Weight loss and weight maintenance interventions for adults with intellectual disabilities

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Summary

Background

The prevalence of obesity is higher in adults with intellectual disabilities (ID) than in the general population, with increased rates of secondary health risks and increased mortality rates.

Multi-component weight loss interventions have been advocated by current UK clinical guidelines for all adults without ID. Such interventions incorporate dietary changes that produce an energy deficit, increased levels of physical activity and the use of behavioural approaches to promote and sustain changes in physical activity and dietary patterns, followed by a weight maintenance intervention.

However, UK clinical guidelines have reported that the evidence base for the treatment of obesity in adults with ID is minimal. New evidence in this area of research could be used for the development of accessible weight management interventions for adults with ID and lead to a sustainable clinically significant weight loss.

Methods

Study 1: A systematic review aiming to evaluate the clinical effectiveness of weight management interventions in adults with ID and obesity using recommendations from current clinical guidelines for the management of obesity in adults. Full text papers published between 1982 to 2011 were sought by searching the Medline, Embase, PsycINFO and CINAHL databases. Studies were evaluated based on 1) intervention components, 2) methodology, 3) attrition rate 4) reported weight loss and 5) duration of follow up. The assessment of the quality of the studies and interventions was based on the criteria of the Centre for Reviews and Dissemination (CRD) (University of York) and the PRISMA checklist.

Study 2: The evidence base for the development of weight maintenance interventions in adults with ID is limited. This study presents the findings of the second phase of a multi-component weight management programme for adults with ID and obesity (TAKE 5). A total of 31 completers of the 16 week weight loss intervention of the TAKE 5 programme were invited to participate in a 12 month weight maintenance intervention. The TAKE 5 weight maintenance intervention included monthly one to one sessions and monthly phone calls, using the recommendations of the Glasgow and Clyde Weight Management Service (GCWMS) and of the National Weight Control Registry. The intervention provided a dietary advice based on the estimated energy requirements of each participant, advice to improve physical activity and behavioural approach techniques to facilitate changes in physical and dietary patterns. Participants' body weight, BMI, waist circumference (WC) and levels of physical activity were measured before and after the intervention. Paired *t* tests were used to assess differences in anthropometric and physical activity measurements.

Study 3: 52 participants of the TAKE 5 weight loss programme were individually matched by baseline characteristics (gender, age and BMI) with two participants without ID of the GCWMS programme. Non parametric significance tests were used for comparisons between groups in terms of weight and BMI change and rate of weight loss. In addition, data from the 52 completers with ID of the TAKE 5 weight loss intervention were used to perform a univariate logistic regression analysis for the identification of socio-biological predictors for absolute weight loss and clinically significant weight loss at 16 weeks.

Study 4: Semi-structured interviews were used to explore the experiences of 24 carers that supported participants of the TAKE 5 weight loss programme. The transcripts were analysed qualitatively using the qualitative data software analysis package, ATLAS ti 5.2 software. Thematic analysis was used to examine potential themes within data.

Results

Study 1: Twenty two studies met the inclusion criteria. The interventions were classified according to inclusion of the following components: behaviour change alone, behaviour change plus physical activity, dietary advice or physical activity alone, dietary plus physical activity advice and multi-component (all three components). The majority of the studies had the same methodological limitations: no sample size justification, small heterogeneous samples, no information on randomisation methodologies. Eight studies were classified as multi-component interventions, of which one study used a 600 kilocalorie (2510 kilojoule) daily energy deficit diet. Study durations were mostly below the duration recommended in clinical guidelines and varied widely. No study included an exercise program promoting 225-300 minutes or more of moderate intensity physical activity per week but the majority of the studies used the same behaviour change techniques. Three studies reported clinically significant weight loss (≥ 5%) at six months post intervention.

Study 2: 28 participants completed the TAKE 5 weight maintenance intervention. Most of the participants (50.4%) maintained their weight (mean weight change=-0.5kg; SD= 2.2) within ± 3% from initial body weight at the end of the weight maintenance intervention. There was no statistically significant change in BMI and WC at 12 months from BMI and WC at the end of the 16 week weight loss intervention. There was no statistically significant decrease in the time spent in sedentary behaviour and no statistically significant increase in the time spent in light and in moderate to vigorous physical activity. At the end of the weight maintenance intervention participants spent less days walking (at least 10 minutes) than at the end of the end of the weight loss intervention (P<0.05).

Study 3: There were no significant differences between participants with ID and participants without ID in the amount of weight loss (median:-3.6 vs. -3.8, respectively, P=0.4), change in BMI (median: -1.5 vs. -1.4, P=0.9), success of achieving 5% weight loss (41.3% vs. 36.8%, P=0.9) and rate of weight loss across the 16 week intervention. Only, initial weight loss at four weeks was positively correlated with absolute weight loss at 16 weeks (P<0.05).

Study 4: Three themes emerged from the analysis: Carers' perceptions of participants' health; barriers and facilitators to weight loss; and carers' perceptions of the weight loss intervention. Data analysis showed similarities between the experiences reported by the carers who supported participants who lost weight and participants who did not. Lack of sufficient support from people from the internal and external environment of individuals with ID and poor communication among carers, were identified as being barriers to change. The need for accessible resources tailored to aid weight loss among adults with ID was also highlighted.

Conclusions

Study 1: Weight management interventions in adults with ID differ from recommended practice and further studies to examine the effectiveness of multi-component weight management interventions for adults with ID and obesity are justified.

Study 2: The TAKE 5 weight maintenance intervention can effectively support adults with ID maintain their weight. Assessment of the cost effectiveness of the TAKE 5 weight management programme is justified.

Study 3: The TAKE 5 multi-component weight loss intervention in its current structure can be equally effective for adults with ID as in adults without ID and obesity. A study with a larger sample could facilitate the identification of sociological and biological predictors for weight loss in adults with ID.

Study 4: This study identified specific facilitators and barriers experienced by carers during the process of supporting obese adults with ID to lose weight. Future research could utilise these findings to inform appropriate and effective weight management interventions for individuals with ID.

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Publications arising from this thesis

Articles

1. Spanos, D., Hankey, C.R., and Melville, C.A. (2013) Comparing the effectiveness of a multi-component weight loss intervention in adults with and without intellectual disabilities. Journal of Human Nutrition and Dietetics. ISSN 0952-3871 (In Press)
2. Miller, S., Penpraze, V., Pert, C., Robinson, N., and Melville, C.A. (2013) Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: a qualitative study. Journal of Intellectual Disability Research .volume 57, Issue 1; 90-102

A copyraight apporval has been provided to the author to use the above articles as part of the thesis. Please see Appendix 9.

Short communications

1. Spanos, D., Hankey, C., Boyle, S., Koshy, P., Macmillan, S., Matthews, L., Miller, S., Penpraze, V., Pert, C., Robinson, N., and Melville, C.A. (2011) Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: a qualitative study. European Congress on Obesity (ECO). Abstracts of the 18th European Congress on Obesity, Istanbul, 25-28 May 2011. Poster Sessions. Obesity Reviews, 12, 63-279.
2. Spanos, D., Hankey, C., Boyle, S., Koshy, R., Macmillan, S., Mathews, L., Miller, S., Penpraze, V., Pert, C., Robinson, N. & Melville, C.(2011). Carers' perspectives on a weight loss intervention for obese adults with intellectual disabilities: a qualitative study. Proceedings of the Nutrition Society, 70, Issue OCE1 ,E19,Cambridge University Press.

Author's Declaration

"I hereby declare that I am the sole author of this thesis". My involvement in each study included:

Study 1: Systematic review

- Conceived the study
- Designed the methodology
- Carried out the systematic review
- Analysis and interpretation of the findings

General Methods:

- Weight management coordinator for the Take 5 Weight loss study
- Designed the structure of the intervention sessions
- Delivered the intervention for 30 participants
- Designed the materials/resources used in the intervention
- Participated in the writing up of the published manuscript

Study 2: TAKE 5 Weight maintenance intervention

- Conceived the study
- Designed the methodology
- Delivered the intervention
- Designed the materials/resources used in the intervention
- Collected pre and post intervention data
- Analysis of data
- Interpretation of the data

Study 3: Assessment of TAKE 5 weight loss intervention

- Conceived the matching populations study
- Designed the methodology

- Analysis of matching populations data
- Interpretation of the data
- Analysis of the data on predictors for weight loss
- Interpretation of the data on predictors for weight loss

Study 4: Qualitative study

- Conceived the study
- Designed the methodology
- Designed the qualitative questionnaires
- Carried out the qualitative interviews
- Analysis and interpretation of the findings

“This Thesis has not been submitted in any form for another degree or professional qualification.”

Dimitrios Spanos

Lists of Abbreviations

American Association on Intellectual and Developmental Disabilities	AAIDD
Body mass index	BMI
British Diabetic Association	BDA
cardiovascular disease	CVD
Coronary heart disease	CHD
Glasgow and Clyde Weight Management Service	GCWMS
Health Survey for England	HSE
Intellectual disabilities	ID
kilograms	kg
Kilojoule	KJ
Kilocalories	Kcal
National Institute for Health and Clinical Excellence	NICE
Organisation for Economic Co-operation and Development	OECD
Randomised controlled trial	RCT
Physical Activity Level	PAL
Scottish Health Survey	SHS
Scottish Intercollegiate Guidelines Network	SIGN
Standard deviation	SD
standardised morbidity ratio	SMR
Waist circumference	WC
weighted mean difference	WMD
World Health Organisation	WHO
Very low calorie diet	VLCD

*"**Article 25 Health**: States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability…"*

United Nations (2006), Convention on the Rights of Persons with Disabilities and Optional Protocol, Article 25 Health, page 18 (available from: http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf)

Chapter 1 Background

1.1 Introduction

The epidemic of obesity (World Health Organisation-WHO, 2003) is an important health issue for adults with and without intellectual disabilities (ID). Before examining the evidence-base on obesity management in adults with ID, this chapter will set the scene by providing an overview of the more extensively investigated issue of obesity in adults without ID and a more detailed description of the evidence in adults with ID and obesity. This chapter will provide an outline of the determinants associated with obesity in both population groups, followed by a description of the evidence on weight management in adults without ID.

1.1.1 Definition of Intellectual Disabilities

The tri-dimensional definition of ID by the American Association on Intellectual and Developmental Disabilities (AAIDD) (Schalock *et al.* 2010) is the most widely accepted and defines ID as:

“a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18”

ID can be identified with the use of IQ testing (IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning) and by the use of tests that determine limitations in adaptive behaviour. These tests assess:

- Conceptual skills e.g. language and literacy; money, time, and number concepts; and self-direction.
- Social skills e.g. interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.

- Practical skills e.g. activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Except from the tri-dimensional definition of ID, professionals use IQ scores to assess an individual's impairment and classify them to four levels of ID (Holland, 2011). The four classifications of ID based on IQ scores are:

- mild learning disability: 50 -70 IQ score
- moderate learning disability: 35 - 50 IQ score
- severe learning disability: 20 - 35 IQ score
- profound learning disability: Below 20

Professionals are advised to take into consideration the community environment typical of an individual's peers, culture, linguistic diversity and cultural differences in the way people communicate, move, and behave when defining and assessing ID(Schalock *et al*. 2010).

The WHO (2007) in a survey of global resources and services for adults with ID reported that many terms are used to refer to ID including mental retardation, mental handicap, and learning disabilities. The survey found that the term mental retardation was most commonly used by all six regions of the WHO, especially low income countries, and the term ID was more commonly used by high income countries. ICD-10 was the diagnostic instrument or classification system most commonly used to refer to ID. However, WHO (2007) does not provide information on the diagnosis codes used (e.g. F79 for unspecified ID, F70 for mild ID). The different terms used in different countries make difficult the estimation of the global prevalence of ID but also suggest there could be inconsistencies with reviews of evidence from international research.

International epidemiological data, estimates the prevalence of ID to range from three to five per 1000 of the general population in developed nations, and is estimated to be higher in developing countries (Fujiura *et al*. 2005).

The term intellectual disabilities (ID) is used throughout this thesis.

1.1.2 Definition of Obesity

The International Statistical Classification of Diseases (ICD-10) has recognised the health burden of obesity (Diagnosis code E66.9) by specifying obesity as a disease in its own right (WHO 1977). The classification can be found in chapter IV under the subsection "Obesity and Other Hyperalimentation" (codes E66.0 to E66.9) (WHO 2007). Obesity is characterized by an excessive enlargement of body fat stores to an extent that impairs health (Garrow and James 2000; Organisation for Economic Co-operation and Development 2011). For epidemiological and practical purposes the WHO (1995) identified basic anthropometry and the use of Body Mass Index (BMI) as the single most portable, universally applicable technique to assess the size of the human body and to define obesity.

1.1.2.1 Body mass index as a measure of obesity

BMI is an internationally accepted measure of general adiposity used as a simple index of weight for height used to classify underweight, overweight and obesity in adults. It is defined as the weight in kilograms (kg) divided by the square of the height in meters (m) (kg/m^2) (WHO 2000). An adult is classified as obese when BMI ≥ $30kg/m^2$ (see table 1.1). BMI is age and sex independent (WHO 2004). In addition, Flegal *et al.* (2009) compared BMI with percentage of fat (measured with dual-energy X-ray absorptiometry in a large US population sample) and concluded that overall BMI could correspond well within groups and could distinguish categories of body fatness. However, it has to be noted that BMI does not provide evidence on body shape and distributions of body fat, making it less reliable to identify the risks associated with central adiposity (Evans *et al.* 2012).

1.1.2.2 Waist circumference as a measure of obesity

The WHO (2008) highlighted the adverse health implications of abdominal fat mass such as cardiovascular disease and diabetes, and identified the importance of waist circumference and waist-hip ratio measurements for the prediction of associated health risks. Waist circumference is a simple index to estimate intra-abdominal fat mass and total body fat and can be used to identify individuals that may benefit from weight management interventions (Lean *et al.* 1995); waist circumference has a high specificity for the prediction of health risks (Han *et al.* 1997) and is a good predictor of mortality from specific causes, such as cancer and respiratory diseases (Leitzman *et al.* 2011). The assessment of the usefulness of waist circumference and waist hip ratio showed that both methods are associated with disease risk but measuring hip circumference can be less practical than waist measurements (WHO 2008). It is recommended that the combination of BMI and waist circumference measurements is used for the classification of obesity and association with disease risk using the following cut off points (as suggested in the NIH Practical guide to obesity 2000):

Table 1.1: Combined recommendations of body mass index and waist circumference cut-off points made for overweight or obesity, and association with disease risk

	Body mass index	**Obesity class**	**Disease risk (relative to normal weight and waist circumference)**	
			Men<102cm Women <88cm	Men>102cm Women>88cm
Underweight	<18.5			
Normal	18.5-24.9			
Overweight	25.0-29.9		Increased	High
Obesity	30.0-34.9	I	High	Very high
	35.0-39.9	II	Very high	Very High
Extreme obesity	>40.0	III	Extremely high	Extremely high

Source: Adapted from NHLBI Obesity Education Initiative (2000)

The measurement of waist in those with a BMI more than 35kg/m^2 does not add to the predictive value of the BMI classification (SIGN 2010). Therefore, waist measurement is not recommended for these individuals (NICE 2006).

1.2 Obesity prevalence

1.2.1 Obesity levels in adults without intellectual disabilities

According to the Organisation for Economic Co-operation and Development (OECD) (2011) obesity has increased and reached epidemic proportions. Over 50% of the adult population in developed and developing countries (19 out of the 34 OECD countries) report that they are overweight or obese. The highest rate of obesity is reported in the United States and Mexico (≥30%) and the lowest in Japan and Korea (≈4%). Obesity prevalence has more than doubled over the past 20 years in Australia and New Zealand to 25% and 27%, respectively, and has increased by half in the United Kingdom and the United States (14% to 23% and 23% to 34%, respectively) (OECD 2011).

The Health Survey for England (HSE) is a series of annual surveys that aims to record the health and the health related behaviours in adults and children living in England. According to the published trend tables of 2010, obesity in adults (aged 16 and over) has increased. In more detail, the percentage of men and women with a BMI within a healthy range decreased between 1993 and 2010, from 41.0% to 30.9% among men and from 49.5% to 40.4% among women and the proportion of men with obesity increased from 13.2% in 1993 to 26.2% in 2010 and from 16.4% to 26.1% for women. Overall, 26% of adults were classified as obese in 2010. The same trend between 1993 and 2010 was also reported for abdominal adiposity in adults living in England, using the definition of the USA's National Institute of Health Adult Treatment Panel III (2011), with 20% of men with a raised waist circumference (more than 102cm) increased to 34% and 26% of women with a raised waist circumference (more than 88cm) from 26% increased to 46%. The most recent publication on obesity trend in US from 1999 to 2010 (Flegal *et al.* 2012) does not provide information on trends on waist circumference not allowing comparisons with data from UK.

The Scottish Health Survey (2010), a survey that recorded the health of children and adults living in Scotland, also reported an increase in the level of obesity in adults. Prevalence of obesity (BMI ≥30) among adults (aged 16-64) in Scotland has continued to increase since 1995 (17.2%) to reach 27.4 % in 2010.

The Foresight report (2007) has predicted that the levels of obesity in adults (aged between 21 and 60) in England will increase to 36% for males and 28% for females by 2015 and 47% for men and 36% for women by 2025.

1.2.2 Obesity levels in adults with intellectual disabilities

Obesity can be an important health issue for adults with ID and evidence consistently shows that the prevalence of obesity is higher in this population group than in the general population. An overview of studies on major health risks in adults with ID, published from 1999 to 2010, reported that in industrialized countries the rate of obesity in adults with ID is higher than the general population, reaching an estimate of 50.5% (Haveman *et al.* 2010).

A review of 12 published articles between 1985 and 2006 showed that the national and international prevalence of obesity in adults with ID has increased in the last 20 years and is higher than in the general population (Melville *et al.* 2007). For example the prevalence of obesity in men with ID ranged from 2% to 45.2% compared to 3.9% to 20.3% in men without ID and in women with ID from 15% to 50.5% compared to 3.6% to 28% in women without ID. However, the authors stated that caution should be exercised in interpreting the findings of this review because the heterogeneity identified in these studies affects the robustness of the evidence-base. Examples of heterogeneity observed within these studies include the differences in sampling strategies, and measurement methodology.

Studies following the review by Melville *et al.* (2007) continue to report a high prevalence of obesity in this population group compared to data on adults without ID from national surveys. Melville *et al.* (2008) compared data collected from a health screening programme for adults with ID (16 years and over, n=945) Greater Glasgow with data from the Scottish Health Survey (2003). The overall comparison showed that 39.3% (165) of women and 27.8% (146) of men with ID in this study were obese, compared with 25.1% of women and 22.7% of men in the Greater Glasgow health board sample from the Scottish Health Survey.

Bhaumik *et al.* (2008) also found in a more recent study a higher prevalence of obesity in women with ID when compared with the general population but this was not the case in men. The study examined BMI distribution in adults with ID (≥ 25yrs old, n=952) from the Leicestershire Learning Disability Register who participated in a programme of universal health checks and home interviews with their carers. The health checks included BMI measurements. Comparisons with the general population (data from the Health survey for England, 1998) revealed higher levels obesity in women with ID (23% and 32%, respectively) but not in men (19% and 15%, respectively). Standardisation for age showed the same finding since the standardised morbidity ratio (SMR stratified by sex and Down syndrome) for obesity was slightly lower in men with ID compared with the general population (SMR=0.80; 95% CI=0.64–1.00), but elevated significantly in women with ID (SMR=1.48; 95% CI=1.23–1.77). The study also reported a greater prevalence of underweight in both men and women with ID than in the general population, especially in those that needed support in drinking and eating and those with very poor level of understanding.

Gale *et al.* (2009) collected evidence from 28 General Practitioners (GP) in Bristol. Available BMI data from 688 adults with ID (16 years and over) allowed comparisons with data from the general population (data from the National Centre for Health Outcomes Development 2008) and showed that prevalence of obesity was 10% higher in adults with ID than the general population in the South West of England (33% vs 24%). However, the study reported that inexperience of primary care staff and GPs in working with people with ID could lead to underestimation of the presence of ID among the patients and possibly to an underestimation of the prevalence of obesity in this population group. In addition, BMI data were not available for 37% of the total sample contributing to a second underestimation of the prevalence of obesity.

In contrast to these studies a USA study by Moran *et al.* (2005) did not show a higher prevalence of obesity in adults with ID (20 to 29 and 50 to 59 years of age) than in adults without ID. The study used a robust methodology by recruiting a sample of adults with ID age, matched with adults without ID from the same geographical area and the same primary care practices from 1990 to 2003. However, the ID sample included more adults (205) from more restrictive environments and less (120) from least restrictive environments. This means that some individuals with ID had stricter and more structured supervised support of their dietary habits and some people lived independently with potentially less supervised dietary habits. In addition a great proportion of the sample with ID was identified as having severe ID and severe mental illness. The next section on risk factors for obesity will show that living arrangements and level of ID could determine the nutritional status of individuals with ID and should be taken into consideration when studies assess the prevalence of obesity or underweight in this population group.

The findings of Moran *et al.* (2005) were supported by another study in the USA that showed that the prevalence of obesity in adults (20 years and older) with ID did not differ from the prevalence of obesity in adults without ID (Stancliffe *et al.* 2011). This large study (total sample: 8,911) used data from a sample drawn from the 2008–2009 National Core Indicators (NCI) program of the U.S. ID services and made comparisons with the general population that was included in the 2007–2008 National Health and Nutrition Examination Survey (NHANES). The prevalence of obesity was equal to 33.8% in adults without ID and 33.6% in adults with ID.

The health burden of obesity in adults with ID had been also examined and discussed in other international studies, since 2007 Jeevanandam (2009) identified the limited evidence in the literature on ID in Asia and reviewed the evidence regarding prevalence, epidemiology and services for this population group. Based on data from health screenings in Singapore, the prevalence of obesity was equal to 42.1% in a sample of 817 adults with moderate ID. In New Zealand, Stedman and Leland (2010) compared a much smaller sample of people with ID (98) with the general population (Ministry of Health 2008). The study reported significantly higher levels of obesity in adults with ID (51%) than the general population (29.9%). Wallace and Schluter (2008) assessed the risk factors for CVD in adults with ID living in Australia and in a sample of 85 reported that 70% were obese or overweight.

The more recent Melville *et al.* (2008), Bhaumik *et al.* (2008), Gale *et al.* (2009), Moran *et al.* (2005), Jeevanandam (2009) and Stedman and Leland (2010) present similar limitations in their sampling strategies to previous studies (Melville *et al.* 2007). Small sample sizes and the differences in the samples make comparisons between the studies difficult and should not lead to generalisations to the wider populations of adults with ID. Recruitment of samples from no specific geographical areas (urban and suburban areas), living in the community with carers or independently or living in institutions, inclusion of people with a variety of ID and people who have full time and part time support make the samples heterogeneous. However, the overall evidence suggests that obesity is a significant clinical problem in adults with ID.

1.3 The economic burden of obesity

The increasing prevalence of obesity is also associated with increasing economic costs for the society and the health care system of a country. The economic costs of obesity and its consequences can include the direct treatment, the cost of dependence on state benefits, and indirect costs such as loss of earnings and reduced productivity (Foresight report 2007). A systematic review of 32 international articles (1990-2009) found that 0.7% to 2.8% of total healthcare expenditures of a country were spent for the obesity alone. In addition, obese individuals (BMI≥30kg/m^2) were found to have medical costs that were approximately 30% greater than those individuals with a healthy BMI (≤ 25 kg/m^2) (Withrow and Alter, 2011).

The Foresight report (2007) used as a base the estimated costs of obesity and overweight in England in 2002 (nearly £7 billion) (The House of Commons Health Select Committee) and estimated that the annual NHS costs for obesity alone will be £3.9 billion for 2015 and £7.1 billion per for 2050 and the wider annual total costs of overweight and obesity will be £27 billion for 2015 and £49.9 billion for 2050. Similar economic patterns are also reported for Scotland, with total costs to Scottish society in 2007 and 2008 estimated as £457 million, predicted to double by 2030 and range from £0.9 billion to £3 billion.

1.4 Determinants of obesity

1.4.1 Determinants of obesity in adults without intellectual disabilities

The process of weight gain is based on the “First law of Thermodynamics” and the principles of energy balance (Bray 2005). The human body needs energy for the maintenance of body functions and as a fuel for daily physical activities (Hill

2006). The human body stays in a state of energy balance when the energy that derives from food and drinks is equal to the energy used as fuel for several physiological processes (Spiegelman and Flier 2001). A positive energy balance is attributed to a higher energy intake than expended, leading to excess storage of fat and weight gain (Bray 2003).

However, the aetiology of obesity is not always a simple single explanation. As a result of the universal incline of industrialisation, urbanisation, and mechanisation the aetiology of weight gain is likely to be complex and multi-factorial (WHO 2003). There has been extensive research into the determinants of obesity showing interrelated associations between the most distinctive aetiological factors such as unhealthy dietary patterns and sedentary lifestyles with socioeconomic inequalities and obesogenic environments (WHO 2003; Giskes *et al*. 2010; Papas *et al*. 2007). The Foresight Report (2007) uses the obesity system diagrams to illustrate the complexity of the aetiology of obesity. However, the report has simplified process to weight gain by subdividing the determinants into 4 main themes: physiology (genetic predisposition), individual activity, physical activity environment, food consumption, food production, individual psychology and social psychology. The identified key variables from the report include: level of primary appetite control, force of dietary habits, level of physical activity and levels of psychological ambivalence. Using the Foresight report as a base, this section will focus on the following key determinants to provide a holistic but clear explanation of the complex mechanisms: Diet, physical activity, gender, age, socio-economic status, obesogenic environment, obesogenic medication.

1.4.1.1 Diet

There is a worldwide increase in the consumption of high energy-dense foods and sugary drinks, potentially contributing to the increasing prevalence of obesity (WHO 2003; Mendoza *et al*. 2007). Energy density is defined “as the amount of energy per unit weight of a food or beverage (kilocalories per gram or kilojoules per gram)” (Pérez-Escamilla *et al*. 2012). A review by WHO (2003) reported that there is convincing evidence to support the relationship between the consumption of high energy-dense foods and obesity. In general, foods that are considered as high energy dense foods are highly processed foods, foods high in fat and saturated fat, added sugars, low in unrefined carbohydrates with very poor nutritional value. Drewnowski (2004) provides examples of the foods that provide the most dietary energy per unit weight including potato chips (23 kJ/g), chocolate (22 kJ/g), or doughnuts (18 kJ/g) and explains that these foods may not be very high in sugar or fat but are dry.

Even though there is evidence to support the connection between the consumption of high energy dense foods and weight gain, there is no consistency from the studies in the way of specifying the energy density (Pérez-Escamilla *et al.* 2012). For example, based on a review by Pérez-Escamilla *et al.* (2012), some studies determine energy density based on the consumption of foods only or foods and beverages together.

The consumption of meals from fast food restaurants has been identified as a potential contributor to excess energy intake and subsequently obesity (Bowman and Vinyard 2004; McAllister *et al.* 2009). A review by Prentice and Jebb (2003) showed that the average energy densities from three leading fast food outlets was 1.7 fold higher than the energy density from the average British diet (1167, 1087 , 1054 kJ 100 g^{-1} vs. 670 kJ 100 g^{-1} respectively). However, a study by Anderson and Matsa (2011) showed that people consume more calories in fast food restaurants but they compensate by eating less in other occasions, leading to a very small increase of the daily energy intake when eating in these restaurants.

Interestingly, the link between the increased consumption of energy dense foods and obesity could be also seen in terms of the growing price difference between these foods and healthy foods (Drewnowski and Darmon 2005). According to Drewnowski and Darmon (2005), energy dense foods such as refined grains, added sugars, and added fats constitute the lowest cost sources of energy and these are the foods that low income populations prefer to consume. The Family Food (2010) survey examined household purchases of food and drinks in the UK between 2007 and 2010 and reported significant upward trends in household expenditure on energy dense foods like butter, sugar and preserves. However, total energy intake per person fell by 0.5% in 2010 (Total energy intake in 2010: 2,292 kcal/ person per day and total energy intake in 2009: 2,303kcal).

One of the recommended strategies to help individuals to achieve and maintain a healthy weight is to follow a healthy balanced diet (NICE 2006). Based on the revised recommendations of the Scientific Advisory Committee on Nutrition (SACN 2011) the average energy requirements for adults to maintain a healthy body weight are estimated as 2605kcal for men and 2079kcal for women. In addition, the total energy content of a healthy balanced diet should comprise ≤ 35% from fat, ≤ 11% from saturated fat, ≥ 50% from carbohydrate and ≤11% from sugars (SACN 2011; COMA 1991).

1.4.1.2 Physical activity

The WHO (2003) and the Foresight report (2007) have highlighted the potential link between physical inactivity or sedentary living and the risk for weight gain and obesity. Sedentary behaviour can be defined as the class of behaviours that involve low levels of energy expenditure that do not increase energy expenditure substantially above the resting level (1.0–1.5 METs) including watching television or videos, playing video games, and using the computer (Ford *et al.* 2005; Proper *et al.* 2011) or an average intensity of daily physical activity with a Physical Activity Level (PAL) less than or equal to 1.4 (Saris *et al.* 2003; WCRF 2009).

The revised recommendations of the UK Chief Medical Officers (CMOs 2011) for physical activity in UK and the prevention of weight gain include at least 150 minutes of moderate intensity activity or 75 minutes of vigorous intensity activity spread across the week or combinations of moderate and vigorous intensity activity. In addition all adults are advised to minimise the amount of time spent being sedentary (sitting) for extended periods.

