICE (2014^a) guideline, but 93% (13) of the adults with Down Syndrome lost weight compared to 76% (19) of participants with other diagnoses. Additionally, 62% ($n=9$) of participants with Down Syndrome achieved $\geq -5\%$ weight loss versus 16% ($n=4$) of participants with other diagnoses, and significant differences in weight loss achievements were found between the two groups ($t(37) = -2.8, p < .01$), indicating that this intervention may be particularly beneficial to adults with Down Syndrome. Eleven out of the fourteen adults with

Down Syndrome included in this study were aged between 20 and 30, with the eldest aged 42. Since age was correlated with weight loss and older adults were shown to lose less weight, this may be a confounding variable in this result, and one that requires further investigation in future research. Additionally, since the majority of adults with Down Syndrome were in parent-led groups, and since involvement of caregivers is known to positively influence weight loss, this may also be a confounding variable requiring further research.

6.4.4 Concept Acquisition

The results of the summary tests at the end of the HPES demonstrated that most people continued to regard exercise as the main contributor to weight loss. As was described in the focus groups at the beginning of this project, the majority of service centres incorporate regular exercise activities into their programmes, and many families encourage and support walking, swimming and Special Olympics activities. What was also apparent from the focus groups was the lack of emphasis and support for practical healthy eating programmes and activities. Internationally, the Special Olympics provides many exercise opportunities for children and adults with ID (Special Olympics, 2020). There is no such organisation for diet and healthy eating, and emphasis on creating healthier eating for now lies predominantly in research rather than practice. The drive from research must be to find a way to influence practice.

Two areas that participants struggled with were portion sizes, and the durations and intensities required around exercise. In the case of portion sizes, the research shows that portion sizes have grown in restaurants, ready-made meals and home served meals over the last 2 decades, and that when larger portion sizes are presented people consume more (Centers for Disease Control and Prevention, 2006). Further research into portion size consumption versus serving size guidelines for adults with ID would be beneficial. The hand portion size system (unlockfood.ca, 2018) used in this project provides a simple, functional method for measuring portion sizes that is readily available in all environments. From the concept acquisition test at the end of the

HPES, the results suggest that this system requires more targeted and specific teaching than our HPES allowed for. Further research into the use of this system for portion size measurement in healthy eating studies would benefit the literature. In the case of exercise, the expected weekly durations and intensities set out in the guidelines are in most cases too big a jump from current exercise status for many adults with ID to take notice (Frey, 2004). Set exercise programmes that systematically and subtly increase exercise duration and intensity for predominantly sedentary adults would be beneficial for service centre staff. The majority of exercise in the service centres included in this project were run by staff and consisted mainly of a walking programme. Other programmes that were run by fitness instructors specifically contracted into service centres, were often only weekly and for a longer duration and higher intensity than the more obese Service Users could maintain.

Whilst the results of the summative test were varied, the correlation between knowledge of health messages and final weight losses was significant. When the HPES and MCI weight losses were separated for this correlation, the HPES alone was significant but the MCI alone was not. This indicates that increasing knowledge of health messages alone influences weight loss. Since the correlation remained significant for the total combined weight losses (HPES + MCI) this suggests that the influence of health messages prevails. Research into the specific messages that are important and how to best teach these would benefit the research and guide future training for MCIs. The focus groups indicated that the main health messages present in service centres is focused on exercise. There was a larger emphasis on increasing dietary knowledge than exercise knowledge during the HPES, which may suggest that these type of health messages play more of a role in successful weight loss for adults with ID.

6.4.5 Food Knowledge

Initial baseline levels of food knowledge taken from the flashcards for Study 1 were low (total mean % correct = 52, SD = 11, range 26 to 66) particularly for foods that fell in the Yellow category (total mean % correct = 29, SD = 17, range 0 to 61). Basic

knowledge was demonstrated for foods such as fruits, vegetables and brown bread as good foods to eat, i.e., Green category, and sweet treats, take-aways and alcohol as foods to avoid, i.e., Red category. At the post- HPES measure some participants knowledge had reduced illustrating that this low level of knowledge was also not fluent knowledge. Participants in Study 2 demonstrated more knowledge in their initial baseline responses on the HealthyTaps app, with the total mean % correct = 64 (SD = 14, range 41 to 90), however, all of Study 1 participants provided a single response to each of the 185 foods in their baseline measure whereas Study 2 participant responses on the app ranged from 20 to 2135 responses over the 185 foods. What was noticeable in both studies was that the Yellow category held the lowest levels of knowledge. The majority of health promotion interventions are geared towards promoting consumption of more fruit, vegetables and brown breads whilst reducing consumption of sweets, cakes, take-away foods and alcohol (Bergström et al., 2013; Mann et al., 2006; Marshall et al., 2003). The knowledge reflected in our findings illustrates that these messages are reaching adults with ID and being retained by them, however, this type of knowledge does not account for all of the other foods regularly consumed such as eggs, fish, cereals, yogurts, snacks, ready-made meals, sandwich fillers, home-made dinners, restaurant meals, and so on. In fact, with only this level of knowledge it is feasible to think that if you had a sandwich with brown bread for your lunch that you are eating healthily, regardless of the fact that the filling had large portions of butter, coleslaw, and cheese included. When looking at the number of participants that possessed > 70% knowledge in each of the categories again only the Green and Red categories showed approximately a third of participants at this level, and the Yellow category had zero. Some qualitative studies investigating food knowledge in adults with ID are available in the literature and suggest similar basic levels of knowledge (Kuijken et al., 2016). Quantitative studies using self-report questionnaires to assess dietary knowledge have been conducted with carers and have also shown low levels of knowledge to be present (Hamzaid, Flood, Prvan & O'Connor, 2018; Melville et al., 2009), which further impacts the situation.

The majority of participants in both studies (84%) made significant gains in food knowledge. Larger gains were found from using the HealthyTaps game which may be as a result of the accessibility, immediate feedback, and reinforcement that the app provides compared to flashcards. More importantly, the majority of participants increased their knowledge to > 70% in all 3 categories: Green = 75% of participants, Yellow = 63% of participants, and Red = 88% of participants. Food knowledge is an under-researched area with adults with ID and the literature would benefit greatly from more work in this area. However, knowledge alone did not demonstrate a significant correlation with weight losses in this study ($r_s(29) = -.19, p = .31$), a finding similar to those by Shahsanai, Farajzadegan, Sichani, Heidari & Omid (2018) and Kaufer-Horwitz et al. (2014) with the general population. That said knowledge levels must increase to be able to be used alongside other tools to promote behaviour change in diet (Kaufer-Horwitz et al., 2014). Food knowledge in adults with ID must increase across food types to enable functional choices and gain a balance between foods that can be eaten regularly, foods that can be eaten with limits, and foods that should be avoided if possible. Coupled with this knowledge should be an overriding system of consumption rules to guide decision-making, such as The HealthyTaps Programme provides.

6.4.6 Social Validity

The intervention was viewed positively by both participants and carers. All participants agreed that the information was easy to understand, that the programme was enjoyable and that they were glad to have participated. The majority also felt that goals were achievable, and they would recommend the programme. Some negativity was expressed around ease of use of the app, however, this was expressed by participants who did not own their own smartphone and so may have needed a longer training period on how to use the app prior to the weight loss programme. Many adults with ID have difficulty accessing technology (Dawe, 2006) and as such future interventions incorporating technological solutions may need to allow for individualised training needs and durations.

All responses from the carers were positive with regards to the content, implementation, ease of use and subsequent results of the intervention. One carer strongly disagreed that ‘There would be more interest in this program if service centres knew more about it’, but clarified this response by suggesting that service centres would not feel in a position to provide resources to support the program and would not be motivated to do so.

6.4.7 Limitations

Since this study was a pilot project to test feasibility for a larger scale RCT it did not incorporate a control group in either of the studies. However, the replicate Study 2 demonstrated similar levels and patterns of anthropometric changes to the original Study 1, illustrating reliability in the intervention effects. Future research would benefit from a treatment as usual control group where participants are matched to other service users in their service centre, or a comparison group where comparison participants use an MCI with an energy deficient diet component. There was no initial analyses of ability and comfort in using technology, and subsequently no measure as to how this may have affected usage and the ability to self-manage using the HealthyTaps app. Future trials of the intervention would benefit from assessing this skill and incorporating adequate technology training measures. No measures were conducted to test accuracy of the food intake or exercise logging. The majority of studies have also been unable to assess the accuracy of self-report food monitoring information (Harris et al., 2017; Melville et al., 2011; Saunders et al., 2011; Ptomey et al., 2018). Future trials of this intervention would benefit from a period where accuracy in self-monitoring is concentrated on and reinforced as is best practice in good self-management programmes (Cooper, Heron & Hughes, 2005). Many studies do use pedometers and accelerometers to assess the accuracy of self-monitoring and whether it reflects the exercise engagement of each participant (Harris et al., 2017; Melville et al., 2011; Saunders et al., 2011; Ptomey et al., 2018), and this would be a beneficial addition to The HealthyTaps Programme. Ideally, an automatic upload from a FitbitTM type wearable, providing the duration and intensity of exercise engaged in each day, would eliminate errors caused by manual logging whilst still

providing the feedback necessary to evaluate performance against guidelines. This type of system would also allow participants to direct more of their attention to food intake, which has the potential to provide larger weight losses.

6.4.8 Conclusion

This pilot project has demonstrated that a large scale RCT is feasible from a recruitment, attrition and attendance perspective. Significant results were achieved in weight losses, reductions in % body fat, and reductions in BMI as a result of The HealthyTaps Programme. Not only did results reach statistical significance from pre-HPES to post-MCI measures, they were clinically significant at $\geq -5\%$ weight loss for approximately one third of participants. Completion rates, mean % weight loss and number of participants achieving $\geq -5\%$ weight loss all met the standards for an effective weight management lifestyle intervention set out by NICE (2014^a) for the general population. Whilst follow-up measures showed small gains in weight, and % body fat, 41% of participants continued to lose weight demonstrating their ability to self-manage their healthy lifestyle choices. For those that re-gained weight after demonstrating weight losses, it may be necessary to continue with regular consultations as a long-term support. This strategy is one which is used successfully by members of the general population in programmes such as Weight WatchersTM, and Slimming WorldTM. The fact that attendance was significantly correlated with weight loss in this study further supports this as being a necessary addition for some. One of the most interesting results found in this pilot project was the significant effect that the intervention had on weight loss, % body fat and BMI for adults with Down Syndrome, who are identified in the literature as a high-risk population for obesity. The majority of participants with Down Syndrome in this study were young adults who owned and were proficient in using smartphone apps. Conducting research with a broader demographic range of adults with Down Syndrome would be a worthwhile contribution to the literature.

Whilst food knowledge was not a predictor of weight loss, increases in food knowledge were significant and future research in this area would highlight how knowledge interacts with other weight management tools to affect weight loss. In particular, research to understand current food knowledge should be explored and assessed in its functionality to assist decision-making around food choices. Additionally, any health intervention attempting to increase knowledge around food and exercise should incorporate a measure to assess whether knowledge actually accrued and whether this knowledge can be, and is, applied in a functional manner to effect behaviour change. A specific area of need is the development of a portion size measurement system that is accessible and again results in behaviour change by reducing actual portion sizes consumed to align with recommendations.

Whilst this intervention was not successful for all of the participants involved, all found the content easy to understand, enjoyed the programme and were glad to have taken part. Initial pilot project results are extremely encouraging for this intervention and further research on a larger scale is warranted since the use of the HealthyTaps smartphone app as a self-monitoring and self-evaluating tool, coupled with trained consultants has the potential to reach a wide audience.

Chapter 7 Discussion

Discussion: Utilising bespoke technology to assist people with intellectual disabilities in self-managing their weight: blending a Health Psychology and Behaviour Analytic approach

7.1 Broad Overview

The need for effective research-proven interventions that achieve clinically significant weight loss for adults with ID is critically important in counteracting the increasing trend towards obesity. The systematic review in Chapter 2 of this thesis sought to dissect the components included in current weight management interventions for adults with ID and evaluate their effectiveness, in order to inform the design of a novel weight management intervention. The qualitative research conducted in Chapters 3 and 4 provided valuable insight into the supports, barriers, current lifestyles' and knowledge of Irish adults with ID in relation to healthy eating and exercise. This information added depth and understanding of factors that could aid or hamper the effectiveness of the proposed weight management intervention in producing lifestyle changes necessary for weight loss. In particular these chapters highlighted the need for the weight management intervention to increase food knowledge, incorporate achievable reinforcement strategies, and rely on self-management of healthy choices as the basis to the intervention due to the diversity in supports available to participants. The focus groups conducted for Chapter 5 highlighted issues relating to smart mobile technology usage, mainly the lack of ownership, range of abilities, and differences in confidence in using this technology and concerns over costs. This knowledge focused the design of the HealthyTaps app by ensuring the input modes remained as simple as possible and that only relevant functional feedback visuals were provided. Additionally, the need to operate the app at no personal expense in credit usage was a priority. In Chapter 6, two studies, an original and a replication study, formed the basis for evaluating the novel weight management intervention, named The HealthyTaps Programme, which was designed as an HPES followed by an MCI that utilised the HealthyTaps app as a self-management tool. Both studies demonstrated that the intervention was successful and that it exceeded the guidelines for successful weight management lifestyle interventions for the general population (NICE, 2014^a).

7.2 Chapter Analysis

7.2.1 Systematic Review

The systematic review conducted in Chapter 2 of this thesis was conducted in order to understand the components present in weight management interventions for adults with ID and evaluate their individual and combined effectiveness. This review was the starting point for devising the components necessary to include in the design of The HealthyTaps Programme, undertaken in Chapter 6. The most recent systematic review evaluating the range of weight management interventions for adults with ID was conducted in 2013 (Spanos et al., 2013^a). Whilst this review separated studies by their components, crossover between categories was apparent and the components did not align with guidelines available for the general population (NICE, 2014^a). Additionally, a substantial amount of research had been conducted since, which warranted the need for a more up to date review.

The systematic review followed similar methods to the Spanos et al. (2013^a) review using procedures laid out for Cochrane Reviews, and identified 34 studies eligible for inclusion. From these 34 studies, six categories of components were systematically described, and a further category was suggested, as the basis for a ‘Component Guideline’ for weight management interventions for adults with ID. Utilisation of this ‘Component Guideline’ as a framework for describing the components included in future research projects would ensure comparisons between weight management lifestyle interventions were more accurate. Like previous reviews, this review also identified multi-component interventions as the most effective for weight loss in adults with ID (Spanos et al., 2013^a; Harris et al., 2018^a), which aligns with recommendations for the general population (NICE, 2014^a; SIGN, 2010). An MCI was therefore, chosen as the type of intervention to be used for The HealthyTaps Programme in this project, as is detailed in Chapter 6.

7.2.2 Diet and Exercise Focus Groups

The initial phase of the pilot project in this thesis involved a series of focus groups designed to gain insights into diet and exercise for adults with ID, to influence the design of a multi-component weight management intervention.

Chapter 3 reports the findings from seven focus group discussions with adults with ID, conducted to gain insight into their lifestyles regarding dietary habits and exercise. Forty-five adults with ID aged between 19 and 59 contributed to the discussions. The questions were designed to elicit information regarding perceived support systems, perceived barriers, current knowledge, and current habits in relation to healthy eating and exercise. Many of the findings around barriers and facilitators were similar to previous research available in the literature (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005; Kuijken et al., 2016; Lorentzen & Wikstrom, 2012; Cartwright et al., 2015), which indicates that lived experiences in relation to diet and exercise for Irish adults with ID are comparable to adults with ID in other Westernised societies. However, novel to this thesis is the finding that the majority of facilitators related to exercise, whereas the majority of barriers related to diet. This comparison is new to the literature since no studies have previously examined barriers and facilitators for both diet and exercise simultaneously for adults with ID. Since a healthy, low-calorie diet is the largest contributor to weight loss it is pertinent to note that overweight adults with ID in this study perceive this factor to present with the most obstacles. An additional novel finding of this research is that the majority of the adults involved perceived increasing exercise to be the main point of emphasis for achieving weight loss. This perception is further supported by the fact that families, service centres and Special Olympics provide more regular support for exercise than for healthy eating initiatives. This is also apparent in the lack of ID specific healthy eating programmes and support groups that are available. Whilst increasing exercise is beneficial to health, and indeed weight loss when coupled with dietary change, it is impossible to out-run a bad diet (Kraft, 2015). This message must be stressed and more systematically targeted through service centres, parental groups,

and ID specific organisations if the focus for weight loss is to change more towards diet.

In terms of motivating healthy behaviours, internal motivation was mainly relied upon for change, and the majority of the comments again referred to exercise. Internal motivation alone appears to be inadequate for weight loss for the adults included in this study since the majority are obese and lead predominantly sedentary lifestyles. Thirty percent of the comments around motivation related to some form of external motivation, with 87% of these comments again relating to exercise, and the remaining comments relating to losing weight in general rather than any specific reference to diet. There is a large body of evidence supporting the positive effects of external reinforcement in weight loss for adults with ID (Foreyt & Parks, 1975; Rotatori et al., 1980; Fox et al., 1984; Fox et al., 1985; Fisher, 1986; Croce, 1990; Croce & Horvat, 1992; Sailer et al., 2006; Bazzano et al., 2009; Saunders et al., 2011; Martinez-Zaragoza et al., 2016; Ptomey et al., 2018). It is concerning that these techniques are not being promoted more and embedded within service centres and specialised ID organisations to support adoption and maintenance of healthier practices in relation to both dietary and exercise changes. Greater emphasis, understanding and use of external reinforcement is paramount to creating environments that encourage and support healthier choices.

Poor knowledge in relation to diet and exercise is also an area lacking focus and direction, both in research and practice in terms of skill building. This study showed that basic knowledge of healthy and unhealthy foods was present, a factor already suggested in the literature (Kuijken et al., 2016). This low level of knowledge is not adequate to enable individuals to make informed decisions about food. The results of this study extended the literature by demonstrating the imbalance between knowledge of unhealthy foods, and knowledge of healthy foods, with participants demonstrating more knowledge of which foods were unhealthy foods. Knowledge did not however reflect action since current dietary habits mainly involved unhealthy foods. Adults with ID would benefit from expanding their knowledge of food preparation skills of a larger variety of healthy foods prior to focussing on foods that should be removed or

restricted from regular consumption. This would allow for growth in their dietary range, rather than limiting the choice available. In addition, the increases in knowledge may make healthy foods more desirable and indeed more habitual. It would also allow them to choose healthier foods without feeling pressurised into a diet that is immediately linked to the denial of preferred unhealthy foods. When a larger range of healthy foods become a more regular part of their food intake, more focus could be placed on reducing the unhealthy fattening foods gradually. This type of gradual change in diet has the potential to provide longer-term lifestyle change rather than the short-term changes brought about by prescribed energy deficient diets. McCullough (2020) writes that “strict menu prescriptions: any fad diet that is difficult to follow for one or two days isn’t sustainable and will create a negative experience for eating healthy and make losing weight seem unattainable”. Whilst prescribed energy deficient diets may not all be classed as fad diets, providing a larger range of options and continuously working towards making healthier choices will be more likely to lead to lifestyle change, whilst still providing autonomy of choice.

The findings from these focus groups highlighted several important factors for consideration in the design of the MCI. Since the majority of current supports revolved around exercise and since dietary changes make the most impact to weight loss, the intervention needed to focus more on dietary changes. Some initial HPES were required to set the scene and increase knowledge around food and exercise. In the main, the HPES for participants, staff and families needed to shift dietary change to the forefront for weight loss rather than exercise. Additionally, increasing knowledge of foods to eat, foods to limit and foods to avoid was essential to providing a functional decision-making tool for dietary choices. Finding a balance between helping participants visualise the effects of regularly eating too many high calorie foods, whilst not giving the message that these foods were no longer allowed, was important. A method to aid planning and tracking of food intake, coupled with real-time feedback of consumption to allow for self-evaluation and self-management of choices was an important cog currently missing for most adults with ID in Ireland. Since the level of carer supports varied greatly between participants, the move towards more autonomy in food consumption is a necessary one. Additionally, since service

centres also vary greatly in the culture they employ with respect to healthy eating, greater knowledge and autonomy in food choices is needed. Whilst dietary change was the main focus, the majority of the participants led sedentary lives. The HPES also needed to stress the importance of exercise in increasing health outcomes in a way that participants could relate to. Encouraging any increase in exercise and exploring different exercise types was needed along with a gradual move towards the recommended durations and intensities. Since internal motivation alone had not proven to elicit the necessary changes in lifestyle choices needed to lose weight for these participants, the addition of external reinforcement strategies was deemed paramount to the success of the MCI.

The focus groups described in Chapter 4 compared the lived experiences of two groups of adults with ID that attended the same service centre, but who differed in weight status and healthy lifestyle behaviours. This study was designed to investigate factors that potentially aid weight loss for adults with ID. This type of comparison has not been conducted previously in the literature. Many of the experiences in relation to diet and exercise were similar between the two groups and again reflected previous findings (Bodde & Seo, 2009; Temple & Walkley, 2007; Messent et al., 1999; Frey et al., 2005; Kuijken et al., 2016; Lorentzen & Wikstrom, 2012; Cartwright et al., 2015). However, interesting differences between groups were discovered. In particular the group that successfully lost weight and engaged in healthier lifestyle behaviours had internalised health messages and made the link between lifestyle choices, weight, and health outcomes. This study did not facilitate a detailed investigation into why these participants had internalised the health messages and formed these links whilst the other group had not. However, it is possible that this factor plays a role in driving healthier choices. A summative test was conducted at the end of the HPES to assess whether internalisation of health messages delivered during the HPES had been achieved in this study and whether this did indeed influence weight loss. The summative test checked for understanding of the concepts that had been taught and whether participants had retained those concepts. The summative test results were also correlated with weight loss, indicating that internalisation of health messages

indeed plays a role in weight loss, though how much influence and which messages are important would require further research.

Ten of the twelve participants in this study were overweight and whilst all knew they were overweight none were aware of the extent to which they were overweight and obese was not a word used by any to describe their weight. It is possible that to internalise health messages, people need to be able to relate them to themselves. It would be advantageous to develop an easy access visual poster that shows the particular health concerns relative to each BMI category. This would allow people who are seeking help with weight loss to personalise the risks associated with their actual weight status and provide another possible source of internal motivation. The effect this may have on actual weight loss would be an interesting subject for future research to evaluate. When it came to external motivation the successful weight loss group were responding to the reinforcement contingencies in place in the service centre for exercise engagement and healthy eating, whereas the other group were not. To engage those who do not respond to current reinforcing contingencies present in the service centres it may be necessary to look at the particular barriers surrounding engagement. For example, one service centre had a chart for counting how many pieces of fruit were eaten each day and how many litres of water had been drunk. At the end of the week the group with the most cumulative units of fruit eaten and litres of water drank, won a prize. Some service users may have their lunches provided by family and may not have fruit included, nor have money available to purchase these, which immediately excludes them. Health behaviours chosen by the service centres must ensure equal accessibility, which could be the provision of free access to fruit each day in this particular example. For some service users eating one piece of fruit a week may initially be a good start for them and so it would be beneficial for points to be weighted towards individuals rather than equal for each person, i.e., eating one piece of fruit per week for this person could be given 5 points. Providing external reinforcement for health behaviours is a great start for all service centres, however, being informed as to how they can be individualised is necessary to engage more people. Another external factor noted to motivate healthy eating and continued exercise was the positive feedback the successful group received when people began

to notice their weight loss. It is important to note the power that this could have in maintaining healthy behaviours and as such service centres and families need to be provided with coaching on how to deliver this feedback regularly and effectively to encourage continued maintenance of health behaviours. It is also worth noting at this point the effect that service centres and families can have in modelling healthy habits. The effect of external reinforcement contingencies and positive feedback will be further enhanced by supportive environments with service centres and families modelling healthy behaviours too (Reid, Field, Jones, DiLemma & Robinson, 2019). Creating healthy cultures in both service centres and homes is of essence to long-term change.

7.2.3 Technology Focus Groups

Chapter 5 describes the results from five focus group discussions with adults with ID, conducted to gain insight into their experiences and opinions regarding smart mobile technology. This information was necessary to inform the design of the app to be utilised as a self-management tool in the MCI. Twenty-six adults with ID aged between 19 and 59 contributed to the discussions. The questions were designed to elicit information regarding comfort levels, issues around functionality and use, and opinions on how this technology could aid weight loss. Many of the barriers to mobile technology use were similar to those found in the literature, such as lack of technology ownership, high costs, lack of skills and confidence, and poorly accessible designs (Smith, 2014; Weafer, 2010; Boot et al., 2018; Roberts & Hernandez, 2018), which indicates that technology issues are the same for Irish adults with ID as for adults with ID in other Westernised societies. The main uses of mobile technology were for leisure purposes such as playing games, watching YouTube videos, and listening to music, which is similar to other studies in the literature (Patrick et al., 2020). Again, as with other studies in the literature, Social Media use was predominantly non-existent due to either imposed restrictions or the fear created by cautionary messages from staff and family delivered with the intent of ensuring safe use of technology (Weafer, 2010). Whilst caution must be applied by all of us when using social media platforms, we also balance these concerns with the positive aspects of social media

use, such as connecting with others. When it came to using technology to help self-manage lives, the most advanced use was wake-up alarms or reminders for appointments. None of the adults in this study had used mobile technology to help them manage any aspect of health. The use of mobile technology to aid self-management for adults with ID is an under-utilised resource with potentially wide-reaching implications. More financial investment is needed to provide the necessary resources for adults with ID to successfully access suitable mobile technologies, suitable accessible apps, and much needed expert training.

The main issues raised that required thought in the design of the MCI app were: suitable visuals for those with poor literacy skills, ease of use, a functional system to aid decision-making around food choices, simplicity of feedback, and ensuring app use did not incur costs. Other factors raised that had the potential to jeopardise use of the app were: a lack of smart technology ownership for some participants, lack of smart technology skills, fear of using smart technology, and a lack of support from staff and families in using the app. Whilst self-management is the ultimate goal, it is necessary to initially rely on support from both staff and families if skills are lacking and fear of use is present. The HealthyTaps app was designed with these issues considered by ensuring pictures and generic symbols accompanied text, the minimum amount of steps were required to log information, the feedback system supported decision-making, and the app only uploaded information to the database when the phone accessed Wi-Fi. Funding was secured to provide smartphones to those participants that did not own their own, for the sole purpose of accessing the HealthyTaps app. The HPES was designed to include two sessions of training on the HealthyTaps app and a minimum of two weeks with 24-hour access for practice, prior to participants being asked to use it for weight loss. Participants would also be continually coached on using the app during consultations over the 16-week MCI, and staff and parent app training was scheduled to ensure participants would have support in using the app. At least one staff member from each service centre and one family member from parent led groups were identified to provide support in using the app during the MCI.

7.2.4 The HealthyTaps Programme

The majority of the MCIs in the literature review incorporated health promotion education into their individual consultations during the MCI, with information mainly focusing on the specifics of the diet, exercise and behaviour change components that were included in their interventions (Harris et al., 2017; Melville et al., 2011; Saunders et al., 2011; Ptomey et al., 2018). Only one study conducted a short series of generic health education sessions prior to the MCI beginning (Martinez-Zaragoza et al., 2016). No MCI study to date has evaluated both the individual and combined effects of a health promotion intervention, followed by an MCI with the same participants. The majority of the MCIs in the literature have utilised a prescribed energy deficient diet as the basis for the dietary component. Whilst some MCIs have utilised the ‘Enhanced Stop Light Diet’, which is built on the same concept as our ‘Traffic Light Diet for Intellectual Disabilities’, this has been an add on to a prescribed element. No study to date has relied solely on a functional food categorisation system with generic consumption guidelines, and self-management skills for dietary change. Additionally, no study to date has reported findings based on the use of a bespoke mobile app as the self-monitoring and self-management tool to assist weight management in adults with ID.

When evaluating the two phases of The HealthyTaps Programme, HPES and MCI, separately it is clear that the MCI has the largest effect on weight loss, which reflects the consensus that both the Chapter 2 systematic review and current literature supports (Spanos et al., 2013^a). In the HPES alone, 67% (n=26) of participants had lost weight and the mean weight loss from pre- to post- HPES intervention achieved statistical significance. Whilst these results are encouraging and mirror results from other health promotion interventions (Chapman et al., 2005; Mann et al., 2006; Pett et al., 2013), the mean weight loss did not reach $\geq -3\%$ and less than 8% (n=3) of participants achieved $\geq -5\%$ losses. In the MCI alone 77% (n=30) of participants had lost weight and the mean weight loss from pre- to post- MCI intervention achieved statistical significance. The mean weight loss from the MCI alone came close to the recommended -3% and 23% (n=9) of participants achieved $\geq -5\%$ losses. Most

effective was the combined results of the HPES and MCI together, with 82% (n=32) of the participants losing weight, the mean weight loss surpassing -3% and reaching statistical significance from pre- to post- intervention, and 31% (n=12) of participants achieving $\geq -5\%$ weight loss. This indicates that the combination of a dedicated HPES followed by an MCI may prove to be more effective than an MCI alone. In addition, results suggest that this combination can achieve results that satisfy acceptable weight management lifestyle intervention criteria for the general population. The strong, positive correlation between summative test scores at the end of the HPES and final weight losses further supports the rationale that health promotion has a part to play in overall weight loss. Additionally, internalisation of health promotion messages was raised as a parameter that may influence successful weight loss, from the comparison study in Chapter 4 of this thesis. Studies with the general population have also found health knowledge to influence both increased exercise and healthier dietary habits (Lenneis & Pfister, 2017; McDermott, 2011; Dallaire et al., 2012). The challenge is in understanding what parts of the HPES were important in influencing weight loss, and how best to improve upon these. The three areas that scored highest for participants in this study were (1) the core concepts (that both healthy diet and exercise are needed for weight loss, but that healthy diet has the larger influence), (2) the traffic light food categorisations and consumption rules, and (3) the benefits of exercise, which may indicate the importance of including these types of health messages in future health promotion interventions.

During the MCI, attendance was the only factor to show significant correlation with weight loss. Whilst this is valuable information it is difficult to understand what particular parts of attending actually influenced weight loss. For example, how much did the weigh-ins, performance feedback, individualised goal setting, reiterating of health messages, or reinforcement strategies each contribute to weight losses? Future studies should explore these variables further as this would be important to identify the most salient, and indeed the redundant, factors that make up the current popular format for weight management interventions for adults with ID. Of particular interest is that Group B in Chapter 4 of this thesis identified external reinforcement as a factor that potentially influences weight loss, and external reinforcement was delivered

during weekly consultation sessions to all those who had sufficiently engaged in using the app. Whilst this relationship needs teasing out in future research, what is worthy of note is that regular consultations play the largest role in influencing weight loss for adults with ID. It cannot be ignored that participants in the parent-led groups achieved larger weight losses than service-led groups, highlighting the increased benefit of family support. However, 78% of participants in service-led groups had also achieved weight losses. Since not all people with ID have access to family carers at home, and since not all family carers are motivated towards achieving a healthy lifestyle themselves, the ability to self-manage is of great importance.

The exceptional results achieved by adults with a diagnosis of Down Syndrome cannot be emphasised enough. This population have been identified as particularly at-risk of obesity and are often focused on in weight management and health research (Ordonez et al., 2014; Mendonca et al., 2011; Mendonca et al., 2009; Pérez et al., 2018; Silva et al., 2017). The weight losses achieved by adults with Down Syndrome in this study are greater than the highest results achieved to date of the MCIs available in the literature (Ptomey et al., 2018). For example, the weight loss figures for adults with Down Syndrome in this study were -7.4% mean weight loss and 93% achieving $\geq -5\%$ weight loss, compared with -7% mean weight loss and 33% achieving $\geq -5\%$ weight loss in the Ptomey et al. (2018) study. Croce (1990) did achieve a mean weight loss of -7.73% and 100% of participants achieving $\geq -5\%$ weight loss, however, only three participants were involved and the methods used in this intervention would be deemed too restrictive in ethical terms for research today. Fifty percent of the adults with Down Syndrome were part of parent-led groups, which was a strong influencing factor in the success of the results for adults with Down Syndrome in this study. Indeed, when the results were isolated and compared between the parent-led groups and the service-led groups for adults with Down Syndrome, the strong influence that parents had is clear. The results for parent-led groups of adults with Down Syndrome far exceeded any results from MCIs to date (-11.1% mean weight loss and 86% of this group achieving $\geq -5\%$ weight losses). What also stands out though is that even the service-led adults with Down Syndrome achieved better results than adults with other IDs in the service-led groups, which further supports the notion that the particulars of

this intervention may be especially suited to those with a diagnosis of Down Syndrome.

Whilst the recommended 12 month follow-up duration was not possible to assess due to the time limitations of a PhD, the results at 3 months follow-up were encouraging, with 41% of participants continuing to lose weight by utilising the HealthyTaps app as a self-management tool to aid health choices. As was mentioned previously, attendance at the weekly consultations during the MCI demonstrated a strong, positive correlation with weight loss, which suggests that this additional support mechanism may be necessary for some people to continue to lose or maintain weight in the longer-term. How long this support needs to continue and whether it performs best when embedded in services or as an add on service provided by an external health consultant is unclear. What is apparent however, from these pilot results is that adults with ID are indeed capable of using smart mobile technology to self-manage their food and exercise choices in a way that achieves weight loss. They also show that weight loss can be achieved by providing a simple but functional system for food decisions that nudges the majority of consumption towards lower-calorie nutritious foods without the need to prescribe a short-term energy deficient diet. How this system for weight loss with adults with ID will fare out in terms of long-term lifestyle change remains unknown at present but continued weight loss for 41% of participants without continued support is promising.

Whilst food knowledge was not significantly correlated with weight loss, what was important was that knowledge of whether foods were healthy, okay sometimes, or unhealthy had increased for the majority of participants. By providing three simple categorisations of foods the balance of knowledge between healthy, okay, and unhealthy foods had somewhat equalised, dispelling the myth that losing weight meant being deprived of food. Increasing food knowledge allows the removal of one of the common barriers listed by adults with ID in achieving healthy eating (Kuijken et al., 2016; Lorentzen & Wikstrom, 2012; Cartwright et al., 2015). However, to be effective in changing habits this knowledge must be accompanied by the ability to access healthier foods and prepare healthier meals, two other barriers known to stand in the

way of self-management in diet (Kuijken et al., 2016; Lorentzen & Wikstrom, 2012; Cartwright et al., 2015). This intervention did not have the scope to target these additional barriers, however, knowledge increases provide a start to eating more healthily. The simplicity of the TLD-ID categorisation system and accompanying consumption guidelines allows knowledge to translate to a functional system for decision-making. The use of the food game in HealthyTaps app allowed learning to take place independently since immediate feedback was provided by the app. The added element of token reinforcement provided in the game incentivised participants to play and strive for better results. This remote method of increasing food knowledge allows for individuals to access the learning platform at times that suit them. It also ensures that the teaching process is labour free and cost-effective. The data captured by using the HealthyTaps app allows for secondary analysis of the types of foods that are well known by the majority and also common errors. This information is important in understanding the types of foods that users may require more education and information on during the HPES phase of future weight management interventions.

Designing a successful ID specific weight management programme with assistive self-management technology is only of value if the people that need it perceive it to be acceptable in terms of effort involved and social acceptability. The high completion rates and high attendance rates suggest that the effort was acceptable to those who participated. Additionally, the results of the social validity questionnaires show that the programme was positively perceived, and they would recommend it to others. Only one comment was made in relation to a service centre not recommending the programme, but this comment was reflective of a perceived negative culture within the organisation rather than a fault with The HealthyTaps Programme. The use of mobile app technology to aid self-management of health choices is also common practice in the general population (Crone-Todd, 2012), supporting the social acceptability of the HealthyTaps app as a suitable method of self-management of weight for adults with ID.