According to the HSE (2008), overweight or obese men and women were less likely to meet the public health recommendations (30 minutes of moderate physical activity 5 days/week) compared with men and women who were not overweight or obese. In more detail, 32% of obese men and 19% of obese women did not meet the recommendations compared with 46% of men and 36% of women who were not overweight or obese. Obese men and women had the highest rates of low activity (36% and 46% respectively). In addition, men and women that were not overweight or obese spent fewer minutes on average in sedentary time (591 minutes for men, 577 minutes for women) than those who were obese (612 minutes for men, 585 minutes for women).

1.4.1.3 Gender

Overall international statistics on the prevalence of obesity show that the average rates of obesity are similar in women and men. However, in some countries like USA (Flegal *et al.* 2010) and in some low income countries like South Africa, Chile, Turkey and Mexico the proportion of women classified as obese is higher than men (WHO 2003; OECD 2011).

The prevalence of obesity in UK is similar for both genders (HSE 2011; SHS 2010). According to the HSE (2010) obesity levels in England were 26% in men and in women and according to the SHS (2010) the proportion of women (aged 16-64) classified as obese in Scotland was only slightly higher than men (28.9% vs. 27.4%, respectively).

However, according to HSE (2010) in England the mean BMI was higher in men than in women with a higher proportion of men (42%) than women (32%) being overweight. In addition, 68% of men were classified as overweight or obese in comparison with 58% of women. A lower proportion of men (31%) than women (40%) had a BMI in the normal range but women were significantly more likely than men to have a raised waist circumference (46% and 34% respectively). A similar pattern was also reported for women and men in Scotland in 2010, with men being more likely than women to be overweight or obese (67.8% versus 62.4%) (SHS 2010).

Some of the potential explanations for the higher prevalence of obesity in women in some countries include cultural preferences for women to be overweight (Prentice 2006) and socio-economic differences (education and income) between men and women (Ball *et al.* 2002). Higher levels of obesity in men has been attributed to the fact that men are less concerned or aware of being overweight and are less likely to take action about weight problems (Paeratakul *et al*. 2002; Taylor *et al*. 2008).

1.4.1.4 Age

Even though the increase of obesity is reported in all age groups the prevalence differs across the life span (Foresight report 2007).

The SHS (2010) reported that the prevalence of obesity increased by age until late middle-age, from 13.3% in those aged 16-24 to a peak of 38.3% in those aged 55-64. However, prevalence for the two oldest age groups was lower (33.0% in those aged 65-74 and 29.9% in those aged 75 and over). Similar patterns were also identified in the HSE (2010) with the lowest prevalence of obesity in the 16-24 age groups (12% in men, 9% in women), and increased in the older groups reaching a prevalence of 34% in men and 28% in women in the 55-64 age groups.

The same relationship between age and obesity identified in the HSE (2010) and SHS (2010) has been also reported in the analysis of nutritional status of adults in the USA (Ogden *et al*. 2012). Ogden *et al*. (2012) showed that the prevalence of obesity for the years 2009-2010 was different by age but only for women. In more detail, among women, 42.3% of those aged 60 and over were obese compared with 31.9% of women aged 20–39. Among men there was no significant difference in obesity prevalence by age.

Some of the potential explanations for the increase risk of obesity with age include the process of weight gain as people get older reaching peak values at 50–59 years of age, due to a decrease of metabolic rate, decrease of physical activity, decrease of fat free mass and increase of fat mass with aging (Zamboni *et al*. 2005; Villareal *et al*. 2005).

1.4.1.5 Socioeconomic status

Several studies report that the dietary habits, physical activity patterns and weight gain are strongly related to the socioeconomic status of an individual but the pathways that explain this relationship are not well defined (Ball and

Crawford 2006). The findings of national surveys and reviews reveal that people and especially women of lower socioeconomic status (poor education or low income) tend to consume nutritionally poorer diets and are less physically active than those of higher socio-economic status (Ball and Crawford 2006; Low Income Diet and Nutrition Society (LIDNS) 2007; Giskes *et al.* 2009). The WHO (2003) suggested that people with low socioeconomic status are at higher risk of being obese because they are more susceptible to obesogenic environments and are more likely to follow the ''default choices'' on offer.

The LIDNS study (2007) that was conducted between 2003 and 2005 aimed to record the dietary habits and the nutritional status of the people within the low income population living in UK. Comparisons of the dietary habits with the general population (National Diet and Nutrition Surveys (NDNS) (1994/1995, 2000/2001) showed that people from the low income group had a higher consumption of fat, non-diet soft drinks, meat and processed meat products, pizza and table sugar. In addition, comparisons of the nutritional status showed a higher proportion of obesity in women from the low income group than women from the general population (19-64 yrs old 31% vs. 20%, 65 yrs old and over 35% vs. 23%, respectively). There was little difference in the prevalence of obesity in men aged 19-64 yrs old but a higher prevalence of obesity in men aged 65 yrs old and over (29% vs.17%).

The percentage of men and women in the LIDNS with raised measures of central obesity was higher than in the NDNS. In more detail, 34% of men aged 19-64 years old in LIDNS had a raised waist circumference compared with 29% in NDNS. Similar differences were also reported for women (44% vs. 26%, respectively).

Differences in the physical activity levels followed the same patterns with the differences in the dietary habits when comparisons were made with data from the HSE 2003 and the SHS 2003. People from the low income group were found to be less active than men and women in England/Scotland for each age group. Some of the potential barriers to high physical activity levels in low income groups include unemployment, cost, requirements for childcare, and the presence of leisure/exercise facilities or knowledge of their existence.

A review of 37 longitudinal studies by Ball and Crawford (2006) tested the hypothesis that persons of lower socioeconomic status (SES) in developed countries are at increased risk of weight gain. The review reported that the occupational status was inversely associated with weight gain for both men and women. However, different indicators of SES were not always associated with weight gain in the same way. For example lower status occupation was more consistently associated with weight gain than education and income.

A systematic review of 47 studies across Europe that examined the relationship between socioeconomic status, dietary patterns and weight gain reported that diet plays an important role in overweight and obese populations (Giskes *et al.* 2009). Giskes *et al.* (2009) found that people from socioeconomically disadvantaged groups have a lower intake of fruit and vegetables and fibre. However, the study did not find a strong relationship between obesogenic dietary patterns including the consumption of energy dense diets and the consumption of energy dense drinks or the total intake of fat and weight gain. This was attributed to the inconsistency in the findings of the studies or because some of these factors were not examined thoroughly.

1.4.1.6 Obesogenic environment

According to Swinburn *et al.* (1999) an obesogenic environment is defined as "the sum of influences that the surroundings, opportunities, or conditions of life have on promoting obesity in individuals or populations." Some of the factors that change dietary behaviour and physical activity patterns leading to obesity include the low prices of energy dense foods (Drewnowski and Darmon 2005), the availability of fast food outlets (Fleischhacker *et al.* 2011), the physical ease of assessing food and drink access, and the advancement of technology that affects energy expenditure by decreasing walking opportunities and manual occupations (Foresight report 2007).

A scoping review by Kirk *et al.* (2010) assessed the research examining links with the environment and the development and occurrence of obesity. The majority of the studies examined the effect that the physical micro-environment has on weight gain and to a lesser extent the impact of the macro-environment. This means that the majority of the studies have focused on how urban design and transportation systems affect the BMI of individuals or groups in homes, schools and workplaces and fewer studies have focused on how the media, food production and marketing may influence diet, physical activity or weight at a population level. However, the relationship between the environment and obesity is characterised as very “complex” and the current research shows limitations in the methodology of assessing the impact that the environment has on diet (Kirk *et al.* 2010).

This was supported by a systematic review by Giskes *et al.* (2011) that also reported that there is more evidence showing the associations between the environment and weight status and less evidence showing the effect of the environment on diet. The review reported that there was a greater prevalence of overweight and obesity in areas where there was a lower accessibility to supermarkets but greater accessibility to takeaways outlets. However, the evidence of the association between the environment and diet was inconsistent (Giskes *et al.* 2011).

Despite the complexity of the ways that the environment affects diet, physical activity and weight gain and the difficulties in assessing this relationship, the reviews agree that there is a need for studies to explore this area of research more extensively (Foresight report 2007; Kirk *et al.* 2010; Giskes *et al.* 2011).

1.4.1.7 Obesogenic medication

Several studies have reported the impact of drug treatments on the development of obesity (Schwartz *et al.* 2004; Leslie *et al.* 2007; McCloughen and Foster 2011). A review of 43 studies showed that medication used for chronic conditions can lead to a weight gain of 10kg at 52 weeks (Leslie *et al.* 2007). Medications known for their obesogenic effect are antipsychotics, antidepressants, lithium, valproate for the treatment of epilepsy, beta blockers for the management of CVD and insulin in Type 2 diabetes. The majority of these medications are the first line medications used for the treatment of the relevant medical conditions. More recently, a review by McCloughen and Foster (2011) showed that second generation antipsychotics like clozapine and olanzapine can lead to rapid weight gain followed by a plateau for several months and then with a weight gain again within one year.

The side effects of the obesogenic medications and especially of the psychotropic ones include increase of appetite by altering serotonin and dopamine levels and decrease of metabolic rate leading to weight gain (Virk *et al.* 2004). Thiazolidinediones that are used for the control of blood glucose in diabetes lead to weight gain by improving insulin sensitivity and promoting differentiation of fat cells through their effect on Peroxisome Proliferator-Activated Receptor gamma (PPAR-γ) (Mitri and Hamdy, 2009). Beta blockers may reduce cardiac response to exercise and decrease basal metabolic rate leading to less energy expenditure (Sharma *et al.* 2001). In addition patients may feel tired and exercise less. Antihistamines that block Histamine 1 receptors prevent the anorexigenic mechanism of histamine and increase appetite by reducing leptin's central activity (Ratliff *et al.* 2010). It has to be noted that weight gain as a side effect of the medication leads to a noncompliance of the patients to the drug treatment and subsequently to a relapse of the medical symptoms (Nihalani *et al.* 2011).

1.4.2 Determinants of obesity in adults with intellectual disabilities

The identification of determinants of obesity in adults with ID is relevant to the prevention of obesity and for the development of weight management interventions specialised to the needs of this population group (Dietz 2000; Melville *et al.* 2007).

1.4.2.1 Diet

Similar to the general population people with ID are susceptible to unhealthy dietary habits and have the same needs for a healthy balanced diet (Rimmer 1999). Robertson *et al.* (2000) examined the dietary habits of people with ID (n=500) and assessed the quality of their diet in different residential settings in UK. Data on food frequency were collected from the care staff and were compared with the criteria of Tameside and Glossop Health Needs Survey (1997) for a poor or fatty diet. The authors reported that only seven to eight per cent of the sample had a healthy balanced diet and 16% to 22% were consuming four helpings of fruit and vegetables per day. This was supported by a questionnaire survey carried out for adults with ID (n=250) living in family settings (125) and residential settings (125) in Ireland that also revealed a daily poor intake of fruit and vegetables (> 4 helpings, 42.4%) but showed a very good compliance with ideal levels of sugar and fat consumption when compared with the general population (72.5% vs 17%, respectively) (McGuire *et al.* 2007).

All the above studies report a very low prevalence of alcohol consumption. Robertson *et al.*(2000) showed that 45 to 96% of the participants were non-alcohol drinkers and Bertoli *et al.*(2006) reported lower consumption of alcohol in adults with ID than in adults without ID living in Italy (Milan)($p<0.05$). McGuire *et al.* (2007) reported occasional alcohol consumption equal to 24.2%.

Very few studies have examined the association between unhealthy dietary habits and the risk of developing obesity in adults with ID. Draheim *et al.*(2002) assessed the dietary habits of 145 participants with mild ID living in the community in USA and found that participants with lower dietary fat intakes (≤ 35% of total intake) were at lower risk of developing abdominal obesity (OR-95%, CI=0.31(0.12-0.79). However, Cunningham *et al.* (1990) in a sample of 332 individuals with ID living in institution in Ireland and Braunschweig *et al.* (2004) in a sample of 48 individuals with Down syndrome living in the community in Chicago (USA) reported no significant associations between dietary intakes and BMI or waist circumference.

It is difficult to review the evidence and make an overall estimation of the dietary habits of people with ID and make comparisons with the evidence for people without ID due to the small number of studies, the methodological limitations (e.g. sample size) and differences among the studies. For example Draheim *et al.* (2002) assessed the nutritional status of the participants by using the “Block Screening Questionnaire for Fat Intake” but Cunningham *et al.* (1990) used semi-weighing techniques over four consecutive days. In addition, data were based on reports made by the participants with assistance from the carers who support them or on entirely second hand reporting made by the carers. This method can affect the reliability of assessing health behaviours of people with ID

(McGuire *et al.* 2007). Other differences among the studies are related to the samples and the different locations e.g. adults living in community settings for Braunschweig *et al.* (2004) and Druheim *et al.* (2002) but children and adults living in institutions for Cunningham *et al.* (1990). Some data come from UK and Ireland and others from USA.

1.4.2.2 Physical activity

There is a greater prevalence of inactivity and sedentary lifestyles in adults with ID than in people with no ID (Havercamp *et al.* 2004; Bartlo and Klein 2011). Robertson *et al.* (2000) defined inactivity based on the Healthy Survey for England (1993) as doing activity of moderate or vigorous intensity less than 12 times in 4 weeks. When the study compared activity levels with the general population it showed that men and women with ID living in village communities are more likely to lead inactive lifestyles than men and women without ID (83% and 97% vs. 53% and 64%, respectively, $p<0.001$). This was supported by another population study, examining data from people who are able to be physically active, and also showed that people with ID are less physically active than people with no ID in all age groups (HSE1998) (Emerson *et al.* 2005).

Current guidelines for health improvement in the general population recommend 150 minutes of moderate intensity physical activity per week (NICE 2006, CMO 2011). It is recommended that this physical activity should be spread across the week by engaging in 30 minutes on 5 or more days each week (CMO 2011). A review of four studies assessing the physical activity of adults with ID in Australia, Canada and US showed that the proportion of study participants who meet current clinical guidelines ranges from 17.5% to 33% (Stanish *et al.* 2006). Some of the most common physical activities followed by adults with ID include low intensity walking, cycling, dancing, chores and work and Special Olympics. Messent *et al.* (1999) suggested that there is lack of choices that could empower adults with ID to follow the recommendations for a healthy physical activity pattern.

Finlayson *et al.* (2011) used an activity monitor called activPAL (PAL Technologies Ltd. UK) to assess actual levels and patterns of physical activity in community based adults with ID (aged 16 and over) living in Greater Glasgow. The study compared the findings with the recommended 10,000 steps per day (Tudor-Locke and Bassett 2004) and found that only 27% of the participants who were mainly public transport users were achieving the recommended amount of steps. Based on self-reported weight measurement, the rest of the participants (73%) who were not achieving the 10,000 steps were mainly overweight (p <0.05).

High levels of inactivity were also shown by Melville *et al.* (2011) that also took place in Glasgow. The study with the use of accelerometers showed that in a small sample of participants (n=45) the mean time spent at baseline in moderate to vigorous intensity was only 13 min per day. In addition, the participants spent a mean of 612 min per day sedentary activity.

Some of the predictors for low levels of physical activity in adults with ID as identified by Finlayson *et al.* (2009) include: faecal incontinence, epilepsy, immobility and older age. The study explained that these type physical conditions prevent adults with ID from water based activities and cycling but also affect environmental requirements such as needed assistance to perform activities. All these barriers have an impact on the confidence of these individuals to become more active. Finlayson *et al.* (2009); Messent *et al.* (1998) and Temple (2007) reported that lack of choice, lack of support to access and participate in activities and lack of day centre placements and daytime employment can also act as barriers for adults with ID to become more active.

There is no consistency in the methodologies used by all these studies. There is a variety of assessment techniques used e.g. direct measurements: accelerometers, pedometers, observation systems and indirect measurements: diaries questionnaires, there is a variety of definitions classifying healthy physical activity levels e.g. 10,000 steps, 30 minutes of moderate physical activity and a variety of measured outcomes e.g. percentage of inactivity, hours spent exercising or walking. In addition, Stanish *et al.* (2006) explained that most evidence on physical activity levels derive from studies that have focused on adults with mild to moderate ID, since people with profound ID frequently experience medical conditions that affect their ability to be physically active.

Regardless of the differences in methodology and the accuracy of the measurements, research consistently reports low levels of physical activity in adults with ID.

1.4.2.3 Gender

Contrary to the studies in the general population, studies in adults with ID show higher rates of obesity in women than in men. Comparisons of adults with ID with the general population show a higher prevalence of obesity among women with ID and a difference ranging from 18% to 30% but for the men the differences are much smaller ranging from 6% to 13% (Melville *et al.* 2007). A study on the prevalence of obesity in adults with ID in New Zealand showed that significantly more women with ID were obese (65.3%) than women without ID (30.2%) and significantly more men with ID (43.9%) were obese than men without ID (29.75%). The study also reported that more women with ID were in obesity Class II (35-39.99kg/m^2) and class III (≥40kg/m^2), than women without ID (25% and 18.7% vs 7.5% and 5.3%, respectively) (Stedman and Leland 2010).

The increased prevalence of obesity in women is also reported in comparisons within the populations with ID. Bhaumik *et al.* (2008) reported that women were three times more likely to be obese as men (OR 0.36; 95%CI 0.25-0.53 for men). This was supported by Melville *et al.* (2008) that reported that women were more likely to be obese than men with ID (OR 1.68, 95% CI 1.28-2.21; x^2= 29.6, p < 0.001). The study showed that the mean BMI of women with ID (28.8, range 12.3-59, SD 7.8) was significantly greater than the mean BMI of men with ID (26.7, range 12.6-49, SD 5.9) (p < 0.001). Higher obesity rates in women were also reported by Moran *et al.* (2005).

1.4.2.4 Age

Contrary to the findings of studies in the general population that show obesity prevalence increasing with age (Flegal *et al.* 2010; Rennie and Jebb 2005; Lobstein and Leach 2007), several studies in adults with ID show no significant associations between age and obesity (Melville *et al.* 2007). This was supported by other studies like Bhaumik *et al.* (2008) that did not find an association between obesity and age and Mevlille *et al.* (2008) that also did not find a significant correlation between age and BMI for women (r = 0.03, p= 0.61) or men (r = 0.02, p= 0.62).

Other studies like Emerson *et al.* (2005) reported that obesity in adults with ID is prevalent at a younger age. In more detail the study showed that when compared with men from the general population prevalence rates for obesity were lower among men with ID only within the 65-74 years age group ($p<0.05$) and comparisons with women in the general population showed prevalence rates for obesity higher among women with ID within 16-24 and 35-44 years age. However, Yamaki (2005) reports that obesity is an issue in people with ID at early adulthood and in later life.

1.4.2.5 Level of Intellectual Disabilities

Studies that have examined the association between levels of ID and prevalence of obesity consistently report that weight gain that leads to obesity is more common in individuals with mild ID. On the other hand, profound ID is associated with the risk of becoming underweight (Melville *et al.* 2007).

Robertson *et al.* (2000) assessed the relationship between level of ID and obesity in adults (n=540) living in village communities, residential campuses and dispersed housing. The study used the Adaptive Behavior Scale (Nihira *et al.*1993) to assess the abilities and skills of the person and the presence of additional physical and sensory impairments and used the Aberrant Behavior Checklist (Aman *et al.*1995) to provide a quantitative measure of the severity of challenging behaviour. The study reported that more able individuals were more likely to be obese ($r=0.1444$, $p<0.001$).

A bivariate and multivariate analysis of data in a sample of 1542 adults with ID also showed that most able and moderately able people with ID were at greater risk of becoming obese (odds ratio=2.0) (Emerson *et al.* 2005). This was supported by Bhaumik *et al.* (2008) who also identified mild ID as a risk for becoming obese ($p<0.0001$). Melville *et al.* (2008) reported that men and women with profound ID had a 52% and 71% lower risk, respectively than men and women with mild ID.

A study in Finland used different classification criteria and found that more adults with slight ID (IQ 35-70) (14.3%) were obese than those with serious ID (IQ<35) (7.8%) (Simila and Niskanen 1991). This was supported by Hove (2004) who also reported higher prevalence of obesity in people mild ID than those that have moderate or severe ID (26.6% vs. 14.5% vs. 10.6%, respectively). Adults with mild ID tend to reach the highest prevalence of obesity between 50-60 years of age in comparison with adults with severe ID (38.7% vs. 33.3%, respectively) (Moran *et al.* 2005).

It should be noted that these studies like most studies in ID have used different terms, definitions and diagnostic criteria for the level of ID. For example Simila *et al.* (1991) and Moran *et al.* (2005) used IQ levels to classify levels of ID but Robertson *et al.* (2000) used the Aberrant Behaviour Checklist. In addition, the prevalence of obesity was maybe underestimated since mild ID can be under diagnosed by health services (Hove 2004). None of the studies have proposed reasons for the direct relationship between mild ID and obesity but they have looked at other factors that are related to level of ID and may contribute to the development of obesity e.g. independence and living arrangements.

1.4.2.6 Environment - Living arrangements

A review of the evidence from studies that explored the environmental factors linked to obesity in adults with ID show a strong association between less restrictive environments and obesity (Rimmer and Yamaki 2006). Four more studies that were not included in this review have investigated this relationship in adults with ID who live in different residential settings.

Bryan *et al.* (2000) assessed the nutritional vulnerability of people with ID in the community by measuring weight changes after one year of discharge from institutions. The study showed that the level of overweight for males and females increased within one year by six per cent and five per cent, respectively. An extensive examination of the effect the environment has on people with ID showed that individuals who live in less restrictive settings are more likely to experience obesity (Robertson *et al*. 2000). In more detail, people with ID are more likely to be obese when they live in settings where the service user has a tenancy (odds ratio=2.95), less sophisticated procedures are in place for the support of the resident (odds ratio=2.66) and with less senior staff ratio (odds ratio=1.91).

Moran *et al*. (2005) defined the most restrictive environments community training homes and intermediate care facilities and the least restrictive environments as family homes, private boarding homes, supervised apartment living or residence in a private home. Similar to other studies a higher prevalence of obesity was seen in adults with ID (30 to 40 years old) living in the least restrictive environments than the most restrictive environments (33% vs. 12.8%, respectively, $p<0.05$). This work was supported by Bhaumik *et al*. (2008) who also showed that individuals who live independently or with family were at higher risk of becoming obese than those who live in residential care (odds ratio=3.28).

Proposed pathways of the environmental influence on the development of obesity include the impact of not living in a restrictive institution but living in the community where there is a great availability of food choices. People with ID, who live independently in the community with less support and with more staff who provide foods based on their food choices, are not prepared for the implications of the lifestyle patterns they adopt (Rimmer and Yamaki 2006). Individuals with ID due to cognitive impairments may not be able to foresee the consequences of obesity (Smyth and Bell 2006) and they may have less health knowledge because they are excluded from education and health promotion strategies (Emerson and Baines 2010). In addition, depending on their level of ability, they may not be able to manage their own environment or benefit from education and health promotion strategies.

1.4.2.7 Genetic syndromes

Research has identified about 30 genetic disorders that have obesity as a clinical feature and are associated with ID, dysmorphic features and organ developmental abnormalities (Farooqi and S O'Rahilly 2005). Studies have suggested that the genes responsible for some forms of ID could also be responsible for the presence of severe obesity, with an early onset. In general, it is believed that these genes could act directly in the brain or in the periphery affecting food intake and energy metabolism (Delrue and Michaud 2004). The role of genetic syndromes in weight gain will be considered by describing the four genetic syndromes that are most commonly associated with obesity: Prader-willi syndrome, Bardet Biedl, Cohen syndrome and Down syndrome.

a) Prader-Willi syndrome

Prader–willi syndrome is a genetic disorder with a recongisable pattern of dysmorphic features and major neurologic, cognitive, endocrine and mental health problems. Prader–willi syndrome is rare syndrome that affects one in 22000 to 25000 births (McAllister *et al.* 2011). Progressive obesity starts at 1 to 6 years of age. Additional characteristics such as ID and uncontrolled hyperphagia contribute to morbid obesity. The syndrome is also accompanied by abnormal regulation of body fat and metabolism. Growth hormone treatment in children and adults could be used to decrease fat mass, increase lean body mass and increase mobility (Sode-Carlsen *et al.* 2011). Prevention and treatment of obesity in individuals with Prader–Willi syndrome include mainly vigorous control of the food environment, rigorous supervision, a low calorie, well balanced diet and regular exercise (Goldstone *et al.* 2008).

b) Bardet Biedl

Bardet Biedl syndrome is an autosomal recessive condition characterized by neurological, problems speech and language deficits, central obesity, occasionally diabetes mellitus and many other clinical features (Beales *et al.* 1999). It is a very rare syndrome with a low prevalence estimated as one in 125000 to one in 160000 in Europe (Janssen *et al.* 2011). The progression of truncal obesity usually starts in the first year of life. A possible etiology for the development of obesity in the Bardet Biedl syndrome is the dysfunction of the cilia of the hypothalamic neurons in the brain affecting the regulation of hunger.

Treatment of obesity in Bardet Biedl syndrome usually follows the same principles as for the Prader-Willi syndrome.

c) **Cohen syndrome**

Cohen syndrome is a very rare genetic disorder. Studies suggest that obesity in Cohen syndrome is overstated (Stein *et al.* 2011). Usually half of these individuals are overweight but only one fifth are obese. The type of obesity seen in this population group is mainly truncal distribution of fat and not generalized obesity (Chandler *et al.* 2003). The genetic associations between obesity and Cohen syndrome are not yet understood.

d) **Down syndrome**

Down syndrome also called Trisomy 21 is the most commonly recognized genetic cause of ID that affects the cognitive and the physical development of an individual. Data from studies, of varying levels of quality, show that individuals with Down syndrome are at higher risk of becoming overweight or obese (Haveman *et al.* 2010; Melville *et al.* 2007). More details are provided below of the findings from studies that examined the prevalence of obesity in adults with Down syndrome compared with other populations of adults with ID but without Down syndrome or compared with adults without ID.

Bhaumik *et al.* (2008) in sample of 598 adults with ID who were obese or overweight indentified 125 people with Down syndrome. Comparisons within the sample of adults with ID showed that 50% of the adults with Down syndrome were classified as obese. Down syndrome was identified as a risk factor for obesity (OR 2.30; 95%CI 1.40–3.80). The same increased risk was found when compared with data from the general population (SMR 1.39; 95% CI 1.06–1.82). This was supported by Robertson *et al.* (2000) who also showed that in a sample of 500 participants with ID living in UK, Down syndrome was found as a risk factor for becoming obese (odds ratio=2.54).

In a smaller sample of people with Down syndrome classified as obese or overweight (58 out of 298 people with Down syndrome), Melville *et al.* (2008)

reported that both males and females were significantly more likely to be obese or overweight ($p<0.05$). In a previous study, Melville *et al.* (2005) examined obesity in a sample of 247 adults with ID and Down syndrome (mean age 37.24 years), paired with a control group of individuals with ID but no Down syndrome. The paired groups were matched for age, gender and accommodation type. The study showed that women with Down syndrome were more likely to be overweight or obese (odds ratio=2.17) than their matched pairs but men more likely to be overweight and less likely to be obese than their matched pairs (odds ratio=0.85).

In a sample of adults with ID, Moran *et al.* (2005) reported that 15.6% out of 58 adults (20 to 30 years old) with Down syndrome were obese. The same study reported an elevated risk for obesity for adults with Down syndrome with a steady increase of proportion in obesity in each consecutive decade. Similarly, Henderson *et al.* (2007) in an equally small sample of 64 adults with Down syndrome (mean age 43.8) in UK 20% were found to have a BMI greater than $35kg/m^2$

The reason for the association between Down syndrome and obesity are not very clear but proposed mechanisms include alterations in energy balance, decreased resting metabolic rate, hypotonicity leading to hypoactivity and defects in the secretion of leptin (Allison *et al.* 1995; Luke *et al.* 1994; Mendoca *et al.* 2010; Proto *et al.* 2007).

1.4.2.8 Obesogenic medication

A cross sectional study that collected data on 500 participants from 17 services in UK reported an overuse of psychotropic medication in adults with ID for the treatment of “challenging behaviour” and showed a 27% to 56% use of antipsychotics in two different residential settings (Robertson *et al.* 2000). The study reported that a higher BMI was a predictor for regular receipt of antipsychotics and antidepressants. Bokszanska *et al.* (2003) assessed the effectiveness of two atypical antipsychotics that are commonly used in adults with ID in a sample of 50 adults with ID and showed that both medication can be very effective in treating symptoms but can also cause weight gain within one year of administration (Bokszanska *et al*. 2003). However, Faulkner *et al*. (2009) assessed the impact of an inpatient psychiatric environment on the prevalence obesity suggested that although psychotropic medications have an effect on obesity other factors like access to unhealthy diet and decreased physical activity in settings like these can be greater contributing factors than a drug treatment itself.

Summary

The prevalence of obesity in adults with ID is high and according to most studies it is higher than in the general population. Some of the identified determinants for obesity in adults with ID are the same as in adults without ID including unhealthy dietary habits and sedentary behaviours, female gender and the use of obesogenic medication. Other factors like genetic syndromes, mild ID and type of obesogenic environment such as living in less restrictive environments are strongly related to the socio-clinical characteristics of people with ID.

1.5 Health consequences associated with obesity

Obesity can have a negative impact on health outcomes and on health care resources because it is associated with a range of comorbidities (Dixon 2010). According to SIGN (2010) obesity can increase the risk of a variety of health conditions including asthma, some forms of cancer, cardiovascular disease, dementia, depression, diabetes, fertility, pregnancy gastroesophagael reflex, kidney and liver disease, pancreatitis and mortality. However, this section will describe the most predominant health consequences associated with obesity including Type 2 diabetes, cardiovascular disease, cancer, musculoskeletal disorders, respiratory diseases , depression and mortality (Loveman *et al*. 2011) (see table 1.2).