7.3 Methodological Limitations of the Research

7.3.1 Systematic Review

Whilst there were a healthy number of studies that satisfied inclusion criteria for the review, many of these studies did not specifically target weight loss. In particular some of the health promotion studies targeted improved health practices, and some of the physical activity studies targeted cardiovascular health, with anthropometric changes reported as secondary outcomes. The development of a standardised ‘Component Guideline’ aided the grouping of studies as per the components included, which allowed for effective overall comparisons between types of interventions. However, since there was no standardised form of reporting body composition changes between the studies, comparison of outcomes was somewhat limited. The inclusion of standardised body composition changes such as the mean percentage weight loss, and the number of participants achieving $\geq -5\%$ weight losses, would allow more robust comparisons between studies, as well as the comparison of intervention effectiveness against the NICE (2014^a) guidelines.

The lack of data available to evaluate both maintenance procedures and follow-up measures, and the vast difference in the durations of these between studies, meant that no proper evaluation could be achieved. Eighteen of the studies provided either maintenance or follow-up measurements, but only three out of the six with maintenance phases met or exceeded the recommended 6 month maintenance intervention duration, and only two out of the fifteen reporting follow-up measures had durations greater than the recommended 12 months duration (NICE, 2014^b; SIGN, 2010). Short-term maintenance or follow-up periods are unreliable to evaluate the extent to which an intervention can produce lasting weight losses.

7.3.2 Focus Groups

The questions designed for use in Chapters 3 and 4 for diet and exercise, did not specifically ask about barriers or facilitators. However, the open-ended nature of these questions provoked discussions that elicited opinions and experiences clearly relating to personal issues and supports present for diet and exercise needs. Additionally, the

researchers encouraged expansion in discussions that were relevant to these aspects. No quantifiable assessment of knowledge or current habits was performed and so the analysis may not be representative of all knowledge and current habits, but comments relating to these factors were easily identifiable within the transcripts and provide a broadly comprehensive picture.

The information gleaned from data sheets sometimes contradicted the narrative during discussions. For example, many people living at home with family stated in the discussions that their meals were provided for them and that they had little say in what they ate. In contrast these same participants reported a mixture of independence and reliance in shopping and meal preparation on the data sheets. Many adults with ID perceive themselves to have independence in their food shopping and meal preparation as they occasionally purchase items from supermarkets and prepare meals for themselves. In reality the majority of adults who live at home with family, eat meals that are bought and prepared for them. It is interesting to know however, that these adults perceive themselves to also have independence and choice as this will enable them to feel empowered when it comes to initiating dietary change.

The participants recruited for the study in Chapter 3 encompassed a wide demographic range for the variables noted as confounding variables in weight loss for adults with ID. The participants were representative of both male and female genders, a wide range of ages, all categories of BMI representing overweight and obesity, and included 16 (36%) participants with a diagnosis of Down Syndrome. Living arrangement was the only limited confounding variable as the majority of participants lived at home with their families. Whilst the findings in Chapter 3 may not fully incorporate the views and experiences of adults with ID who live independently, the majority of adults with ID in Ireland currently live at home with their families (Census, 2016), and so the results remain representative of the majority of adults with ID in Ireland. Generalisation of the results from Chapter 4 are limited since the total number of participants was small, the second group recruited was a convenience sample, and both groups were from the same service centre and geographical area. However, comparing two groups who accessed the same day service supports and opportunities provided

us with a unique opportunity to make direct comparisons as to why some people engage with opportunities and some don't, which led to identifying potential influencing factors for successful weight loss. The depth of discussions in the technology focus groups in Chapter 5 varied between the groups depending on their knowledge and experience with smart technology. Some groups contributed greatly, and others contributed little. Where groups had little to talk about during the discussion due to their lack of ownership, experience and use of smart technology, this lack of information in contrast with the wealth of information from other groups was in itself valuable insight.

7.3.3 The HealthyTaps Programme

The original design for this project was a multiple baseline design across groups, however, due to a lengthy ethics process this design became no longer feasible within the timeframe of the PhD. The duration required to recruit matched control groups was also not feasible in the remaining timeframe, so splitting the recruited groups and conducting a replication design was agreed as best fit. Whilst this design is not as robust as a multiple baseline across groups or a matched control group design, the remit for this study was as a pilot to test the feasibility of running a full RCT in the future. The replication study produced similar results to the original study on all anthropometric measures for each of the separate phases of the HPES and the MCI, and for the combination of both, demonstrating that the intervention had the same effect. Attrition rates were low and attendance during the intervention was high which bodes well for a future RCT.

The amount of daily practice of the food flashcards between Week 3 and Week 10 of the HPES for Study 1 participants was not monitored in any way so no measure of how much practice each participant engaged in was present. However, 83% of those tested at baseline and post- HPES had made gains in their knowledge. How much could be attributed to the HPES sessions rather than daily practice of the flashcards is unknown, but what is important is that the majority of participants had increased their knowledge around food types. For some participants knowledge dropped between pre- and post- measures indicating that baseline knowledge was not fluent. Future

research would benefit from incorporating a regular measure of knowledge fluency rather than a pre- and post- type measure.

A number of factors relating to smart technology use may have limited the efficacy of the MCI intervention for some participants. For those who did not own their own smart technology there was not enough time allowed for in the intervention to familiarise themselves with using smart technology prior to being asked to use the app to self-manage food intake and exercise. For those who did own their own smart technology comfort levels and abilities were mixed which also affected usage. However, individual coaching to resolve difficulties in using the app formed part of the weekly consultations to help reduce the effect that poor technology skills had on the intervention success. For a variety of reasons, not all participants carried their smartphones with them at all times which meant food intake and exercise logging was often by memory rather than in-situ, a factor known to under-estimate consumption (Ptomey et al., 2013). It would be a useful addition to the intervention to provide a lengthier training period on using the HealthyTaps app and to find ways to eliminate barriers that stop participants from accessing their smartphones throughout the day, particularly during mealtimes. Some participants reported difficulties in identifying the correct colour category of foods they were consuming, which affected food intake logging. Future revisions of the app may benefit from a text or verbal search option of actual food items to allow identification of the colour category to log. Staff and parents had been provided with the app and a support manual to allow them to access the food categories as part of their supporting role, however, there was no measure included in the study to assess whether this support was utilised or effective. Ensuring that each participant has real-time access to an adequately trained support person may prove advantageous for future replications of this intervention.

Not all participants completed the summative testing at the end of the HPES, however, it was clear from those who did that food types and exercise benefits were topics that had been clearly understood whereas portion sizes and exercise rules were areas of misunderstanding by the majority. Follow-up measures were also only available for some of the participants, which limits the true picture of weight changes at 3 months

post-intervention. However, even if the 7 participants without follow-up data had all put on weight from post- intervention to follow-up, the percentage of participants continuing to lose weight would be 33% which is still a considerable number of participants achieving self-management.

The parent-led groups of adults with Down Syndrome achieved the best results of all groups, however, it should be noted that these were all young adults in their twenties who owned smartphones and who demonstrated proficient skills in using smart technology. The other adults with Down Syndrome who were part of service-led groups were predominantly in their twenties and thirties and again all owned their own smartphones. It is difficult to know how much the younger age profile and confidence in using smart technology contributed to the superior results for this population, however, upskilling all age groups in smartphone use could only benefit all adults with ID. It is also worth noting again that these groups had the benefit of family support, which is known to produce better results (Martinez-Zaragoza et al., 2016; Ptomey et al., 2018).

7.4 Future Directions

Adoption of the suggested ‘Component Guideline’, and reporting of outcome measures as per the NICE (2014^a) guidelines, would improve the quality of future health intervention research studies for adults with ID, and enhance subsequent reviews by ensuring evaluations compare interventions based on their components, and comparisons are made between the same outcome measures. Whilst the systematic review from Chapter 2, and previous reviews in the literature maintain that MCIs are the most effective types of lifestyle interventions for weight management in people with ID, the number of studies available that incorporate the three distinct components are limited (n=6), and the literature would benefit from a larger pool of research to draw conclusions from. In particular, the literature lacks adequate information relating to weight maintenance, and post-intervention follow-up measures for MCIs. It would be pertinent to gain more insight into the longer-term efficacy of

MCIIs that incorporate short term energy deficient diets, since these are currently the favoured dietary component in MCIIs for adults with ID.

In terms of the perceived barriers and facilitators reported by adults with ID, the literature is plentiful for exercise but sparse for diet. Addressing this balance is extremely important since dietary change will have the biggest impact on weight. By discussing both diet and exercise in the same research it was possible to make the comparison that exercise had more facilitators than diet, and diet had more barriers than exercise. Future research designed to explore this in more detail would benefit the literature as this study indicates that current practices in service centres and family units lean more towards increasing exercise rather than improving diet. Research exploring effective ways to shift the focus of weight loss towards diet as the main component, with exercise as an accompanying component would be beneficial, especially since the HPES method used in this intervention did not manage to change participant's perspectives away from exercise as the best way to lose weight.

The focus groups touched on the issue that adults with ID possess only a basic knowledge of foods, and that knowledge of healthy eating is predominantly weighted towards exclusion of foods rather than the addition of healthier foods. The analysis of food knowledge conducted during the HPES food flashcard task and subsequent food game in the HealthyTaps app confirmed that food knowledge was limited, and that more unhealthy foods could be identified than healthier ones. The simple but functional system for categorising foods that the TLD-ID utilises provides adults with ID with a tool to make decisions around their food choices. The food game in the HealthyTaps app is ideal to teach the categorisations in a wide-reaching and cost-effective way. This section of the HealthyTaps app has the ability to function independently as a learning platform to teach the health value of the majority of common foods. Health promotion interventions often seek to increase food knowledge but usually concentrate on a basic range of foods and rarely group foods in such a way as to provide a comprehensive system for decision-making. It would be of value to explore how weight is impacted simply by using the HealthyTaps food game, along with the food category meanings (GREEN is healthy, YELLOW is okay

but limit amounts, and RED is unhealthy). Not only would this be of interest for all adults and children with ID, but this would also be of interest for children without ID to perhaps help influence healthier eating patterns from a young age. For example, assessing dietary intake before and after use of the HealthyTaps food game in different cohorts of primary school children based on age and socio-economic status, could identify the HealthyTaps food game as an efficient and accessible educational product which could be utilised as part of the school curriculum to teach healthy eating.

What was unsuccessfully taught in the HPES in this project and what remains an area of difficulty for people with ID, and indeed most of the general population, is an understanding of the recommended portion sizes for different foods. Not only is type of food eaten important for weight loss but the amount is too. Finding an effective method to teach this to adults with ID is paramount to supporting future MCIs. Using parts of the hand to measure portion sizes is in theory a system that is accessible in all environments, however, the 2-sessions dedicated to teaching this in the HPES were not enough to establish this system. The HealthyTaps programme relies on food intake logging to reflect not only the food type but also the number of portions consumed. There was no actual measure of portions taken during the project, but portion sizes were discussed during the one to one weekly consultations as part of the accuracy of logging discussions. Developing an effective method for teaching the hand system for portion sizes would greatly benefit any healthy eating programme or weight management intervention for adults with ID. Since most of us regard recommended portion sizes as small, and since the majority of meals that adults with ID consume are provided by others, dissemination of the hand system to service centres and families would also be beneficial.

Knowledge of weight status was also an area that warrants further examination. Whilst people in the study were aware that they were overweight none used the term obese, and so people with ID may be unaware of the extent of their weight gain, and how much they need to lose weight to decrease health risks. Additionally, when the successful weight loss group in Chapter 4 were initially weighed by the researchers four were still overweight, with one classified as obese and two just below the BMI

cut-off for obesity. On visual inspection alone both researchers and the service centre manager had categorised these participants as slightly overweight, possibly since they were comparing them to very overweight people included in the other group. This is a worrying factor since the overweight body image has become more normalised, which in turn means that staff may not realise the extent to which people under their care need to lose weight. There is a gap in the current literature in comparing staff perspectives of weight status to actual weight status of those they support. This is an incredibly important piece of research as it has the potential to show that service centre staff do not identify the true extent of weight loss needed for health reasons. Another layer to this research could be to assess each individual's programme to see whether weight management initiatives form part of their individual service plan and to what extent their programmes reflect their need for weight loss. This may also highlight the differences between cultures in service centres with respect to the promotion of behaviours that lead to a healthy lifestyle.

In terms of bringing The HealthyTaps Programme further, this pilot project was conducted to test the feasibility of an RCT. The results suggest that running an RCT would be the next step to test the efficacy of this intervention. However, certain aspects of The HealthyTaps Programme could be improved upon prior to running an RCT. Firstly, it would be useful for all participants to reach a pre-determined pre-requisite level of competence in smart technology use prior to being asked to use the HealthyTaps app. Additionally, the food categorisation game should be available for a number of weeks beforehand to allow participants to familiarise themselves with food colours prior to being asked to log their consumption. Again, set criteria for food knowledge should be achieved before being asked to use the HealthyTaps app to log food intake. By establishing acceptable pre-requisite levels for these skills for all participants it is possible to reduce the effects that variation in these has on the end results. This project did not include a step for reinforcing accurate self-monitoring, a feature that many self-management programmes incorporate, and this addition would also benefit The HealthyTaps Programme. Establishing accuracy in self-monitoring prior to setting food consumption goals and guidelines, may provide the behavioural momentum needed to maintain accuracy of logging over the MCI phase. It would also

be interesting to see what affect the simple act of food intake logging alone has, without individualised goals and guidance amounts being provided. Exercise logging would benefit from an automated system through the use of a wearable device such as a Fitbit (Under Armour, 2020). By linking the app directly to such a device the pressure to remember to log this component disappears, and participants only have to pay attention to the visual feedback on their cumulative exercise each day. Additionally, this would ensure a more accurate picture of physical activity throughout the day without the need to understand durations and intensities of exercise at a specific level for logging. That is providing participants adhered to wearing them. With this system automated it would allow participants to concentrate their efforts on the food section within HealthyTaps app.

The current HealthyTaps Programme provides reinforcement for using the app to log food intake and exercise engagement, and for playing the food game. Additionally, reinforcement is provided for weight losses achieved. In a review of dietary research with the general population in 2013, Dr Sherry Pagoto stated that the most significant factor associated with weight loss was behavioural adherence to the programme goals. Future replications of The HealthyTaps Programme should incorporate a measure of adherence to individual weekly goals set, and to the guidelines for food intake and exercise. This measure should play a larger role in the visual feedback during one-to-one consultations and a further layer of reinforcement for adherence should be devised. More individualised reinforcement, whilst difficult to implement, would also be beneficial.

Since the duration of this PhD did not allow for a 12-month follow-up measure to be conducted it is important that an RCT allows for this, especially since the end goal of The HealthyTaps Programme is to achieve self-management and lifestyle change, rather than just adherence to a short term energy deficient diet component. It would also be an advantage to compare the results between groups who have no consultations during the 12-month follow-up period with groups who continue to have a monthly consultation. This would allow examination of whether long-term supports are

required to sustain the momentum required to continue to lose or maintain weight and induce true lifestyle changes.

7.5 Conclusion

The results of the systematic review in Chapter 2 and the subsequent results from The HealthyTaps Programme support MCIs as the most effective types of intervention in effecting weight loss in adults with ID. The most recent review of MCIs conducted by Harris et al. (2018^a) stated that only MCIs with an energy efficient diet of -500kcal or more produced significant and clinical weight losses. The HealthyTaps Programme shows that adherence to a short term -500kcal energy deficient diet is not a necessary component to effect significant or clinical weight loss, that provision of a simple food categorisation system, and visual feedback display to support functional decision-making is effective. Additionally, the ability to utilise a system for decision-making in food choices has the potential to provide a long-term method for self-management and lifestyle change. Whilst this research was only an initial pilot of The HealthyTaps Programme, the results are extremely encouraging. To improve on the quality of the research and indeed to improve the outcomes for a larger proportion of participants, several changes to the programme have been mentioned above. However, what remains undebatable is the encouraging start to this programme with results exceeding those determined acceptable for interventions with the general population, and in particular the exceptional results achieved for adults with Down Syndrome. What was particularly encouraging was the continued weight losses for 41% of participants at the 3-month follow-up measure as this demonstrates that The HealthyTaps Programme does indeed assist adults with ID to self-manage healthier lifestyles.