Table 1.2: Health risks associated with obesity

Greatly increased risk (relative risk>3)[a]	**Moderately increased risk** (relative risk 2-3)[a]	**Slightly increased risk** (relative risk 1-2)[a]
Type 2 diabetes	Coronary heart disease	Cancer (breast cancer in postmenopausal women, endometrial cancer, colon cancer)
Gallbladder disease	Hypertension	Reproductive hormone abnormalities
Dyslipidaemia	Osteoarthritis (knees)	Polycystic ovary syndrome
Insulin resistance	Hyperuricemia and gout	Impaired fertility
Breathlessness		Low back pain due to obesity
Sleep apnoea		Increased risk of anaesthesia complication
		Fetal defects associated with maternal obesity

[a] relative risk approximate

Source: Adapted from Loveman *et al.* (2011) The clinical effectiveness and cost effectiveness of long-term weight management schemes for adults: a systematic review. Health Technology Assessment 2011; Vol. 15: No. 2

1.5.1 Type 2 Diabetes

There are two types of diabetes mellitus: Type 1 and Type 2 (Diabetes UK 2010). Diabetes has been defined as a metabolic disorder that results from a defect in insulin secretion; insulin action or both (Nield *et al.* 2008). In Type 1 diabetes the body's immune system attacks the beta cells in the pancreas that produce insulin and in Type 2 the body has developed an abnormal resistance and does not produce enough insulin or the body cannot use the insulin effectively (Deshpande *et al.* 2008)

Diabetes was estimated to have a global prevalence of 285 million in 2010 and expected to affect 439 million people by 2030 (Shaw *et al.* 2010). It is estimated that 90% to 95% of the diabetes cases are Type 2 diabetes (Diabetes UK 2010; Deshpande *et al.* 2008). Untreated diabetes leads to long term complications such as retinopathy, nephropathy and neuropathy due to chronic elevated levels of plasma glucose (Nield *et al.* 2008).

A study in Denmark assessed the health profile of 868 people with ID registered with 71 GP practices (Straetmans *et al.* 2007). Comparisons with a matched sample without ID (1:5) showed that per 1000 people more people with ID (n=112) were diagnosed with diabetes than people without ID (n=62). However, there was no clarification on type of diabetes being diagnosed. There are some small population studies on the prevalence of type 2 diabetes in adults with Prader Willi syndrome in UK (Butler *et al.* 2002) but there is no extensive data on diabetes and adults with ID in UK (Emerson 2010).

Many studies have found a strong association between obesity and Type 2 diabetes (Colditz *et al.* 1995; Mokdad *et al.* 2003; Koh-Banerjee *et al.* 2004). The pathophysiology that connects obesity and the development of Type 2 diabetes includes the inability of β cells to compensate for the chronic glucose excess; increased glucagon secretion and reduced incretin response; hypoadiponectinaemia and inflammation of the adipose tissue, increased endogenous glucose production and development of peripheral insulin resistance (Pi-Sunyer 2000; Nolan *et al.* 2011). Therefore, studies have focused on the impact of weight management on Type 2 diabetes and have shown that weight loss interventions with resulting weight loss of 10% can lead to a 25% reduction in fasting plasma glucose (Anderson *et al.* 2003).

1.5.2 Cardiovascular diseases

Coronary heart disease (CHD) and stroke are the leading conditions in the global burden of cardiovascular diseases (CVD) (Caterson *et al.* 2004). Both conditions are the leading causes of death in high income and low income countries being responsible for more than a fifth of all deaths worldwide in 2001 (Lopez *et al.* 2006). The prevalence of CVD is higher in adults with ID than in the general population, especially in individuals with mild ID living in the community (Draheim 2006).

It is estimated that for every 2 kg/m^2 increase in BMI there is a 14% increase in relative risk for CHD (York *et al*. 2004). There is a pathophysiological association between CHD and obesity (National Task Force on the Prevention and Treatment of Obesity 2000). Accumulation of excessive adipose tissue due to obesity causes adaptations and alterations in the structure of the heart. This is followed by an increased blood and plasma volume and increased cardiac output leading to the abnormal function of the heart, hypertension and the development of heart failure (Poirier *et al*. 2006). In addition, adipose tissue is an important source of inflammatory factors called adipocytokines and adipokines known for playing an important role in the atherosclerotic process and subsequently leading to CVD (Lyon *et al*. 2003; Marinou *et al*. 2010).

A meta-analysis of 25 prospective studies with two million participants showed an association between obesity and an increasing risk of ischemic stroke (Strazzullo *et al*. 2010). For every 2 kg/m^2 increase in BMI there is a 4% increase in relative risk for stroke (York *et al*. 2004). This is attributed to hypertension, to the complications of Type 2 diabetes such as the thickening of the vascular walls affecting the blood flow and to the effect of cytokines, secreted by the adipose tissue, on insulin resistance and inflammation of the vascular wall (Lawes *et al*. 2008; Kissela *et al*. 2005; You *et al*. 2004.).

Current studies and clinical guidelines for the reduction of the risk of cardiovascular diseases recommend weight reduction in individuals with obesity (Lavie *et al*. 2009; SIGN 2007; NICE 2010). A small weight loss of 5-10% may lead to 0.5% reduction in HbA1c, a 5mmHg decrease in systolic blood pressure, a 5mg/dL increase in HDL cholesterol and a 40mg/dL decrease in triglycerides (Wing *et al*. 2011). However, the likelihood to reach these benefits increase when weight loss is greater than 10%. For example Wing et al. (2011) showed that the odds ratio to reach 0.5% reduction in HbA1c increased from 3.52 to 5.44 and to reach a 5mmHg decrease in systolic blood pressure increased from 1.56 to 2.29. According to Tzotzas *et al*. (2010) there is need for substantial weight loss exceeding the 10% of initial weight to succeed reduction in conditional cardiovascular risk factors including on fibrinogen levels and C-Reactive Protein.

1.5.3 Cancer

Excess visceral adiposity is believed to increase risk of a variety of cancers (Thun *et al.* 2010). A 5 kg/m^2 increase in BMI is associated with approximately a 10 per cent increase in the mortality for all cancers (Teucher *et al.* 2010). The "million woman study" showed that five per cent of all cancers among post-menopausal women in UK are associated with excess body weight (Reeves *et al.* 2007). Excess body weight increases the risk for a variety of malignancies including endometrial, post-menopausal breast, oesophageal and colon/rectum cancer (Dossus *et al.* 2010; Healy *et al.* 2010; WHO 2003).

It has been estimated that the incidence of cancer in the general population will increase by 50% by the year 2020 (WHO 2002). There is no extensive epidemiological data on the incidence of cancer in adults with ID, with estimations appearing lower than the general population and varying from 5% to 18% (O'Regan and Drummond 2008). However, the increased life expectancy in adults with ID will change the prevalence of age related health risks such as cancer (Tuffrey-Wijne *et al.* 2009). There is also poor examination of the incident of cancer and the link with specific factors in adults with ID but some studies suggest that cervical cancer, breast cancer and colorectal cancer could be potentially linked with obesity (Hogg and Tuffrey-Wijne 2008).

Proposed patho-physiological explanations and biological mechanisms for the link between obesity and cancer include insulin resistance, sex steroids, adipokines, obesity related inflammatory markers and oxidative stress (Renehan *et al.* 2008; Key *et al.* 2003). Research shows that moderate physical activity (Friedendreich *et al.* 2002), a healthy balanced diet (Gonzalez and Riboli, 2010) and weight control (Parker and Folsom 2003; Wahnefried *et al.* 2008) could be beneficial in the prevention of cancer.

1.5.4 Musculoskeletal disorders

The prevalence of musculoskeletal conditions can be affected by lifestyle factors such as physical inactivity and obesity (WHO 2003). According to Cooper *et al.* (2000) the risk for knee osteoarthritis increases with BMI. Similarly, in a ten year cohort study of 1675 participants in Norway, high BMI (≥30kg/m^2) was significantly associated with knee and hand osteoarthritis (Grotle *et al.* 2008). Excess weight and obesity have a mechanical effect on joint destruction but also a systemic effect due to alterations of lipid and glucose metabolism that could contribute to the development of osteoarthritis (Pottie *et al.* 2006). A five per cent weight loss within a 20 week period in individuals with obesity and osteoarthritis can lead to symptomatic relief (Cristensen *et al.* 2007).

1.5.5 Respiratory diseases

Obesity increases the risk for the development of respiratory diseases including obstructive sleep apnoea, obesity-hyperventilation syndrome, asthma, pneumonia and chronic obstructive pulmonary disease (Murugan and Sharma *et al.* 2008). Increased accumulation of adipose tissue in and around the ribs, diaphragm and abdominal area reduces factional residual capacity and causes or exacerbates pulmonary dysfunction (Salome *et al.* 2010). Studies have shown that weight loss can improve symptomatic control of chronic respiratory diseases (Poulain *et al.* 2006).

1.5.6 Depression

Several studies have confirmed the link between obesity and depression (Faith *et al.* 2002; Luppino *et al.*2010; Zhao *et al.* 2011) but others do not (Atlantis and Baker 2008; Gariepy *et al.* 2010). According to a review of 25 studies by Faith *et al.* (2011), there is a better evidence base supporting the “obesity to depression” pathway than the “depression to obesity” pathway. This means that obesity increases the risk of developing depression (odds ratio range 1.0 to 2.0) but being depressed may not increase the risk of becoming obese. Markovitz and Friedman (2008) proposed the following three mechanisms that explain the reciprocal relationship between these two health conditions: behavioural (e.g. repeated dieting), cognitive (e.g. body image dissatisfaction) and social (e.g. stigma).

Depression has been also linked with higher levels of attrition in weight loss programmes (Moroshko *et al.* 2011). However other studies report that this is not the case (Ludman *et al.* 2010) and weight loss after weight management in adults with obesity and depression can lead to a decrease of symptoms of depression (Dixon *et al.* 2003; Simon *et al.* 2010; Linde *et al.* 2011).

1.5.7 Mortality

A review of 26 observational studies examined the relationship between BMI and mortality of all causes, CHD, CVD and cancer (McGee *et al.* 2005). The study showed that there was little increase in risk for all-cause mortality among the overweight group but they confirmed that obesity is a significant risk factor for overall mortality caused by CHD and CVD. In more detail comparisons with individuals from the lowest BMI category, showed that individuals with obesity (BMI≥30kg/m^2) have a relative risk of death, mortality caused by CHD and cardiovascular disease (CVD) of 1.22, 1.57 and 1.48, respectively. However, the summary relative risk among the obese participants for death from cancer was 1.07.

The same patterns in mortality were reported by Whitlock *et al.* (2009), a study that analysed the association between BMI and mortality in 57 prospective studies with a total sample of 894 576 participants in Europe, Israel, US, Australia and Japan. The study showed that mortality was lowest at about 22·5–25 kg/m^2 and a 5kg/m^2 increase in BMI was associated with a 30% higher overall mortality (hazard ratio per 5 kg/m^2 [HR] 1·29 [95% CI 1·27–1·32]). In more detail, at 30–35 kg/m^2 median survival was reduced by two-four years and at 40-45 kg/m^2 it was reduced by 8–10 years.

According to Patja *et al.* (2000) reporting findings from a 35 year cohort study, there is no difference in mortality rates between adults with ID and adults without ID. However, this is one of the very few large population based mortality studies on people with ID (Maulik *et al.* 2011). Other studies report that adults with ID have a shorter life expectancy than the general population, with all-cause mortality rates in adults with moderate to severe ID three times higher than in adults with ID (Tyrer and McGrother 2009; Emerson 2010). The most common identified causes of mortality include congenital malformations, diseases of the nervous system or sense organs (Tyrer and McGrother 2009). In addition people with ID are at higher risk of mortality related to respiratory infections, diseases of the genitourinary system and digestive system, cerebrovascular disease, mental disorders and accidental deaths (Tyrer and McGrother 2009).

Obesity has also been identified as a high risk predictor for individuals with Down syndrome (Yang *et al.* 2002). However, the lack of extensive epidemiological data on mortality make it difficult to identify strong links to obesity related health risks and mortality in this population group.

Summary

Several evidence in adults without ID have shown that obesity is associated with an increasing risk of a variety of co-morbidities and mortality. However, there is limited evidence examining the links between obesity in adults with ID and associated health risks, especially mortality. In general, studies in adults without ID report that weight loss interventions can have positive health effects on obesity related co-morbidities.

1.6 Weight management interventions for adults without intellectual disabilities

There are many different types of weight management interventions that focus on promoting changes in the lifestyle of an individual with obesity. This section will describe some of the most common types of weight management interventions but will not describe pharmacological, surgical and internet based interventions, even though they have shown to be effective in adults without ID, they have not been assessed in research for adults with ID(Hamilton *et al.* 2007). Therefore, this section will describe four types of interventions that have been examined and assessed in adults with ID:

- Dietary
- Physical activity
- Psychological/behavioural
- Multi-component

1.6.1 Dietary interventions

Dietary modifications have been the foundation of most weight loss interventions for the management of obesity for years (Laddu *et al.* 2011). The following section provides a description of the different types of dietary interventions.

1.6.1.1 Energy deficit diets

The core method of estimating individual energy requirements and the energy deficit per day that is needed to lead to weight loss have changed over the years (Frost *et al.* 2007). An important step in the method of energy prescription was introduced by James and Lean (1986) when they reported that energy deficit diets should be based on individual basal metabolic rates using specific formulas and not on under reported dietary histories recorded by the individuals with obesity. It was also recommended that energy deficit diets should aim for only 600kcal deficit per day (James and Lean 1986). This realistic amount of energy deficit can lead to a loss of adipose tissue and sustained weight loss of 0.5kg per week, contributing to improved compliance from individuals with obesity. For example, during a small negative energy balance, an individual is more able to control the physiological responses to appetite for the subsequent restoration of energy balance (Frost 2007; Wynne 2005).

The theory of James and Lean (1986) was tested by Frost *et al.* (1991) showing that a significantly greater mean weight loss 5.0±2.6kg at 12 weeks and greater compliance in obese individuals after following an energy deficit diet (closer to 500kcal), based on the energy requirements of the participants than based on diet histories (mean weight loss 2.9±3.5kg). This was further tested by Leslie *et al.* (2002), where a 600kcal energy deficit diet was compared to a generalised low calorie diet, where the daily deficit could be in excess of 1800kcal per day. This study showed that attrition was lower in the 600kcal group, supporting its value as the preferred dietary approach for weight loss.

However, current systematic reviews and meta-analyses have examined the effectiveness of energy deficit diets, with different amounts of energy restriction and not focusing specifically on 600kcal energy deficit diets. For example Avenell *et al.* (2004) included 600kcal energy deficit diets as part of "low fat diets" and reported that these types of diet were associated with a weight loss of –5.31 kg (95% CI –5.86 to –4.77 kg) at 12 months. This level of weight loss was also associated with the prevention of health risks including Type 2 diabetes, and hypertension. A systematic review of 52 weight loss interventions by Weinheimer *et al.*(2010) showed that 75% of the overweight or obese participants that followed an energy restriction diet, 60% of which were prescribed <500 kcal/day energy deficit, had an absolute loss of body weight of between 5 and 10kg.

1.6.1.2 Very low calorie diet

A very low calorie diet (VLCD) usually provides less than 800 kcal per day or less than 50% of an individual's predicted resting energy expenditure (Tsai and Wadden 2006; Atkinson 1989). The composition of VLCD includes 0.8-1.5 grams of high quality protein per day, and the recommended allowances of minerals, vitamins, trace elements and essential fatty acids (Mustajoki and Pekkarinen 2001). VLCD can lead to several metabolic and physiological changes including a weight loss of 1.5kg per week for individuals with a BMI 30-35kg/m^2 and weight loss of 1.5-2.5kg per week for individuals with a BMI >40 kg/m^2 (Mustajoki and Pekkarinen 2001).

This type of diet is usually prescribed to individuals with a BMI ≥ 30kg/m^2 ,is not recommended for long term use, and is known for being effective in short-term weight loss but not in long term weight loss (Baker *et al.* 2009; Laddu *et al.* 2011). A meta-analysis of the findings of six RCTs showed that VLCD (mean weight loss of 16.1 ± 1.6%) led to a greater weight loss than low calorie diets (LCD) (800 to 1800 kcal per day) (mean weight loss of 9.7 ± 2.4%) at 12.7 ± 6.4 weeks (mean prescription period) (mean difference of 6.4 ± 2.7%, P= 0.0001) (Tsai and Wadden 2006). However, follow up measurements ranging from one to five years showed that participants who followed VLCD and LCD regained 62% and 41% of lost weight, respectively.

Avenell *et al.* (2004) included only three RCTs that compared VLCD (<1000 kcal/day) with LCD (1000 – 1600 kcal/day) and reported no significant difference in effectiveness for weight loss using VLCD. However, Avenell *et al.* (2004) examined the results for long term weight loss only, reporting that VLCD led to WMD weight change at 12 months of –0.15 kg (95% CI= –2.73 to 2.43 kg) and at 18 months of –1.13 kg (95% CI=-5.32 to 3.06 kg). Only one small RCT (n=38), showed that VLCD produce greatest weight loss at 12 months than any other type of diet when compared with no treatment (mean weight change= –13.40 kg, 95% CI= –18.43 to –8.37 kg).

1.6.1.3 Dietary composition

Weight management interventions have also focused on the effectiveness of dietary interventions based on their macronutrient composition, especially for low carbohydrate/ high protein diets versus low fat diets (usually<25% of energy) (Schoeller *et al.* 2005; Laddu *et al.* 2011). Several studies agree that low carbohydrate diets can have a greater effect on weight loss at six months than low fat diets but not at 12 months (Nordmann *et al.* 2006; Hession *et al.* 2008). Proposed mechanisms for low carbohydrate diets and weight loss include the high content of protein promoting satiety and the consumption of energy due to the process of gluconeogenesis (Dubnov-Raz and Berry 2008).

A meta-analysis by Nordmann *et al.* (2006) of five RCTs examined the difference in weight loss between low carbohydrate diets (allowing a maximum intake of 60 g of carbohydrates per day) without energy intake restriction and low fat diets (allowing a maximum of 30% of the daily energy intake from fat) with energy intake restriction in individuals with a BMI ≥25kg/m^2. The study reported that participants from the low carbohydrate group lost more weight at six months than the low fat group (WMD= −4.3 kg, 95% CI= −5.6 to −3.0). However, there was no significant difference between the two groups at 12 months for the three trials that reported 12 month follow up measurements. Meta-analysis of the lipid values obtained from intention to treat data showed that Low Density Lipoprotein (LDL) levels decreased more in individuals from the low-fat diets group, but High Density Lipoprotein (HDL) values increased more in individuals from the low-carbohydrate diet groups at six months. Nordmann *et al.* (2006) reported large dropout rates for both diet groups at 12 months but not significantly different (31% to 48% for the low-carbohydrate diet vs. 37% to 50% for the low-fat diet).

The findings of Nordmann *et al.* (2006) were supported by another systematic review and meta-analysis of 13 RCTs that compared low carbohydrate diets (including high protein (HP) /ketogenic diets, ≤ 40–60 g carbohydrate/d) to low fat diets (30% or less daily energy from dietary fat) (Hession *et al.* 2008). Hession *et al.* (2008) reported greater weight loss for low carbohydrate diets at six months than low fat diets. However the difference decreases at 12 months. The meta-analysis found a WMD in weight change equal to -4.02 kg in favour of the LC/HP group at six months ($P < 0.00001$) and a WMD in weight change equal to -1.05 kg ($P < 0.05$) only at 12 months. However, the low fat diets were more effective in reducing total cholesterol and LDL than low carbohydrate diets at 6 months. Hession *et al.* (2008) found that there was a higher attrition rate for the low fat diets than the low carbohydrate diets, suggesting a preference of the participants for the latter at six months.

Both Nordmann *et al.* (2006) and Hession *et al.* (2008) reported the short term benefits of low carbohydrate diets. However, Crowe (2005) highlighted that there is a limited evidence base for the long term (≥12 months) efficacy of low carbohydrate diets and for the long term side effects that these diets could have in individuals “at risk” (e.g. individuals with elevated LDL-cholesterol, nutritional deficiencies or renal disease).

Another diet that has been assessed in relation to the effect it has on weight loss is the Mediterranean diet, a diet mainly seen in countries surrounding the Mediterranean basin. It is difficult to define the exact composition of the Mediterranean diet, but the main pattern of the diet initially formed and described in the 1960s includes high consumption of fruit, vegetables, legumes, nuts and seeds, olive oil, fish, moderate consumption of dairy foods, and low consumption of red and processed meat (Trichopoulou and Lagiou, 1997; Buckland *et al.* 2008). In contrast to the low fat diets (usually<25% of energy), the fat content of the Mediterranean diet is usually higher (30-40% of energy). However, a recent meta-analysis of 16 RCTs comparing the Mediterranean diet with a control group (seven out of 16 were low fat diets), reported that overweight and obese participants in the Mediterranean diet group lost more weight than the control groups (Esposito *et al.* 2011). The mean weight loss increased when the Mediterranean diet included an energy restriction component (1200 to 1800kcal diets) (-3.88 kg) and recommended increased physical activity (-4.01 kg).

It has to be noted that a RCT by Sacks *et al.* (2009) after allocating overweight participants (n=811) to four diet groups (two diets low-fat, two high-fat, two average-protein, two high-protein, with a dose–response test of carbohydrate intake from 35 to 65% of energy and a 750kcal energy deficit) showed that the food composition of the diet appeared to have a little effect on weight loss at six months as long the diet has an energy deficit. The diets had the same effect on weight maintenance at two years follow up.

1.6.1.4 Low glycaemic Index diets

Diets prescribed for the treatment of obesity have been also classified as low or high glycaemic index (GI) diets based on the total glycaemic load values of the menu (Pawlak *et al.* 2003). Foods with a low GI could play an important role in weight loss because they promote a slow release of glucose in the bloodstream with a subsequent decreased stimulation of insulin (Brand Miller *et al.* 2002). The slow insulin response leads to a less quick hunger response and less overeating than a fast insulin response caused by high GI diet (Ludwig 2002; Brand Miller *et al.* 2009). It has been suggested that low GI foods prevent overeating also by increasing satiety (Esfahani *et al.* 2009).

A meta-analysis of four RCTs by Thomas *et al.* (2009) showed that weight loss was significantly greater in obese or overweight participants receiving the low GI advice compared with those receiving the comparison diet (high GI diets, energy restricted diets) (duration of intervention: five weeks to six months) (WMD for body mass: -1.1 kg, 95% CI= -2.0 to -0.2, $P < 0.05$). However, a recent review of 20 studies reported that even though there is some evidence to support that low GI diets are more effective than other dietary interventions (low fat, high GI, energy restricted diets) in weight loss, there is a need for more consistent findings from a better quality of studies (Esfahani *et al.* 2011).

1.6.1.5 Commercial and Primary care weight management

The number of individuals with obesity that enrol in commercial weight management programs has increased but the evidence supporting the research behind these programs and the effectiveness in short and long term weight loss is minimal (Hamilton and Greenway 2004; Laddu *et al*. 2011). A systematic review of commercial programs in the United States (eDiets.com, Health Management Resources, Take Off Pounds Sensibly, OPTIFAST, and Weight Watchers) showed that there is limited evidence base evaluating the effectiveness of these programmes for weight loss (Tsai and Wadden 2005). The systematic review also reported that this type of weight management was associated with high costs for three months programme (reaching $2000 for "Optifast"), high attrition rates and weight regain within one to two years.

A recent RCT by Jolly *et al*. (2011) found that commercial weight management programmes are more clinically effective and cost effective when compared with primary care weight management services. Overweight and obese men and women (n=740) were randomly allocated to one of the following 12 week programs: Weight Watchers, Slimming World, Rosemary Conley, the Size Down programme, general practice and pharmacy programs, and 12 free sessions at a local authority run leisure centre (comparator). The study showed that all of the programs lead to a significant weight loss at the end of the intervention (three months), with some programmes like Weight Watchers leading a clinically significant weight loss. In addition, all the programs lead to a significant weight loss at 12 months apart from the primary care groups (general practice and pharmacy). The greatest weight loss at three months (4.4kg; SD=4.3) was reported for Weight Watchers, a programme delivered via group sessions and using a food point system. However, the Weight Watchers had a drop out of 20.7% that was not thoroughly explained and the results included a high proportion, 39.7% of self –reported weights. The estimated costs for each participant ranged from the lowest value for commercial programmes (£71.37, Slimming world) to the highest value for general practice equal to £112.73 per participant.

Very few primary care weight management services in the UK have published evaluations in practice, with “The Counterweight Programme” reporting a mean weight loss of 3.0kg (95% CI = −3.5 to −2.4 kg) at 12 months (Ross *et al.* 2008), and the Glasgow and Clyde weight management service reporting that 35% of the patients losing more than 5kg at 3 months (Morrison *et al.* 2012). However, these studies should be seen as reviews of service outcomes and not as studies that follow the principles of RCTs.

Finally, other commercial weight management programs that have started to evolve aiming to face the cost barriers surrounding the face to face weight management and become more relevant to the new lifestyles are the web-based weight management programs (Arem and Irwin 2011). However there is insufficient evidence to support the effectiveness of web-based interventions for weight loss in obesity (Kodama *et al.* 2011).

1.6.2 Physical activity interventions

Physical activity can play an important role in obesity management because it can generate a negative energy balance and promote weight loss (Donnelly *et al.* 2009).

1.6.2.1 Effectiveness

Several meta-analyses and systematic reviews of weight management interventions agree that physical activity can lead to weight loss but the effectiveness increases when combined with a dietary intervention (McTigue *et al.* 2003; Avenell *et al.* 2004; Franz *et al.* 2007; Schaar *et al.* 2010; Weinheimer *et al.* 2010).

A recent meta-analysis of 13 reviews of RCTs reported that single component interventions such as diet or physical activity interventions can be effective and lead to weight loss (Schaar *et al.* 2010). However, dietary interventions have a significantly greater effect on weight loss than physical activity interventions but a combination of both is a better treatment to induce weight loss especially during the first weeks of the intervention. For example Avenell *et al.* (2004), one of the included reviews in Schaar *et al.* (2010), reported that the addition of a physical activity intervention to diet led to an additional weight change of -1.95kg (95% CI= –3.22 to –0.68 kg) at 12 months.

A systematic review of 51 RCTs by Franz *et al.* (2007) identified six studies that included physical activity as a weight loss intervention. According to the findings physical activity interventions led to a mean weight loss of 2.4kg at six months and a mean weight loss of 1.0kg at 24 months. However, the combination of diet and physical activity intervention led to a weight loss equal to 7.9kg at six months. Franz *et al.* (2007) also conducted a meta-analysis of four RCTs and showed a significant effect size estimate for physical activity interventions only at 12 months, resulting in about 1.9±3.6kg more weight loss for the physical activity groups than the participants that received advice alone.

The systematic review and meta-analysis conducted for NICE (2006) and using data from Pritchard *et al.* (1997), Wood *et al.* (1988) and Anderssen *et al.* (1996) reported that physical activity interventions can lead to a summary weight loss of 3.09kg (95% CI=-4.00 to –2.18) at 12 months when compared with no treatment. The physical activity intervention was defined as a minimum of 30 minutes three times a week. However, NICE (2006) found that physical activity combined with a 600kcal/deficit or low fat diet can lead to a median weight loss of -5.60 kg (range= –5.10 kg to –8.70 kg) at 12 months when compared with diet alone –4.10 kg (range= –4.00 kg to –5.10 kg). The physical activity intervention was defined as minimum of 45 minutes three times a week.

A systematic review of 52 RCTs and quasi-experimental designs of weight management interventions for overweight or obese adults reported similar results to Schaar *et al.* (2010) (Weinheimer *et al.* 2010). Physical activity interventions (mainly aerobic exercise interventions) lead to less body weight loss compared to the dietary (energy restriction diets) and dietary plus physical activity interventions, with 94% of the participants losing less than 5kg and even losing less than 5% body weight. The reported percentage of the participants who lost weight between 5 to 10kg following an energy restriction diet was 75%. The addition of the physical activity led to similar results with 67% of the participants losing 5 to 10kg.

1.6.2.2 The intensity of physical activity

The benefits of physical activity in the treatment of obesity management appear to depend on the intensity of the intervention (Jakicic and otto 2005; Catenacci and Wyatt 2007).

A systematic review of nine RCTs and 22 non-randomised trials reported that short term studies (≤16 weeks) show a dose-response relationship between physical activity interventions and reduction in total body fat but long term studies (≥26 weeks) do not (Ross and Janssen 2001). The average energy expenditure of the physical activity interventions in short term RCTs was equal to 2200kcal per week resulting in an average weight loss of 0.26kg/week. Long term RCTs prescribed physical activity interventions of less energy expenditure (1100kcal per week) per week resulting in a smaller mean weight loss per week (0.06kg).

Ross and Janssen (2001) reported that the amount of physical activity and energy expenditure in short and long term studies is not enough to lead to a meaningful weight loss for people with obesity. Therefore, the authors recommended that physical activity interventions as single component weight management interventions, should prescribe exercise programmes of 45-60min of “purposeful walking”, at moderate intensity, on most days of the week leading to an energy expenditure of 3000-3500kcal per week.

Ross and Janssen (2001) were supported by Jakicic and Otto (2005) and O’Gorman and Krook (2008) also reporting that 700kcal to 1000kcal per week of energy expenditure is not enough to promote important weight loss for adults with obesity and suggested at least 60min of physical activity on most days of the week . However, Catenacci and Wyatt (2007) reported that higher amount or length of the physical activity intervention could act as a barrier for participants with obesity to complete an intervention.

In addition, a systematic review of randomised trials of 10 week duration by Katzmarzyk and Lear (2012) reported that the majority of the physical activity interventions consisted of 30-60 minutes of daily moderate to vigorous physical activity for three to five days per week and produced modest beneficial effects on chronic disease risk factors (blood pressure, blood lipids glucose/insulin or C-reactive protein) for individuals with obesity.