Appendices

Appendix A: Adapted Downs & Black (1998) Quality Checklist

QUESTION			YES = 1	NO = 0
Reporting	1	Is the hypothesis/aim/objective of the study clearly described?	Includes clear description of either aim or hypothesis	Does not include clear description of either aim or hypothesis
	2	Are the main outcomes to be measured clearly described in the Introduction or Methods section?	Outcomes clearly described in appropriate section	Outcomes not clearly described or first mentioned in the Results section
	3	Are the characteristics of the patients included in the study clearly described?	Clear description of intervention cohort including selection criteria (even if control group is unclearly described)	Unclear description or no selection criteria for intervention cohort
	4	Are the interventions of interest clearly described?	Clearly described and potential to be reproduced	Not clearly described and difficult to be reproduced
	5	Are the distributions of principal confounders in each group of subjects to be compared clearly described?	Information on Age, Gender, and ID is present for each group (intervention and control) or if only one group then detailed for that group.	Not all confounders detailed
	6	Are the main findings of the study clearly described?	Complete description including pre/post scores	Incomplete description e.g. with just change scores
	7	Does the study provide estimates of the random variability in the data for the main outcomes?	provides standard deviation or inter-quartile range or measure of variability for main outcome measures	no measure of variability (e.g. only mean)
	8	Have the characteristics of participants lost to attrition been described?	if there are no dropouts; or if attrition is less than 15%; or if attrition is between 25-15% but dropout participants have been described	attrition of greater than 15% and no description of dropout participants; or attrition greater than 25%
	9	Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	p-value reported with decimal places (e.g. 0.031)	p-value reported as <0.05
	10	Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	population study; consecutively or randomly sampled	No: states that it is a convenience sample or methods clearly not representative of entire population























































External Validity	11	Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	provides a comparison of study sample to overall population	No: if they score no for the question prior
	12	Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	Intervention performed at home, in community settings or in any adult disability service	No: intervention performed in a lab setting; inpatient hospital setting
	13	Was an attempt made to blind study subjects to the intervention they have received?	participants do not know if receiving experimental intervention or control	No: if only one group; if crossover design with actual control group that does nothing
Internal Validity - Bias	14	Was an attempt made to blind those measuring the main outcomes of the intervention?	clearly state assessors were blinded	No: describe assessors but no mention of blinding; describe assessors and state they were not blinded
	15	If any of the results of the study were based on “data dredging”, was this made clear?	if they followed the aims and only did analyses related to aims; additional analyses but clearly stated that it was a secondary analysis	No: did unplanned analyses that were not related to the aims without mention of why
	16	In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?	same period of time for all groups between last training and post-assessment	No: different time periods between last training sessions and post-assessment without adjustment
	17	Were the statistical tests used to assess the main outcomes appropriate?	appropriate statistical methods	No: obvious error in statistical methods (e.g. using parametric methods for non-normally distributed data)
	18	Was compliance with the intervention/s reliable?	Statement of fidelity to the intervention protocol is present and fidelity is greater than 85%. Attendance at sessions is stated and greater than 85%, or the amount ascertained by the authors.	No statement of fidelity to protocol or fidelity is less than 85%. Attendance at sessions is less than 85% or amount ascertained by authors.
	19	Were the main outcome measures used accurate (valid and reliable)?	if the study measured reliability or validity or if the study referenced prior work (for the majority of outcomes)	No: use non-standardised assessments with no mention of reliability/validity statistics
	20	Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	all participants recruited from the same school, community, or hospital and for single group studies if the source of recruitment is clearly described	No: participants recruited from different schools, communities in different areas (e.g. rural vs city) and for single group studies if there is no information regarding the source of recruitment

Internal Validity - Confounding	21	Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	specifies time period of recruitment and time periods are the same between groups	No: time periods that were very different between groups, or no time period stated
	22	Were study subjects randomised to intervention groups?	clearly states randomisation was performed	No: not randomised
	23	Is the hypothesis/aim/objective of the study clearly described?	Includes clear description of either aim or hypothesis	Does not include clear description of either aim or hypothesis
	24	Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	mention of concealment for both assessors and patients	No: non-randomised studies; concealed from patients not assessors or vice versa; states that assignment was not concealed
	25	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	if studies matched in design for age or gender or ID; or adjusted for age or gender or ID in analyses	No: not matched in design for age or gender or ID and no adjustment in analyses. Single group studies should be answered no unless confounding variables are reported as effects on outcomes.
	26	Were losses of participants at post-measures taken into account?	if the study reports losses and it is greater than or equal to 85%; study reports no losses at post-measures	No: less than 85% losses at post-measures
Sample Size	27	Was the number of subjects either >50 or was a sample size calculation provided?		

Appendix B: Checklist for Autonomy Around Meals

Who do you plan your meals with?						_____
	on my own	with my family	with staff	in a group		
Who do you make your meals with?						_____
	on my own	with my family	with staff	in a group		
What is important to you for your meals?						_____
	cost	easy to make	makes me full	healthy	I like the taste	

Appendix C: Checklist for Food Preferences

									apples	baked potato	bananas	berries	biscuits	broccoli	brown bread	burger and chips	cakes and buns
									raw carrot	cauliflower	cheese	chicken	chilli and rice	Take away	chips	chocolate	cold meat salad
									carrots	cottage pie	crackers	crisps	curry	eggs	fajitas	fish and chips	fizzy drinks
									fruit juice	ham	lasagne	McDonalds or KFC	milk	oranges	pasta	peas	pizza
									potatoes	roast dinner	salad	salmon and veg	sandwiches	sausage and beans	soup	spaghetti bolognese	steak
									stew	stir fry	sweets	tea or coffee	tortilla and dips	turnip	water	white bread	yogurt

Food Type	Category	Reasons
apples	GREEN	As per guidelines and dietician advice
baked potato	RED	Usually have butter and fattening fillings
bananas	GREEN	As per guidelines and dietician advice
berries	GREEN	As per guidelines and dietician advice
biscuits	RED	As per guidelines and dietician advice
broccoli	GREEN	As per guidelines and dietician advice
brown bread	GREEN	As per guidelines and dietician advice
burger and chips	RED	As per guidelines and dietician advice
cakes and buns	RED	As per guidelines and dietician advice
raw carrot	GREEN	As per guidelines and dietician advice
cauliflower	GREEN	As per guidelines and dietician advice
cheese	YELLOW	As per guidelines and dietician advice
chicken	YELLOW	Not green as this is a roast chicken with skin on
chilli and rice	YELLOW	As per guidelines and dietician advice
take away	RED	As per guidelines and dietician advice
chips	RED	Fried chips not oven chips
chocolate	RED	As per guidelines and dietician advice
cold meat salad	GREEN	Assumption is no coleslaw or potato salad
carrots	GREEN	As per guidelines and dietician advice
cottage pie	YELLOW	As per guidelines and dietician advice
crackers	YELLOW	As per guidelines and dietician advice
crisps	RED	As per guidelines and dietician advice
curry	RED	Creamy curry
eggs	GREEN	As per guidelines and dietician advice
fajitas	YELLOW	Yellow due to presence of wraps
fish and chips	RED	As per guidelines and dietician advice
fizzy drinks	RED	As per guidelines and dietician advice
fruit juice	YELLOW	As per guidelines and dietician advice
ham	GREEN	As per guidelines and dietician advice
lasagne	RED	As per guidelines and dietician advice
McDonald's or KFC	RED	As per guidelines and dietician advice
milk	RED	Full-fat milk
oranges	GREEN	As per guidelines and dietician advice
pasta	RED	Creamy sauce on the pasta
peas	GREEN	As per guidelines and dietician advice
pizza	RED	As per guidelines and dietician advice
potatoes	GREEN	As per guidelines and dietician advice
roast dinner	RED	Due to roast potatoes
salad	GREEN	As per guidelines and dietician advice
salmon and veg	GREEN	As per guidelines and dietician advice
sandwiches	RED	Usually have butter and fattening fillings
sausage and beans	RED	Due to sausages
soup	YELLOW	As per guidelines and dietician advice
spaghetti bolognese	YELLOW	As per guidelines and dietician advice
steak	GREEN	As per guidelines and dietician advice
stew	YELLOW	As per guidelines and dietician advice
stir fry	YELLOW	Usually cooked in oil making it yellow
sweets	RED	As per guidelines and dietician advice
tea or coffee	GREEN	As per guidelines and dietician advice
tortilla and dips	RED	As per guidelines and dietician advice
turnip	GREEN	As per guidelines and dietician advice
water	GREEN	As per guidelines and dietician advice
white bread	YELLOW	As per guidelines and dietician advice
yogurt	YELLOW	As per guidelines and dietician advice

Appendix D: Checklist for Regular Exercise Engagement



badminton



basketball



bowling



canoeing



cross trainer



cycling



dancing



exercise bike



dodgeball



GAA football



horse riding



weights in gym



GAA hurling



martial arts



row machine



rugby



running



soccer



swimming



treadmill



tennis



volleyball



walking



yoga

Appendix E: Checklist for Ownership of Technology Types



Tablet



iPad



phone



iPhone



PC



laptop



Kindle



Kindle fire



smartwatch



Fitbit



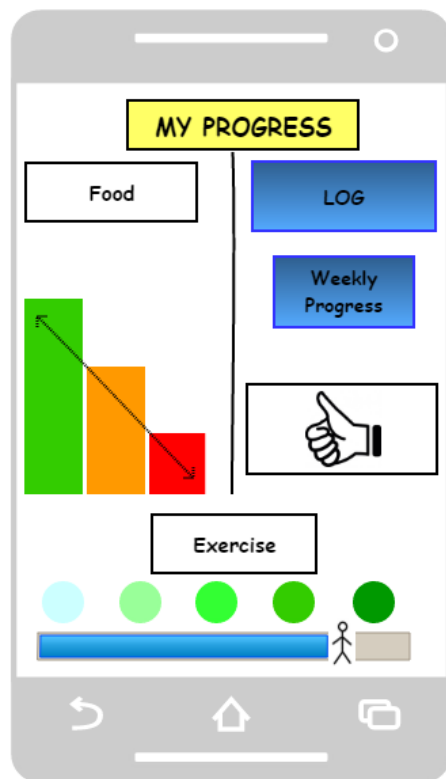
Something else

Appendix F: Checklist for Preferred App Features

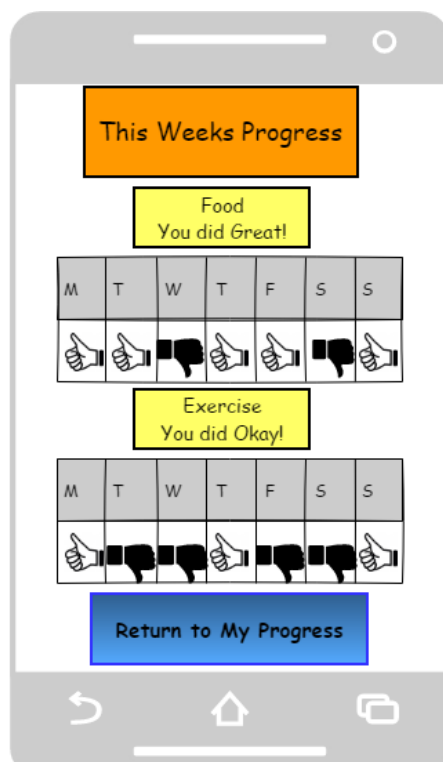
<input type="checkbox"/>	Remind you to exercise
<input type="checkbox"/>	Stay within eating guides
<input type="checkbox"/>	Show a picture of how you are doing
<input type="checkbox"/>	Give you feedback if you are doing well
<input type="checkbox"/>	Give you feedback if you are not doing well
<input type="checkbox"/>	Give you suggestions
<input type="checkbox"/>	Remind you to drink healthy fluids
<input type="checkbox"/>	Track how long you sleep

Anything else _____

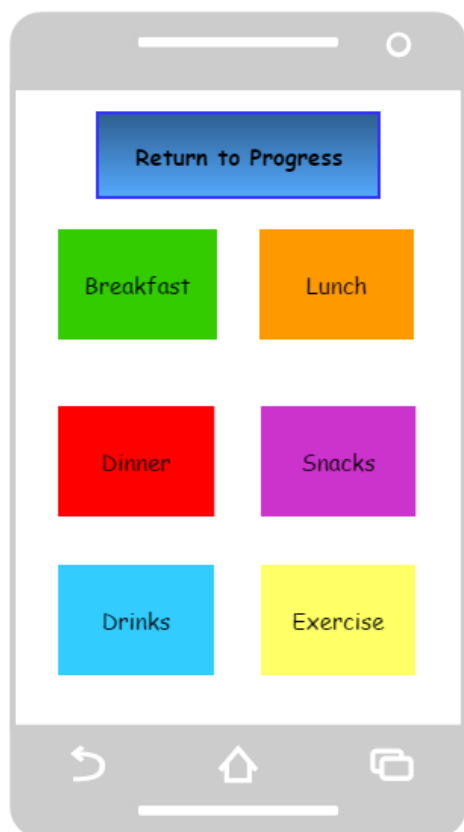
Appendix G: Wireframe Mock-up Screens for App Design



HOME SCREEN WITH DAILY SUMMARY



WEEKLY SUMMARY PAGE



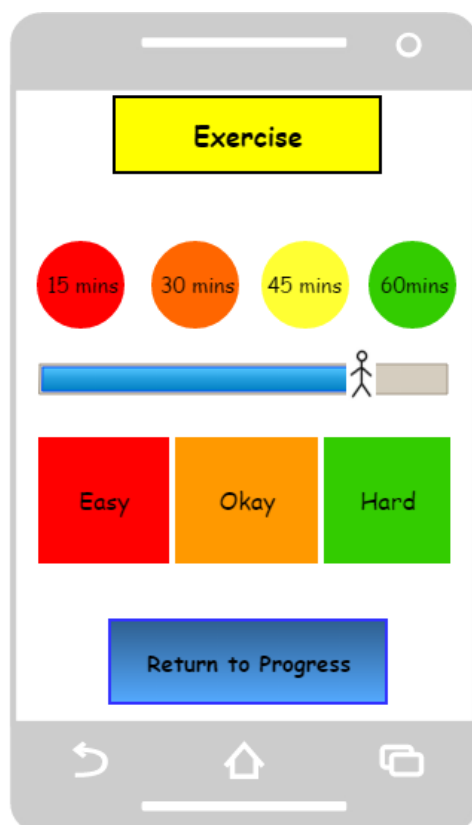
FOOD LOGGING PAGE 1



FOOD LOGGING PAGE 2













EXERCISE LOGGING PAGE 1
















EXERCISE LOGGING PAGE 2

Appendix H: Daily Food Diary Layout

<div>WEEK</div> <div>DAY</div>	Lean Meat & fish		
	Processed Meat & Fish		
	Breads, Cereals & Carbs		
	Fruit & Veg		
	Lean Dairy		
	Dairy		
	Lean Fluids		
	Fluids		
	Treats		
Exercise			

Appendix I: Examples of Food Lists by Colour Categories

Sample of Green Foods List

Category	Food Descriptor	Image	Portion Size Descriptor	Portion Size Image
Fruit	Apple		1	
Fruit	Banana		1 Medium	
Fruit	Orange		1	
Fruit	Pear		1	
Fruit	Grapes		Handful	
Fruit	Strawberries		Handful	
Fruit	Raspberries		Handful	
Fruit	Plum		2 small	
Fruit	Blueberries		Handful	

Sample of Yellow Foods List

Category	Food Descriptor	Image	Portion Size Descriptor	Portion Size Image
Fruit	Tinned Fruit		1/2 tin	
Fruit	Dried Fruit		Handful	
Carbs	Crackers		3	
Carbs	Oven Wedges or Chips		Fist	
Bread	White Bread		Hand	
Bread	Bagel		1/2	
Bread	Roll / Baguette		Hand	
Bread	Wrap		1	
Bread	Pitta		Hand	
Meat	Cottage Pie		Palm	

Sample of Red Foods List

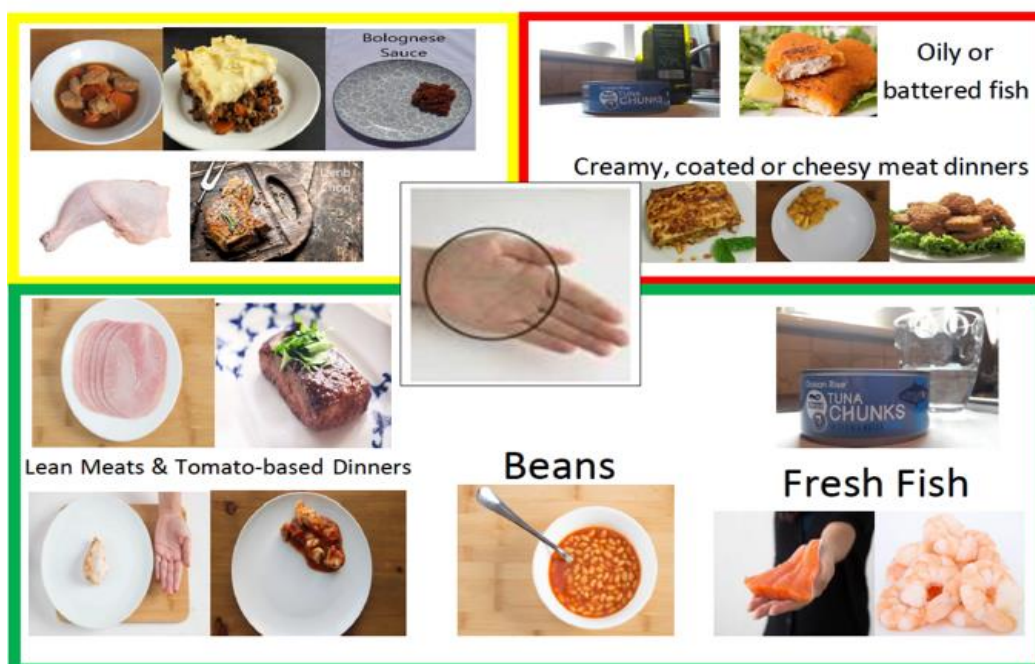
Category	Food Descriptor	Image	Portion Size Descriptor	Portion Size Image
Carbs	Mash potato made with milk and butter		Fist	
Carbs	Chips (deep fried)		Fist	
Carbs	Fried Rice		Fist	
Carbs	Fried Noodles		Fist	
Carbs	Potato Waffles		1	
Bread	Naan Bread		1/3	
Cereals	Sugary Cereals		Fist	
Cereals	Porridge made with full fat milk		Fist	
Meat	Sausages		2	
Meat	Rashers / Bacon		2	

Appendix J: Samples of Portion Size Guides

Fist Portion Size Foods



Palm Portion Size Foods



Appendix K: Weekly Training Topics for Participants and Carers

Participant 10-Week HPES – Topics by Week

Week	Participant Training Topics
Week 1	How to lose weight: <ul style="list-style-type: none"> • Twin Pillars of diet and exercise • Introduction to the TLD-ID food categorisation system • Substitute foods • Portion sizes by plate • Introduction to using your hand for portion sizes
Week 2	Recap core concepts from Week 1 + Exercise: <ul style="list-style-type: none"> • Benefits of exercise • Daily durations and intensities • Suggestions for individual exercises • Suggestions for group exercises • How to make an exercise plan • Recording progress
Week 3	Recap core concepts from previous weeks + TLD-ID: <ul style="list-style-type: none"> • Introduction to general rules • Common foods and their colour categorisation • Practical activity with food flashcards (Baseline for food knowledge) • Daily guidelines
Week 4	Recap core concepts from previous weeks + Portion Sizes: <ul style="list-style-type: none"> • Using your hand to measure how much food • Practicing the different hand shapes • Relating common foods to the different hand shapes • Meal suggestions: food colours and portion sizes
Week 5	Recap core concepts from previous weeks + Changing Behaviours: <ul style="list-style-type: none"> • Changing habits • Temptation • Choice and responsibility
Week 6	Recap core concepts from previous weeks + Self-management Strategies: <ul style="list-style-type: none"> • Goal setting • Tracking • Planning for difficulties • Reviewing achievements • Rewarding achievements
Week 7	Recap core concepts from previous weeks + Identifying and measuring portion sizes of real food items.
Week 8	Recap core concepts from previous weeks + App Training: <ul style="list-style-type: none"> • How to track food and exercise
Week 9	Recap core concepts from previous weeks + App Training: <ul style="list-style-type: none"> • How to read the app feedback • Points system and reinforcement systems
Week 10	Recap core concepts from previous weeks. Review and practice using app.

Participant 7-Week HPES – Topics by Week

Week	Participant Training Topics
Week 1	How to lose weight: <ul style="list-style-type: none"> • Twin Pillars of diet and exercise • Introduction to the TLD-ID • Substitute foods • Portion sizes by plate • Introduction to using your hand for portion sizes
Week 2	Recap core concepts from Week 1 + Exercise: <ul style="list-style-type: none"> • Benefits of exercise • Daily durations and intensities • Suggestions for individual exercises • Suggestions for group exercises • How to make an exercise plan • Recording progress
Week 3	Recap core concepts from previous weeks + TLD-ID: <ul style="list-style-type: none"> • Introduction to general rules • Common foods and their colour categorisation • Practical activity with food flashcards (Baseline for food knowledge) • Daily guidelines
Week 4	Recap core concepts from previous weeks + Portion Sizes: <ul style="list-style-type: none"> • Using your hand to measure how much food • Practicing the different hand shapes • Relating common foods to the different hand shapes • Meal suggestions: food colours and portion sizes
Week 5	Recap core concepts from previous weeks + Identifying and measuring portion sizes of real food items.
Week 6	Recap core concepts from previous weeks + App Training: <ul style="list-style-type: none"> • How to track food and exercise
Week 7	Recap core concepts from previous weeks + App Training: <ul style="list-style-type: none"> • How to read the app feedback • Points system and reinforcement systems

COS 3-Week HPES – Topics by Week

Week	Participant Training Topics
Week 1	<p>How to lose weight:</p> <ul style="list-style-type: none"> • Twin Pillars of diet and exercise • Calorie intake vs output and guidelines <p>Diet:</p> <ul style="list-style-type: none"> • Traffic Light Diet for Intellectual Disabilities food categorisation system • Practical activity with food flashcards (Baseline for food knowledge) • Food substitutions • Practical interactive visual demonstration of different daily eating plans • Examples of food colours for different meal plans across the day • Portion sizes by plate • Introduction to using your hand for portion sizes <p>Exercise:</p> <ul style="list-style-type: none"> • Daily durations and intensity levels <p>Supporting:</p> <ul style="list-style-type: none"> • Benefits of active COS • Support vs pressure • Negative messaging • Effective support and positive feedback • Getting organised • Externalising health choices
Week 2	<p>Recap core concepts from Week 1.</p> <p>Diet:</p> <ul style="list-style-type: none"> • Determining and measuring portion sizes with real food items, based on hand sizes. • Deciding on colour and number of foods <p>Changing behaviours:</p> <ul style="list-style-type: none"> • Setting up the environment to avoid temptations • Eating habits for all <p>Self-Management:</p> <ul style="list-style-type: none"> • Supporting choice and responsibility • Supporting goal setting, tracking, and reviewing • Providing verbal and tangible reinforcement • Contingencies
Week 3	<p>Recap core concepts from previous weeks.</p> <p>App and Reinforcement Training.</p>

Appendix L: Outline of Summative Testing for HPES

Summative Test Questions

1. CORE CONCEPTS

- a) What 2 things do we need to do to lose weight? (4 points)
- b) Which one helps us to lose more weight: eating healthy or exercising? (1 point)

2. FOOD TYPES AND RULES

- a) Match the statement to the right colour on the traffic lights. (3 points)
- b) Match the slogan to each colour board (Go, Slow down, and Stop Think). (3 points)
- c) Match the amounts of foods per day to each colour board (12-15 per day, 6 or less per day and 0 or max 1 per day). (3 points)
- d) Match the foods to the correct colour category: Green, Yellow or Red. (12 points)

3. PORTION SIZES

- a) Which hand shows us the biggest amount of food that we can eat, and which hand shows us the smallest amount of food that we can eat. (2 points)
- b) Match the foods to the correct hand portion size. (12 points)

4. EXERCISE BENEFITS

- a) Circle or tick 3 things that exercise is good for. (3 points)

5. EXERCISE RULES

- a) Match the time to the effort for exercise. (3 points)

References

- Abbott, S. & McConkey, R. (2006), The barriers to social inclusion as perceived by people with intellectual disabilities, *Journal of Intellectual Disabilities*, Vol 10 (3), 275-287.
- Adolfsson, P., Sydner, Y.M., Fjelstrom, C., Lewin, B. & Andersson, A. (2008), Observed dietary intake in adults with intellectual disability living in the community, *Food & Nutrition Research*, 52:1, 1-13.
- Agrawal, P., Gupta, K., Mishra, V. & Agrawal, S. (2015), The Psychosocial Factors Related to Obesity: A Study Among Overweight, Obese and Morbidly Obese Women in India, *Women & Health*, 55, 623-645.
- Anastasiou, C.A., Karfopoulou, E. & Yannakoulia, M. (2015), Weight regaining: From statistics and behaviors to physiology and metabolism, *Metabolism Clinical and Experimental*, Vol 64, 1395 to 1407.
- Anderson, M. (2015), The Demographics of Device Ownership, Retrieved 25th November 2019 from <https://www.pewresearch.org/internet/2015/10/29/the-demographics-of-device-ownership/>
- Anderson, M. & Perrin, A. (2017), Technology use among seniors, Retrieved 22nd November 2019 from <https://www.pewresearch.org/internet/2017/05/17/technology-use-among-seniors/>
- Anderson, W.L., Armour, B.S., Finkelstein, E.A. & Weiner, J.M. (2010), Estimates of State-Level Health-Care Expenditures Associated with Disability, *Public Health Reports*, Volume 125, pages 44-51.

Antal, M., Zajkás, G., Rajháthy, B., Nagy, K., Szántó, É., Thur, M., Dworschák, E., Gergely, A., Bedö, M. & Biró, G. (1988), Longitudinal examinations in the course of dietotherapy of mentally retarded obese in-patients, *Zeitschrift für Ernährungswissenschaft*, Vol 27, 101-108.

Apple Inc. (2020), Human Interface Guidelines: Accessibility, Retrieved 4th February 2020 from <https://developer.apple.com/design/human-interface-guidelines/accessibility/overview/introduction/>

Asbury, J.E. (1995), Overview of focus group research, *Qualitative Health Research*, Vol 5 (4), 414-420.

Atlantis, E. & Ball, K. (2008), Association between weight perception and psychological distress, *International Journal of Obesity*, 32, 715-721.

Ayaso-Maneiro, J., Dominguez-Prado, D.L. & Garcia-Soidan, J.L. (2014), Influence of weight loss therapy programs in body image self-perception in adults with intellectual disabilities, *International Journal of Clinical and Health Psychology*, 14, 178-185.

Banks, S. (2016), National Disability Services: Chronic Illness and People with Intellectual Disability – Prevalence, Prevention and Management, Retrieved on 20th August 2019 from <https://www.nds.org.au/images/LearnNDevelop/Chronic-Illness-and-People-with-Intellectual-Disability.PDF>

Bazzano, A.T., Zeldin, A.S., Shihady Diab, I.R., Garro, N.M., Allevato, N.A., Lehrer, D., and the WRC Project Oversight Team (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*, Volume 37, Number 6S1S201-S208.

Beange, H., Lennox, N. & Parmenter, T.R. (1999), Health targets for people with an intellectual disability, *Journal of Intellectual & Developmental Disability*, 24:4, 283-297.

Beart, S., Hawkins, D., Stenfert Kroese, B., Smithson, P. & Tolosa, I. (2001), Barriers to accessing leisure opportunities for people with learning disabilities, *British Journal of Learning Disabilities*, 29, 133–138.

Bell, A.J. & 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.

Bennett, A.E. & Cunningham, C. (2014), A qualitative evaluation of a healthy cookery course in Ireland designed for adults with mild to moderate intellectual disability, *Journal of Intellectual Disabilities*, Vol. 18(3) 270–281.

Bergström, H., Hagströmer, M., Hagberg, M. & Elinder L.S. (2013), A multi-component universal intervention to improve diet and physical activity among adults with intellectual disabilities in community residences: A cluster randomised controlled trial, *Research in Developmental Disabilities*, 34, 3847–3857.

Bergström, H., Elinder, L.S. & Wihlman, U. (2014), Barriers and facilitators in health education for adults with intellectual disabilities—a qualitative study, *Health Education Research*, Vol 29(2), 259-271.

Bertoli, S., Battezzati, A., Merati, G., Margonato, V., Maggioni, M., Testolin, G. & Veicsteinas, A. (2006), Nutritional status and dietary patterns in disabled people, *Nutrition, Metabolism & Cardiovascular Diseases*, 16, 100-112.

Bhaumik, S., Watson, J.M., Thorp, C.F., Tyrer, F. & McGrother, C.W. (2008), Body mass index in adults with intellectual disability: distribution, associations and service implications: a population-based prevalence study, *Journal of Intellectual Disability Research*, volume 52 part 4 pp 287–298.

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

Bodde, A.E., Seo, D., Frey, G.C., Lohrmann, D.K. & Puymbroeck, M.V. (2013), Developing a Physical Activity Education Curriculum for Adults with Intellectual Disabilities, *Health Promotion Practice*, Vol 13(1), 116-123.

Boer, P.H. & Moss, S.J. (2016), Effect of continuous aerobic vs. interval training on selected anthropometrical, physiological and functional parameters of adults with Down syndrome, *Journal of Intellectual Disability Research*, Vol 60(4), 322–334.

Bollard, M. (2003), Going to the doctor's: The findings from a focus group with people with learning disabilities, *Journal of Learning Disabilities*, Vol 7(2), 156-164.

Boot, F.H., Owour, J., Dinsmore, J. & MacLachlan, M. (2018), Access to assistive technology for people with intellectual disabilities: a systematic review to identify barriers and facilitators, *Journal of Intellectual Disability Research*, Volume 62(10), 900–921.

Bond, L., Carroll, R., Mulryan, N., O'Dwyer, M., O'Connell, J., Monaghan, R., Sheerin, F., McCallion, P. & McCarron, M. (2020), Biopsychosocial factors associated with depression and anxiety in older adults with intellectual disability: results of the wave 3 Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing, *Journal of Intellectual Disability Research*, Vol 64 (5), 368-380.

Braun, V. and Clarke, V. (2006), Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3 (2), 77-101.

Breazeale, R. (2017), S.M.A.R.T. Goals: Vital to resiliency, *Retrieved on 2nd March 2019 from* <https://www.psychologytoday.com/us/blog/in-the-face-of-adversity/201705/smart-goals>

Brownell, K.D., Kersh, R., Ludwig, D.S., Post, R.C., Puhl, R.M., Schwartz, M.B. & Willett, W.C. (2010), Personal Responsibility And Obesity: A Constructive Approach To A Controversial Issue, *Health Affairs*, 29(3), 379-387.

Buchanan, R.A. (2019), History of Technology, *Retrieved on 24th January 2019 from* <https://www.britannica.com/technology/history-of-technology/Technology-and-education>

Buijs, P.C.M., Boot, E., Shugar, A., Fung, W.L.A. & Bassett, A.S. (2017), Internet Safety Issues for Adolescents and Adults with Intellectual Disabilities, *Journal of Applied Research in Intellectual Disabilities*, 30, 416–418.

Callaghan, P. (2004), Exercise: a neglected intervention in mental health care?, *Journal of Psychiatric and Mental Health Nursing*, 11, 476–483.

Cambridge, P. & McCarthy, M. (2001), User focus groups and Best Value in services for people with learning disabilities, *Health and Social Care in the Community*, 9(6), 476–489.

Carmona, R.H., Giannini, M., Bergmark, B. & Cabe, J. (2013), The Surgeon General's call to action to improve the health and wellness of persons with disabilities: Historical review, rationale, and implications 5 years after publication. *Disability and Health Journal*; 3(4), 229-232.

Carr, D. & Friedmann, M.A. (2005), Is Obesity Stigmatizing? Body Weight, Perceived Discrimination, and Psychological Well-Being in the United States, *Journal of Health and Social Behaviour*, Vol.46, 244-259.

Carter M.C., Burley VJ, Nykjaer C. & Cade J.E. (2013), Adherence to a smartphone application for weight loss compared to website and paper diary: pilot randomized controlled trial, *Journal of Medical Internet Research*, 15(4), e32. doi: 10.2196/jmir.2283.

Cartwright, L., Reid, M., Hammersley, R., Blackburn, C. & Glover, L. (2015), Food choice by people with intellectual disabilities at day centres: A qualitative study, *Journal of Intellectual Disabilities*, Vol. 19(2) 103–115.

Casey, A., Boyd, C., MacKenzie, S. & Rasmussen, R. (2012), Dual-Energy X-Ray Absorptiometry to Measure the Effects of a Thirteen-Week Moderate to Vigorous Aquatic Exercise and Nutritional Education Intervention on Percent Body Fat in Adults with Intellectual Disabilities from Group Home Settings, *Journal of Human Kinetics*, Volume 32, 221-229.

Caton, S., Chadwick, D., Chapman, M., Turnbull, S., Mitchell, D. & Stansfield, J. (2012), Healthy lifestyles for adults with intellectual disability: Knowledge, barriers, and facilitators, *Journal of Intellectual and Developmental Disability*, 37:3, 248-259.

Census (2016), Press Statement Census 2016 Results Profile 9 - Health, Disability and Carers, Retrieved 8th January 2020 from <https://www.cso.ie/en/csolatestnews/pressreleases/2017pressreleases/pressstatementcensus2016resultsprofile9-healthdisabilityandcarers/>

Centers for Disease Control and Prevention [CDC] (2006), Do Increased Portion Sizes Affect How Much We Eat?, Retrieved on 16th August 2018 from https://www.cdc.gov/nccdphp/dnpa/nutrition/pdf/portion_size_research.pdf

Centers for Disease Control and Prevention [CDC] (2010), Overweight and Obesity among people with disabilities, *Retrieved on 6th April 2019 from* <https://www.cdc.gov/ncbddd/disabilityandhealth/documents/obesityFactsheet2010.pdf>

Centers for Disease Control and Prevention [CDC] (2019^a), National Center for Health Statistics, National Health Interview Survey (2017): Table of Summary Health Statistics - Table A-15. Body mass index among adults aged 18 and over, by selected characteristics: United States, 2017, *Retrieved 17th June 2019 from* <https://www.cdc.gov/nchs/nhis/shs/tables.htm>

Centers for Disease Control and Prevention (2019^b), Increasing Physical Activity Among Adults with Disabilities, *Retrieved on 20th January 2020 from* <https://www.cdc.gov/ncbddd/disabilityandhealth/pa.html>

Chan, J.M., Lambdin, L., Graham, K., Fragale, T. & Davis, C. (2014), A Picture-Based Activity Schedule Intervention to Teach Adults with Mild Intellectual Disability to Use an iPad During a Leisure Activity, *Journal of Behavioral Education*, 23:247–257.

Chance, P. (2014), *Learning and Behaviour: 7th Edition - Chapter 12*, Wadsworth, Cengage Learning.

Chang, V.W. & Christakis, N.A. (2001), Extent and Determinants of Discrepancy Between Self-Evaluations of Weight Status and Clinical Standards, *Journal of General Internal Medicine*, Vol 16, 538-543.

Chapman, M.J., Craven, M.J., & Chadwick, D.D. (2005), Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities, *Journal of Intellectual Disabilities*, vol 9(2) 131–144.

Chapman, M.J., Craven, M.J., & Chadwick, D.D. (2008), Following up Fighting Fit: The long-term impact of health practitioner input on obesity and BMI amongst adults with intellectual disabilities, *Journal of Intellectual Disabilities*, vol 12(4) 309–323.

Cochrane Developmental, Psychosocial and Learning Problems (2014), Data collection form for intervention reviews: RCTs and non-RCTs, Retrieved 10th November 2016 from <https://dplp.cochrane.org/data-extraction-forms>

Condasky, M., Ledikwe, J.H., Flood, J.E. & Rolls, B.J. (2012), Chefs' Opinions of Restaurant Portion Sizes, *Obesity*, Vol. 15 No. 8, 2086-2094.

Connolly, A. & Davies, B. (2018), Health Survey for England 2017: Adult and child overweight and obesity, Retrieved 17th June 2019 from <https://files.digital.nhs.uk/3F/6971DC/HSE17-Adult-Child-BMI-rep.pdf>

Cooper, J.O., Heron, T.E. & Heward, W.L. (2014), *Applied Behaviour Analysis: 2nd Edition*, Essex: Pearson Education Limited.

Cooper, S., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F. & Morrison, J. (2015), Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis, *BMC Family Practice*, 16:110, 1-11.

Croce, R. (1990), Effects of Exercise and Diet on Body Composition and Cardiovascular Fitness in Adults with Severe Mental Retardation, *Education and Training in Mental Retardation*, 176-187.

Croce, R. & Horvat, M. (1992), Effects of Reinforcement Based Exercise on Fitness and Work Productivity in Adults with Mental Retardation, *Adapted Physical Activity Quarterly*, 9,148-178.

Crone-Todd, D.E., (2012), Keeping Track to Avoid Losing Track. *The Current Repertoire*, 28(3), 6-8. Retrieved from <http://www.behavior.org/resources/683.pdf>

Curry, 2015), Fundamentals of Qualitative Research Methods: Focus Groups (Module 4), Retrieved 6th September 2017 from <https://www.youtube.com/watch?v=cCAPz14yjd4>

Dagnan, D. & Sandhu, S. (1999), Social comparison, self-esteem and depression in people with intellectual disability, *Journal of Intellectual Disability Research* Volume 43(5), 372-379.

Dairo, Y.M., Collette, J., Dawes, H. & Oskrochi, G.R. (2016), Physical activity levels in adults with intellectual disabilities: A systematic review, *Preventive Medicine Reports* 4 (2016) 209–219.