The benefits of physical activity interventions also depend on the type of exercise completed. The majority of studies have focused on assessing and promoting the benefits of aerobic exercise for weight loss and fewer studies have focused on assessing the benefits of resistance training ("during which muscles work or hold against an applied force or weight" Chodzko-Zajko *et al.* 2009) as a treatment of obesity (Strasser and Schobersberger 2010; Ismail *et al.* 2012).

A systematic review and meta-analysis by Ismail *et al.* (2012) assessed the effect of aerobic exercise vs. resistance exercise training on visceral fat. Most of the reviewed studies included aerobic training interventions that ranged from four to 52 weeks, prescribed for one to 7 days per week and with intensities that ranged from 49% to 85% of peak aerobic capacity. The authors reported that even though this type and amount of exercise was less than public health recommendations for the management of obesity, aerobic exercise could still have an important effect on visceral fat and weight reduction. The study found a significant relationship between mean weight loss and visceral fat reduction ($r2 = 0.17$, $P < 0.05$), but there was no evidence to suggest that mean intensity of aerobic exercise had an effect on visceral fat reduction ($r2 < 0.15$ for both). In addition, weight reduction was not as significant as visceral fat reduction in all of the studies. Resistance training did not have the same significant effects on visceral fat reduction as aerobic exercise (Ismail *et al.* 2012).

However, a meta-analysis by Thorogood *et al.* (2011) showed that moderate aerobic exercise for 12 weeks to 12 months is not an effective weight management intervention for weight loss in adults with obesity. Aerobic exercise can have modest effects on cardiovascular risk and lipid levels but Thorogood *et al.* (2011) reported that this type of physical activity like any type of physical activity could be more effective when combined with a dietary intervention.

1.6.3 Psychological/ behavioural interventions

Psychological interventions in weight management aim to change cognitive behaviour, leading to a change in eating habits or activity patterns of individuals with obesity (NICE 2006). The intervention may be based on a specific theory such as the stages of change in the Transtheorytical model or the Social Cognitive theory (Loveman *et al.* 2011). Types of psychological interventions include behavioural and cognitive behavioural therapy, psycho-dynamic therapy, humanistic therapy and group therapy (Dyson 2010).

The majority of the psychological interventions use behavioural and cognitive therapies but the exact definition and the description of their content varies (NICE 2006; Greaves *et al.* 2011). This inconsistency among the studies acts as a barrier when reviewing the effectiveness of this type of interventions (Avenell *et al.* 2004; Greaves *et al.* 2011; Loveman *et al.* 2011). However, most of these therapies incorporate the following techniques (Avenell *et al.* 2004; McTigue *et al.* 2003; Shaw *et al.* 2005; Jacob and Isaac 2012):

1.6.3.1 Self-monitoring

Self-monitoring is a component of self-regulation theory and is used in weight management interventions in encouraging participants to self-evaluate their progress towards their goals (Kanfer 1991). This can happen by asking participants to monitor their weight, the type and the amount of their food intake and the levels of their daily physical activity (Wadden *et al.* 2007). A systematic review (22 studies) of the use of self-monitoring in weight management has shown that this behaviour change technique is associated with weight loss, with stronger evidence coming from RCTs using self-weighing techniques and dietary self-monitoring (Burke *et al.* 2011). However, the review highlights the need for higher quality of studies that will explore the dose and the frequency of self-monitoring for successful weight loss.

1.6.3.2 Problem solving

During Problem solving process an individual develops coping strategies for specific situations in everyday life that are seen as problematic (D’Zurilla and Goldrfried 1971). Improving the problem-solving skills of individuals has been used as a behaviour change technique in smoking cessation trials (Lancaster and Stead 2008) and in the treatment of mood disorders (Cuijpers *et al*. 2007) but also in obesity with promising results (Murawski *et al*. 2010). In more detail, Murawski *et al*. (2010) recruited 272 women with obesity (BMI = 36.5 ± 4.8) to a six month weight management programme based on Social Cognitive Theory. The study used the "Social Problem Solving Inventory-Revised" to assess problem solving abilities of the participants and showed that a greater improvement in ability of problem solving was associated with greater weight loss ($r = -0.15$, $P < 0.05$) at six months. The same effect was also seen with the adherence to the programme ($r = 0.20$, $P < .01$).

1.6.3.3 Goal setting

The idea of goal setting has been introduced and identified as an essential component of different theoretical frameworks used in weight management programmes. These theoretical frameworks include the control theory (Carver and Scheier 1982) and the theory of reasoned action (Fishbein and Ajzen 1975). Locke and Latham (2002) suggested that goal setting can help an individual to reach a desirable performance e.g. weight loss by the following four mechanisms: (1) goals can direct effort and attention to activities related to the desirable performance, (2) goals have an energising function by requiring greater efforts for an individual to reach higher goals, (3) goals affect persistence and (4) goals can have an indirect action through knowledge and strategies related to the desirable performance. According to a review of community based studies by Pearson (2012) specific goal setting accompanied by other techniques such as regular feedback (reviewing the goals) can lead to a positive behaviour change in overweight and obese adults. However, only two out of the 16 studies that set specific dietary and physical activity goals reported significant weight loss when compared with groups of no treatment or groups with general advice.

1.6.3.4 Stimulus control

Stimulus control is the technique that helps an individual to identify and then modify the cues that trigger overeating or lead to sedentary behaviours (environmental cues) (Van Dorsten and Lindley, 2008).The modification of the cues includes practical alterations of the environment such as changing food portions by changing serving plates or purchasing specific food items (Jacob and Isaac 2012).

1.6.3.5 Relapse prevention

Relapse prevention is a technique that supports individuals in coping with setbacks that could act as barriers to the maintenance of their weight loss and the sustainability of the behaviour change (Marlatt and George 1984).

1.6.3.6 Cognitive restructuring

Cognitive restructuring is the process of identifying and replacing irrational or negative beliefs and thoughts with rational or neutral ones (Wadden and Stunkard 2005; Fabricatore 2007). This technique teaches individuals with obesity frequently challenged with thoughts of poor self-esteem and body image and with great expectations for weight loss to “change their internal dialogue” (Foreyt and Poston 1998).

1.6.3.7 Effectiveness

According to Pearson (2012) it is difficult to review the effectiveness of specific behaviour change techniques responsible for positive behaviour changes in weight management because the majority of psychological interventions incorporate a variety of these techniques and have not been assessed in isolation in relation to weight loss.

Several reviews have examined the effect of psychological interventions as a single or a combination treatment (psychological plus diet or psychological plus activity) for obesity in adults (NICE 2006; Dyson *et al*. 2010; Greaves *et al*. 2011). A meta-analysis of four reviews of RCTs (12 months or over duration) including only adults with obesity reported that behavioural therapy combined with other weight loss approaches can play an important role in weight reduction (NICE 2006).

Shaw *et al.* (2005) one of the included systematic reviews in NICE (2006), reported that behaviour therapy as a single intervention can lead to significantly greater weight loss than a placebo (WMD -2.5 kg; 95% CI -1.7 to -3.3). However, the weight loss was greater when the intensity of the behaviour therapy increased and when behavioural therapy was combined with a diet or exercise intervention. Similar results were also reported for cognitive-behaviour therapy when compared with diet/exercise intervention (WMD -4.9 kg; 95% CI -7.3 to -2.4). A second review of RCTs, also included in NICE (2006), showed that the addition of behaviour therapy diet change versus diet alone was associated with a significant effect on weight change at 12 months (WMD -7.67kg; 95% CI-11.97 to-3.36kg (Avenell *et al.* 2004).

The meta-analysis by NICE (2006) was supported by a systematic review of 30 reviews of interventions aiming to improve dietary and physical activity patterns of adults in high risk of developing diabetes (Greaves *et al.* 2011). The review reported that the effectiveness of this type of interventions can increase if a well-planned strategy of behavioural approach techniques is included.

1.6.4 Multi-component interventions

Multi-component weight loss interventions are defined as the interventions that involve a combination of diet, exercise and behaviour therapy simultaneously (Loveman *et al.* 2011). According to a systematic review by Kirk *et al.* (2012) single component interventions are more effective in improving a targeted behaviour such as diet or physical activity but multi-component interventions can lead to greater weight loss. A review of systematic reviews and meta-analysis reported that multi-component interventions can have a modest but significant effect on weight loss but there is no strong evidence to support that any one of these individual components is more effective than the other (Dyson *et al.* 2010).

A meta-analysis of 36 RCTs for overweight or obese adults showed that a combination of behaviour therapy with exercise and diet led to a greater weight loss at six months when compared with diet and exercise alone (WMD: -4.9 kg; 95% CI-7.3 to -2.4) (Shaw *et al.* 2005). This was supported by Franz *et al.* (2007)

that reported a mean weight loss of 7.9kg (8.5%) at six months in multi-component weight loss interventions.

Regarding the long term effects of weight loss interventions, Kirk *et al.* (2011) reported that multi-component interventions are more successful in preventing weight gain than two component interventions. A systematic review showed that interventions that incorporate diet, exercise and behaviour therapy together can lead to improved weight loss up to 36 months (Avenell *et al.* 2004). Dombrowski *et al.* (2010) reviewed the effects of behavioural interventions for obese adults on behaviour, weight and disease risk factors and identified 25 out of 44 randomised control trials that compared multi-component interventions with waiting list control/usual care. According to the findings, the interventions that used behaviour therapy and focused on diet and physical activity together have more consistent beneficial effects over time regarding weight than studies that have focused on diet or physical activity alone.

Loveman *et al.* (2011) assessed the clinical effectiveness of 12 randomised controlled multi-component trials in overweight and obese participants and reported that weight loss was small and not clinically significant and the variability between the studies in the methodology, strategy and follow up make it difficult to draw robust conclusions about the effectiveness of these interventions.

However, a systematic review of reviews by Greaves *et al.* (2011) that focused on specific intervention components and the effects in adults at risk of type 2 diabetes found that interventions that promote dietary change alone or dietary and physical activity together can lead to a clinically significant weight loss (3-5 kg at 12 months, 2-3 kg at 36 months). The effectiveness increased when using well defined behaviour change techniques leading to weight loss equal to 4.5 kg at a median six months of follow up.

There is an extensive literature assessing weight loss interventions in individuals with obesity and despite the inconsistent quality of the studies, the evidence base along with clinical guidelines (NICE 2006; SIGN 2010; Lau *et al.* 2007; Seagle *et al.* 2009) support the use of multi-component weight loss interventions that incorporate dietary modification, alterations in physical activity and behaviour change.

1.6.5 Structure of multi-component interventions

In order to define the strategies used in multi-component interventions this thesis examined the studies that incorporated diet, physical activity and behavioural therapy simultaneously, and were included in two systematic reviews by Dombrowski *et al.* (2010) and Loveman *et al.* (2011). Both studies included RCTs in adult population groups and used similar reliable methodologies to assess the quality of the studies.

The quality of the multi-component interventions has been assessed and analysed in detail by Dombrowski *et al.* (2010) and Loveman *et al.* (2011). Both studies agree that the methodology of the RCTs varied considerably, random allocation was not always described, and the majority of the studies did not report blinding of the assessors, participants and care providers. Loveman *et al.* (2011) reported that because of a lack of methodological information, ranking according to methodological rigor and risk of bias was not possible for the 12 RCTs. The review found that five studies provided inadequate information or did not provide sufficient information to assess risk of bias from drop out and seven studies were at high risk of bias because their analysis and interpretation did not account for missing data. Dombrowski *et al.* (2010) also reported that only 21 studies out of 44 RCTs provided numbers of participants that dropped out and the reasons of attrition.

To examine the components of these interventions in detail a table of Dombrowski's *et al.* (2010) was modified by including only the 25 studies that incorporated diet, physical activity and behaviour therapy simultaneously and by adding six more studies reviewed by Loveman *et al.* (2011) that have focused mainly on obese participants (mean BMI≥ 30kg/m^2). The table of 31 multi-component studies includes a further description of the interventions e.g. behavioural approach theories, behavioural strategies used and weight loss maintenance (Table 1.3).

1.6.5.1 Diet

Multi-component interventions have used a variety of dietary approaches. These can be divided into three categories based on their description:

- Diets with a specific energy deficit
- Very low and low calorie diets
- Low in fat / high in carbohydrate diets

Energy deficit diets

Four studies prescribed diets to the participants, aiming for specific amounts of daily energy deficit. The energy deficit ranged from 500 to 1000kcal/day (Knowler *et al.* 2002; Villareal *et al.* 2006; Djuric *et al.* 2002; Mefferd *et al.* 2007). The majority of these diets aimed for an energy content of fat equal to less than 30% kcal and 20% from protein. The diet also focused on the consumption of adequate amounts of fruit and vegetables and high fibre foods. Villareal *et al.* (2006) was the only study that asked the participants to take daily multivitamin supplements.

Low and very low calorie diets

Only, Weinstock *et al.* (1998) used a 925kcal per diet in the form of liquid meals combined with a shelf-stable dinner entrée and two cups of salad. This was later replaced by a higher in calories conventional diet (1200 to 1500 kcal/ day). Similarly, Wing *et al.* (1998) offered a very low calorie diet ranging from 800kcal to 1000kcal, gradually increasing flexibility and aiming for dietary goals equal to 1200 to 1500kcal/day. A very low calorie diet was also used by Lindstrom *et al.* (2003) to boost weight loss after six months of low fat dietary intervention. However, the calorie content was not reported in the study. Lindstrom *et al.* (2003) offered cooking classes and shopping tours.

Although some of the diets were not labelled as low calorie diets, researchers had set specific lower limits of energy content. Blumenthal (2000) had set lower dietary goals equal to 1200kcal/day for women and 1500kcal/day for men but

Stevens *et al.* (1993) and Wing *et al.* (1985) had set an average limit of 1200 kcal/day and 1000kcal/day, respectively. In some studies the calorie content of the dietary intervention depended on the initial body weight of the individual or the initial body weight and the gender together. Therefore, for Jeffery *et al.* (1998) and Tate *et al.* (2007), participants were advised to follow a 1000 kcal/day and 1500 kcal/day depending on specific baseline body weights. For Burke *et al.* (2008) female participants were instructed to follow a 1200kcal and male participants had to follow a 1500kcal if baseline weight was less than 90.5kg. Burke *et al.* (2008) was also the only study that offered a vegetarian low calorie diet compared with a standard low fat diet. To aid weight loss and improve dietary habits Jeffery *et al.* (1998) offered structured menus and shopping lists and Burke *et al.* (2008) offered cooking classes and shopping tours.

Low fat / high carbohydrate diets

Most of the studies focused on the fat and carbohydrate content of the diet and were based on national and international recommendations for a healthy balanced diet e.g. The Canadian Nutrition Recommendations (2003), British Diabetic Association (1989), “Balance of Good Health” recommendations (Food Standards Agency 1994), American Diabetic Association (1989). Based on these recommendations a diet should provide 50-55% energy content from total carbohydrate and no more than 35% from total fat. The energy content of the diets specified in these RCTs was mainly composed of ≤ 30% kcal from fat and 50-60% kcal from carbohydrate with an exception of a vegetarian diet where the energy content from carbohydrate was equal to 70-75% kcal (Toobert *et al.* 2000). Additional information on nutritional components included fibre content, restrictions on saturated and cholesterol content and intake of alcohol and salt. The dietary intervention of three studies included the consumption of two already established and well researched diets: the Mediterranean diet and the DASH diet (Toorbet *et al.* 2005; Elmer *et al.* 2006; Burke *et al.* 2007).

Summary

Most of the studies followed the principles of a healthy balanced diet and focused specifically on the energy content of fat and the consumption of high fibre foods. In some cases, dietary prescription was based on gender and baseline weights. To improve dietary patterns, some studies reported offering cooking classes and visits to local supermarkets.

1.6.5.2 Physical activity

In table 1.4, there was a variety of recommendations on the amount and intensity of the physical activity. However, most of the studies recommended a 30 minute per day of moderate physical activity, or 210 minutes per week. Recommendations were also be in the form of amount of energy expenditure e.g. 1000 to 1500kcal per week (Wing *et al*. 1998; Jeffery *et al*. 1998). Some of the studies incorporated into the intervention voluntary training classes (Villareal *et al*. 2006; Knowler *et al*. 2002; Agnus Collins *et al*. 1997; Blumenthal *et al*. 2000; Mefferd *et al*. 2007; Wing *et al*. 1985; Wing *et al*. 1998) and others relied exclusively on simple physical activity recommendations (Clark *et al*. 2004; Burke *et al*. 2007; Deakin *et al*. 2006; Djuric *et al*. 2002; Edelman *et al*. 2006; Goodrick *et al*. 1998; Hardcastle *et al*. 2008; Keyserling *et al*. 2002; Menard *et al*. 2005; Oldroyd *et al*. 2006; Reeves *et al*. 2001; Southard *et al*. 2003; Toobert *et al*. 2005; Elmer *et al*. 2006). The training classes included walking, aerobic exercises and muscle strengthening exercises. Recommended intensity and frequency of physical activity was not always reported (Logue *et al*. 2005).

Summary

Overall, the recommendations on physical activity in multi-component weight loss interventions followed the principles of national and international guidelines for the management of obesity. However, very few studies provided specific physical activity prescriptions. Physical activity classes comprised a common component of the physical activity interventions.

1.6.5.3 Behaviour therapy

Four RCTs based their behaviour therapy components on “the LEARN programme” (Goodrick *et al*. 1998; Reeves *et al*. 2001; Blumenthal *et al*. 2000;

Djuric *et al.* 2002). This programme was developed by Dr Brownell K.D. in 1989 (Brownell *et al.* 2000) and uses educational process to help individuals to learn important information and apply them to everyday life. The word LEARN stands for: Lifestyle, Exercise, Attitude, Relationships and Nutrition. Four studies used "Trans-theoretical therapy" and the model of "stages of change" (Linstrom *et al.* 2003; Logue *et al.* 2005; Oldroyd *et al.* 2006; Elmer *et al.* 2006). The "stages of change" model (Prochaska *et al.* 1994) and assesses an individual's readiness to change and uses specific strategies and mechanisms to help the individual achieve and maintain behaviour changes. According to the trans-theoretical model "change" is a process involving progress through a series of five stages: Pre-contemplation, Contemplation, Preparation, Action and Maintenance.

In four studies behaviour therapy was influenced by the "Social Cognitive Theory" (Elmer *et al.* 2006; Djuric *et al.* 2002; Agnus-Collins *et al.* 1997; Toobert *et al.* 2005). According to this theory an individual's expectations, beliefs, self-perceptions, goals and intentions play an important role in behaviour change (Bandura 1986). Toobert *et al.* (2005) also used a "social- ecologic approach" as part of the behaviour therapy, using a multilevel pyramid model of social-environmental support and highlighting the influence that family, friends and health care resources can have in health outcomes (Glasgow *et al.* 2000).

Most of the studies provided the participants with the same set of techniques to change eating and activity habits. These techniques that teach individuals essential behavioural and cognitive skills for changing unhealthy behaviours include: self-monitoring, goal setting, stimulus control, problem solving, being assertive and cognitive restructuring. In more detail, participants were instructed to keep food and activity diaries, to set specific and realistic goals (e.g. usually 1kg weight loss per week), to avoid experiences and settings that increase probability of repeating unhealthy behaviour, to identify problems and a variety of solutions and to monitor negative thoughts that act as a barrier to their goals.

Motivational interviewing (Rollnick *et al.* 2010) was also used as an important mechanism in the support of behaviour change by helping participants explore and resolve ambivalence (Hardcastle *et al.* 2008). It was also used as part of a

“Motivational Enhancement Therapy” aiming to produce rapid, internally motivated change by helping participants to use their own resources (Elmer *et al.* 2006).

Weinstock *et al.* (1998) used the same intervention used by Wadden and Foster (1992), an intervention that uses all the above behaviour change techniques, but also provided the participants with a 200 page manual based on a modified version of the OPTIFAST programme (a VLCD programme). Although, the authors did not provide details on this manual, Tsai and Wadden (2005) report that the behaviour therapy in OPTIFAST is focused on stress management and social support.

Behavioural approach techniques were mainly delivered by dieticians, nutritionists and physical activity specialists (Villareal *et al.* 2006; Lindstrom *et al.* 2003; Agnus Collins *et al.* 1997; Deakin *et al.* 2006; Djuric *et al.* 2002; Hardcastle *et al.* 2008; Oldroyd *et al.* 2006; Reeves *et al.* 2001; Southard et a. 2003; Toobert *et al.* 2005; Elmer *et al.*2006). In some studies behavioural therapy was delivered by psychologists (Wing *et al.* 1985; Wing *et al.* 1998; Goodrick *et al.* 1998) or other health or non-health professionals trained in nutrition and behaviour therapy (Knowler *et al.* 2002; Edelman *et al.* 2006; Keyserling *et al.* 2002; Kirkman *et al.* 1994; Menard *et al.* 2005).

As part of the behavioural therapy participants were encouraged to set a realistic target weight loss. Only 10 out of the 32 studies had set a specific target weight loss for their participants. The weight loss target could be set in the form of kg e.g. five kg from baseline weight in six months (Agnus-collins *et al.* 1997; Blumental *et al.* 2000; Stevens *et al.* 1993) or percentage of weight loss e.g. 5-10% weight loss in six months (Djuric *et al.* 2002; Villareal *et al.* 2006). Most of these studies aimed for a realistic target weight loss of one kilogram per week. Other studies did not specify the period of the weight loss that this should be achieved e.g. six months or 12 months (Goodrick *et al.* 1998; Knowler *et al.* 2003; Burke *et al.* 2008; Elmer *et al.* 2006).

Summary

Several studies specified the exact model of theory or combination of theories they used to develop a behaviour therapy and some studies described only the mechanisms/ techniques to promote and support behaviour change.

1.6.5.4 Resources

There was no specification in the majority of the studies about the resources used during the intervention. However, most of the studies provided the participants with food and exercise diaries to record their food intake and their physical activity, respectively and weight charts to record the progress of their weight loss. In seven studies, group and individual sessions were accompanied by written information in the form of handouts (Agnus Collins *et al.* 1997; Djuric *et al.* 2002; Knowler *et al.* 2002; Lindstrom *et al.* 2003; Elmer *et al.* 2006; Oldroyd *et al.* 2006; Villareal *et al.* 2006) and one study specified the use of booklets on diet and physical activity (Clark *et al.* 2004).

Resources that focused on dietary knowledge and change of dietary habits included recipes (Agnus Collins *et al.* 1997; Elmer *et al.* 2006), menus (Logue *et al.* 2005) and a "Doctors Pocket Guide of Calorie, Fat and Carbohydrate Counter" (Villareal *et al.* 2006). In order to improve physical activity Djuric *et al.* (2002) and Mefferd *et al.* (2007) provided the participants with pedometers and Logue *et al.* (2005) provided walking maps and walking trails. Two studies provided self – help manuals for the support of behaviour change of the participants (Weinstock *et al.* 1997; Wing *et al.* 1998).

1.6.5.5 Format

Most of the multi-component weight loss interventions were delivered in group based sessions (13 studies) or a combination of individual and group sessions (11 studies). Individual sessions alone were less frequently offered as part of the intervention. Phone call contacts discussing the progress of the participants and reinforcing behaviour change messages was also a part of some interventions (seven studies) and two studies specified the use of emails as a form of contact between interventionists and participants.

1.6.5.6 Weight maintenance phase

The majority of the studies in table 1.3 did not include weight loss maintenance as part of their research aims and none of the studies used a weight loss maintenance definition. Seventeen studies of the RCTs did not provide a weight loss maintenance intervention and three studies examined weight loss maintenance but did not specify whether they offered a relevant input to support participants maintain their weight after an intensive weight loss phase (usually six months).

Only nine studies specified a weight loss maintenance intervention. However, contrary to the weight loss phase, weight loss maintenance phase was less efficiently described. There was no consistency in the format of the interventions, making it difficult to conclude an overall description. The maintenance interventions ranged from six weeks to 12 months. Clark *et al.* (2004) and Burke *et al.* (2007) incorporated telephone contacts as part of their intervention. Face to face meetings could be in the form of group or individual consultations or combination of both.

The content of the weight loss maintenance phase varied among the three RCTs that fully described their intervention. Elmer *et al.* (2006) focused mainly on behaviour therapy, discussing the motivation and the barriers to maintain a behavioural change but Goodrick *et al.* (1998) focused more on ideas that will support a healthy lifestyle including healthy eating and healthy cooking.

Stevens *et al.* (1993), during the 12 months of weight loss maintenance, continued the multi-component intervention, offering monthly group or individual discussions on diet, exercise and behaviour. Discussions on problem solving and group physical activities were also included. The sessions were participant centered and adapted to their needs. Participants were advised to continue to monitor their weight and exercise. Weinstock *et al.* (1997) provided a multi-component weight loss maintenance intervention (six months) that followed the same principles as Stevens *et al.* (1993) but the participants were also provided with a manual based on the OPTIFAST programme (Sandoz Nutrition Co. 1988). The participants had also to present a “weight biography”, sharing their weight loss experiences, identifying their personal barriers to maintain weight loss and solutions or changes that they should have made to maintain their weight loss.

Although, Burke *et al*. (2008) did not include a weight loss maintenance intervention, the 12 months weight loss intervention was followed by six months of a maintenance phase. During this period there was no further contact with the participants. However, discussion on maintenance was a part of the behavioural therapy during the latter months of the weight loss phase. The behavioural intervention included discussion topics on identification of barriers in maintaining new patterns of eating and exercising, problem solving strategies and highlighting the importance of being physical active for effective weight loss maintenance (Burke *et al*. 2006).

Summary

The studies in table 1.3 show that key components of a multi-component weight loss intervention are:

- A dietary prescription in the form of a healthy balanced diet with a set energy deficit (500kcal to 1000kcal) or with low calorie content from fat (≤30%kcal) and high calorie content from carbohydrate (≥50%kcal)
- Advice to increase physical activity patterns to moderate levels of 30 minutes per day, sometimes accompanied by exercise classes (e.g. walking)
- Behaviour therapy based on a specific theory and using relevant behaviour change techniques.