Dallaire, C., Lemyre, L., Krewski, D. & Gibbs, L.B. (2012), The Gap Between Knowing and Doing: How Canadians Understand Physical Activity as a Health Risk Management Strategy, *Sociology of Sport Journal*, 29, 325 -347.

Dawe, M. (2006), Desperately seeking simplicity: how young adults with cognitive disabilities and their families adopt assistive technologies, *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, Montreal, Canada*. doi: 10.1145/1124772.1124943.

De Castella, T. (2014), Who, What, Why: What is an 'obesogenic' environment?, Retrieved 14/06/2019 from <https://www.bbc.com/news/blogs-magazine-monitor-27601593>

Deloitte, (2019), Global Mobile Consumer Survey 2019: The Irish cut, Retrieved 8th February 2020 from <https://www2.deloitte.com/ie/en/pages/technology-media-and-telecommunications/articles/global-mobile-consumer-survey.html>

Department of Health, (2005), Research Governance Framework for Health and Social Care: Second Edition, Retrieved 18th January 2017 from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf

Department of Health/Ipsos MRBI (2015) Healthy Ireland 2015 Survey Summary of Findings, Department of Health, Retrieved 25th March 2017 from <http://health.gov.ie/wp-content/uploads/2015/10/HealthyIreland-Survey-2015-Summary-of-Findings.pdf>

Depression and Bipolar Support Alliance (2020), Medications for Mood Disorders, Retrieved 9th September 2020 from <https://www.dbsalliance.org/wellness/treatment-options/medications/>

Dictionary.com (2020), Definition of Technology, Retrieved on 24th January 2020 from <https://www.dictionary.com/browse/technology>

Divajeve, D., Retat, L., Shaw, A., Brown, M., & Webber, L. (2014), Risk factor-based modelling for Public Health England, Retrieved from <http://www.ukhealthforum.org.uk/prevention/pie/?entryid43=38207>

Doherty, A.J., Jones, S.P., Chauhan, U. & Gibson, J.M.E. (2018), Eating well, living well and weight management: A co-produced semiquantitative study of barriers and facilitators experienced by adults with intellectual disabilities, *Journal of Intellectual Disabilities*, 1–19.

Doran, C.M., Einfeld, S.L., Madden, R.H., Otim, M., Horstead, S.K., Ellis, L.A. & Emerson, E. (2012), How much does intellectual disability really cost? First estimates for Australia, *Journal of Intellectual & Developmental Disability*, 37(1): 42–49.

Downs, S.H. & Black, N. (1998), The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions, *Journal of Epidemiological Community Health*, 52, 377–384.

Draheim, C.C., Stanish, H.I., Williams, D.P. & McCubbins, J.A. (2007), Dietary Intake of Adults With Mental Retardation Who Reside in Community Settings, *American Journal on Mental Retardation*, Volume 112(5), 392–400.

Dustan, H.P. (1989), Obesity and Hypertension, *Clinical Cardiology*, 12, IV, 66-71.

Eden, K. & Randle-Phillips, C. (2017), Exploration of body perception and body dissatisfaction in young adults with intellectual disability, *Research in Developmental Disabilities* 71, 88–97.

Emerson, E. (2005), Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England, *Journal of Intellectual Disability Research*, Volume 49(2), 134-143.

Epstein, L.H., Wing, R.R., Koeske, R., Andrasik, F. & Ossip, D.J. (1981), Child and Parent Weight Loss in Family-Based Behavior Modification Programs, *Journal of Consulting and Clinical Psychology*, Vol. 49, No. 5, 674-685.

European Parliamentary Research Service, (2018), Assistive technologies for people with disabilities - Part III: Perspectives, needs, Retrieved 28th March 2020 from [https://www.europarl.europa.eu/RegData/etudes/IDAN/2018/603218/EPRS_IDA\(2018\)603218\(ANN3\)_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/IDAN/2018/603218/EPRS_IDA(2018)603218(ANN3)_EN.pdf)

Ewing, G., McDermott, S., Thomas-Koger, M., Whitner, W. & Pierce, K. (2004), Evaluation of a Cardiovascular Health Program for Participants With Mental Retardation and Normal Learners, *Health Education & Behavior*, Vol. 31 (1): 77-87.

Finkelstein, E.A., Trogon, J.G., Cohen, J.W. & Dietz, W. (2009), Annual Medical Spending Attributable to Obesity: Payer and Service Specific Estimates, *Health Affairs*, Vol.28, No.5, w822-w831.

Finlayson, J., Jackson, A., Cooper, S., Morrison, J., Melville, C., Smiley, E., Allan, L. & Mantry, D. (2009), Understanding Predictors of Low Physical Activity in Adults with Intellectual Disabilities, *Journal of Applied Research in Intellectual Disabilities* 2009, 22, 236–247.

Fisher, E. (1986), Behavioral Weight Reduction Program for Mentally Retarded Adult Females, *Perceptual and Motor Skills*, 62, 359-362.

Fisher, M.H., Baird, J.V., Currey, A.D. & Hodapp, R.M. (2016), Victimization and Social Vulnerability of Adults with Intellectual Disability: A Review of Research Extending beyond Wilson and Brewer, *Australian Psychologist*, 51, 114–121.

Fitbit Inc. (2019), Fitbit Wearable Devices, Retrieved 26th March 2020 from <https://www.fitbit.com/us/home>

Food Standards Agency (2009), The Eatwell Plate, London: Food Standards Agency, Retrieved on 25th October 2018 from www.food.gov.uk

Foreyt, J.P. & Parks, J.T. (1975), Behavioral Controls for Achieving Weight Loss in the Severely Retarded, *Journal of Behavioral Therapy and Experimental Psychiatry*, Vol 6, 27-29.

Foster-Schubert, K.E., Alfano, C.M., Duggan, C.R., Xiao, L., Campbell, K.L., Kong, A., Bain, C., Wang, C.Y., Blackburn, G. McTiernan, A. (2012), Effect of diet and exercise, alone or combined, on weight and body composition in overweight-to-obese post-menopausal women, *Obesity (Silver Spring)*, 20(8), 1628–1638.

Fox, R.A., & Rotatori, A.F., (1982). Prevalence of obesity in mentally retarded adults. *American Journal of Mental Deficiency*, 87, 228-230.

Fox, R.A., Haniotes, H. & Rotatori, A. (1984), A Streamlined Weight Loss Program for Moderately Retarded Adults in a Sheltered Workshop Setting, *Applied Research in Mental Retardation*, Vol 5, 69-79.

Fox, R.A., Rosenberg, R. & Rotatori, A.F. (1985), Parent Involvement in a Treatment Program for Obese Retarded Adults, *Journal of Behavioral Therapy and Experimental Psychiatry*, Vol 16, 45-48.

Fraser, M. & Fraser, A. (2001), Are people with learning disabilities able to contribute to focus groups on health promotion?, *Journal of Advanced Nursing*, 33(2), 225-233.

Frey, G.C. (2004), Comparison of Physical Activity Levels Between Adults With and Without Mental Retardation, *Journal of Physical Activity and Health*, 1, 235-245.

Frey, G.C., Buchanan, A.M. & Rosser-Sandt, D.D. (2005), “I’d Rather Watch TV”; An examination of Physical Activity in Adults with Mental Retardation, *Mental Retardation*, Vol 43(4), 241-254.

GameSparks (2020), The Average Gamer: How the Demographics Have Shifted, Retrieved 2nd December 2019 from <https://www.gamesparks.com/blog/the-average-gamer-how-the-demographics-have-shifted/>

Gates, B. & Waight, M. (2007), Reflections on conducting focus groups with people with learning disabilities, *Journal of Research in Nursing*, Vol 12(2), 111-126

Geller, J. & Crowley, M. (2009), An Empowerment Group Visit Model as Treatment for Obesity in Developmentally Delayed Adults, *Journal of Developmental and Physical Disabilities*, 21:345–353, DOI 10.1007/s10882-009-9147-7.

- Gibbons, M. C., Fleisher, L., Slamon, R. E., Bass, S., Kandadai, V., & Beck, J. R. (2011), Exploring the potential of web 2.0 to address health disparities, *Journal of Health Communication*, 16(1), 77–89.
- Gibbs, S.M., Brown, M.J. & Muir, W.J. (2008), The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study, *Journal of Intellectual Disability Research*, Volume 52(12), 1061–1077.
- Gilbert, T. (2004), Involving people with learning disabilities in research: issues and possibilities, *Health and Social Care in the Community*, 12(4), 298–308.
- Golden, E. & Hatcher, J. (1997), Nutrition Knowledge and Obesity of Adults in Community Residences, *Mental Retardation*, Vol 35(3), 177-184.
- Gortmaker, S.L., Must, A., Perrin, J.M., Sobol, A.M. & Dietz, W.H. (1993), Social and Economic Consequences of Overweight in Adolescence and Young Adulthood, *The New England Journal of Medicine*, Vol.329, No.14, 1008-1012.
- Guest, G., MacQueen, K.M. & Namey, E.E. (2012), Chapter 1 Introduction to Applied Thematic Analysis, Retrieved 17th February 2017 from <https://methods.sagepub.com/book/applied-thematic-analysis/n1.xml>
- Guh, D.P., Zhang, W., Bansback, N., Amarsi, Z., Laird-Birmingham, C. & Anis, A.H. (2009), The incidence of co-morbidities related to obesity and overweight: A systematic review and meta-analysis, *BMC Public Health*, 9:88.
- Haider, S.I., Ansari, Z., Vaughan, L., Matters, H. & Emerson, E. (2013), Health and wellbeing of Victorian adults with intellectual disability compared to the general Victorian population, *Research in Developmental Disabilities* 34, 4034–4042.

Hamilton, S., Hankey, C.R., Miller, S., Boyle, S. & Melville, C.A. (2007), A review of weight loss interventions for adults with intellectual disabilities, *Obesity Reviews*, 8, 339–345.

Hamzaid, N.H., Flood, V.M., Prvan, T. & O'Connor, H.T. (2018), General nutrition knowledge among carers at group homes for people with intellectual disability, *Journal of Intellectual Disability Research*, 62(5), 422-430.

Harris, L., Hankey, C., Murray, H. & Melville, C. (2015), The effects of physical activity interventions on preventing weight gain and the effects on body composition in young adults with intellectual disabilities: systematic review and meta-analysis of randomized controlled trials, *Clinical Obesity* 5, 198–210.

Harris, L., Hankey, C., Jones, N., Pert, C., Murray, H., Tobin, J., Boyle, S. & Melville, C. (2017), A cluster randomised control trial of a multi-component weight management programme for adults with intellectual disabilities and obesity, *British Journal of Nutrition* (2017), 118, 229–240.

Harris, L., Melville, C., Murray, H. & Hankey, C. (2018^a), The effects of multi-component weight management interventions on weight loss in adults with intellectual disabilities and obesity: A systematic review and meta-analysis of randomised controlled trials, *Research in Developmental Disabilities*, 72, 42-55.

Harris, L., McGarty, A.M., Hilgenkamp, T., Mitchell, F. & Melville, C.A. (2018^b), Correlates of objectively measured sedentary time in adults with intellectual Disabilities, *Preventive Medicine Reports*, 9, 12–17.

Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S. & Strydom, A. (2009), Report on the State of Science on Health Risks and Ageing in People with Intellectual Disabilities, *IASSID Special Interest Research Group on Ageing and Intellectual Disabilities/Faculty Rehabilitation Sciences, University of Dortmund*.

Haymes, L.K., Storey, K., Maldonaldo, A., Post, M. & Montgomery, J. (2015), Using applied behavior analysis and smart technology for meeting the health needs of individuals with intellectual disabilities, *Developmental Neurorehabilitation*, 18:6, 407-419.

Health Information and Quality Authority [HIQA] (2014), Guidance on Risk Management, Retrieved 21st January from <https://www.hiqa.ie/reports-and-publications/guides/guidance-risk-management>

Healthline (2020), 26 weight loss tips that are actually evidence-based, Retrieved 14th September 2020 from <https://www.healthline.com/nutrition/26-evidence-based-weight-loss-tips>

Heller, T., Ying, G., Rimmer, J.H. & Marks, B.A. (2002), Determinants of Exercise in Adults with Cerebral Palsy, *Public Health Nursing*, Vol. 19 No. 3, 223–231.

Heller, T., Hsieh, K. & Rimmer, J. (2008), Barriers and Supports for Exercise Participation Among Adults with Down Syndrome, *Journal of Gerontological Social Work*, 38:1-2, 161-178, DOI: 10.1300/J083v38n01_03.

Hithersay, R., Strydom, A., Moulster, G. & Buszewicz, M. (2014), Carer-led health interventions to monitor, promote and improve the health of adults with intellectual disabilities in the community: A systematic review, *Research in Developmental Disabilities* 35, 887–907.

Hollis, J.F., Gullion, C.M., Stevens, V.J., Brantley, P.J., Appel, L.J., Ard, J.D., Champagne, C.M., Dalcin, A., Erlinger, T.P., Funk, K., Laferriere, D., Lin, P., Loria, C.M., Samuel-Hodge, C., Vollmer, W.M., Svetkey, L.P. & the Weight Loss Maintenance Trial Research Group (2008), Weight Loss During the Intensive Intervention Phase of the Weight-Loss Maintenance Trial, *American Journal of Preventative Medicine*, 35(2): 118–126.

- Hove, O. (2003), Weight survey on adult persons with mental retardation living in the community, *Research in Developmental Disabilities*, 25, 9–17.
- Howard, N.J., Hugo, G.J., Taylor, A.W. & Wilson, D.H. (2008), Our perception of weight: Socioeconomic and sociocultural explanations, *Obesity Research & Clinical Practice*, 2, 125–131.
- Hsieh, K., Rimmer, J.H & Heller, T. (2014), Obesity and associated factors in adults with intellectual disability, *Journal of Intellectual Disability Research*, Vol 58, Part 9: 851-863.
- Humphries, K., Traci, M.A. & Seekins, T. (2007), Food on Film: Pilot Test of an Innovative Method for Recording Food Intake of Adults with Intellectual Disabilities Living in the Community, *Journal of Applied Research in Intellectual Disabilities*, 21, 168–173.
- Inclusion Ireland (2014), Information Pack: A Guide to Disability Law and Policy in Ireland, Retrieved on 5th March 2020 from <https://www.inclusionireland.ie/sites/default/files/attach/basic-page/512/informationpack-march2014.pdf>
- Jackson, N. & Jackson, E. (1998), Choice-making for people with a learning disability, *Learning Disability Practice*, Volume 1(3), 22-25.
- Jenaro, C., Flores, N., Vega, V., Cruz, M., Pérez, M.A. & Torres, V.A. (2018), Cyberbullying among adults with intellectual disabilities: Some preliminary data, *Research in Developmental Disabilities*, 72, 265-274.
- Jenkinson, J.C. (1993), Who Shall Decide? The Relevance of Theory and Research to Decision-making by People with an Intellectual Disability, *Disability, Handicap & Society*, 8:4, 361-375.

Jinks, A., Cotton, A. & Rylance, R. (2011), Obesity interventions for people with a learning disability: an integrative literature review. *Journal of Advanced Nursing* 67(3), 460–471. doi: 10.1111/j.1365-2648.2010.05508.x.

Joachim, R. (1977), The use of self-monitoring to effect weight loss in a mildly retarded female, *Journal of Behavioral and Experimental Psychiatry*, Vol 8, 213-215.

Johnson, J. (2020), Do you ever play games at home or elsewhere on any device?, Retrieved 4th February 2020 from <https://www.statista.com/statistics/300513/gaming-by-demographic-group-uk/>

Johnson, F. & Wardle, J. (2005), Dietary Restraint, Body Dissatisfaction, and Psychological Distress: A Prospective Analysis, *Journal of Abnormal Psychology*, Vol. 114, No. 1, 119–125.

Johnson-Taylor, W.L., Fisher, R.A., Hubbard, V.S., Starke-Reed, P. & Eggers, P.S. (2008), The change in weight perception of weight status among the overweight: comparison of NHANES III (1988–1994) and 1999–2004 NHANES, *International Journal of Behavioral Nutrition and Physical Activity*, 5:9, 1-6.

Jones, M.C., Walley, R.M., Leech, A., Paterson, M., Common, S. & Metcalf, C. (2007), Behavioral and Psychosocial Outcomes of a 16-Week Rebound Therapy-Based Exercise Program for People With Profound Intellectual Disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, Volume 4 Number 2, 111–119.

Jones, N., Melville, C.A., Tobin, J. & Gray, F. (2015^a), A retrospective evaluation of an adapted group weight management intervention for adults with intellectual disabilities: Waist Winners Too, *British Journal of Obesity* 1: 132–40.

Jones, N., Melville, C.A., Harris, L., Bleazard, L. & Hankey, C.R. (2015^b), A qualitative study exploring why adults with intellectual disabilities and obesity want to lose weight and views of their carers, *BMC Obesity*, 2:49, 1-7.

Jones, M., Morris, J. & Deruyter, F. (2018), Mobile Healthcare and People with Disabilities: Current State and Future Needs, *International Journal of Environmental Research and Public Health*, 15, 515.

Kaehne, A. & O'Connell, C. (2010), Focus groups with people with learning disabilities, *Journal of Intellectual Disabilities*, vol 14(2), 133–145.

Kairey, L., Matvienko-Sikar, L., Kelly, C., McKinley, M.C., O'Connor, E.M., Kearney, P.M., Woodside, J.V. & Harrington, G.M. (2018), Plating up appropriate portion sizes for children: a systematic review of parental food and beverage portioning practices, *Obesity Reviews*, 19, 1667–1678.

Kasen, S., Cohen, P., Chen, H. & Must, A. (2008), Obesity and psychopathology in women: a three-decade prospective study, *International Journal of Obesity*, 32, 558-566.

Katz, D.A., McHorney, C.A. & Atkinson, R.L. (2000), Impact of Obesity on Health-related Quality of Life in Patients with Chronic Illness, *Journal of General Internal Medicine*, 15, 789-796.