Other factors that have been identified by the national and international guidelines as important in the management of obesity but they were not incorporated in most of the studies in table 1.3 include:

- A target weight loss
- A weight loss maintenance intervention

Table 1.3: Multi-component weight loss interventions

Study	Participants	Interventions	Outcomes
Argus-Collins 1997 USA	Co-morbidity: type 2 diabetes. Sex: 52 women, 12 men. Age, mean (SD) in years: (a) 62.4 (5.9) (b) 61 (5.7). BMI, mean in kg/m^2: (a) 33.9 (b) 34.9. Weight, mean (SD) in kg: (a) 93.3 (18.6) (b) 94.9 (20.1).	**(a)** Counselling intervention: Group and individual sessions. **Diet:** Diabetic Exchange Lists for meal planning, <30% from fat, ~55–60% kcal from carbohydrate, 12–20% from protein. **Activity**: moderate physical activity ≥3 days/week, training 30 min weekly sessions for 12 weeks. **Behaviour:** Social Action Theory, goal setting, relapse prevention, portion control, avoid triggers. Handouts, recipes and a folder. Other: weight loss of ≥4.5 kg at the rate of ≤0.9/week. **Maintenance:** Not provided **(b)** Control group: Usual care. **Allocated:** (a) 32 (b) 32. **Dropout (%):** (a) 6.25 (b) 21.9 at 6 months.	Follow-up(s): 3 and 6 months. Outcomes: weight, total cholesterol, LDL, HDL, TGs, HbA1c, SBP, DBP, kcal, fat (% kcal), PASE. **Results:** (a): -2.8% net difference weight loss at 6 months
Blumenthal 2000 USA	Co-morbidity: hypertension. Sex: (a) 34 women, 21 men (b) 29 women, 25 men (c) 11 women, 13 men. Age, mean (SD) in years: (a) 48.5 (1.2) (b) 46.6 (1.2) (c) 47.2 (1.8). BMI, mean (SD) in kg/m^2: (a) 32.1 (4.0) (b) 32.8 (4.0) (c) 32.6 (5.1). Weight, mean (SD) in kg: (a) 93.3 (17.7) (b) 95.4 (14.5) (c) 94.0 (17.3).	**(a)** Weight management group: Group sessions. **Diet:** 5,021 J (1,200 kcal) for women, 6,276 J (1,500 kcal) for men, 15–20% of energy from fat. **Activity:** scheduled and supervised exercise sessions 4-5 times/ week. **Behaviour:** LEARN manual, dealing with pressures to eat, coping with relapse, distinguish cravings from hunger, diaries. Other: 0.5–1kg weight loss/week. **(b)** Exercise group: **Activity:** same as weight management group. **Maintenance:** last 6 weeks of the program, individualized plans for maintaining changes made during the past 6 months. **(c)** Control group: Waiting list. **Allocated:** (a) 55 (b) 54 (c) 24. **Dropout (%):** (a) 16 (b) 19 (c) 8 at 6 months.	Follow-up(s): 6 months. Outcomes: weight, SBP, DBP, FPG, kcal, fat (g), treadmill time. **Results:** (a) :-7.8kg weight loss at 6 months
Burke 2007 Australia	Co-morbidity: None Sex: (a) 67 women 56 men (b) 67 women, 51 men Age, mean (SD) in years: (a) 57.1 (7.2) (b) 55.5 (7.5) BMI mean (SD) kg m^2: (a) 30.4 (2.9) (b) 29.7 (2.5) Weight, mean (SD) in kg: (a) 86.7 (12.4) (b) 84.2 (10.8)	**(a)** Lifestyle programme: Group and individual sessions. **Diet:** DASH diet low in fat (<30% kcal from fat, 10% kcal from saturated fat), > fruit and vegetables, < salt and sugar, ≥ 4 fish meals/week, ≤ two standard drinks/day. **Behaviour:** goal setting, barriers, self- management, printed modules. **Activity**: accumulate ≥30 min of MIPA on most days, increase incidental activity. Other: decrease baseline weight by 5–10% over 4 months. **Maintenance:** 12 months telephone contacts, 6 individual appointments, newsletter every 3 months. **(b)** Control: Usual care. **Allocated:** (a) 123 (b) 118. **Dropout (%):** (a) 17 (b) 24	Follow-up(s): 4 and 12 months. Outcomes: weight, SBP, DBP, kcal, fat (% kcal), time spent in PA (min/week).**Results:** (a) -2.8kg net change in weight at 4 months -2.5kg at 12 months
Burke 2008 USA	Co-morbidity: None Gender, M : F, n (%): (a) 6 (12.5) : 42 (87.5); (b) 7 (20) : 28 (80); (c) 6 (12.5) : 42 (87.5); (d) 4 (9) : 41 (91) Age (years), mean (SD): (a) 43.2 (9.4); (b) 44.3 (8.4); (c) 43.2 (8.4); (d) 43.2 (8.6) BMI kg/m^2, mean (SD): (a) 34.5 (3.9); (b)34.1 (3.5); (c) 32.9 (4.1); (d) 33.7 (4.3) Weight (kg), mean (SD): (a) 97.2 (12.9); (b) 96.7 (12.1); (c) 92.4 (16.1); (d) 91.8 (15.4)	**(a)** Standard diet: Group sessions. **Diet:** reduce maximum daily calorie intake to 1200 kcal (women) 1500 kcal (men) for those weighing < 90.5 kg at baseline; 1500 kcal (women) 1800 kcal (men) for those weighing > 90.5 kg at baseline. Minimum daily intake 1000 kcal. > 25% fat of total kcal intake, not > 10% fat. **Activity:** walk 50 min/week initially, increasing to 150 min/week by week 6. Cooking classes, shopping tours. **Behaviour:** goal setting, self-monitoring, modifying environment, problem-solving, modifying 'all or nothing' thinking, preventing relapse. Other: 1kg per week. **(b)** lacto-ovo-vegetarian diet: **Diet:** same as (a) but no meat, poultry and fish. **Activity**: same as (a). **Behaviour:** same as (a). **(c)** No preference for standard diet: **Diet** same as (a). **Activity:** same as (a). **Behaviour:** same as (a). **(d)** No preference for lacto-ovo-vegetarian diet: Diet same as (b). **Activity:** same as (a). **Behaviour:** same as (a). **Maintenance:** Not provided. **Allocated:** (a) 48 (b) 35 (c) 48 (d) 45. **Attrition (%):** 34	Follow-up(s): 6, 12 and 18 months. Outcomes: weight BMI, cholesterol, triglycerides, glucose levels, insulin levels, BP, WC. **Results:** % weight change (a) -3.9kg, (b) -5.3, (c)-8.0, (d)-7.9 at 18 months

Source: Adapted from Dombrowski *et al.* (2010) and Loveman *et al.* (2011)

Table 1.3: continued

Study	Participants	Interventions	Outcomes
Clark 2004 UK	Co-morbidity: type 2 diabetes. Sex: 42 women, 58 men. Age, mean in years: 59.5. BMI, mean (SD) in kg/m^2: (a) 32.40 (4.49) (b) 31.30 (5.01). Weight, mean in kg: not given.	**(a)** Lifestyle intervention. Individual sessions, phone calls. **Diet**: Self-selected goal(s) for lifestyle change. **Activity:** Self-selected goal(s) for lifestyle change. Booklets on diet and activity were given. **Behaviour:** goal setting, mechanisms to face barriers, self-efficacy. **Maintenance:** Phone calls at week 1, 3 and 7, meetings at week 12 and 24, goal setting progress, problem solving. **(b)** Control group: Usual care. **Allocated:** (a) 50 (b) 50. **Dropout (%):** (a) 8 (b) 4 at 52 weeks.	Follow-up(s): 3 and 12 months. Outcomes: weight, total cholesterol, LDL, HDL, TGs, HbA1c, FHQ (Block fat screener), PASE. **Results:** (a): no weight change
Deakin 2006 UK	Co-morbidity: type 2 diabetes. Sex: 152 women, 162 men. Age, mean (SD) in years: (a) 61.3 (9.7) (b) 61.8 (11.0). BMI, mean (SD) in kg/m^2: (a) 30.8 (5.3) (b) 30.6 (5.7). Weight, mean (SD) in kg: (a) 83.2 (14.5) (b) 82.8 (17.6).	**(a)** X-PERT programme: Group sessions. **Diet:** Based on the British Nutrition Foundation's 'Balance of Good Health'. **Activity**: Exercise on prescription scheme (individual exercise recommendations from GP). **Behaviour:** empowerment and discovery learning. **Maintenance:** Not provided. **(b)** Control group: usual care. **Allocated:** (a) 157 (b) 157. **Dropout (%)**: (a) 4.5 (b) 10.2.	Follow-up(s): 4 and 14 months. Outcomes: weight, T cholesterol, LDL, HDL, TGs, HbA1c, SBP, DBP, fat (% kcal), Summary of self-care, activity (PA). **Results** : (a): -0.3kg weight loss at 6 months, -0.5kg at 14 months
Djuric 2002 USA	Co-morbidity: breast cancer. Sex: all women. Age, mean (SD) in years: 51.7 (8.4). BMI, mean (SD) in kg/m^2: (a) 35 (1.2) (b) 35.5 (1.1) (c) 36.8 (8) (d) 34.9 (1.2). Weight, mean (SD) in kg: (a) 95.5 (5) (b) 91.4 (2.7) (c) 100.5 (5) (d) 95 (3.6).	**(a)** Weight Watchers group: no other dietary or exercise instructions. **(b)** Individualised group. Group, individual sessions and phone calls. **Diet:** 500–1,000 kcal/d deficit, 20–25% kcal from fat, 20% from protein, high fibre foods. **Activity:** 30–45 min/day of MPA most days, pedometers provided. **Behaviour:** The LEARN programme, Bandura's social cognitive theory, self-efficacy, outcome expectancy, self-regulatory, environmental influences. Written info on diet, activity, behaviour. Other: decrease of 10% of baseline weight over 6 months. **(c)** Comprehensive group. Same as (b) and (a) together. **Maintenance:** After the study women could approach WW for weight regain prevention **(d)** Control group: usual care. **Allocated:** (a) 11 (b) 13 (c) 11 (d) 13. **Dropout (%):** (a) 27.3 (b) 30.8 (c) 9.1 (d) 7.7 at 12 months.	Follow-up(s): 3, 6, and 12 months. Outcomes: weight, total cholesterol, LDL, HDL, TGs, FPG, kcal, fat (% kcal). **Results:** (a): -2.6kg at 12 months (b): -8.0kg at 12 months(c): -9.4kg at 12 months
Edelman 2006 USA	Co-morbidity: One or more of: diabetes, hypertension, dyslipidemia, smoking, or BMI >25 anthropometric measurements. Sex: 124 women, 30 men. Age, mean (SD) in years: (a) 52.2 (5.2) (b) 53.4 (4.8). BMI, mean (SD) in kg/m^2: (a) 33.3 (7.8) (b) 34.1 (7.7). Weight, mean in kg: not given.	**(a)** Personal Health Planning: Group, individual sessions, phone calls, e-mails. **Diet and Activity:** change of behaviours linked to cardiovascular risk (e.g. 'focus of commitment to healthier behaviours' or 'education on the topics of nutrition, PA …'). **Behaviour:** goal setting, relapse prevention, creating behaviour change, risk prevention. **Maintenance:** Not provided. **(b)** Control group: usual care. **Allocated**: (a) 77 (b) 77. **Dropout (%):** (a) 27.3 (b) 14.3 at 10 months.	Follow-up(s): 5 and 10 months. Outcomes: weight, SBP, DBP, lipid profiles, days exercise/ week. **Results :** (a): - 1 kilogram weight loss –not specified at 5 or 10 months

Source: Adapted from Dombrowski *et al.* (2010) and Loveman *et al.* (2011)

Table 1.3: continued

Study	Participants	Interventions	Outcomes
Elmer 2006 USA	Co-morbidity: hypertension. Sex: (a) 174 women, 94 men (b) 154 women, 115 men (c) 172 women, 101 men. Age, mean (SD) in years: (a) 50.2 (8.6) (b) 50.2 (9.3) (c) 49.5 (8.8). BMI, mean (SD) in kg/m^2: (a) 33.0 (5.5) (b) 33.3 (6.3) (c) 32.9 (5.6). Weight, mean (SD) in kg: not given.	**(a)** Established group: Group and Individual sessions. **Diet:** ≤100 mmol/day of Na, ≤30 ml/day alcohol for men and 15 ml/day for women. **Activity:** at least 180 minutes/week of MIPA. **Behaviour:** Social cognitive theory, Behavioural self-management, Stages-of-change model, motivational enhancement. Weight charts, goal setting, recipes. **(b)** Established + DASH diet. **Diet:** same as (a) plus ≤ 7% kcal from saturated fat, ≤ 25% of kcal from fat. **Activity:** ≥180 minutes/week of MIPA. **Behaviour:** same as (b) **Maintenance:** 12 monthly group sessions, 3 individual visits. 30-60 minute sessions based on participants' specific concerns, goals, motivation. Other: weight loss ≥ 6.8 kg if BMI ≥ 25 kg/m^2. **(c)** Advice only group. **Diet:** reduced Na diet. **Activity:** engaging in regular MIPA. **Allocated:** (a) 268 (b) 269 (c) 273. **Dropout (%):** (a) 6 (b) 6 (c) 0 at 18 months.	Follow-up(s): 6 and 18 months. Outcomes: weight, DBP, SBP, kcal, fat (% kcal), kcal/kg. **Results:** (a): -4.9kg weight loss at 6 months, -3.8kg weight loss at 18 months; (b): -5.8kg weight loss at 6 months; -4.3kg weight loss at 18 months
Goodrick 1998 USA	Co-morbidity: binge eating disorder. Sex: all women. Age, mean (SD) in years: (a) 89.04 (10.15) (b) 87.71 (9.58) (c) 86.49 (9.83). BMI, mean (SD) in kg/m^2: (a) 33.50 (3.46) (b) 33.16 (3.21) (c) 32.22 (2.97). Weight, mean (SD) in kg: (a) 89.04 (10.15) (b) 87.71 (9.58) (c) 86.49 (9.83).	**(a)** Dieting treatment: Group sessions. **Diet:** reducing fat (40 g/day), increasing complex carbohydrates. **Behaviour**: LEARN programme, self-monitoring, stimulus control, problem solving, goal setting, social support and eating a variety of foods. **Activity:** 4–5 h/week at an intensity based on training heart rate. Other: weight loss averaging 0,454 kg/ week. **(b)** Non-dieting treatment. **Diet:** 'gradual reductions of fat without feelings of deprivation'. **Activity:** home-based walking program with gradually attained goal of 4–5 h/week. **Maintenance:** After 6 months 26 biweekly maintenance classes for 12 months. Discussion topics including holidays, parties, and special events; more meatless meals; quick dinner ideas; importance of vegetables in daily meals; making low-fat lunches, snacks, and desserts; and setting realistic goals and keeping them. **(c)** Control group: waiting list **Allocated:** (a) 79 (b) 78 (c) 62. **Dropout (%):** (a) 15.2 (b) 16.7 (c) 6.5 at 18 months for (a) and (b) and 6 months for (c).	Follow-up(s): 6 and 18 months. Outcomes: weight, Kcal/kg/day. **Results:** (a): -0.6% weight loss at 6 months
Hardcastle 2008 UK	Co-morbidity: CHD risk factors (hypertension, hypercholesterolemia) Sex: 240 women, 118 men. Age, mean (SD) in years: (a) 50.1 (10.5) (b) 50.41 (10.8) BMI, mean (SD) in kg/m^2: (a) 33.67 (5.4) (b) 34.28 (7.0) Weight, mean (SD) in kg: (a) 93.7 (17.1) (b) 91.73 (17.2)	**(a)** Counselling intervention: Individual sessions. **Diet:** individualised depending on readiness to change. **Activity:** individualised depending on readiness to change. **Behaviour:** The transtheoritical model and motivational interviewing. An initial leaflet with information on diet and activity. **Maintenance:** Not provided. **(b)** Control group: usual care **Allocated:** (a) 203 (b) 131. **Dropout (%):** (a) 38.4 (b) 29	Follow-up(s): 6 months. Outcomes: weight, total cholesterol, LDL, HDL, triglycerides, SBP, DBP, fat (% kcal fat), overall PA (met/min/week). **Results:** (a): 9% reached 5% weight loss at 6 months

Source: Adapted from Dombrowski *et al.* (2010) and Loveman *et al.* (2011)

Table 1.3: continued

Study	Participants	Interventions	Outcomes
Jeffery 1995 USA	Co-morbidity: none Total N:202 Sex:101men, 101 women Age (years), mean: 37 BMI kg/m^2, mean: 31	**(a)** Standard behavioural treatment (SBT): Group sessions. **Diet:** 1000 kcal/day if or 1500 kcal/day based on body weight. **Activity:** walk or bike the equivalent of 250 kcal/ week and gradually increase to a minimum of 1,000 kcal/ week. **Behaviour:** stimulus control techniques, problem solving strategies, social assertion, goal-setting, reinforcement techniques for motivation, replacement of negative thinking, relapse prevention, social support, self-monitoring. **(b)** SBT + food provision (FP): **Diet:** same as (a) plus were provided with food each week for 18 months. Premeasured and packaged dinners and breakfasts for 5 days per week. **Activity:** same as (a). **Behaviour:** same as (a). **(c)** SBT + incentives (I): **Diet:** same as (a). **Activity:** supervised walking sessions plus personal trainer. **Behaviour:** same as (a) plus an incentive program through which each participant could earn financial rewards up to $25 per week for achieving and maintaining weight loss. **(d)** SBT+ I + FP: **Diet:** same as (a) and (b). **Activity:** same as (a) **Behaviour:** same as (c). **(e)** Control **Maintenance:** Monthly meetings for but not clear if were focused on weight loss maintenance. **Allocated:** (a) 40, (b) 40, (c) 41, (d) 41, (e) 40. **Drop out (%):** 88 completed 30 months	Follow-up(s): 18 and 30 months. Outcomes: weight **Results:** (a) -4.6kg mean weight loss at 18 months, + 0.6kg at 30 months, (b) - 6.6kg mean weight loss at 18 months, + 2.2kg at 30 months (c) -4kg mean weight loss at 18 months, +1.6kg at 30 months (d) -6.4kg mean weight loss at 18 months, + 1.6kg at 30 months (e) 0 mean weight loss at 18 months, + 0.6kg at 30 months
Jeffery 1998 USA	Co-morbidity: None Sex: 29 men, 167 women Age (years), mean (SE): (a) 40.0 (1.3); (b) 41.5 (1.3); (c) 41.0 (1.3);(d) 42.6 (1.4); (d) 40.7 (1.4) BMI, kg/m^2, mean (SE): (a)31.4 (0.3); (b) 31.5 (0.3); (c) 31.4 (0.3); (d) 31.5 (0.4); (e) 30.6 (0.4) Body weight (kg), mean (SE): (a) 85.6 (1.7);(b) 87.1 (1.6); (c) 84.7 (1.6); (d) 87.7 (1.7); (e)85.7 (1.7)	**(a)** Standard behavioural therapy (SBT): Group sessions. **Diet:** 1000 kcal/day if weight was < 91kg and 1500 kcal/day if weight was 91 kg, restrict fat to 20% or less of calories (22 g/day for 1000 kcal and 33g/day for 1500 kcal). Given weekly menus for five breakfasts and dinners along with grocery shopping lists. **Activity:** walk or bike the equivalent of 250 kcal/ week and to gradually increase to a minimum of 1,000 kcal/ week. **Behaviour:** stimulus control, problem solving, social assertion, goal-setting, enhancing of motivation, altering self-defeating thoughts, relapse prevention, social support. **(b)** SBT + supervised exercise: **Diet:** same as (a). **Activity:** supervised walking sessions. **Behaviour:** same as (a). **(c)** SBT + trainer (SBTT): **Diet:** same as (a). **Activity:** same as (b) plus personal trainer. **Behaviour:** same as (a). **(d)** SBT+ incentive (SBTI): **Diet:** same as (a). **Activity:** same as (b) plus reward **Behaviour:** same as (a). **(e)** SBT + trainer + incentive (SBTTI): **Diet:** same as (a). **Activity:** same as (b) and (c) **Behaviour:** same as (a). **Maintenance:** Monthly meetings but not clear if were focused on weight loss maintenance. **Allocated:** (a) 40, (b) 41, (c) 42, (d) 37, (e) 36. **Drop out (%):** total 22	Follow-up(s): 6 and 18 months. Outcomes: exercise behaviours weight, attendance at walks; habitual energy and fat intake depression and binge eating. **Results:** (a) -8.3kg mean weight loss at 6 months, - 7.6kg at 18 months, (b)-6kg at 6 months, -3.8kg at 18 months (c)-5.6kg at 6 months, -2.9kg at 18 months (d)-6.7kg at 6 months, -4.5kg at 18 months, (e)-7.9kg at 6 months, -5.1kg at 18 months.
Keyserling 2002 USA	Co-morbidity: type 2 diabetes. Sex: all female. Age, mean in years: (a) 58.5 (b) 59.8 (c) 59.2. BMI mean kg/m2: (a) 36.2 (b) 34.6 (c) 36.2. Weight, mean in kg: (a) 95 (b) 91.9 (c) 95.7.	**(a)** Clinic and Community intervention: Group and individual consultation, phone calls **Diet:** 2-3 dietary goals selected according to dietary risk assessment. Reduction of fat content. **Activity:** 2-3 activity goals selected according to PA assessment. **Behaviour:** readiness to change, social support **(b)** Clinical intervention. **Diet:** 2-3 same as (a) **Activity:** same as (a). **Maintenance:** Not provided. **(c)** Control group: usual care **Allocated:** (a) 67 (b) 66 (c) 67. **Dropout (%):** (a) 19.4 (b) 10.6 (c) 14.9 at 12 months.	Follow-up(s): 6 and 12 months. Outcomes: weight, total cholesterol, HDL, HbA1c, kcal, kcal expended/day. **Results:** Weight gain for all groups

Source: Adapted from Dombrowski *et al.* (2010) and Loveman *et al.* (2011)

Table 1.3: continued

Study	Participants	Interventions	Outcomes
Kirkman 1994 USA	Co-morbidity: type 2 diabetes. Sex: 3 women, 272 men. Age, mean (SD) in years: (a) 63.9 (8.6) (b) 63.2 (8.3). % above ideal weight (SD): (a) 130.6 (23.8) (b) 130.6 (193.2). Weight, mean in kg: not given.	**(a)** Intervention group: Individual. Phone calls. **Diet and Activity:** prescriptions from GP (not specified) to improve glycaemic control. **Behaviour:** encourage behaviour change **(b)** Control group. **Maintenance:** Not provided. **Allocated:** (a) 204 (b) 71. **Dropout (%)**: not given.	Follow-up(s): 12 months. Outcomes: weight, T cholesterol, LDL, HDL, TGs. **Results:** No weight loss
Knowler 2002 Finland	Co-morbidity: elevated fasting and post-load plasma glucose concentrations. Sex: (a) 737 women, 345 men (b) 710 women, 363 men (c) 747 women, 335 men. Age, mean (SD) in years: (a) 50.6 (11.3) (b) 50.9 (10.3) (c) 50.3 (10.4). BMI, mean (SD) in kg/m2: (a) 33.9 (6.8) (b) 33.9 (6.6) (c) 34.2 (6.7). Weight, mean (SD) in kg: (a) 94.1 (20.8) (b) 94.3 (19.9) (c) 94.3 (20.2).	**(a)** Intensive lifestyle intervention: Group and individual sessions. **Diet:** 500–1,000 kcal/day deficit, 25% kcal from fat. **Activity:** Advice ≥700 kcal/week (equivalent to 150 min of MPA). Voluntary activity sessions. Other: 7% weight loss of initial body weight. **Behaviour:** goal setting, self-monitoring, stimuli control, problem solving. **(b)** Lifestyle recommendations plus Metformin group. 850 mg of metformin daily. Written information. **(c)** Lifestyle recommendations plus Placebo control group: Written information. **Maintenance:** Not provided. **Allocated:** (a) 1,079 (b) 1,073 (c) 1,082. **Dropout (%):** 92.5 of participants had attended a scheduled visit within previous 6 months.	Follow-up(s): 6, 12, 18, 24, 30, 36, 42, and 48 months. Outcomes: weight, HbAc1, FPG, kcal, fat (% kcal). **Results:** (a) 50% reached a 7% weight loss at 6 months, -5.6 kg at 6 months
Laitinen 1993 Finland	Co-morbidity: type 2 diabetes. Sex: 49 women, 37 men. Age, mean (SD) in years: (a) 52.2 (7) (b) 54.2 (6.5). BMI, mean (SD) in kg/m2: (a) 33.95 (5.3) (b) 33.5 (4.7).	**(a)** Intervention group: **Diet:** planned energy restriction, ≤ 30% kcal from fat, ≤10% of kcal saturated fat, ≤300 mg/day dietary cholesterol, fatty acids ≥20% of energy unsaturated fat, and increase carbohydrates (e.g. fruits, berries, and vegetables). **Activity:** increase frequency of exercise sessions to 3–4/week, lasting 30–60 min each. **Behaviour:** behaviour modification topics, e.g. what to do instead of eating and how to manage parties; goals **Maintenance:** Not provided. **(b)** Control group: Usual care. **Allocated:** (a) 40 (b) 46. **Dropout (%):** (a) 5 (b) 4 at 15 months.	Follow-up(s): 3, 15 and 24 months. Outcomes: weight, total cholesterol, HDL, TGs, HbA1c, FPG, kcal, fat (% kcal fat). **Results:** (a): 5.5% weight loss at 15 months
Lindstrom 2003 Finland	Co-morbidity: impaired glucose tolerance. Sex: (a) 176 women, 81men (b) 174 women, 91 men. Age, mean (SD) in years: (a) 55 (7) (b) 55 (7). BMI, mean (SD) in kg/m2: (a) 31.4 (4.5) (b) 31.1 (4.5). Weight, mean (SD) in kg: (a) 86.7 (14.0) (b) 85.5 (14.4).	**(a)** Lifestyle intervention: Group and individual sessions. **Diet:** <30% kcal from fat, <10 kcal from saturated fat≥15 g / 1,000 kcal from fibre, VLCD after 6 months. Cooking classes. **Behaviour:** Stages of behavioural change (Prochaska 1992) **Activity:** MIPA ≥30 min/day-Activity and resistance training was also offered. Other: weight reduction 0.5kg to 1kg per week. Printed material was provided. **Maintenance:** After one year, meetings every 3 months of less intensive intervention. **(b)** Control group: usual care. **Allocated:** (a) 265 (b) 257. **Dropout (%):** (a) 12.8 (b) 21 at 3 years.	Follow-up(s): 12 and 36 months. Outcomes: weight, total cholesterol, HDL, TGs, HbA1c, FPG, kcal, fat (% kcal), LTPA (min/week). **Results:** (a): 5.1% weight loss at 12 months

Source: Adapted from Dombrowski *et al*. (2010) and Loveman *et al*. (2011)

Table 1.3: continued

Study	Participants	Interventions	Outcomes
Logue 2005 USA	Co-morbidity: None Sex (M:F): (a) 97 : 232 (b) 110 : 226 BMI n (%): **(a)** 25–29.9 59 (18) **(b)** 73 (22) 30–34.9 119 (36) 107 (32) 35–39.9 69 (21) 82 (24) 40.0 + 79 (24) 74 (22)	**(a)** Trans-theoretical Model and Chronic Disease Paradigm. Individual, phone calls. **Diet:** based on either the United States Department of Agriculture (USDA) Food Guide Pyramid (Dietary Guidelines for Americans) or a standard prescription to reduce calories, increase fruit and vegetables, reduce fat. **Activity:** a standard prescription to increase activity and exercise- no details provided. Mall walking maps, descriptions of local walking trails. **Behaviour:** Prochaska "stages of change". Workbooks that corresponded to their most recent SOC profile. **(b)** Augmented usual care: **Diet:** same as (a). **Activity:** No information. **Behaviour:** Self-monitoring. **Maintenance:** Not provided. **Allocated:** (a) 329, (b) 336. **Attrition (%):** (a) 37 (b) 46 at 18 months, (a) 31 (b) 38 at 24 months	Follow up(s): 6, 12, 18 and 24 months. Outcomes: weight, Waist girth; blood lipids; BP; behavioural and cognitive-based estimates of daily energy intake and total energy expenditure; psychosocial assessments; physical and mental health. **Results:** (a) -0.39kg mean weight loss at 24 months, (b) -0.16 kg at 24 months
Mefferd 2007 USA	Co-morbidity: Breast cancer. Sex: (a) 56 Women (b) 29 women. Age, mean (SD) in years: 56.3 (8.2). BMI, mean (SD) in kg/m2: 31.0 (4.2). Weight, mean (SD) in kg: 84.7 (12.6)	**(a)** Intervention group: Group, individual sessions, phone calls. **Diet:** 500–1000 kcal/day deficit. High fibre foods and adequate protein intake. **Activity:** one h/d of moderate to vigorous PA. Muscle strength group sessions. Pedometers. **Behaviour:** goal setting, self-monitoring, diaries, cognitive restructuring, monitoring positive and negative thinking and actual behaviour. **Maintenance:** Not provided **(b)** Control group: waiting list. **Allocated:** (a) 56 (b) 29. **Dropout (%):** (a) 16 (b) 0.	Follow-up(s): 4 months. Outcomes: weight, total cholesterol, HDL, TGs, moderate + vigorous PA. **Results:** (a): 7% weight loss at 4 months
Menard 2005 Canada	Co-morbidity: type 2 diabetes. Sex: (a) 9 women 27 men (b) 14 women 22 men. Age, mean (SD) in years: (a) 55.9 (8.6) (b) 53.7 (7.5). BMI, mean (SD) in kg/m2: (a) 32.6 (5.7) (b) 32.9 (5.5). Weight, mean (SD) in kg: (a) 93.5 (20.1) (b) 88.5 (18.5).	**(a)** Intervention group: Individual, phone calls. **Diet:** 50–55% kcal from carbohydrates, ≤30% kcal fat, ≤10% kcal from saturated fat. **Activity:** home based exercise sessions, 3–4 times/week, 45–55 minutes, intensity at 50–80% of maximum heart rate. Other: After 3 months pharmacological therapy was introduced. **Behaviour:** support and assessment of motivation. **Maintenance:** Not provided **(b)** Control group: usual care. **Allocated:** (a) 36 (b) 36. **Dropout (%):** (a) 16.7 (b) 19.5 at 18 months.	Follow-up(s): 6, 12 and 18 months. Outcomes: weight, LDL, HDL, TGs, HbA1c, SBP, DBP, FPG, kcal, fat (g), METs. **Results:** Weight gain
Oldroyd 2006 UK	Co-morbidity: impaired glucose tolerance. Sex: (a) 19 women, 16 men (b) 10 women, 22 men. Age, mean (CI) in years: (a) 58.2 (41, 75) (b) 57.5 (41, 73). BMI, mean (SD) in kg/m2: (a) 30.4 (5.6) (b) 29.9 (4.9). Weight, mean (SD) in kg: (a) 83.3 (16.6) (b) 85.5 (14.2).	**(a)** Intervention group. Individual sessions. **Diet:** 30% kcal from fat, polysaturated to saturated fat ratio of 1.0, 50–55% kcal from carbohydrate, 20g/1000kcal of fibre. Written information educational material. **Activity:** 20–30 min of aerobic activity for 2–3 times/ week. Information leaflet on exercise facilities in the area. **Behaviour:** Prochaska- Trans-theoretical therapy. **Maintenance:** Not provided **(b)** Control group: no advice. **Allocated**: (a) 39 (b) 39. **Dropout (%):** (a) 38.5 (b) 23.1 at 24 months.	Follow-up(s): 6, 12 and 24 months. Outcomes: weight, T.cholesterol, LDL, HbA1c, FPG, kcal, fat (g), % engaging in regular PA. **Results:** (a) 54% reached -1kg weight loss at 6 months / 63% reached -1kg weight loss at 24 months

Source: Adapted from Dombrowski *et al.* (2010) and Loveman *et al.* (2011)

Table 1.3: continued

Study	Participants	Interventions	Outcomes
Reeves 2001 USA	Co-morbidity: binge eating disorders Sex: all female. Number of patients within age range (n) in years: (a) 27–39 (14), 40–45 (19), 46–50 (13); (b) 27–39 (9), 40–45 (14), 46–50 (13). BMI, mean in kg/m2: (b) 33.8, (a) 31.8. Weight, mean (SD) in kg: (a) 89.36 (9.53) (b) 86.64 (14.52).	**(a)** Intervention group: Group sessions. **Diet:** decrease fat intake. **Activity:** five 45-min walking sessions/ week. **Behaviour:** The LEARN programme, self-monitoring, stimulus control, contingency management, goal setting, cognitive restructuring. **Maintenance:** Not provided **(b)** Control group: Waiting list. **Allocated:** (a) 59 (b) 39. **Dropout (%):** (a) 28.3 (b) 7.7 at 6 months.	Follow-up(s): 6 months. Outcomes: weight, kcal, fat kcal). **Results:** (a) :- 1% weight loss at 6 months
Southard 2003 Canada	Co-morbidity: Cardiovascular disease. Sex: (a) 17 women, 36 men (b) 9 women, 42 men. Age, mean (SD) in years: (a) 61.8 (10.8) (b) 62.8 (10.6). BMI, mean (SD) in kg/m2: (a) 31.1 (6.8) (b) 29.2 (4.8).Weight, mean (SD) in kg: (a) 89 (b) 91.99.	**(a)** Special intervention. Individual and group discussions-Internet- email. **Diet:** dietician feedback to dietary practice. **Activity:** individual instructions by case managers. Illustrated graphs with progress were provided. **Behaviour:** self-monitoring, rewards. **Maintenance:** Not provided **(b)** Control group: Usual care. **Allocated:** (a) 53 (b) 51. **Dropout (%):** (a) 6 (b) 2.	Follow-up(s): 6 months. Outcomes: weight, T.cholesterol, HDL, LDL, TGs, SBP, DBP, MEDFICTS (indicating fat intake), min weekly exercise. **Results:** (a)-1.7kg w.loss at 6 months
Stevens 1993 USA	Co-morbidity: high-normal diastolic BP N=564 Sex: 65.7% males, 34.3% females Age (years), mean (SD): 43.3 (6.1) BMI kg/m^2, n (%): mean (SD): Men BMI 31.0 (2.9) kg/m^2, women BMI 30.9 (3.6) kg/m^2 Weight kg, mean: approximately 90.5 for both interventions	**(a)** Weight loss intervention: Individual and group sessions. **Diet:** reduction of T. energy intake by reducing fat, sugar and alcohol intake, average energy intake not below 1200 kcal, no upper limit stated. **Activity:** walk 3 days/ week for a minimum of 20 min. /session. Goal: 4-5 days/ week 30 and 45 min, intensity 40%-55% of heart rate reserve. **Behaviour:** self-management, relapse prevention, short-term goals, problem solving. **Maintenance:** 12 monthly meetings. Type and number of contacts varied. Attendance options: any one or combination: (1) monthly group sessions, (2) group weigh-in, (3) individual weigh-in, (4) individual counselling. **(b)** Control: usual care. **Allocated:** (a) 308, (b) 256. **% Drop out:** unclear	Follow-up(s): 6, 12 and 18 months. Outcomes: weight, attendance, BP. **Results:** (a) -4.7kg mean weight loss for men, -1.6kg mean weight loss for women.
Stevens. 2001 USA	Co-morbidity: high-normal blood pressure N=1191 Sex: (a) 37% females, 63% males, (b) 31.7% female, 68.3% males Age (years), mean (SD): (a) 43.4(6.1), (b) 42.3 (6.1) BMI kg/m^2 , mean (SD): 31 (2.9) males, 30.9 (3.6) females	**(a)** Weight loss group. Individual and group sessions. **Diet:** <1500kcal for men and <1200kcal for women, decrease consumption of fat, sugar and alcohol. **Activity:** gradual increase to 30-45min/d, 4-5days/week, moderate intensity 40% to 55% of heart rate reserve, brisk walking. Behaviour: self-management, self-monitoring, goal setting, problem solving. **(b) Control group:** Usual care. **Maintenance:** Not provided Allocated: (a) 595, (b) 596. **Drop out:** at 18 months 50 were not included in the analysis in the (a) group and 45 in the (b) group; at 36 months these rates were 48 and 42, respectively	Follow-up(s): 18 and 36 months. Outcomes: weight **Results:** (a) -2kg mean weight loss at 18 months,-0.2kg at 36 months. (b)-0.7kg mean weigh loss at 18 months, 1.8kg weight gain at 36 months

Source: Adapted from Dombrowski *et al.* (2010) and Loveman *et al.* (2011)

Table 1.3: continued

Study	Participants	Interventions	Outcomes
Tate 2007 USA	Co-morbidity: hypertension (drug treated) N=202 Sex: 58% females, 42% males Age (years), mean (SD): 42.2 (6.4) BMI kg/m^2 : mean (SD): BMI 31.7 (2.6) kg/m2, range 26–44 Weight kg, mean: approximately 90.5 for both interventions	**(a)** Standard Behavioural Treatment: Group sessions. **Diet:** goal to reduce daily energy intake to 1000–1500 kcal depending on initial body weight, < 20% of energy as fat. **Behaviour:** stimulus control, problem solving, goal setting, social support, motivation, relapse prevention. **(b)** High physical activity treatment: **Diet:** same as (a). **Behaviour:** same as (a). **Activity:** goal was to build up to an energy expenditure of 2500 kcal/week by the end of the first 6 months of the intervention (roughly equivalent to walking < 75 minutes/day). **Maintenance:** Not specified. **Allocated:** (a) 93 (b) 109. **Number drop out:** total 44	Follow-up(s): 6, 12, 18 and 30 months. Outcomes: weight, PA energy exp; Dietary intake, protein g/day; fat g/day; carbohydrate (g/day) **Results:** (a) -6.7kg mean weight loss at 18 months, 3% weight loss at 30 months. (b)-4.1kg mean weight loss at 18 months; 1% weight loss at 30 months.
Toobert 2000 USA	Co-morbidity: coronary heart disease Sex: all women. Age, mean (SD) in years: (a) 64 (10) (b) 63 (11). BMI, mean (SD) in kg/m2: (a) 32 (4.2) (b) 32 (5.5). Weight, mean (SD) in kg: (a) 80 (10) (b) 79 (15).	**(a)** Intervention group: Group sessions. **Diet:** Reversal diet: vegetarian <10% kcal from fat, 70–75% kcal from carbohydrates, 15–20% kcal from protein, 5 mg of cholesterol/day. Cooking classes. **Activity:** 1 h/day yoga stress management, 1hr exercise programme≥3 days/ week, exercise training twice weekly. **Behaviour:** discussions on barriers, feelings, positive encouragement. **Maintenance:** after the 15 months of intervention- 16 sessions –no further description **(b)** Control group: usual care. **Allocated:** (a) 16 (b) 12. **Dropout (%):** (a) 12.5 (b) 8.3 at 24 months.	Follow-up(s): 4, 12 and 24 months. Outcomes: weight, total cholesterol, LDL HDL, TGs, SBP, DBP, fat (% kcal), Summary of self-care activity (PA). **Results:** (a): - 4.8% weight loss at 12 months
Toobert 2005 USA	Co-morbidity: type 2 diabetes. Sex: all women. Age, mean (SD) in years: (a) 61.1 (8.0) (b) 60.7 (7.8). BMI, meam (SD) in kg/m2: (a) 35.1 (7.7) (b) 35.6 (8.8). Weight, mean (SD) in kg: (a) 92.3 (21.2) (b) 93.9 (23.8).	**(a)** Mediterranean Lifestyle Program: Group sessions **Diet:** more bread; more root vegetables, green vegetables, legumes; more fish; less red meat, replaced by poultry; daily fruit; and avoidance of butter and cream, replaced by olive/canola oil or olive-/canola-based margarine. **Activity:** 30 min of MIPA on most days of the week, then 1 h of MIPA/day. **Behaviour:** Social Cognitive Theory, Goal Systems, Social Ecological theory. **Maintenance:** Not provided **(b)** Control group: Usual care. **Allocated:** (a) 163 (b) 116. **Dropout (%):** 12% after 6 months.	Follow-up(s): 6 months. Outcomes: weight, total cholesterol, LDL, HDL, TGs, Hba1c, SBP, DBP, METs × duration × days baseline adjusted. **Results:** (a) : -0.83kg weight loss at 6 months
Villareal 2006 USA	Co-morbidity: Metabolic syndrome. Sex: (a) 12 women, 5 men (b) 6 women, 4 men. Age, mean (SD) in years: (a) 69 (5) (b) 71 (4). BMI, mean (SD) in kg/m2: (a) 39 (5) (b) 39 (5). Weight, mean (SD) in kg: (a) 100 (14) (b) 103 (20).	**(a)** Intervention group: Group sessions. **Diet:** ≈750 kcal/day deficit, ≈30 kcal from fat, 50% kcal from carbohydrate, 20% kcal from protein. Daily multivitamin supplement. Participants were offered the Doctors Pocket Guide of Calorie, Fat and Carbohydrate Counter, food diary sheets, educational materials. **Activity:** Exercise-training on 3 days/week for 90 min. Other: 1.5% loss of body weight/week, 10% weight loss after 6 months. **Behaviour:** goal setting, self-monitoring, stimulus control, problem- solving skills, identification of high-risk situations, and relapse prevention training. **Maintenance:** Not provided **(b)** Control group: no treatment. **Allocated:** (a) 17 (b) 10. **Dropout (%):** (a) 12 (b) 10.	Follow-up(s): 6 months. Outcomes: weight, LDL, walking speed (m/min). **Results:** (a) 8.4% weight loss at 6 months

Source: Adapted from Dombrowski *et al.* (2010) and Loveman *et al.* (2011)

Table 1.3: continued

Study	Participants	Interventions	Outcomes
Weinstock 1997 USA	Co-morbidity: none Sex: 128 female Age :mean(SD) in years: (a) 42.8 (8.3); (b) 40.0 (9.1); (c) 40.8 (7.9); (d): 41.0 (8.8) BMI kg/m2: mean (SD): (a) 35.3 (4.4); (b) 36.5 (6.0); (c) 37.3 (5.1);(d): 36.4 (5.5) Weight kg, mean (SD): (a) 92.4 (14.8); (b): 96.8 (14.2); (c): 98.7 (12.5); (d): 96.3 (8.8)	**(a)** Diet, strength and aerobic training: Group sessions. **Diet:** 925kcal/d, 4 servings of liquid meal, with a shelf-stable dinner entry plus 2 cups of salad. At week 18 decrease of liquid diet and increase of conventional food, at week 20 consumption of 1200- 1500 kcal/ day. **Activity:** 3 on-site, supervised training sessions / week for the first 28 weeks, 2 workouts/ week from weeks 29 -48, and were unsupervised thereafter. Resistance training and step aerobics. **Behaviour:** Participants were provided a 200-page OPTIFAST manual. Wadden and Foster, (1992): .recording eating behaviour, controlling stimuli, slowing rate of eating, modifying self-defeating, thoughts and emotions, social support, increasing life-style activity. **(b)** Diet, strength training: **Diet:** same as (a). **Activity:** same as (a) no step aerobics but 40 min strength training by week 14. **Behaviour:** same as (a) plus adherence to exercise. **(c)** Diet, aerobic training: **Diet:** same as (a). **Activity:** same as (a) no resistance training but 40min step aerobics by week 14. **Behaviour:** same as (a) plus adherence to exercise. **(d)** Diet alone: same as (a). **Behaviour:** same as (a) **Maintenance:** 6 months-(Wadden *et al*. 1994), manual (Sandoz Nutrition Co., (1988) **Allocated:** (a) 29; (b) 31; (c) 31; (D) 29. **Number drop out:** 29 –no data per group	Follow-up(s): 8, 17, 24 and 48 weeks. Outcomes: FFM and REE, weight, appetite, mood, insulin resistance, glucose tolerance, BP **Results:** (a), (b),(c), (d) –14.3 mean weight loss at week 17 , -16.5 kg at week 24 and -15.1kg at week 44
Wing 1985 USA	Co-morbidity: type 2 diabetes. Sex: 33 women, 20 men. Age, mean (SE) in years: 55.1 (7.28). BMI, mean (SE) in kg/m2: 34.8 (5.10). Weight, mean (SE) in kg: 96.4(2.3).	**(a)** Behaviour modification: Group sessions. **Diet:** self-selected kcal goal, a minimum of 1000kcal/day, <four servings of high sugar foods/week, > fiber intake. Food diaries, calorie book were offered. **Activity:** Group sessions, 1,000 kcal expenditure/ week. **Behaviour:** food diaries, changing physical environment and eating habits, changing of self-statements regarding food. **(b)** Nutrition education. **Diet**: '…given calorie goal at a level comparable to […] the behaviour modification condition'. **Maintenance:** Not provided **(c)** Standard care condition. **Allocated:** 53 overall. **Dropout (%):** 6% overall at 62 weeks.	Follow-up(s): 4 and 16 months. Outcomes: weight, total cholesterol, HDL, TGs, SBP, DBP, FPG. **Results:** (a): -6.3 kg weight loss at 4 months; -1.78kg at 16 months
Wing 1998 USA	Co-morbidity: family history of type 2 diabetes. Sex: 122 women, 32 men. Age, mean (SD) in years: (a) 45.0 (4.7) (b) 46.4 (4.5) (c) 46.3 (3.8) (d) 45.3 (4.9). BMI, mean (SD) in kg/m2: (a) 36.1 (4.1) (b) 36.0 (3.7) (c) 35.7 (4.1) (d) 36.0 (5.4). Weight, mean (SD) in kg: (a) 99.6 (13.0) (b) 99.3 (15.3) (c) 98.7 (15.9) (d) 97.4 (16.0).	**(a)** Diet condition: Group sessions. **Diet:** 800–1,000 kcal/day, 20% of kcal from fat, gradually made more flexible with calorie goals of 1,200–1,500 kcal/day. **Behaviour:** stimulus control, dealing with eating out, assertion, behaviour chain analysis, problem solving, and relapse prevention. **(b)** Exercise condition. Group sessions. **Activity:** gradual increase activity to 1,500 kcal/ week through 5 days/week increases of 250 kcal/ week. **Behaviour:** self –help manual, behavioural group sessions **(c)** Diet-plus-exercise condition. Group sessions. **Diet:** same as (a). Activity: same as (b). Supervised walks. **Behaviour:** self –help manual, behavioural group sessions. **Maintenance:** Not provided **(d)** Control group: Usual care- The Learn manual **Allocated:** (a) 37 (b) 37 (c) 40 (d) 40. **Dropout (%):** (a) 5% (b) 16% (c) 20% (d) 23% at 24 months. Possible comparisons: D-PA vs. UC, D only vs. UC, PA only vs. UC	Follow-up(s): 6, 12, and 24 months. Outcomes: weight, LDL, HDL, TGs, HbA1, SBP, DBP FPG, kcal, fat (% kcal), kcal/week. **Results:** (c) : -10.3kg at 6 months ;- 7.4 Kg at 12 months

Source: Adapted from Dombrowski *et al*. (2010) and Loveman *et al*. (2011)

1.7 Clinical guidelines

The worldwide development of clinical guidelines is necessary to improve the quality of health care (Grol and Grimshaw 2003). Several countries and programmes follow different methods for the development of clinical guidelines but the most consistent procedure is the evidence-based approach where the guidelines make use of electronic database searches, systematic reviews, and meta-analysis of published studies (Burgers *et al*. 2002). However, it is essential for clinical guidelines to be reviewed and updated as often as every three years (Shekelle *et al*. 2001). According to the website of "National Guideline Clearing house" there are 233 national and international guidelines for the management of obesity in adults (published from 1999 to 2011) (http://www.guideline.gov/). All of these guidelines may share similar principles and recommendations. The following section will focus only on the two guidelines published in UK for adults and not for children because the studies developed and analysed for this thesis took place in Scotland and examines weight management in adults.

1.7.1 The National Institute for Health and Clinical Excellence

In 2006 the National Institute for Health and Clinical Excellence (NICE) reviewed the evidence from weight loss interventions in adults and children and published the first guidance in the management of overweight and obesity in adults and children in England and Wales. The guideline aims to improve the effectiveness of care provided to adults with obesity in primary care and recommended the following:

Adults who are overweight or obese should aim for a 5-10% weight loss from initial body weight (0.5-1kg per week). This should be achieved by following a treatment based on multi-component interventions. According to the guideline:

"Multi-component interventions are the treatment of choice. Weight management programmes should include behaviour change strategies to increase people's physical activity levels or decrease inactivity, improve eating behaviour and the quality of the person's diet and reduce energy intake."

In more detail, dietary advice should incorporate a diet with 600kcal/day deficit or low energy content by lowering fat intake, physical activity should be increased to 45-60 minutes of moderate intensity physical activity on five or more days a week and behavioural interventions should include the following strategies:

- self-monitoring of behaviour and progress
- stimulus control
- goal setting
- slowing rate of eating
- ensuring social support
- problem solving
- assertiveness
- cognitive restructuring (modifying thoughts)
- reinforcement of changes
- relapse prevention
- strategies for dealing with weight regain

1.7.2 The Scottish Intercollegiate Guidelines Network

The Scottish Intercollegiate Guidelines Network (SIGN) published a national clinical guideline for the “management of obesity” (2010) aiming to provide evidence based recommendations for the treatment of obesity. The guideline agreed on the same principles as the NICE (2006):

“Weight management programmes should include physical activity, dietary change and behavioural components. “

The SIGN guideline provides the same recommendations on dietary interventions (600kcal energy deficit) and on physical activity (45-60 minutes of moderate physical activity). However, the SIGN guideline makes a distinction in target weight loss between overweight and obese individuals recommending:

- In patients with BMI 25-35 kg/m^2 a 5-10% weight loss (approximately 5-10 kg) is required for cardiovascular disease and metabolic risk reduction.

- In patients with BMI>35 kg/m^2 a greater than 15-20% weight loss which (will always be over 10 kg) will be required to obtain a sustained improvement in co-morbidity.

1.7.3 Both Guidelines

Both guidelines highlight the importance of weight loss maintenance in obesity management and recommend the following:

- People with weight problems should know the difference between weight loss (occurring within six months of treatment) and weight loss maintenance (occurring after the six months weight loss phase).
- There is insufficient evidence to make detailed recommendations on weight loss maintenance. However, people should move towards eating a balanced diet, consistent with other healthy eating advice and continue with regular physical activity to avoid regaining weight.

Based on the review of the evidence from obesity management interventions, guidelines recommend research in the following areas:

- Development of treatment approaches for obesity in patients with ID
- Weight management studies with clear differentiation and assessment of the effects of treatment on weight loss (3-4 months) and on weight loss maintenance (4-12 months or longer)
- Assessment of interventions to support maintenance of weight loss

Chapter 2 Aims of thesis and research questions

2.1 Aims of thesis

1. To examine the effectiveness of weight loss interventions for adults with ID against criteria used in international clinical guidelines for the management of obesity.

2. To examine the effectiveness of a multi-component weight loss maintenance intervention for adults with ID.

3. To identify the factors that influence the effectiveness of a multi-component weight loss intervention for adults with ID, and obesity.

4. To explore the experiences of family and paid carers in supporting adults with ID in a weight loss intervention.

In order to answer these aims the following studies were carried out and detailed in this thesis:

- A systematic review
- A weight maintenance intervention
- An examination of the effectiveness of a weight loss intervention
- A qualitative study

2.2 Research Questions

1. What components are included in weight loss interventions for adults with ID?

2. Are weight loss interventions for adults with ID associated with a clinically significant weight loss (5-10% weight loss from initial body weight)?

3. Do interventions include a weight loss maintenance component?

4. Do participants in a multi-component weight maintenance intervention achieve to maintain their weight loss (a weight change of less than 3%)?

5. Does the multi-component weight loss maintenance intervention decrease the time spent in sedentary behaviour per day to a statistically significant level?

6. Does the multi-component weight loss maintenance intervention increase the level of physical activity to a statistically significant level?

7. Are there statistically significant associations between socio-clinical variables and success of the weight maintenance intervention?

8. Is a multi-component weight loss intervention adapted to the needs of adults with ID and obesity as effective in this population group as it was in those without ID?

9. Are there statistically significant associations between socio-clinical variables at baseline and the likelihood of participants achieving the target weight loss of 5% or more of initial body weight?

10. What were the carers' perceptions of the impact of obesity and perceived benefits of weight loss on participants' health?

11. What role do carers supporting adults with ID and obesity play in implementing a weight loss intervention?

12. What strategies did carers and participants adopt to overcome barriers to change in lifestyle habits during a weight loss intervention?

13. What were carers' perceptions of the acceptability and utility of the multi-component weight loss intervention?

Chapter 3 Study 1: Weight management interventions in adults with intellectual disabilities and obesity-a systematic review

3.1 Introduction

Previous reviews of weight loss interventions in adults with ID found that studies have important methodological weaknesses including small and often unjustified sample sizes, heterogeneous samples and non-randomised designs (Hamilton *et al*. 2007; Biswas *et al*. 2010; Jinks *et al*. 2011; Heller e*t al*. 2011). However, no review to date has examined the effectiveness of these studies against criteria used in international clinical guidelines for the management of obesity (NIH 2000; NICE, 2006; SIGN 2010).

Therefore, this review aims to examine the following research questions:

- What components are included in weight loss interventions for adults with ID?
- Are weight loss interventions for adults with ID associated with a clinically significant weight loss (5-10% or 5-10kg weight loss from initial body weight)?
- Do interventions include a weight loss maintenance component?

3.2 Method

3.2.1 Systematic electronic database searching

The present study comprised an electronic search of four electronic databases for the years 1982-2011: Medline, Embase, PsycINFO and CINAHL. An example of the search terms used can be found in appendix 1 and included ID, mental retardation, learning disorders, mentally disabled persons, developmental disabilities, obese, overweight, weight gain, weight loss, BMI, diet, low fat diet, low calorie diet, diet restriction, behaviour therapy, cognitive therapy, family therapy, lifestyle, exercise, physical activity, physical education, nutrition education, health promotion, health education. Articles were selected on the basis of the presence of these terms in the title and abstract.

3.2.1.1 Inclusion criteria

Previous reviews identified relatively few controlled studies that assessed the effectiveness of weight management interventions in adults with ID. Therefore the selection of studies for this review was not restricted to finding RCT design. Studies were included according to the following eligibility criteria:

- Valid diagnosis of ID at study enrollment
- Adults (≥ 18 years of age)
- Record of weight status (e.g. obese, overweight) based on the diagnostic criteria valid at the time of study
- Non-surgical or pharmacological interventions
- Impact of intervention on total body weight and/or BMI

Studies on pharmacotherapy and surgery and studies that investigated weight management in adults with the following genetic syndromes Prader-Willi syndrome, Cohen syndrome or Bardet-Biedl syndrome were excluded. Studies that included Special Olympics athletes were also excluded. The process of selection of studies for inclusion in the review can be seen in figure 3.1.

3.2.1.2 Data extraction

A standardised data extraction form was developed for this review (please see appendix 1). The data were extracted by one researcher (DS) and then discussed and reviewed by a second researcher (CM). Details of each study were extracted regarding:

- author, title, year of publication
- research question, study design, duration, method of randomization, blinding, length of follow up

- sample characteristics, power calculation, sample size, diagnostic criteria for level of ID and weight status, attrition
- outcome measures: weight and BMI change
- intervention components
- results
- conclusion.

3.2.1.3 Evaluation of studies

Evaluation of quality and results data was undertaken by one reviewer (DS). The findings and points for clarification were discussed with two reviewers with extensive experience of the clinical area and review methodology (CM, CRH). For the assessment of the quality of the studies and interventions a checklist was developed based on the criteria of the Centre for Reviews and Dissemination (CRD) (2009) and the PRISMA checklist (Moher *et al*. 2009) (please see appendix 1). Since the review was likely to include a diverse range of studies it was preferable to consider individual aspects of methodological quality in the quality assessment and synthesis (CRD 2009). Some of the criteria included in the assessment checklist were the following:

- The presence of sampling bias e.g. power calculation, heterogeneity
- Detailed description of the methodology of randomization
- Replicability based on detailed description of intervention
- The level and explanation for attrition
- Follow up measurements

Each study was evaluated using the key recommendations of national and international clinical guidelines for the management of obesity in adults (NIH 2000; NICE, 2006; SIGN 2010). Therefore, studies were assessed based on the components of each intervention and the study outcomes e.g. report of clinically significant weight loss.

3.3 Results

3.3.1 Literature search

Twenty two studies that reported the effectiveness of specific interventions designed to achieve weight loss in adults with ID and obesity met the inclusion criteria and were included in this systematic review (see flow chart of identification of studies and number of excluded studies in figure 3.1).

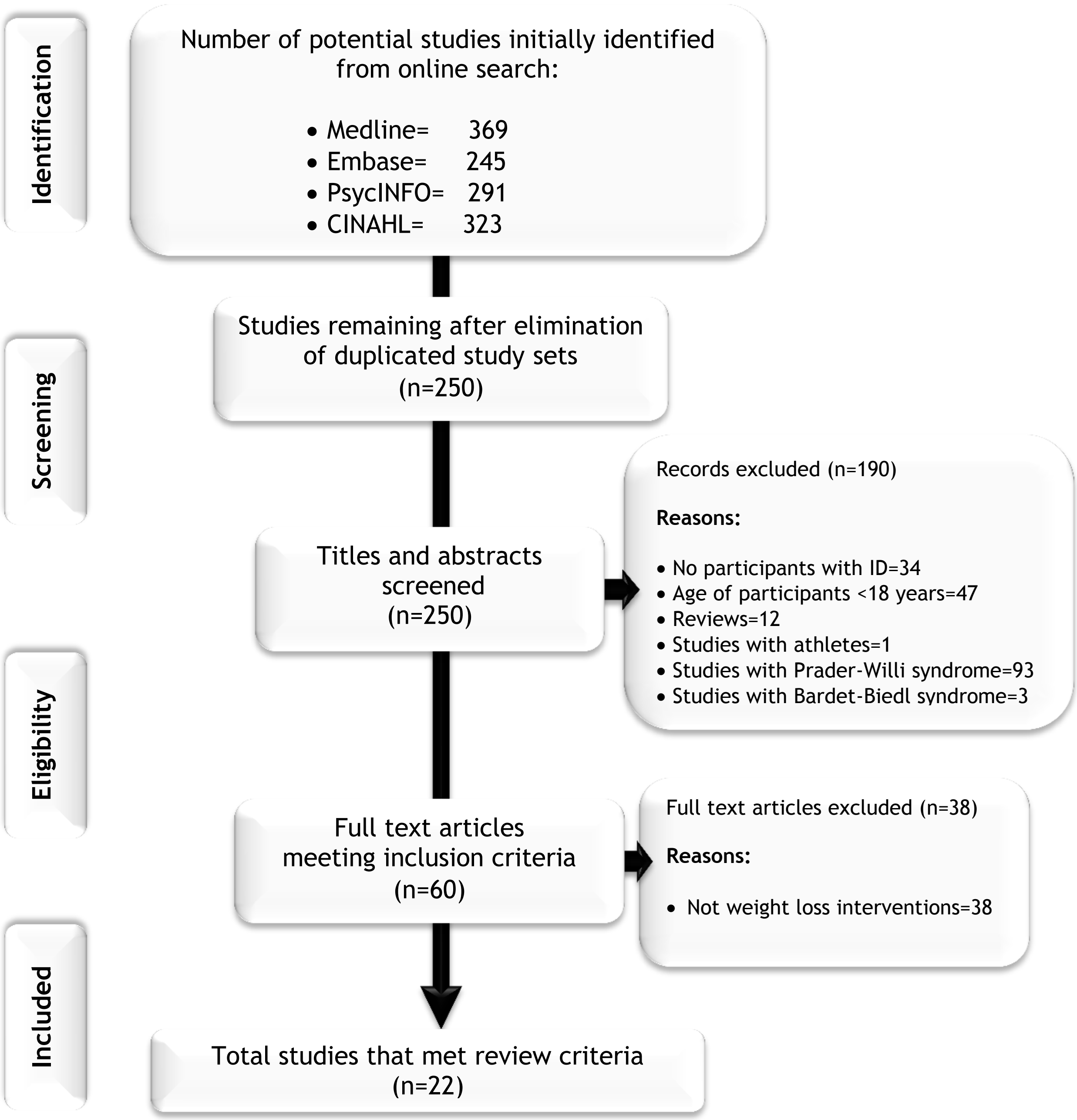
The majority of the studies took place in the USA (n=12), four studies took place in the UK and the rest in Hungary, Italy, South Africa, Portugal, Taiwan and Australia. Most of the studies were classified as uncontrolled before and after quasi-experimental studies. According to Grimshaw *et al.* (2000) quasi-experimental studies often are conducted where there are practical and ethical barriers to conducting randomized controlled trials. In this review when participants were randomly assigned the groups were referred as control groups and when not randomly assigned as comparison groups.

Based on the description of each component and specific definitions of dietary interventions (SIGN 2010) on behaviour change techniques (CRD 2009) and multi-component interventions (Shaw *et al.* 2005) the interventions were classified as:

- Behaviour change
- Behaviour change plus physical activity
- Dietary
- Physical activity
- Diet plus physical activity
- Multi-component (three or more components)

The components of the interventions, the study outcomes and limitations are described in the text. Further details are given in separate tables one to six. The tables report results for mean weight or BMI change, where possible, to allow comparisons with the recommended five kg or five per cent weight loss for the weight management of obesity. Weight change in text is reported as absolute weight loss or weight gain and not as variation, since findings in terms of variation of weight change was not always reported in papers.

Figure 3.1: Process of selection of studies for inclusion in the review



3.3.2 Behaviour change interventions

Single component psychological interventions used behaviour change to provide the participants "with coping skills to handle cues to overeat and manage lapses in the diet and physical activity when they occur" (Shaw *et al.* 2005) (see table 3.1)

Table 3.1. Behaviour change interventions

Study/ Location/ Type	Participants	Intervention	Follow up	Results
Fox *et al*. (1985) USA Community Quasi-experimental with a comparison group	**(a) Parent involvement group** n=8 Weight status: all obese Gender: 4 females, 4 males Age (years)[a] :27(2.7) ID: moderate **(b)Subject involvement** n=7 Weight status: all obese Gender: all males Age (years)[a] :29 (2.2) ID: moderate Attrition/drop out: none	**Duration:** 10 week of 2 group sessions per week (60min each). **(a)** Behaviour change methods based on Rotatori and Fox (1981). Parents involved with intervention strategies e.g. homework and reward systems. **(b)** Same as (a) but parents were not involved. **Maintenance:** 3 monthly meetings reviewing eating and activity behaviours, reward system continued.	10 week 3 month 6 month	**(a)** Mean weight change, kg:- 3.4 (range:-1.81 to -4.9) **(b)** Mean weight change, kg:-1.09 (range: +2.27 to -3.63). Significant between group difference (p<0.05) **(a)** Mean weight change, kg:+ 0.7 (range:+3.6 to -2.7) **(b)** Mean weight change, kg:+0.1 (range:+3.2 to -5.4) No significant between group difference **(a)** Mean weight gain, kg:+1.8 (range: -3.2 to +5.4) **(b)** Mean weight gain, kg:+2.8 (range:0 to +6.8) No significant between group difference
McCarran and Andrasik (1990) USA Community Quasi-experimental with a comparison group	Total n=12, 8 completers Weight status: 22-109% overweight Gender: 7 females, 1 male Age (years): 19-42 ID: cerebral palsy, IQ:50-80 Attrition/drop out:4 drop outs	**Duration:** 14 weeks of 3 group sessions per week (60min each) led by a graduate student and undergraduate. **(a) Home Help group:** Behaviour change methods based on Rotatori and Fox (1981). Frequent contacts with the parents/caretakers by the group leader. **(b) No Help group:** Behaviour change methods same as (a) but with no communication with the parents/caretakers. **Maintenance:** 5 weeks of practicing techniques identified as problematic.	14 weeks 12 months	**(a)** Mean weight change, kg:-2.5[b] **(b)** Mean weight change, kg:-1.2 Significant weight loss for both groups ($p < 0.01$) No significant between group difference Significant reduction in BMI, weight reduction quotient, % overweight for both groups ($p < 0.05$) **(a)** Mean weight change, kg:-1.5 **(b)** Mean weight change, kg:+0.5
Sailer *et al*. (2006) USA Community Uncontrolled Quasi-experimental study	Total n=6 Weight status : all obese Gender: 4 females, 2 males Age (years):34-54 ID: mild Attrition/drop out: none	**Duration:** 10 weekly group sessions (60min each) and phone call contacts. Behaviour change methods based on Rotatori and Fox (1981). **Maintenance:** none reported	10 week 1 month	Mean weight change, kg:-2.5 (range: +0.5 to -8.2) Mean weight change, kg: -1.5 (range: +2.26 to -5.9)

[a] data are mean values (SD)
[b] range not reported

The duration of the interventions varied from 10 to 14 weeks and they were all delivered in group sessions in the community (Fox *et al.* 1985; McCarran *et al.* 1990; Sailer *et al.* 2006). The intervention in only one study was delivered by an individual specialized in ID (McCarran *et al.* 1990). The remaining studies did not provide such information on the method of delivery.