Kaufer-Horwitz, M., Villa, M., Pedraza, J., Domínguez-García, J., Vázquez-Velázquez, V., Méndez, J.P. & García-García, E. (2014), Knowledge of appropriate foods and beverages needed for weight loss and diet of patients in an Obesity Clinic, *European Journal of Clinical Nutrition*, 69, 68–72.

- Kim, J. & Kimm, C.H. (2017), Functional Technology for Individuals with Intellectual Disabilities: Meta-Analysis of Mobile Device-Based Interventions, *Journal of Special Education Apprenticeship*, Vol 6(1), 1-22.
- Koritsas, S. & Iacono, T. (2016), Weight, nutrition, food choice, and physical activity in adults with intellectual disability, *Journal of Intellectual Disability Research*, Volume 60(4), 355–364.
- Kraft, A. (2015), The key to losing weight: “You can’t outrun a bad diet”, Retrieved 1st May 2020 from <https://www.cbsnews.com/news/the-key-to-weight-loss-you-cant-outrun-a-bad-diet/>
- Krahn, G.L., Klein-Walker, D. & Correa-De-Araujo, R. (2015), Persons with Disabilities as an Unrecognized Health Disparity Population, *American Journal of Public Health*, Vol 105 (S2), s198-s206.
- Kruegar, R. & Casey, M. (2015), Focus Groups; A practical guide for applied research (Fifth Edition), *Sage Publications Inc.*
- Kuijken, N.M.J, Naaldenberg, J., Nijhuis-van der Sanden, M.W. & van Schrojenstein-Lantmann de Valk, H.M.J. (2016), Healthy Living According to Adults with Intellectual Disabilities; towards tailoring health promotion initiatives, *Journal of Intellectual Disability Research*, 60(3), 228-241.
- Kushner, R.F. & Foster, G.D. (2000), Obesity and Quality of Life, *Nutrition*, Vol.16, No.10, 947-952.
- Kyle, T. & Kuehl, B. (2013), Prescription Medications & Weight Gain, Retrieved 5th September 2020 from <https://www.obesityaction.org/community/article-library/prescription-medications-weight-gain>

Lai Cheng Chia, G.L., Anderson, A. & McLean, L.A. (2018), Use of Technology to Support Self-Management in Individuals with Autism: Systematic Review, *Review Journal of Autism and Developmental Disorders*, 5, 142-155.

Laing, B.Y., Mangione, C.M., Tseng, C., Leng, M., Vaisberg, E., Mahida, M., Bholat, M., Glazier, E., Morisky, D.E. & Bell, D.S. (2014), Effectiveness of a smartphone application for weight loss compared to usual care in overweight primary care patients: a randomized controlled trial, *Annals of Internal Medicine*, 161, (10_Supplement): S5–12.

Lenneis, V. & Pfister, G. (2017), Health messages, middle-aged women and the pleasure of play, *Annals of Leisure Research*, 20:1, 55-74.

Leslie, J.C. & O'Reilly, M.F. (2003), *Behavior Analysis; Foundations and Applications to Psychology*, East Sussex: Psychology Press.

Liberties College (2020), Social Care QQI Level 5, Retrieved 10th April 2020 from <https://www.libertiescollege.ie/courses/social-care-qqi-level-5/>

Lorentzen, B. & Wikström, B.M. (2012), Healthy lifestyle for people with intellectual disabilities through a health intervention program, *Open Journal of Nursing*, 2, 157-164.

Luppino, F.S., de Wit, L.M., Bouvy, P.F., Stijnen, T.S., Cuijpers, P., Penninx, B.W.J.H. & Zitman, F.G. (2010), Overweight, Obesity and Depression, *Archives of General Psychiatry*, 67(3), 220-229.

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

Mann, J., Zhou, H., McDermott, S. & Poston, M.B. (2006), Healthy Behavior Change of Adults with Mental Retardation: Attendance in a Health Promotion Program, *American Journal on Mental Retardation*, Vol 111 (1), 62-73.

Mann, T., Tomiyama, A.J., Westling, E., Lew, A., Samuels, B. & Chatman, J. (2007), Medicare's Search for Effective Obesity Treatments, *American Psychologist*, Vol. 62, No. 3, 220–233.

Marks, D.F., Murray, M. & Estacio, E.V. (2018), *Health Psychology: Theory, Research and Practice – 5th Edition*, London: Sage Publications Ltd.

Marshall, D., McConkey, R. & Moore, G. (2003), Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities, *Journal of Advanced Nursing*, 41 (2), 147-153.

Martínez-Zaragoza, F., Campillo-Martínez, J. & Ato-García, M. (2016), Effects on Physical Health of a Multicomponent Programme for Overweight and Obesity for Adults with Intellectual Disabilities, *Journal of Applied Research in Intellectual Disabilities*, 29, 250-265.

Material Design, (2020), Material Design: Accessibility, Retrieved 4th February 2020 from <https://material.io/design/usability/accessibility.html#implementing-accessibility>

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

Mayo Foundation for Medical Education and Research [MFMER] (2019), Obesity: Quality of Life, Retrieved on 5th January 2017 from <https://www.mayoclinic.org/diseases-conditions/obesity/symptoms-causes/syc-20375742?p=1>

McCullough, R. (2020), What do you want to pick, fad diet or lifestyle change?, Retrieved on 23rd September 2020 from

<https://www.consumerhealthdigest.com/weight-loss/fad-diet-vs-lifestyle-change.html>

McCarron, M., Lombard-Vance, R., Murphy, E., O'Donovan, M., Webb, N., Sheaf, G., McCallion, P., Stancliffe, R., Normand, C., Smith, V. & May, P. (2018), *Quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability: An evidence review*, Dublin: Health Research Board: Dublin.

McDermott, L. (2011), "Doing Something that's Good For Me": Exploring Intersections of Physical Activity and Health, Women and Exercise: The Body, Health and Consumerism, E. Kennedy & P. Markula (Eds.), 2010, Retrieved on 30th May 2019 from https://www.academia.edu/5172906/Doing_something_thats_good_for_me_Exploring_intersections_of_physical_activity_and_health

McDermott, S., Whitner, W., Thomas-Kogar, M., Mann, J.R., Clarkson, J., Barnes, T.L., Bao, H. & Meriwether, R.A. (2012), An efficacy trial of 'Steps to Your Health', a health promotion programme for adults with intellectual disability, *Health Education Journal*, 71(3) 278–290.

McDonald & Kidney (2012), What is right? Ethics in intellectual disabilities research, *Journal of Policy and Practice in Intellectual Disabilities*, 9(1), 27-39.

Melville, C.A., Hamilton, S., Hankey, C.R., Miller, S. & Boyle, S. (2007), The prevalence and determinants of obesity in adults with intellectual disabilities, *Obesity Reviews*, 8, 223–230.

Melville, C.A., Cooper, S.A., Morrisson, J., Allan, L., Smiley, E. & Williamson, A. (2008), The Prevalence and Determinants of Obesity in Adults with Intellectual Disabilities, *Journal of Applied Research in Intellectual Disabilities*, 21, 425–437.

Melville, C.A., Hamilton, S., Miller, S., Boyle, S., Robinson, N., Pert, C. & Hankey, C.R. (2009), Carer Knowledge and Perceptions of Healthy Lifestyles for Adults with Intellectual Disabilities, *Journal of Applied Research in Intellectual Disabilities*, 22, 298–306.

Melville, C.A., Boyle, S., Miller, S., Macmillan, S., Penpraze, V., Pert, C., Spanos, D., Matthews, L., Robinson, N., Murray, H. & Hankey, C.R. (2011), An open study of the effectiveness of a multi-component weight-loss intervention for adults with intellectual disabilities and obesity, *British Journal of Nutrition*, 105, 1553–1562.

Melville, C.A., Mitchell, F., Stalker, K., Matthews, L., McConnachie, A., Murray, H.M., Melling, C. & Mutrie, N. (2015), Effectiveness of a walking programme to support adults with intellectual disabilities to increase physical activity: walk well cluster-randomised controlled trial, *International Journal of Behavioral Nutrition and Physical Activity*, 12:125.

Melville, C.A., Oppewal, A., Elinder, L.S., Freiburger, E., Guerra-Balic, M., Hilgenkamp, T.I.M., Einarsson, I., Izquierdo-Gómez, R.H., Sansano-Nadal, O., Rintala, P., Cuesta-Vargas, A. & Giné-Garriga, M. (2017), Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities — A systematic review, *Preventive Medicine*, 97, 62–71.

Mendonca, G.V. & Pereira, F.D. (2009), Influence of long-term exercise training on submaximal and peak aerobic capacity and locomotor economy in adult males with Down's syndrome, *Medical Science Monitor*, 15(2): CR33-39.

Mendonca, G.V., Pereira, F.D. & Fernhall, B. (2011), Effects of Combined Aerobic and Resistance Exercise Training in Adults With and Without Down Syndrome, *Archives of Physical Medicine and Rehabilitation*, 92: 37-45.

Mertens, I.L. & Van Gaal, L.F. (2000), Overweight, Obesity and Blood Pressure: The Effects of Modest Weight Reduction, *Obesity Research*, Vol. 8, No.3, 270-278.

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

Mikulovic, J., Vanhelst, J., Salleron, J., Marcellini, A., Compte, R., Fardy, P. & Bui-Xuan, S. (2014), Overweight in intellectually-disabled population: Physical, behavioral and psychological characteristics, *Research in Developmental Disabilities*, 35, 153–161.

Millword, L.J., (2008). Focus Groups. In G. M. Breakwell, S. Hammond, C. Fife-Schaw, & J. A. Smith (Eds.), *Research Methods in Psychology*, (pp. 276-299), London: Sage.

Mkrtchyan, R. (2018), Wireframe, Mock-up, Prototype: What is What?, Retrieved on 14th September 2020 from <https://uxplanet.org/wireframe-mockup-prototype-what-is-what-8cf2966e5a8b>

Moni, K.B., Jobling, A., Morgan, M. & Lloyd, J. (2011), Promoting literacy for adults with intellectual disabilities in a community-based service organisation, *Australian Journal of Adult Learning*, Volume 51(3), 456-478.

Moore, K.A., Gillivray, J., Illingworth, K. & Brookhouse, P. (2004), An investigation into the incidence of obesity and underweight among adults with an intellectual disability in an Australian sample, *Journal of Intellectual & Developmental Disability*, Vol. 29, No. 4, 306–318.

Morgan, L. & Dent, M. (2010), The economic burden of obesity, *Oxford: National Obesity Observatory*, 2010.

National Collaborating Centre for Methods and Tools (2008), *Quality checklist for health care intervention studies*. Hamilton, ON: McMaster University. (Updated 03 October, 2017) Retrieved 6th September from <http://www.nccmt.ca/resources/search/9>

National Disability Strategy Implementation Group, 2013-2015), National Disability Strategy Implementation Plan, 2013-2015, Retrieved on 25th August 2019 from <http://justice.ie/en/JELR/Pages/PB13000321>

National Heart Lung and Blood Institute (2019), Overweight and Obesity: Signs, Symptoms and Complications – Complications, Retrieved on 15th May 2016 from <https://www.nhlbi.nih.gov/health-topics/overweight-and-obesity>

National Institute of Diabetes and Digestive and Kidney Diseases (2012), Do you know some of the risks of being overweight? *National Institutes of Health, Bethesda, MD*. Retrieved from https://www.niddk.nih.gov/health-information/health-topics/weight-control/health_risks_being_overweight/Documents/hlthrisks1104.pdf

National Institute for Health and Care Excellence (2014^a), Obesity: Identification, assessment and management, Retrieved 20 October 2016 from www.nice.org.uk/guidance/cg189

National Institute for Health and Care Excellence [NICE] (2014^b), Weight management: lifestyle services for overweight or obese adults - Public health guideline [PH53], *Retrieved 4th August 2018 from* <https://www.nice.org.uk/guidance/ph53/chapter/1-Recommendations>

National Institute for Health and Care Excellence [NICE] (2015), Challenging Behaviour and Learning Disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges [NG11], *Retrieved 20th September 2020 from* <https://www.nice.org.uk/guidance/ng11>

Neumeier, W.H., Guerra, N., Thirumalai, M., Geer, B., Ervin, D. & Rimmer, J.H. (2017), POWERSforID: Personalized Online Weight and Exercise Response System for Individuals with Intellectual Disability: study protocol for a randomized controlled trial, *Trials*, 18:487, 1-11.

Newzoo.com (2017), Male and Female Gamers: How Their Similarities and Differences Shape the Games Market, *Retrieved 8th January 2020 from* <https://newzoo.com/insights/articles/male-and-female-gamers-how-their-similarities-and-differences-shape-the-games-market/>

NHS (2019), Overcoming the barriers to exercise, *Retrieved 10th June 2019 from* <https://www.nhs.uk/live-well/exercise/overcoming-the-barriers-to-exercise/>

Nind, M. (2008), Conducting qualitative research with people with learning, communication, and other disabilities: Methodological challenges, *ESRC National Centre for Research Methods Review Paper*, 1-24.

Noom Inc., (2020), Weight Loss app, *Retrieved 24th March 2020 from* <https://www.noom.com/#/>

Norvell, N.K. & Ahern, D.K. (1987), Worksite Weight-Loss Intervention for Individuals with Mental Retardation: A Pilot Study, *Education and Training in Mental Retardation*, June, 85-90.

Office of Disease Prevention and Health Promotion (2015), Dietary Guidelines 2015-2020: Appendix 2. Estimated Calorie Needs per Day, by Age, Sex, and Physical Activity Level, Retrieved on 26th November 2016 from <https://health.gov/dietaryguidelines/2015/guidelines/appendix-2/>

Ogunbode, A.M., Fatiregun, A.A. & Ogunbode, O.O. (2009), Health Risks of Obesity, *Annals of Ibadan Postgraduate Medicine*, Vol.7, No.2, 22-25.

Olson, K.E., O'Brien, M.A., Rodgers, W.A. and Charness, N. (2011), Diffusion of Technology: Frequency of Use for Younger and Older Adults, *Ageing International*, 36(1), 123-145.

O'Meara, A. (2020), The percentage of people who regain weight after rapid weight loss and the risks of doing so, Retrieved on 15th September 2020 from <https://www.livestrong.com/article/438395-the-percentage-of-people-who-regain-weight-after-rapid-weight-loss-risks/>

Ordóñez, F.J., Rosety, M.A., Camacho, A., Rosety, I., Díaz, A.J., Fornieles, G., García, N. & Rosety-Rodríguez, M. (2014), Aerobic training improved low-grade inflammation in obese women with intellectual disability, *Journal of Intellectual Disability Research*, Volume 58(6), 583–590.

Oviedo, G.R., Travier, N. & Guerra-Balic, M. (2017), Sedentary and Physical Activity Patterns in Adults with Intellectual Disability, *International Journal of Environmental Research and Public Health*, 14, 1027, 1-14.

Owen, S. (2001), The practical, methodological, and ethical dilemmas of conducting focus groups with vulnerable clients, *Journal of Advanced Nursing*, 36(5), 652-658.

Pagoto, S. (2013), A Call for an End to the Diet Debates, *JAMA*, Vol 310(7), Retrieved 26th April 2020 from <https://edhub.ama-assn.org/jn-learning/audio-player/6515003>

Pal, S., Cheng, C., Egger, G., Binns, C. & Donovan, R. (2009), Using pedometers to increase physical activity in overweight and obese women: a pilot study, *BMC Public Health* 2009, 9:309, 1-9.

Pan, C., Maiano, C. & Morin, A. (2018), Physical self-concept and body dissatisfaction among Special Olympics athletes: A comparison between sex, weight status, and Culture, *Research in Developmental Disabilities*, 76, 1–11.

Paterson, L., McKenzie, K. & Lindsay, B. (2012), Stigma, Social Comparison and Self-Esteem in Adults with an Intellectual Disability, *Journal of Applied Research in Intellectual Disabilities*, 25, 166–176.

Patrick, P.A., Obermeyer, I., Xenakis, J., Crocitto, D. & O'Hara, D.M. (2020), Technology and social media use by adult patients with intellectual and/or developmental disabilities, *Disability and Health Journal* 13, 1-5.

Pérez, C.A., Carral, J.M.C., Costas, A.A., Martínez, S.V. & Martínez-Lemos, R.I. (2018), Water-based exercise for adults with Down syndrome: Findings from a preliminary study, *International Journal of Therapy and Rehabilitation*, Vol 25, No 1, 20-28.

Perez-Cruzado, D. & Cuesta-Vargas, A. (2013), Improving Adherence Physical Activity with a Smartphone Application Based on Adults with Intellectual Disabilities (APPCOID), *BMC Public Health*, 13:1173, 1-6.

- Perry, I. & Dee, A. (2012), The cost of overweight and obesity on the island of Ireland, *Retrieved on 1st April 2017 from* <https://www.safefood.eu/SafeFood/media/SafeFoodLibrary/Documents/Publications/Research%20Reports/Final-Exec-Summary-The-Economic-Cost-of-Obesity.pdf>
- Pett, M., Clark, L., Eldredge, A., Cardell, B., Jordan, K., Chambless, C. & Burley, J. (2013), Effecting Healthy Lifestyle Changes in Overweight and Obese Young Adults With Intellectual Disability, *American Journal on Intellectual and Developmental Disabilities*, Vol. 118, No. 3, 224–243.
- Pew Research Center (2019^a), Mobile Fact Sheet, *Retrieved 4th February 2020 from* <https://www.pewresearch.org/internet/fact-sheet/mobile/>
- Pew Research Center (2019^b), Social Media Fact Sheet, *Retrieved 4th February 2020 from* <https://www.pewresearch.org/internet/fact-sheet/social-media/>
- Ptomey, L.T., Herrmann, S.D., Lee, J., Sullivan, D.K., Rondon, M.F. & Donnelly, J.E. (2013), Photo-Assisted Recall Increases Estimates of Energy and Macronutrient Intake in Adults with Intellectual and Developmental Disabilities, *Journal of the Academy of Nutrition and Dietetics*, Vol 113(12), 1704-1709.
- Ptomey, L.T., Sullivan, D.K., Lee, J., Goetz, J.R., Gibson, C., & Donnelly, J.E. (2015), The Use of Technology for Delivering a Weight Loss Program for Adolescents with Intellectual and Developmental Disabilities, *Journal of the Academy of Nutrition and Dietetics*, 115(1), 112 – 118.
- Ptomey, L.T., Saunders, R.R., Saunders, M., Washburn, R.A., Mayo, M.S., Sullivan, D.K., Gibson, C.A., Goetz, J.R., Honas, J.J., Willis, E.A., Danon, J.C., Krebill, R. & Donnelly, J.E. (2018), Weight management in adults with intellectual and developmental disabilities: A randomized controlled trial of two dietary approaches, *Journal of Applied Research in Intellectual Disabilities*, 00:1–15.