Intervention components

a. Behaviour change

Behaviour change interventions based their intervention on the comprehensive behaviour self-control programme developed by Rotatori and Fox (1981). The intervention accompanied by a specific manual designed by Rotatori and Fox (1981) aims to change the eating habits, activity levels and self-reinforcement patterns of the participants by gradually introducing new behaviour change techniques. The process included seven main steps: 1) increase self-awareness of body weight, 2) control snacking frequency 3) control triggers that lead to overeating 4) adopt a healthy balanced diet 5) self-control of overeating 6) increase physical activity 7) consume low calorie foods(McCarran and Andrasik 1990).

Two key behaviour change techniques were the processes of self-monitoring and self-reinforcement. For this reason participants were asked to complete food diaries and reward themselves for achieving specific changes of their dietary habits. These included: control triggers that lead to overeating, meal consumption to one location in the home, consumption of only one portion of a meal, reducing the rate of eating, reducing snacking frequency, putting the utensils down after each bite, not consuming the whole meal and eating low calorie foods. Physical activity patterns were targeted by recommendation of simple changes in everyday activities (e.g. taking the stairs instead of the elevator). In addition, participants were given weekly homework assignments to ensure practice of the learned techniques at home. Reward strategies were used to support attendance at the sessions, and maintain encouragement and motivation to lose weight.

In a second study using the self-control programme parents had to assist the participants with daily homework and encourage them to practice what they have learned in relation to eating, activity and self-reinforcement (Fox *et al.* 1985). Parents were also involved with a weekly reward procedure and were asked to offer a reward for a weight loss. Another study involved carers by sending written material to them weekly (McCarran *et al.* 1990).

Two studies incorporated a weight loss maintenance intervention (Fox *et al.* 1985; McCarran and Andrasik 1990). In Fox *et al.* (1985) included a maintenance period comprising three-monthly meetings that focused on reviewing new eating and activity behaviours. However, the reward system was used to promote further weight loss during that phase. McCarran and Andrasik (1990) followed the weight loss intervention with a five week weight maintenance phase. During these twice-weekly, 60-minute maintenance training meetings the researchers continued to practice the techniques identified as problematic for the participants and promoted strategies that could help the participants to maintain any weight losses.

Study outcomes

None of these studies reported a clinically significant weight loss of 5-10% of initial body weight, or 5-10kg. Although McCarran and Andrasik (1990) reported a statistically significant weight reduction (p<0.01) this was only equal to 2.5kg at 14 weeks.

Fox *et al.* (1985) reported a mean weight loss of 3.4kg for the group with parent-involvement, which was significantly different from the group with no parent-involvement. However, McCarran and Andrasik (1990) found greater but not significantly different weight loss for participants that had their carers involved than the participants who did not.
Post intervention weight loss was not sustained with Fox *et al.* (1985) reporting weight regain at three and six months follow up.

Study Limitations

Limitations for the behaviour change intervention studies included no sample size justification, small sample size (ranging from six to 15) and no random allocation. The duration of follow up measurements was small with McCarran and Andrasik (1990) being the only study reporting 12 month follow. All participants completed the weight loss interventions in Fox *et al.* (1985) and Sailer *et al.* (2006). McCarran and Andrasik (1990) reported having incidents of drop outs (n=3) due to scheduling conflicts (n=2) and due to family related conflicts (n=1).

3.3.3 Behaviour change plus physical activity interventions

The studies in this section were behaviour change interventions that incorporated specific physical activity advice or a physical activity programme to support increased energy expenditure (see table 3.2).

The length of the interventions varied from eight to 10 weeks and they were delivered in the community (Fox *et al.* 1984; Fisher 1986). Fox *et al.* (1984) reported that the intervention was delivered by a researcher and a recreational therapist but Fisher (1986) did not report the profession of the person delivering the intervention.

Table 3.2. Behaviour change plus physical activity

Study/ Location/ Type	Participants	Intervention	Follow up	Results
Fox *et al*. (1984) USA Community Quasi-experimental study with a control group	**(a) Behaviour Therapy group (BT)** n=8 Weight status, % overweight [a] : 44.4 (35.4) Gender: 5 females, 3 males Age (years)[a] :29.5 (7.2) ID, IQ [a]:42.1 (8.4) **(b) BT + Buddy reinforcement** n=8 Weight status, % overweight [a] : 34.7 (18.3) Age, (years)[a]: 27.5 (5.4) ID, IQ [a] : 46.3 (12.1) Attrition/drop out: none	**Duration:** 10 weeks of 2 group sessions per week (60 min each) led by a researcher and a recreational therapist. **(a)** Behaviour change methods based on Rotatori and Fox.[18] Parents involved with intervention strategies e.g. homework, reward systems. Phone contacts were also included. **Activity:** calisthenics and aerobic exercises (2 times a day) plus walking and using stairs. **(b)** Same as (a) plus participants were paired into 4 buddy teams. **Maintenance:** 5 weekly meetings reviewing behaviour change strategies, applying reinforcement and reducing homework. Weight loss was still promoted.	10 week 15 week 52 weeks	**(a)** Mean weight change, kg:- 3.3 (range:+0.4 to + 7.26) % weight loss: 5.7 **(b)** Mean weight change, kg:-3.72 (range: +1.36 to +7.7) % weight loss:6.6 **(a)** Mean weight change, kg:-0.9 (range:+0.4 to -2.72) **(b)** Mean weight change,kg:-1.04 (range:+0.98 to -3.2) **(a)** Mean weight change, kg:-0.27(range:+2.25 to -3.6) from baseline **(b)** Mean weight change, kg:-1.8 (range:+2.7 to -14.8) Total 37.5% maintained weight. No significant between-group difference at 10 week, 15 week and 52 weeks follow up
Fisher (1986) USA Community Quasi-experimental study with a control group	Total n=17 Weight status: All obese Gender: All females Age (years) ≈ 20 ID: mild to moderate Attrition/drop out: none	**Duration:** 8 week group sessions **(a) Behaviour self-control group**: Behaviour change methods based on Rotatori and Fox[18] **(b) Behaviour self-control group plus physical activity:** Behaviour change methods same as (a). **Activity:** walking (10 min/day increased to 30min by week 8) **Maintenance:** none reported	8 week 4 week	**(a)** Mean weight change, kg : -1[b] **(b)** Mean weight change, kg:-0.6 No significant difference between (a) and (b) **(a)** Mean weight change, kg : +0.6[b] **(b)** Mean weight change, kg: +0.6 No significant difference between (a) and (b)

[a] data are mean values (SD)
[b] range not reported

Intervention components

a. Behaviour change

The behaviour change techniques used in both studies were based on the Rotatori and Fox programme (1981). However Fox *et al.* (1984) eliminated some of the common behavioural strategies including leaving food on plate after eating and conversion techniques of negative reinforcement to diminish cravings. In addition, the study had an illustration of the resources used (food record chart and the “eating habit” record) attached to the publication (Fox *et al.* 1984). Parents were involved the same ways as in Fox *et al.* (1985): support participants with the daily homework and to provide encouragement and reinforcing the main messages of the intervention. No parental involvement was reported in Fisher (1986).

Only Fox *et al.* (1984) included weight maintenance phase of five weeks that immediately followed the 10-week weight loss phase. The weight maintenance phase included meetings where behavioural strategies were reviewed, reinforcement techniques were continued but the daily activity of homework completion was used less intensively. Further weight loss was still promoted.

b. Physical activity

Fox *et al.* (1984) aimed to increase the energy expenditure of the participants by instructing them to perform calisthenics and aerobic exercises but Fisher (1986) focused on walking exercise (10 minutes of walk at the beginning of the intervention to 30 minutes of walk by the end).

Study outcomes

Fox *et al.* (1984) showed that the combination of physical activity and behavioural approaches could lead to weight loss greater than 5% at 10 weeks post intervention. However, Fisher *et al.* (1986) showed that incorporation of physical activity had no effect on weight loss.

Fox *et al.* (1984) also assessed the influence of “buddy reinforcement” in the process of weight loss phase reporting inconsistent contacts and no meaningful relationship was established with assigned partners. Therefore, “buddy reinforcement” had no effect on weight loss in this study.

Study limitations

Once more Fox *et al.* (1984) and in Fisher (1986) did not report power calculations and recruited small sample sizes (ranging from 16-17 participants). Both studies reported a random allocation to one of the two intervention groups studied but did not describe the process of random allocation. Contrary to Fisher (1986), Fox *et al.* (1984) included a 52 week follow up reporting a mean weight change of -0.6kg from baseline. No incidents of attrition were reported in both studies.

3.3.4 Dietary interventions

Dietary interventions all aimed to achieve weight loss with modification to the type, quantity and/or frequency of food and drink consumed to achieve and maintain a hypocaloric energy intake (SIGN 2010). The interventions did not report using behaviour change strategies or advising on appropriate physical activity interventions to assist weight loss (see table 3.3) (Antal *et al.* 1988; Bertoli *et al.*2008)

The intervention in Antal *et al.* (1988) took place in an institution but no information was reported regarding the profession of the people who delivered the intervention. Bertoli *et al.* (2008) reported that the intervention was delivered by a medical practitioner and a dietician in the community.

Table 3.3. Dietary interventions

Study / Location/ Type	Participants	Intervention	Follow up	Results
Antal *et al*. (1988) Hungary Institution Uncontrolled quasi-experimental study	Total n=92 inpatients, recruited:15 Weight status: All obese Gender: 10 females, 5 males Age (years)[a]: females: 38 (13), males: 44 (15) ID: mainly imbeciles and one Down syndrome Attrition/drop out: none	**Duration:** 9 months **Diet:** 30 day rotating menu of 1000 to 1100kcal energy content, containing 125g carbohydrate. Quantity of food was measured once a week. **Maintenance:** none reported	9 months	**Females:** Mean weight change, kg (SD): -16 (2.7) [b] Mean BMI change, Kg/m^2: -12.2 **Males:** Mean weight change, kg (SD): -13 (4.5) Mean BMI change, Kg/m^2: -6.7
Bertoli *et al*. (2008) Italy Community Uncontrolled quasi-experimental study	Total n= 37 Gender: 12 females, 25 males Age (years) [a] : 33.5 (9.2) Weight status: 6 obese/overweight ID: 13 with ID (9 Down syndrome, 4 cerebral palsy), the rest were only physically disabled Drop out: 65%, 24 participants (9 of which with ID)	**Duration:** 12 months of individual nutritional counselling led by doctor and dietician (60 min per session). Phone call consultations (15 min) every 3 months. **Diet:** Personalised dietary protocols based on healthy low fat eating and on LARN recommendations. Parents/ legal tutors of ID participants were asked to support participants e.g. dietary changes and completion of food diaries. **Maintenance:** none reported	12 months	For the 6 obese/ overweight participants at baseline: Mean weight change, kg (SD): -6.8 (4) (p=0.01) [b] Mean BMI change, kg/m^2 (SD): -2.4 (1.4) (p=0.008) Significant reduction in fat mass (p=0.008) No clarification if the 6 participants had ID.

[a] data are mean values (SD)
[b]range not reported

Intervention components

a. Diet

Antal *et al.* (1988) offered a very low calorie diet (1000 to 1100 kcal) to 15 participants with ID and obesity for nine months in the form of a 30 day rotating menu in an institutional setting. There was no further description of the content of the diet. Bertoli *et al.* (2008) offered one to one nutritional counseling to the participants for 12 months in the form of a personalised dietary plan based on their body composition, biochemical parameters and food intake. The plan was focused on the principles of a healthy balanced diet and a reduction in fat intake. Parents and tutors were asked to assist with food recording and facilitate change in dietary habits.

Study outcomes

Antal *et al.* (1988) reported a very high weight loss at nine months (mean weight loss:-13kg and -16kg, respectively). Bertoli *et al.* (2008) reported on the six participants who were classified as obese or overweight a statistically significant decrease in weight (-6.8kg) and BMI (p<0.05) at 12 months. However, there was no clarification of whether these individuals had an ID or not.

Study limitations

Neither of the studies used power calculations or randomization. The sample size ranged from 15 to 37 participants with Antal *et al.* (1988) offering the intervention to a heterogeneous sample of participants with physical disabilities or ID, and Bertoli *et al.* (2008) recruiting only six obese/overweight out of 37. The study did not investigate the impact of these factors on the results. All participants completed the intervention in Antal *et al.* (1988) but Bertoli *et al.* (2008) had a high dropout rate of 65%. The drop out was mainly attributed to lack of social support.

3.3.5 Physical activity interventions

Physical activity interventions provided specific exercise programmes and reported weight or BMI changes. The interventions did not report incorporating behaviour therapy or dietary advice to the participants (Rimmer *et al*. 2004; Moss 2009; Wu *et al*. 2010; Mendoca *et al*. 2011) (see table 3.4).

The majority of the studies (n=3), with the exception of Wu *et al*. (2010) provided a 12 week intervention. The interventions were delivered in group sessions by physiologists (Rimmer *et al*. 2004; Mendoca *et al*. 2011) or carers (Moss 2009). Wu *et al*. (2010) was the only physical activity intervention that took place in a disability institution and not in the community.

Intervention components

a. Physical activity

Physical activity interventions aimed to reduce cardiovascular risk factors, to improve physical fitness and muscular strength of adults with ID. For example Rimmer *et al*. (2004) developed a programme that incorporated regular cardiovascular exercise and activities to improve muscular strength and endurance and Mendoca *et al*. (2011) assessed the effect of aerobic and resistance exercise in exercise economy and peak exercise capacity in adults with Down syndrome.

None of the physical activity interventions included the prescription of 225-330min or more of moderate intensity physical activity per week to facilitate weight loss, as recommended again by clinical guidelines (NICE 2006; SIGN 2010). A total of 135-minutes per week were included in the physical fitness programme by Rimmer *et al*. (2004) and a total of 160-minutes per week by Wu *et al*. (2010). The type of activities varied and included sports, acrobatics, jogging, dancing or walking (Wu *et al*. 2010) treadmill walking, circuit exercises (Rimmer *et al*. 2004; Mendoca *et al*. 2011) and road walking (Moss 2009).

Table 3.4. Physical Activity interventions

Study/ Location/ Type	Participants	Intervention	Follow up	Results
Rimmer *et al.*[23] USA Community Quasi-experimental with a control	**(a) Exercise group** n=30 Weight status : 13% normal, 23% overweight, 64% obese Gender: 53% females, 47% males Age (years) [a] :38.6 (6.2) ID: all Down syndrome **(b) Control group** n=22 Weight status:14% normal weight, 9% overweight, 77% obese Gender: 59% females, 41% males Age (years) [a]:40.6 (6.5) ID: all Down syndrome, Attrition/drop out: none	**Duration:** 12 weeks of 3 exercise group sessions per week (45 min each) led by physiologists and assistants. **(a) Activity:** 30 to 45 min of cardiovascular exercise and 15 to 20 min of muscular strength and endurance. **Maintenance:** none reported	12 weeks	**(a)** Mean weight change, kg :-1 [b] **(b)** Mean weight change, kg: + 1.7 Significant between group difference (p<0.01)
Moss (2009) South Africa Community Uncontrolled quasi-experimental	Total n=100 Weight status, BMI[a] :29.3 (6.8) for females, 29 (8.5) for males Gender: 53 females, 47 males Age (years) [a]: 37.1 (10.1) for females, 39.2 (8.9) for males ID: Intellectually aged between 4-12yr old Attrition/drop out: none reported	**Duration:** 12 weeks of 3 days per week exercise group sessions. **Activity:** 20 min walking the first 4 weeks and completing 30 min of walking the final 4 weeks. **Maintenance:** none reported	3 months	Females: Mean BMI change, kg/m^2:-2.74[b] Males: Mean BMI change, kg/m^2: -3.1
Wu *et al.* (2010) Taiwan Institution Uncontrolled quasi-experimental	Total n=146 weight status: 31% obese, 16.9% overweight, 45.8% normal weight, 6.3% underweight Gender:- Age (years):19-67 ID: 3.4% mild, 30.8%, moderate, 33.6% severe, 32.2% profound, Attrition/drop out: none	**Duration:** 6 months of 4 times per week exercise group sessions (40 min each) led by institutional caregivers. **Activity:** Exercise sessions included sports acrobatics, jogging, dancing, and walking. **Maintenance:** none reported	6 months	Mean weight change, kg: -1.86 (p<0.001) [b] Mean BMI change, kg/m^2 :- 0.84 (p<0.001)
Mendonca *et al.* (2011) Portugal Community Quasi-experimental with a comparison group	**(a) Down Syndrome** n= 13 Weight status, BMI[a] : 29.3 (3.7) Gender: 3 females, 10 males Age (years): 27-50 ID: Down syndrome, mild -moderate ID **(b) No Down syndrome** n= 12 Weight status, BMI [a] : 26.6 (4.5) Gender: 3 females, 9 males Age (years): 27-50 ID: No ID , Attrition/drop out: none	**Duration:** 12 weeks of 3 days per week exercise group sessions led by physiologist and assistants. **Activity:** 2 days combined training separated by one day of endurance training (30min) :treadmill walking or running, dynamic exercises: leg press, chest press, vertical traction, shoulder press, lower back, leg extension, biceps curl, and triceps pushdown, abdominal curls **Maintenance:** none reported	12 weeks	**(a)** Mean BMI change, kg/m^2:-0.4[b] **(b)** Mean BMI change, kg/m^2: 0 No significant difference between (a) and (b)

[a] data are mean values (SD), [b]range not reported

Study Outcomes

None of these studies reported weight loss equal or greater than 5%. However, Wu *et al.* (2010) reported a statistically significant decrease in weight and BMI (p<0.001) at six months.

Despite the minimal effects of physical activity on the weight of the participants, the studies reported positive effects on the cardiovascular fitness, muscular strength, endurance (Rimmer *et al.* 2004), significant decrease in percentage of body fat (-8.0%) and decrease of physical inactivity by 50 % (Moss 2009) and improvement of walking economy (p<0.05) Mendoca *et al.* (2011).

Study limitations

The sample size in the physical activity interventions ranged from 25 to 146 participants. The samples of all of the studies and especially Wu *et al.* (2010) suffered from heterogeneity in relation to the nutritional status and the level of ID of the participants. For example the sample of Wu *et al.* (2010) included 45.8% of participants of normal weight and 6.3% of underweight participants, with levels of ID ranging from mild to profound. Similarly Rimmer *et al.* (2004) recruited participants with normal weight and obesity but all diagnosed with Down syndrome. Mendoca *et al.* (2011) reduced heterogeneity in the sample even more by recruiting participants with Down syndrome with mild to moderate levels of ID only.

Rimmer *et al.* (2004) used power calculations to determine sample size and was the only study that used random allocation. However, the random allocation was not adequately described. None of these studies provided follow up assessments of outcome measures. Mendoca *et al.* (2011) identified that lack of blinded assessors for the collection of the pre and post data could act as one of the limitations of the study.

3.3.6 Dietary plus physical activity interventions

This section includes interventions that provided advice to the participants on how to change their diet and physical activity but did not report using behaviour change techniques to promote the changes (see table 3.5) (Marshall *et al*. 2003; Bradley 2005; Chapman *et al*. 2005, 2008).

The duration of the interventions varied from six weeks to 12 months and were all led by health professionals e.g. nurses (Marshall *et al*. 2003), dieticians (Bradley 2005) or physiotherapists (Chapman *et al*. 2005). The interventions were community based and mainly delivered in group sessions with one exception (Chapman *et al*. 2005).

Intervention components

a. **Diet**

Three studies that reported providing advice or information in diet and physical activity could be also classified as health promotion or health education interventions (Marshall *et al*. 2003; Bradley 2005; Chapman *et al*. 2005). Bradley (2005) and Marshall *et al*. (2003) used educational material covering healthy eating as part of the content. Specifically, Marshall *et al*. (2003) used an adapted content from the "activate materials" produced by the health promotion agency in Northern Ireland, designed to improve healthy eating and exercise patterns.

b. **Physical activity**

Both studies did not report sufficient information regarding advice on physical activity. Chapman *et al*. (2005) developed activity plans in conjunction with support staff and relatives and offered advice on diet but with insufficient description of the information provided.

Table 3.5. Dietary plus physical activity

Study/ Location/ Type	Participants	Intervention	Follow up	Results
Marshall *et al*. (2003) UK Community Uncontrolled quasi-experimental study	Total n=25 Weight status: 12% obese, 32% very obese, 36% overweight, 20% normal weight and underweight Gender:68% males, 32% females Age (years): 30-39 (60%), 12% in their 40s, 12% in their 50s, 12% >60 ID: Down's syndrome (32%) Attrition/drop out: one	**Duration:** 6 weekly group sessions (2hr each) led by nurses. **Diet:** healthy eating. **Activity:** advice to be active **Maintenance:** none reported	6 weeks	(n=20 Overweight and obese participants) Mean weight change, kg : -3.4 (p<0.001) [b] Mean BMI change, kg/m^2:-1.6
Bradley (2008) UK Community Uncontrolled quasi-experimental study	Total n=9 Weight status: 8 out of 9 obese Gender: all females Age (years): over 18 ID: not reported Attrition/drop out: none	**Duration:** 12 months of 34 group sessions (90min to 2hr each) led by a dietitian. **Diet:** information on healthy balanced diet. Food preparation and supermarket visits included. **Activity:** insufficient information. **Maintenance:** none reported	12 months	(n=7) Mean weight change, kg: -6.2 (range: 2.2 to -15.5) Mean BMI change, kg/m^2:-3
Chapman *et al*. (2005.2008) UK Community Quasi-experimental study with a comparison group	Gender: 43% women, 57% men **(a) Intervention group:** n= 38 Weight status: 97% obese and overweight Age (years)[a]: 37.13 (8.75) ID :not reported Attrition rate (1-6 years): 13% **(b) No intervention group:** n= 50 Weight status : 64% obese and overweight Age (years)[a] :43.32 (10.97) Attrition rate (1-6 years): 13% for (a), 20% for (b).	**Duration:** unclear **(a)** Individual sessions led by physiotherapist. **Diet:** advice (no details reported). **Activity:** designed activity programme. Carers were involved in the improvement of lifestyle. **Maintenance:** none reported **(b)** No input	6 months 12 months 6 years	**(a)** Mean BMI change, kg/m^2:-0.32 [b] **(b)** Mean BMI change, kg/m^2: +0.35, (p<0.05) **(a)** Mean weight change, kg:-1.52[b] Mean BMI change, kg/m^2: -0.61 (p<0.05) 42% reached > 1.6kg weight loss **(b)** Mean BMI change, kg/m^2:+ (p<0.05) **(a)** (n= 40), Mean BMI change, kg/m^2:-1.02, Mean weight change, kg: -2.42 (range: -28.13 to 14.49, SD 9.15). **(b)** (n=33), Mean BMI change, kg/m^2:+0.16 Mean weight change, kg: +0.61(range: -18.62 to 16.37, SD 8.81)

[a] data are mean values (SD)
[b] range not reported

Study outcomes

Bradley (2008) reported a weight loss greater than 5kg at 12 months but with no description of statistical analysis used. Marshall *et al.* (2003) reported a significant weight loss ($p<0.001$) for the obese and overweight participants (20 out of 25) at six weeks and Chapman *et al.* (2005) did not report weight changes but reported significant decrease in BMI at six months. After a six year follow up the mean BMI decreased by 1.02kg/m^2 but not significantly for the group that received the intervention and mean BMI increased by 0.16 for the group that did not receive an intervention Chapman *et al.* (2008).

Study limitations

The sample size in the dietary and physical activity interventions ranged from nine to 25. No power calculations or randomization procedure were reported in any of these studies. A major limitation of all three studies was the insufficient description of the intervention components reducing their reproducibility. Similar to other studies in adults with ID, samples were heterogeneous with Marshall *et al.* (2003) recruiting obese, overweight and normal weight participants and Chapman *et al.* (2005) recruiting mainly obese and overweight participants (97%) but not reporting their level of ID.

All participants completed the intervention of Bradley (2008), one person dropped out in Marshall *et al.* (2003)(no reasons reported) and 16 people were excluded from the data analysis of Chapman *et al.*(2005) because of no data available for all time points of measurements or due to extreme weight changes not attributed to the intervention.

Chapman *et al.* (2008) included follow up measurements at six years, with 13% attrition reported for the intervention group and 20% for the usual care group. The study provided a detailed explanation of the attrition, mainly attributed to death or relocation.

3.3.7 Multi-component interventions

The studies in this section are multi-component interventions defined as "a combination of diet and physical activity with a behaviour change strategy to influence lifestyle" (Loveman *et al*. 2011) (see table 3.6) (Jackson and Thorbecke 1982; Harris and Bloom 1984; Ewing *et al*. 2004; Mann *et al*. 2006; Bazzano *et al*. 2009; Geller and Crowley 2009; Melville *et al*. 2011; Saunders *et al*. 2011)

The majority of the multi-component weight loss interventions (n=6) were delivered in group sessions with the exception of the two most recent studies that offered individual interventions (Melville *et al*. 2011; Saunders *et al*. 2011). The qualifications of those who delivered the interventions varied but included health professionals specialized in ID e.g. health educators (Ewing *et al*. 2004) physicians (Geller and Crowley 2009) and dietitians (Melville *et al*. 2011; Saunders *et al*. 2011)

Intervention Components

a. Diet

Two studies included energy deficit diets as part of the intervention (Melville *et al*. 2011; Saunders *et al*. 2011). Melville *et al*. (2011) recommended dietary change based on a personalised dietary prescription that was calculated to achieve an energy deficit of 600 Kcal (2510 kJ) per day and a weight loss of 0.5 kg to 1 kg/week. Saunders *et al*. (2011) recommended a low calorie diet of 1200 to 1300 kcal (5024 to 5442 kJ) per day focusing on the consumption of high volume foods that provide the sensation of fullness (Volumetrics). The dietary intervention also included meal-replacement shakes providing 110 calories per serving and a "Stoplight Guide" classifying food into three coloured categories: green for less than 60 calories, yellow for 60 to 100 calories and red for over 100 calories.

Other studies that included a dietary change component include two studies that offered home visits to the participants to develop individualized dietary plans

(Ewing *et al.* 2004; Mann *et al.* 2006). One study provided dietary information based on the Diabetic Exchange Diet (Harris and Bloom 1984). The rest of the studies provided limited information about the nutritional advice that was offered to the participants. These studies mainly took the form of health education programmes providing general information regarding healthy dietary habits and patterns e.g. healthy meal planning (Jackson and Thorbecke 1982; Bazzano *et al.* 2009; Geller and Crowley 2009). Cooking classes, meal planning and grocery store visits were common activities relevant to diet among the interventions (Mann *et al.* 2006; Bazzano *et al.* 2009; Geller and Crowley 2009; Saunders *et al.* 2011).

b. Physical Activity

None of the multi-component studies provided an exercise programme that promoted 225-300min or more of moderate intensity physical activity per week (NICE 2006; SIGN 2010). Five of the studies incorporated physical activity programmes (sometimes optional) as part of the intervention sessions, offering dancing, aerobic exercises and walking (Harris and Bloom 1984; Mann *et al.* 2006; Bazzano *et al.* 2009; Geller and Crowley 2009; Saunders *et al.* 2011).

Ewing *et al.* (2004) and Mann *et al.* (2006) offered a home visit to develop an individualized physical activity programme for the participants.

Jackson and Thorbecke (1982) provided advice to make simple lifestyle changes e.g. taking the stairs instead of the lift and Melville *et al.* (2011) recommended that participants work towards 30 minutes of moderate intensity physical activity, on at least five days per week.

As part of the intervention Melville *et al.* (2011) used a specially designed DVD aiming to motivate participants to become more active while Geller and Crowley (2009) used an exercise video. Both resources included only people with ID. In addition, Melville *et al.* (2011) provided participants with information regarding local leisure centers that they could attend. Pedometers were also used to motivate participants to be more active through walking (Melville *et al.* 2011; Saunders *et al.* 2011).

c. Behaviour change

The behaviour change techniques that were used as part of the multi-component interventions included goal setting, strategies to improve motivation, problem solving, stimulus control and relapse prevention strategies (Harris and Bloom, 1984; Ewing *et al*. 2004; Mann *et al*. 2006; Melville *et al*. 2011). Geller and Crowley (2009) mainly focused on empowering the participants by enhancing their ability to make choices and by creating feelings of community and success in groups. Self-monitoring was facilitated with weight and food diaries (Jackson and Thorbecke 1982; Melville *et al*. 2011; Saunders *et al*. 2011) and reward systems were used to motivate behavioural change (Jackson and Thorbecke 1982; Bazzano *et al*. 2009; Saunders *et al*. 2011).