Puhl, R. & Brownell, K.D. (2001), Bias, Discrimination and Obesity, *Obesity Research*, Vol.9, No.12, 788-805.

Puyalto, C., Pallisera, M. Fullana, J. & Vila, M. (2016), Doing Research Together: A Study on the Views of Advisors with Intellectual Disabilities and Non-Disabled Researchers Collaborating in Research, *Journal of Applied Research in Intellectual Disabilities*, 29, 146–159.

Rafferty, A.P., Reeves, M.J., McGee, H.B. & Pivarnik, J.M. (2002), Physical activity patterns among walkers and compliance with public health recommendations, *Official Journal of the American College of Sports Medicine*, 1255-1261.

Rajapakse, R., Brereton, M., Roe, P., & Sitbon, L., (2014). Designing with People with Disabilities: Adapting Best Practices of DIY and Organizational Approaches, *Proceedings of the 26th Australian Computer-Human Interaction Conference on Designing Futures: The Future of Design*, 519-522. Retrieved 21st April 2017 from <http://eprints.qut.edu.au/81939/>

Ranjan, S., Nasser, J.A. & Fisher, K. (2017), Prevalence and potential factors associated with overweight and obesity status in adults with intellectual developmental disorders, *Journal of Applied Research in Intellectual Disabilities*, 31(Suppl. 1):29–38.

Reddy, K. (2020), How to Use Technology to Work More Effectively – 20 Best Tips, Retrieved 6th January 2020 from, <https://content.wisestep.com/use-technology-work-effectively/>

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

- Rehfeldt, R. A., Dahman, D., Young, A., Cherry, H., & Davis, P. (2003), Teaching a simple meal preparation skill to adults with moderate and severe mental retardation using video modeling. *Behavioral Interventions*, 18, 209-218.
- Reid, A.E., Field, M., Jones, A., DiLemma, L.C.G. & Robinson, E. (2019), Social modelling of health behaviours: Testing self-affirmation as a conformity-reduction strategy, *British Journal of Health Psychology*, 24, 651–667.
- Reid, K.A., Smiley, E. & Cooper, S. (2011), Prevalence and associations of anxiety disorders in adults with intellectual disabilities, *Journal of Intellectual Disability Research*, Vol 55(2), 172-181.
- Renehan, A.G., Tyson, M., Egger, M., Heller, R.F. & Zwahlen, M. (2008), Body-mass index and incidence of cancer: a systematic review and meta-analysis of prospective observational studies, *Lancet*, 371, 569-78.
- Rimmer, J.H., Braddock, D. & Fujiura, G. (1993), Prevalence of Obesity in Adults With Mental Retardation: Implications for Health Promotion and Disease Prevention, *Mental Retardation*, Vol. 31, No. 2, 105-110.
- Rimmer, J.H., Chen, M. & Hsieh, K. (2011), A Conceptual Model for Identifying, Preventing, and Managing Secondary Conditions in People with Disabilities, *Physical Therapy*, Vol 91 (12), 1728-1739.
- Roberts, T. & Hernandez, K. (2018), Digital Access is not Binary: The 5'A's of Technology Access in the Philippines, *Electronic Journal of Information Systems in Developing Countries*, 85: e12084, 1-14.

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

Rosety-Rodriguez, M., Diaz, A.J., Rosety, I., Rosety, M.A., Camacho, A., Fornieles, G., Rosety, M. & Ordonez, F.J. (2014), Exercise reduced inflammation: but for how long after training?, *Journal of Intellectual Disability Research*, Volume 58(9), 874–879.

Rotatori, A.F., Fox, R. & Switzky, H. (1980), Multicomponent Behavioral Program for Achieving Weight Loss in Adult Mentally Retarded Persons, *Mental Retardation*, Vol. 18, 31-33.

Rotatori, A.F. & Fox, R. (1981), Behavioral Weight Reduction Program for Mentally Handicapped Persons: A Self-Control Approach, *Baltimore: University Park Press*.

Rotatori, A.F., Switzky, H. & Fox, R. (1981), Behavioral Weight Reduction Procedures for Obese Mentally Retarded Individuals: A Review, *Mental Retardation*, Vol. 19, 157-161.

Safe Food Ireland, (2012), The Cost of Overweight and Obesity on the Island of Ireland, Retrieved 18th October 2017 from <https://www.safefood.eu/SafeFood/media/SafeFoodLibrary/Documents/Publications/Research%20Reports/Final-Exec-Summary-The-Economic-Cost-of-Obesity.pdf>

Sailer, A.B., Miltenberger, R.G., Johnson, B., Zetocha, K., Egemo-Helm, K. & Hegstad, H. (2006), Evaluation of a Weight Loss Treatment Program for Individuals with Mild Mental Retardation, *Child & Family Behavior Therapy*, 28:2, 15-28, DOI: 10.1300/J019v28n02_02.

Sari, H.Y., Yilmaz, M. Serin, E., Kisa, S.S., Yesiltepe, O., Tokem, Y. & Rowley, H. (2016), Obesity and hypertension in adolescents and adults with intellectual disability, *Acta Paulista de Enfermagem* 29(2):169-177.

Sarwer, D.B., Wadden, T.A. & Foster, G.D. (1998), Assessment of Body Image Dissatisfaction in Obese Women: Specificity, Severity and Clinical Significance, *Journal of Consulting and Clinical Psychology*, Vol.66, No.4, 651-654.

Saunders, R.R., Saunders, M.D., Donnelly, J.E., Smith, B.K., Sullivan, D.K., Guilford, B. & Rondon, M.F. (2011), Evaluation of an Approach to Weight Loss in Adults with Intellectual or Developmental Disabilities, *Intellectual and Developmental Disabilities*, Vol 49(2), 103-112.

Schnepel, S., Krähenmann, H., Dessemontet, R.S. & Opitz, E.M. (2019), The mathematical progress of students with an intellectual disability in inclusive classrooms: results of a longitudinal study, *Mathematics Education Research Journal*.

Schurrer, R., Weltman, A. & Brammell, H. (1985), Effects of Physical Training on Cardiovascular Fitness and Behavior Patterns of Mentally Retarded Adults, *American Journal of Mental Deficiency*, Vol 90(2), 167-169.

Scottish Intercollegiate Guidelines Network [SIGN] (2010), 115 - Management of Obesity: A national clinical guideline, Retrieved on 26th October 2016 from <http://www.sign.ac.uk/pdf/sign115.pdf>

Shahsanai, A., Farajzadegan, Z., Sichani, Z.H., Heidari, K. & Omid, R. (2018), Assessment of the Relationship between Nutritional Knowledge and Anthropometric Indices in Isfahan Children and Adolescent, *Advanced Biomedical Research*, 7: 110.

Sheehan, R. & Hassiotis, A. (2017), Digital mental health and intellectual disabilities: state of the evidence and future directions, *Evidence Based Mental Health*, Vol 20 No 4, 107-111.

Silva, V., Campos, C., Sá, A., Cavadas, M., Pinto, J., Simões, P., Machado, S., Murillo-Rodríguez, E. & Barbosa-Rocha, N. (2017), Wii-based exercise program to improve physical fitness, motor proficiency and functional mobility in adults with Down syndrome, *Journal of Intellectual Disability Research*, Volume 61(8), 755–765.

Simila, S. & Niskanen, P. (1991), Underweight and overweight cases among the mentally retarded, *Journal of Mental Deficiency Research*, 35, 160-164.

Siperstein, G.N., Parker, R.C. & Drascher, M. (2013), National snapshot of adults with intellectual disabilities in the labor force, *Journal of Vocational Rehabilitation* 39 (2013) 157–165.

Smith, A. (2014), Older Adults and Technology Use, Retrieved 22nd November 2019 from <https://www.pewresearch.org/internet/2014/04/03/older-adults-and-technology-use/>

Smyth, C.M. & Bell, D. (2006), From biscuits to boyfriends: the ramifications of choice for people with learning disabilities, *Journal compilation*, 34, 227–236.

Sohler, N., Lubetkin, E., Levy, J., Soghomonian, C. & Rimmerman, A. (2009), Factors Associated with Obesity and Coronary Heart Disease in People with Intellectual Disabilities, *Social Work in Health Care*, 48:1, 76-89, DOI: 10.1080/00981380802451160.

Son, S., Jeon, B. & Kim, H. (2016), Effects of a walking exercise program for obese individuals with intellectual disability staying in a residential care facility, *Journal of Physical Therapy Science*, 28(3): 788–793.

Spanos, D., Melville, C.A. & Hankey, C.R. (2013^a), Weight management interventions in adults with intellectual disabilities and obesity: a systematic review of the evidence, *Nutrition Journal*, 12:132, 1-16.

Spanos, D., Hankey, C.R., Boyle, S., Koshy, P., Macmillan, S., Matthews, L., Miller, S., Penpraze, V., Pert, C., Robinson, N. & Melville, C.A. (2013^b), Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: a qualitative study, *Journal of Intellectual Disability Research*, Volume 57(1), 90–102.

Spanos, D., Hankey, C., Boyle, S. & Melville, C. (2014), Comparing the effectiveness of a multi-component weight loss intervention in adults with and without intellectual disabilities, *Journal of Human Nutrition and Dietetics*. 27, 22–29, doi:10.1111/jhn.12051.

Spanos, D., Hankey, C.R. & Melville, C.A. (2016), The Effectiveness of a Weight Maintenance Intervention for Adults with Intellectual Disabilities and Obesity: A Single Stranded Study, *Journal of Applied Research in Intellectual Disabilities*, 29, 317–329.

Special Olympics Ireland, (2019), Get Involved, Retrieved 22nd July 2019 from <https://www.specialolympics.ie/our-work/get-involved>

Special Olympics (2020), About Us, Retrieved 10th April 2020 from <https://www.specialolympics.org/about>

Stancliffe, R.J. & Anderson, L.L. (2017), Factors associated with meeting physical activity guidelines by adults with intellectual and developmental disabilities, *Research in Developmental Disabilities*, 62, 1–14.

Statistica (2020), Worldwide mobile app store revenues in 2015, 2016 and 2020, Retrieved 4th February 2020 from <https://www.statista.com/statistics/220186/total-global-in-app-revenue-forecast/>

Stedman, K.V. & Leland Jnr, L.S. (2010), Obesity and intellectual disability in New Zealand, *Journal of Intellectual & Developmental Disability*, 35:2, 112-115.

Stevens J., Truesdale K. P., McClain J. E. & Cai J. (2006) The definition of weight maintenance, *International Journal of Obesity* 30, 391–399.

Stewart, L., Beange, H. & Mackerras, D. (1994), A Survey of Dietary Problems of Adults with Learning Disabilities in the Community, *Mental Handicap Research*, Vol 7(1), 41-50.

Stice, E. & Shaw, H.E. (2002), Role of body dissatisfaction in the onset and maintenance of eating pathology A synthesis of research findings, *Journal of Psychosomatic Research*, 53, 985– 993.

Stokes, H., Turnbull, M. & Wyn, J. (2013), Young People with a Disability: Independence and Opportunity A Literature Review, *The University of Melbourne - Youth Research Centre, Research Report 39*.

Strohacker, K., Galarraga, O. & Williams, D.M. (2014), The Impact of Incentives on Exercise Behavior: A Systematic Review of Randomized Controlled Trials, *Annals of Behavioral Medicine*, 48(1): 92–99.

Sullivan, M., Karlsson, J., Sjostrom, L., Backman, L., Bengtsson, C., Bouchard, C., Dahlgren, S., Jonsson, E., Larsson, B. & Lindstedt, S. (1993), Swedish obese subjects (SOS): an intervention study of obesity – baseline evaluation of health and psychosocial functioning in the first 1743 subjects examined, *International journal of obesity and related metabolic disorders: journal of the International Association for the Study of Obesity*, Sep 17(9), 503-512.

Sundblom, E., Bergström, H. & Elinder, L.S. (2015), Understanding the Implementation Process of a Multi-Component Health Promotion Intervention for Adults with Intellectual Disabilities in Sweden, *Journal of Applied Research in Intellectual Disabilities*, Vol 28(4), 296-306.

Swinburn, B.A., Sacks, G., Hall, K.D., McPherson, K., Finegood, D.T., Moodie, M.L. et al. (2011), Obesity 1 - The global obesity pandemic: shaped by global drivers and local environments, *Lancet*, 378, 804–814.

Temple, V.A. (2007), Barriers, enjoyment and preference for physical activity among adults with intellectual disability, *International Journal of Rehabilitation Research*, 30(4), 281-287.

Temple, V.A. & Walkley, J.W. (2007), Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability, *Journal of Intellectual and Developmental Disability*, 32(1), 28-38.

The Victorian Healthy Eating Enterprise (2015), *Healthy choices: food and drink classification guide: A system for classifying foods and drinks*, Brunswick: Impact Digital.

Townsend, T. & Lake, A. (2017), Obesogenic environments: current evidence of the built and food environments, *Perspectives in Public Health*, Vol 137 (1), 38-44.

Under Armour Inc. (2020), MyFitnessPal app, Retrieved 11th April 2020 from <https://www.myfitnesspal.com/>

unlockfood.ca (2018), Handy Guide to Serving Sizes, Retrieved 17th December 2016 from <https://www.unlockfood.ca/EatRightOntario/media/PDFs-new-website/Portions%20Toolkit/Handy-Servings-Guide-EN-v04-July-2018.pdf>

US Department of Agriculture (2019), Choose My Plate, Retrieved 23rd September 2018 from <https://www.choosemyplate.gov/>

U.S. Department of Health and Human Services (2018), *Physical Activity Guidelines for Americans, 2nd edition*. Washington, DC: U.S. Department of Health and Human Services; 2018.

Vandelanotte C., Muller, A.M., Short, C.E., Hingle, M., Nathan, N., Willaims, S.L., Lopez, M.L., Parekh, S. & Maher, C.A. (2015), Past, Present, and Future of eHealth and mHealth Research to Improve Physical Activity and Dietary Behaviors, *Journal of Nutrition Education and Behavior*, Volume 48, Number 3, 219-228.

van den Bos, K.P., Nakken, H., Nicolay, P.G. & van Houten, E.J. (2007), Adults with mild intellectual disabilities: can their reading comprehension ability be improved?, *Journal of Intellectual Disability Research*, Vol 51(11), 835-849.

W3C (2019), Cognitive Accessibility at W3C, Retrieved 29th October 2019 from <https://www.w3.org/WAI/cognitive/>

Wang, S.S, Brownell, K.D. & Wadden, T.A. (2004), The influence of the stigma of obesity on overweight individuals, *International Journal of Obesity*, 28, 1333-1337.

Wang, Y.C., McPherson, K., Marsh, T., Gortmaker, S.L. & Brown, M. (2011), Obesity 2 - Health and economic burden of the projected obesity trends in the USA and the UK, *Lancet*, 378, 815–825.

Wang, M.L., Pbert, L. & Lemon, S.C. (2014), The influence of family, friend, and coworker social support and social undermining on weight gain prevention among adults, *Obesity (Silver Spring)*, 22(9): 1973–1980. doi:10.1002/oby.20814.

Wansink, B., Painter, J.E. & North, J. (2005), Bottomless Bowls: Why Visual Cues of Portion Size May Influence Intake, *Obesity Research*, Vol. 13 No. 1, 93-100.

Weafer, J.A. (2010), Chapter Two - The views and experiences of people with intellectual disabilities, Retrieved 17th January 2020 from

<http://nda.ie/Publications/Social-Community/Independent-and-Community-Living-Focus-Group-Consultation-Report/Chapter-Two-The-views-and-experiences-of-people-with-intellectual-disabilities/>

Wehmeyer, M.L. (1998), National Survey of the Use of Assistive Technology by Adults with Mental Retardation. *Mental Retardation*, 36(1), 44-51. doi:

[10.1352/0047-6765\(1998\)036<0044:NSOTUO>2.0.CO;2](https://doi.org/10.1352/0047-6765(1998)036<0044:NSOTUO>2.0.CO;2)

Wilson, N.J., Jaques, H., Johnson, A. & Brotherton, M.L. (2017), From Social Exclusion to Supported Inclusion: Adults with Intellectual Disability Discuss their Lived Experiences of a Structured Social Group, *Journal of Applied Research in Intellectual Disabilities*, 30, 847–858.

World Health Organisation (2016), *Global Observatory for eHealth: Global diffusion of eHealth: making universal health coverage achievable. Report of the third global survey on eHealth*, Geneva: WHO Document Production Services.

World Health Organisation (2018), Disability and Health: Fact Sheet, Retrieved 10th April 2019 from <https://www.who.int/en/news-room/fact-sheets/detail/disability-and-health>

World Health Organisation (2019), Obesity and overweight: Fact Sheet, Retrieved on 09th April 2019 from <http://www.who.int/mediacentre/factsheets/fs311/en/>

World Health Organisation [WHO] Europe (2019), Health Topics – Definition: Intellectual Disability, Retrieved on 20th June 2019 from

<http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability>

World Medical Association Declaration of Helsinki (2002), WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects, Retrieved 4th December 2016 from <https://jamanetwork.com/journals/jama/fullarticle/1760318>

WW International, Inc. (2020), Weight Watchers, Retrieved 3rd April 2020 from <https://www.ww.ie/>

Zoppo, A. & Asteria, C. (2008), Letter to the Editor: Obesity treatment and cardiovascular prevention in mentally retarded subjects, *International Journal of Obesity*, 32, 1034.