Harris and Bloom (1984) and Bazzano *et al*. (2009) invited the main carers of all participants to be present during the sessions of the weight loss intervention. However, no description of their role was reported in the study. Saunders *et al*. (2011) asked carers to assist participants when they appeared to be having difficulties to respond to specific questions. Jackson and Thorbecke (1982) described a similar role for the parents to Fox *et al*. (1984, 1985) but parents were also instructed to deliver punishment statements when participants ate “prohibited foods” or withdraw a reward if weight increased. Melville *et al*. (2011) also invited the carers to be present at the sessions, assisting the consultation where appropriate, encouraging the participants during the weight loss process.

Saunders *et al*. (2011) was the only multi-component intervention that recommended to participants at the conclusion of the dietary intervention ways of increasing calorie intake to prevent further weight loss. This was followed by a six month less intensive phase, involving monthly meetings but discontinuing the request that participants complete food and exercise records, stopping the supply of low calorie shakes and the incentive rewarding.

Table 3.6. Multi-component interventions

Study/ Location/ Type	Participants	Intervention	Follow up	Results
Jackson and Thorbecke (1982) Australia Community Quasi-experimental study with a control group	Gender: all females **(a)Treatment group** n= 6 Weight status: 10% overweight Age (years), mean: 21.8 ID, mean IQ : 38.17 **(b) Control group** n=6 Age (years), mean: 23.5 ID, mean IQ :40.33 Attrition/drop out: none	**Duration:** 14 weeks of every 2 weeks group sessions (60min each) led by a teacher. **(a)** 7 sessions with the parents, 6 sessions with group members and the teacher. **Diet:** Advice on healthy eating diet, avoid fad diets. **Activity:** General advice on physical activity e.g. using stairs instead of elevator. **Behaviour:** self-monitoring, reward, punishment, change of rate of eating, reinforcement. **Maintenance**: none reported **(b)** No intervention	17 weeks 3 month 6 month 12 month	**(a)** Mean weight change, kg: -5.75[b] **(b)** Mean weight change, kg:-0.59 **(a)** Mean weight change, kg :-6.25 **(b)** Mean weight change, kg :-0.59 **(a)** Mean weight change, kg: -6.08 **(b)** Mean weight change, kg: +0.33 **(a)** Mean weight change, kg: -7.33 **(b)** Mean weight change, kg: 0.00 Significant weight reduction of (a) across all the follow up
Harris and Bloom (1984) USA Community Quasi-experimental study with a comparison group	Total n= 21 Weight status:- **(a) Completers** n=10 Gender: 8 females, 2 males Age (years) [a]: 22.7(6.37) ID, IQ [a] : 52.5 (12.80) **(b) Non completers:** 11 Attrition/drop out: 11	**Duration:** 7 weekly group sessions and 1 hour booster session 26 weeks after the first session. **(a) Diet:** education on healthy balanced diet, distinguishing high and low calorie foods, diabetic exchange diet (ADA, 1977). **Activity:** 5-10 min aerobic exercise at the end of session. **Behaviour:** stimulus control, self-monitoring, self-reinforcement, goal setting, self-contacting. Carers attended the sessions. **Maintenance:** none reported	7 week 12 months	**(a)** Mean weight change, kg:-3.0 (p<0.05) [b] **(a)** Mean weight change, kg :-0.76 **(b)** Mean weight change, kg :+2.39 (p<0.05) (p<0.05)
Ewing *et al*. (2004) USA Community Quasi-experimental study with a comparison group	**(a) participants with ID** Total n= 154, final n= 92 Weight status, BMI[a] : 35.4 (7.0) Gender: 54.4% females Age (years) [a] : 39.7 (11.5) ID, IQ[a] : 50.2 (14.3) Attrition/drop out: 18.8% **(b) no ID** Total n= 270, final n= 97 Weight status, BMI[a]:38.4 (8.6) Gender: 84.5% females Age (years) [a]:49.9 (11.48) Attrition/drop out: 30%	**Duration:** 8 week intervention. The “HELP” intervention (Health Education Learning Program) led by health educators. 8 group sessions and 2 to 4 home visits. **Diet:** a home visit to develop dietary plan and do a grocery visit. **Activity:** a home visit to develop an exercise programme e.g. walking routes, optional brisk walk after the sessions. **Behaviour:** motivation to change, relapse prevention, avoidance of “automatic thinking”. **Maintenance**: none reported	2 months	**(a)** Mean BMI change, kg/m^2 : 0 [b] **(b)** Mean BMI change, kg/m^2: -0.89 No significant difference between (a) and (b)

[a] data are mean values (SD)
[b]range not reported

Table 3.6. Multi-component interventions cont.

Study/ Location/ Type	Participants	Intervention	Follow up	Results
Mann *et al*. (2006) USA Community Uncontrolled quasi-experimental study	Total n=324, available data for 192 Weight status, BMI[a] : 35.38 (6.85) Gender:66.7% females, 33.3% males Age (years) [a] : 38.6 (11.5) ID, IQ[a] : 50.7 (13.3) Attrition/drop out: 20%	**Duration:** 8 weekly group sessions (90min each) using health education "Steps to Your Health" led by trained staff . home visits. **Diet:** individual dietary plan and a grocery store visit. **Activity:** optional brisk walking and individual exercise programme. **Behaviour:** motivation to change, relapse prevention, barriers to change. **Maintenance:** none reported	9 weeks	Mean BMI change, kg/m^2 : -0.31[b] (p<0.05)
Bazzano *et al*. (2009) USA Community Uncontrolled quasi-experimental study	Total n= 85 signed up, 44 completers Weight status: 36.4% overweight, 38.6% obese, 18.2% very obese Gender: 61% females, 39% males Age (years): 18-59 ID: 68% mental retardation, 25% ≈mental retardation, Cerebral palsy, epilepsy, and autism diagnosed in 15% to 20% Attrition/ drop out: 35%	**Duration:** 7 months of 2 weekly group sessions (120 min each) led by professionals specialized in ID. "The Healthy Lifestyle Programme" focusing on health education and peer mentoring. Phone calls included. **Diet:** education and cooking demonstration. **Activity:** education and supervised physical activity (90min). Exercise in local parks and fitness facilities. **Behaviour:** behaviour modification and reward systems. Carers were encouraged to attend the sessions. **Maintenance:** none reported	7 months	Mean weight change, kg:-1.2 (p<0.05) [b] Mean BMI change, kg/m^2: -0.5 (p<0.05) [b]
Geller and Crowley (2009) USA Community Uncontrolled quasi-experimental study	Total n= 45 Gender: 25 females, 18 males Weight status: obese/ overweight:- Age (years): average 42.6 ID: not reported Attrition/ drop out: 2 dropped out, 14 completed 18 month measurements	**(a):** Empowerment model. 1st year: Twice weekly sessions led by a physician (60min each): Group and individual sessions based on the" Funk" model. **Diet:** meal planning, cooking demonstrations. **Activities:** music chairs, dancing, exercise to music. **Behaviour:** Activities creating feelings of community, feelings of success and of being important. **(b):** 2nd year, once weekly group sessions -same as (a) **Weight maintenance:** none reported	2 months 6 months 12 months 18 months	**(a)+(b)** (n=43) Mean weight change, kg:-0.26[b] **(a)+(b)** (n=38) Mean weight change, kg:-0.78 **(a)+(b)** (n=36) Mean weight change, kg:-0.74 **(a)+(b)** (n=14) Mean weight change, kg:-2.73
Melville *et al*. (2008) UK Community Uncontrolled quasi-experimental study	Total n= 54 Weight status, BMI[a] : 40 (8.03) Gender:40.7 % males, 59.3% females Age (years) [a]:48.3 (12.01) ID: 31.5% mild, 31.5% moderate, 35.2% severe, 1.9% profound. Attrition/drop out: 3 dropped out, 4 non completers on time	**Duration:** 6 months of 9 sessions every 2-3 weeks individual consultations (45-60min each) based on the GCWMS led by a dietician and a medical graduate. **Diet:** 600kcal/d energy deficit diet. **Activity:** aim for 30min of moderate physical activity for 5 days per week. **Behaviour:** goal setting, problem solving, cue avoidance, stimulus control. Carers were encouraged to assist if needed. **Maintenance:** none reported	6 months	Mean weight change, kg (SD): -4.47 (4.45) (p<0.0001) [b] Mean BMI change, Kg/m^2:-1.82 (p<0.0001)

[a] data are mean values (SD)
[b]range not reported

Table 3.6. Multi-component interventions cont

Study/ Location/ Type	Participants	Intervention	Follow up	Results
Saunders *et al*. (2011) USA Community Uncontrolled quasi-experimental study	Total n= 79 registered, Weight status: mean BMI 38.0 Gender: 41% males, 59% females (6 month completers) ID: not reported Attrition/drop out: 73 six month completers, 43 twelve month completers	**Duration:** 6 months of one individual session (60-90min) and monthly consultations (30min each) led by dietician, behaviour analysts, physiologists. **Diet:** a 1200 to 1300kcal/d diet based on volumetrics, at least 5 portions of fruits and vegetables; up to three low-calorie, meal/snack-replacement shakes; two packaged entrees of less than 300 calories each and other low calorie items, 2 shake mixes from Health Management Resources (HMR) daily (110kcal per serving). **Activity:** Optional. A game board aiming to increase number of steps. **Behaviour:** praise, problem solving, reward system. Carers could assist if needed. **Maintenance:** 6 months of less intensive meetings. Weight loss could continue if wanted.	6 months	(n=73) Mean weight change, kg:-6 [b] Mean BMI change kg/m^2 ≈-2.7 % mean weight loss: 6.3

[a] data are mean values (SD)
[b]range not reported

Study outcomes

All of the multi-component interventions reported a decrease in weight, or BMI but it appears that the biggest weight loss was that reported by the two interventions that recommended energy deficit diets (Melville *et al.* 2011; Saunders *et al.* 2011). At six months follow up Saunders *et al.* (2011) reported a 6.3% weight loss from baseline and Melville *et al.* (2011) reported a mean weight loss of 4.3%. Melville *et al.* (2011) reported that 36% of the participants reached a 5% weight loss. An intervention that involved the parents of the participants intensively reported a 6.07% weight loss at week 17 and a total weight loss of 10.36% from baseline, at 12 months (Jackson and Thorbecke 1982). The weight loss (5.75kg) in adults with ID that completed the intervention was significantly different from the controls (0.59kg) that were not offered an intervention ($p<0.05$).

Study limitations

The majority of the studies of multi-component weight loss interventions recruited small numbers of participants not based on pre-treatment sample size estimations (n=12-192), and included obese and overweight participants, based on BMI scores. Only one study limited inclusion criteria to participants with obesity (Melville *et al.* 2011). No power calculations and no randomization were used by any of the multi-component studies.

Two studies reported weight changes at follow up at least 12 months from baseline (Jackson and Thorbecke 1982; Harris and Bloom 1984). All of the multi-component studies reported attrition or dropout rates with the highest attrition rate up to 35% (Saunders *et al.* 2011). Bazzano *et al.* (2009) reported that barriers to attendance included lack of motivation to exercise, transportation, childcare, conflicting work schedules, and language translation needs. Ewing *et al.* (2004) showed that when home visits were added to the analysis of attendance at more than four classes of the intervention, attendance was higher among the group with home visits (87%) compared with those without a home visit (79%).

3.4 Discussion

Inconsistency in the methodology of the studies and insufficient information regarding the components of the interventions used made their classification into a specific category difficult. The physical activity and behaviour change components of the interventions were more clearly described in most of the studies in comparison with the dietary aspects of the interventions. This limitation can affect the reproducibility of the studies and has been also identified in weight management studies for adults without ID (Loveman *et al.* 2011).

What components are included in weight loss interventions for adults with ID?

Several clinical guidelines recommend that obesity management interventions should use a multi-component model that incorporates advice on dietary behaviour and physical activity patterns (NIH 2000; NICE 2006; SIGN 2010; Loveman *et al.* 2011) and should also include behaviour change techniques to help individuals achieve sustainable changes in these lifestyle areas. However, few studies (n=8) were classified as multi-component interventions in this review.

A 600kcal energy deficit is identified as a realistic amount of energy deficit that can lead to a loss of adipose tissue and sustained weight loss of 0.5kg per week, ensuring a better compliance from individuals with obesity (Wynne *et al.* 2005; Frost *et al.* 2007;). However, very few studies in this review used energy deficit diets with Melville *et al.* (2011) being the only study that offered a 600kcal energy deficit diet to the participants. The lack of studies examining the effectiveness of energy deficit diets in this population group may be related to the challenging issues that may arise implementing a significant change in the routine of an individual with ID, especially when the individual has autism (Emerson and Baines 2010). It is possible that researchers and carers may consider that a healthy balanced diet will not disturb the dietary patterns of an individual with ID to a great extent and will not cause distress. However, a 600kcal energy deficit diet can be based on the same principles as a healthy balanced diet requiring small changes for a small sustained weight loss. This issue has not been investigated by other studies or reviews but a qualitative investigation on the opinions and beliefs of researchers and carers could provide an explanation.

The benefit of physical activity in the management of obesity depends on the amount and the intensity of the intervention (Jakicic and Otto 2005; Catenacci and Wyatt 2007). Clinical guidelines for the treatment of obesity recommend more than 225-300kcal min per week of moderate intensity physical activity (NICE 2006; SIGN 2010). None of the studies provided an exercise programme that followed these recommendations. However, this amount of exercise may not be realistic for adults with ID, a population group with a very sedentary behaviour (Matthews et *al*. 2011) and resistant to change daily routines (Mahy *et al*. 2010). This means that adults with ID may require longer periods to reach and sustain this amount of daily physical activity than adults without ID.

Behaviour change techniques in weight management aim to support and maintain changes in cognitive behaviour, leading to a change in eating habits or activity patterns of individuals with obesity (NICE 2006). Most common behaviour change techniques used in studies for adults with ID in this review are the same with those identified in interventions for adults without ID: self-monitoring, goal setting, reward strategies and relapse prevention (Shaw *et al*. 2005; McTigue *et al*. 2003; Avenell *et al*. 2004; Jacob and Isaac 2012). However, contrary to the behaviour change techniques used in weight management interventions for adults without ID (Loveman *et al*. 2011) the intervention for adults with ID did not state if they were based on a specific theory (e.g. stages of change of the Transtheroytical model of change or the Social Cognitive theory).

Several studies in this review reported that carers were involved at different levels with poor description of their role and with only three of them describing the impact of their involvement on weight loss (Jackson and Thorbecke 1982; Fox *et al*.1985; McCarran and Andrasik 1990). Willner *et al*. (2004) reported that carers can have a vital role in motivating individuals with ID in the process of cognitive therapy and readiness to change. This was supported by Spanos *et al*. (2012) that explored in depth the role and the experiences of the paid and family carers that participated in Melville *et al*. (2011). According to the qualitative study the carers provide encouragement and praise to the participants in a weight loss intervention and assist in the process of goal setting, essential mechanisms for behaviour change in obesity management.

The majority of the interventions were delivered in group sessions. Group sessions could be regarded as more preferable due to improved cost effectiveness (Renjilian *et al*. 2001) but there is insufficient evidence to support the effectiveness of group therapy for weight management versus individual therapy (Avenell *et al*. 2004; Greaves *et al*. 2011). No studies in this review explored or commented on which method is the most suitable way of delivering a weight loss intervention for adults with ID.

To reduce health inequities that adults with ID frequently experience while using health services (Campbell and Martin 2010) weight loss interventions should be made accessible by tailoring the intervention to the cognitive, communication and literacy abilities of adults with ID (Ziviani *et al*. 2004). Some of the reviewed studies highlighted the importance of developing an intervention based on the needs of the people with ID by describing the resources and the adaptations that had to be followed (Fox *et al*. 1984; Marshall *et al*. 2003; Melville *et al*. 2011).

Are weight loss interventions for adults with ID associated with a clinically significant weight loss (5-10% weight loss from initial body weight)?

Even though there were studies that did not report robust statistical analysis, the majority of the studies reported weight loss based on weight or BMI. Some studies reported changes in waist circumference (Bradley 2008; Jackson and Thorbecke 1982; Melville *et al*. 2011; Saunders *et al*. 2011) or waist hip ratio (Bertoli *et al*. 2008; Moss 2009) but the results are not reported in this review.

According to clinical guidelines for obesity and weight management, for individuals with BMI 25-35 kg/m^2 with no comorbidities present a 5-10% weight loss (approximately 5-10kg) is required for the reduction of obesity related health risks(NIH 2000; NICE 2006; SIGN 2010). Three studies reported a clinically significant weight loss within six months: one behaviour change and physical activity intervention (Fox *et al*. 1984), and two multi-component interventions

(Jackson and Thorbecke 1982; Saunders *et al*. 2011). Other studies reported a clinically significant weight loss at nine months (Antal *et al*. 1988) and at 12 months (Bertoli *et al*. 2008; Bradley 2005). Limitations and the differences in methodology and intervention components do not allow comparisons or support of the effectiveness of these studies. However, the lack of energy deficit diets and the lack of recommended levels for physical activity, may explain the poor weight loss outcomes in these studies.

Do interventions include a weight loss maintenance component?

Weight loss maintenance following a weight loss intervention is important, showing that individuals who have lost weight and maintained their weight have made sustainable lifestyle changes that will prevent future weight gain or health risks (NIH 2000; NICE 2006; SIGN 2010). However, research for weight management in the general population has mainly focused on the development and evaluation of weight loss strategies and has not examined extensively the effectiveness of weight maintenance interventions that follow a weight loss phase (Stevens *et al*. 2006). Only four studies out of the 22 in this review offered a structured weight loss maintenance intervention (Fox *et al*. 1984, 1985; McCarran and Andransik 1990; Saunders *et al*. 2011), with weight loss being still promoted in two of these studies (Fox *et al*. 1984, 1985).

Methodological limitations

A major limitation of this literature is the absence of sample justifications (not powered) and small sample sizes (ranging from six to 192). A review of 20 studies in this population group showed that lack of direct contact when inviting individuals with ID to participate in a study, inclusion of invasive procedures such as blood testing and the procedures of taking consent lead to a poor participation in the studies for adults with ID (Cleaver *et al*.2010)

Only two studies recruited participants from institutional settings (Antal *et al*. 1988; Wu *et al*. 2010) and the rest from community settings. Samples were usually heterogeneous, especially in relation to the level of ID. Some studies used strict inclusion criteria and offered an intervention only to participants that had mild to moderate ID and others offered an intervention to participants with a variety of ID. This may have an impact on the level of support from the carers leading the studies to generalisations of the effectiveness of their intervention. Level of ID was reported as mean IQ scores (Ewing *et al*. 2004) or percentage of mild, moderate and profound ID (Melville *et al*. 2011) or not reported (Bradley 2008; Chapman *et al*. 2005).

The same pattern of sample heterogeneity was also seen in relation to the weight status of the participants. For example Melville *et al*. (2011) delivered a multi-component weight loss intervention to obese participants only but Chapman *et al*. (2005) offered a diet and physical activity intervention to a group of participants who were normal weight or were obese or overweight (64%) and Wu *et al*. (2010) to a sample group that included normal weight and underweight participants. Most of the studies provided the same intensity of intervention to participants that were obese, overweight and sometimes normal weight. According to clinical guidelines(NICE 2006; SIGN 2010) the intensity of a dietary intervention (600kcal energy deficit) can be the same for overweight and obese individuals but the intensity of the physical activity intervention and the targets of weight loss may need to change based on the BMI and the associated risks of an individual.

Only four studies reported using randomised allocation (Jackson and Thorbecke 1982; Fox *et al*. 1984; Fisher 1986; Rimmer *et al*. 2004). Allocation concealment to the intervention or control groups was unclear for all these studies. RCTs are regarded as the most “powerful tool” in research, especially for the evaluation of healthcare interventions (Cleaver *et al*. 2010). However, it is essential for these studies to explain the process of random allocation because a detailed description ensures that these studies are truly randomized aiming to reduce the potential for bias (Bowling 2002). For example, studies that report of being randomized but not reporting using a method of concealment and have allocated participants by using the date of birth (odd and even numbers) are not regarded as randomized (CRD 2012).

There was no consistency in the duration of the interventions varying from two months to 12 months. According to a recent clinical guideline (SIGN 2010) most individuals are able to lose weight actively for about three to six months and so studies reporting 'weight loss' at 12 months actually measure a mixture of weight loss and weight maintenance.

According to the clinical guidelines, the effectiveness of weight loss interventions is also associated with the duration that the weight loss is maintained (NIH 2000; NICE 2006; SIGN 2010). This aspect of weight management can be evaluated with long term follow up measurements after the intervention. However, the longest follow up measurements reported in this review were by Chapman *et al.* (2009) at six years followed by one study reporting measurements at 18 months (Geller and Crowley 2009) and four at 12 months (Fox *et al.* 1984 McCarran and Andrasik 1990; Jackson and Thorbecke 1982; Harris and Bloom; 1984)

High attrition levels are common incident among weight loss interventions, with a usual attrition rate range of 30%-60% (Douketis *et al.* 2005). Attrition is used to judge the acceptability of interventions, as it often reflects participants' high weight loss expectations and low initial weight loss (Moroshko *et al.* 2011). The majority of the studies included in this review did not report a high dropout or attrition rate with the exception of one dietary intervention and a multi-component intervention (Bertoli *et al.* 2008; Saunders *et al.* 2011)

Limitations of the review

One of the limitations of this study is that data extraction and evaluation of the studies was not performed separately and independently by two researchers. Using two independent researchers is an unbiased and reliable method. Disagreements should be noted and resolved with the use of third researcher. In addition, the reviewers should have been blinded from the title of the journal and the author details. However, time constraints and resources need to be taken into consideration when performing a systematic review.

A second limitation is that this systematic review is the restriction to electronic databases only. This could lead to publication bias by not identifying studies that have been published in peer reviewed journals. However, this review has identified a greater number of studies than those identified from other reviews.

One of the great difficulties in the review of weight management interventions is the classification of an intervention to a category (e.g. multi-component, physical and dietary interventions) but also the description of their components (e.g. behaviour change). The process can be seen as quite biased and subjective but this is a difficulty that has been also identified in other reviews where different definitions have been used, especially for the multi-component interventions. However, this review described and evaluated the components of each intervention using specific recommendations of national and international guidelines, a method that has not be used in other reviews of this area of research.

Chapter 4 General Methods

4.1 Introduction

TAKE 5 is an uncontrolled pre-post, follow up pilot study. It is a multi-component weight management intervention specifically designed for adults with ID and obesity (Melville *et al*. 2011).

The primary aim of the study was to support participants to deliver a statistically significant decrease in weight (kg) followed by secondary aims including:

- a mean weight loss of 5% of their initial body weight
- a statistically significant increase in the levels of physical activity
- a statistically significant reduction in time spent in sedentary behaviour

The TAKE 5 weight management intervention included two phases:

- Phase 1: weight loss intervention
- Phase 2: weight maintenance intervention

The intervention was based on the weight management programme of the Glasgow and Clyde weight management service (GCWMS), of NHS Greater Glasgow and Clyde.

4.2 Greater Glasgow and Clyde Weight Management Service

The strategy for NHS Greater Glasgow and Clyde to weight management is subdivided into three tiers/levels. The GCWMS was developed in 2004 forming the third tier of NHS between primary prevention (including local authorities) and bariatric surgery for adults with a BMI≥30kg/m^2 with co-morbidities (including sleep apnoea, diabetes, poorly controlled hypertension or poor mobility) or a BMI≥35kg/m^2 with no co-morbidities. The service that provides a structured weight management pathway to surgery comprises of three phases:

- Phase 1: 16 week-group multi-component weight management programme (nine fortnightly sessions). Each session lasting approximately 1.5 hours
- Phase 2: lower-energy structured diet or pharmacological treatment for those that did not maintain weight loss of at least five kg
- Phase 3: weight maintenance. Learning to keep the weight off

Phase 1: weight loss programme

The target weight loss in Phase 1 is 5-10kg (11.5lbs to 21lbs). This means a steady weight loss of 0.5-1kg (1-2lbs) a week. Phase 1 has the following structure:

Diet

- Personalised Dietary Prescription (PDP) (600 kcal Deficit Diet)

Activity

- Increase incidental lifestyle activity
- Increase structured activity

Psychology

- Facilitating behaviour change
- Enhancement of motivation
- Disordered eating
- Cognitive Behaviour Therapy

Topics covered by session in Phase 1 include:

1. The balance of good health, benefits of weight loss, goal setting, setting a target weight, lifestyle diaries
2. PDP, physical activity, taking control of diet
3. Menu planning, shopping and food labelling, binge eating
4. Healthy cooking, take-aways, changing habits and social pressure
5. Unhelpful thinking, mood and overeating
6. Cravings vs. hunger

7. Diet myths, stay motivated to be active, body image
8. Review lifestyle changes, lapses and relapses
9. Principles of weight maintenance and options for phase 2 and phase 3

Phase 2: Low calorie diet or pharmacotherapy

Individuals that did not lose five kg at phase 1 are offered a LCD of 1500 calories per day and meal replacements for breakfast and lunch for three months. The patients who chose pharmacotherapy are offered a dosage of 120 mg Orlistat (Xenical) tablet taken 3 times day within an hour of eating a meal for three months.

Phase 3: Weight maintenance intervention

Patients at GCWMS enter the maintenance phase after completing the six month multi-component weight loss intervention and the low calorie diet treatment or pharmacotherapy (for those that have not lost weight from the multi-component intervention). Patients attend monthly for 12 sessions. All patients are weighed and attend a one hour group session. The skills and knowledge learned during the weight loss phase of the programme are reinforced through group discussion.

Topics covered include:

- Motivation
- Thinking patterns
- Activity barriers and solutions
- Assertiveness
- Coping with lapses and relapses
- Food labelling
- Healthy eating and portion control
- Goal setting
- Control your diet
- Coping with stress
- Alcohol awareness
- Local supports

Maintenance groups at GCWMS are delivered by physiotherapists or technical instructors.

Evaluation of the GCWMS

In 2011 a published evaluation of the effectiveness of the first phase of the service showed that in a sample of 809 patients with obesity (BMI≥35kg/m^2) 35.5% that attended at least half of the 16 weeks of the programme (completers) reduced their body weight by five kg or more (Morrison *et al.* 2011).

A univariate logistic regression analysis of the referred participants with valid data (n=2976), after adjustment for gender, showed that male participants aged 40 years and over (OR=1.39, 95% CI=1.05, 1.82), participants with a BMI ≥ 50kg/m^2 (OR=1.70, 95% CI=1.14, 2.54) and those with depression (OR=1.81, 95% CI=1.35, 2.44) were more likely to reduce their body weight by five kg or more. The presence of diabetes mellitus halved the odds of significant weight loss for both genders (OR=0.55, 95% CI=0.38, 0.81).

The same analysis for completers showed that males (45.3%) were more likely to lose five kilograms or more than females (32.2%). Socio-economic deprivation was associated reduced likelihood of weight loss.

Overall the results of the evaluation show that GCWMS is a clinically effective service and can lead to a 5% weight loss for those adults with obesity that complete the programme. However, there is no evaluation published about the effectiveness of Phase 2 and the long term effectiveness of the service.

4.3 TAKE 5: A multi-component weight management intervention for adults with intellectual disabilities and obesity

4.3.1 Ethics

TAKE 5 was conducted according to the guidelines laid down in the Declaration of Helsinki. In keeping with the Adults with Incapacity (Scotland) Act 2000(16), all procedures involving human subjects/patients were approved by the Scotland Research Ethics Committee A and the relevant local research ethics committee. A detailed protocol of consent, in keeping with the Adults with Incapacity Act 2000, was implemented. This included seeking consent from individuals with ID with the capacity to provide informed consent, and seeking consent from the next of kin or welfare guardian in circumstances where the individual was unable to provide informed consent. Written informed consent was obtained from all participants or next of kin/welfare guardian. Ethical approval letter and information sheets and consent forms can be found in appendix 2.

The ethical approval was extended for studies 2, 3 and 4. According to the Ethics Committee there was no need for procedures on obtaining a new approval for the rest of the studies since the methodologies did not include a randomisation and the studies were seen a continuation of the TAKE 5 weight loss study.

4.3.2 Participants

Potential participants in TAKE 5 were those individuals already referred to dieticians specialised in ID by their general practitioners in primary care or by other specialists ID practitioners. In March 2009, there were 275 individuals identified as potential participants of which 236 had a BMI ≥30 kg/m^2. The number of potential participants decreased by 30% because 13.8% were deceased, the research assistant could not contact 26 individuals (9.5%) and 19% refused to receive information about the study. Therefore, information sheets were sent to 166 individuals. A hundred and one potential participants agreed to meet the research assistant to discuss TAKE 5. To reduce potential bias, and ensure equity of access, a random number sequence was generated (SPSS for Windows, Ref 15.0 Chicago: SPSS Inc.) and the 101 potential participants approached in the random order. The pilot study aimed for 30 individuals completing the intervention. To take account of attrition it was planned to recruit 50 participants.

Inclusion criteria

Individuals were considered eligible for inclusion if they:

- have been diagnosed with ID
- Were aged over 18 years old
- had a BMI ≥30 kg/m^2
- were ambulatory
- absence of specific syndrome: Prader–Willi syndrome, Cohen syndrome or Bardet-Biedl syndrome

Fifty four individuals who met the criteria for inclusion, and provided informed consent, participated in the pilot study.

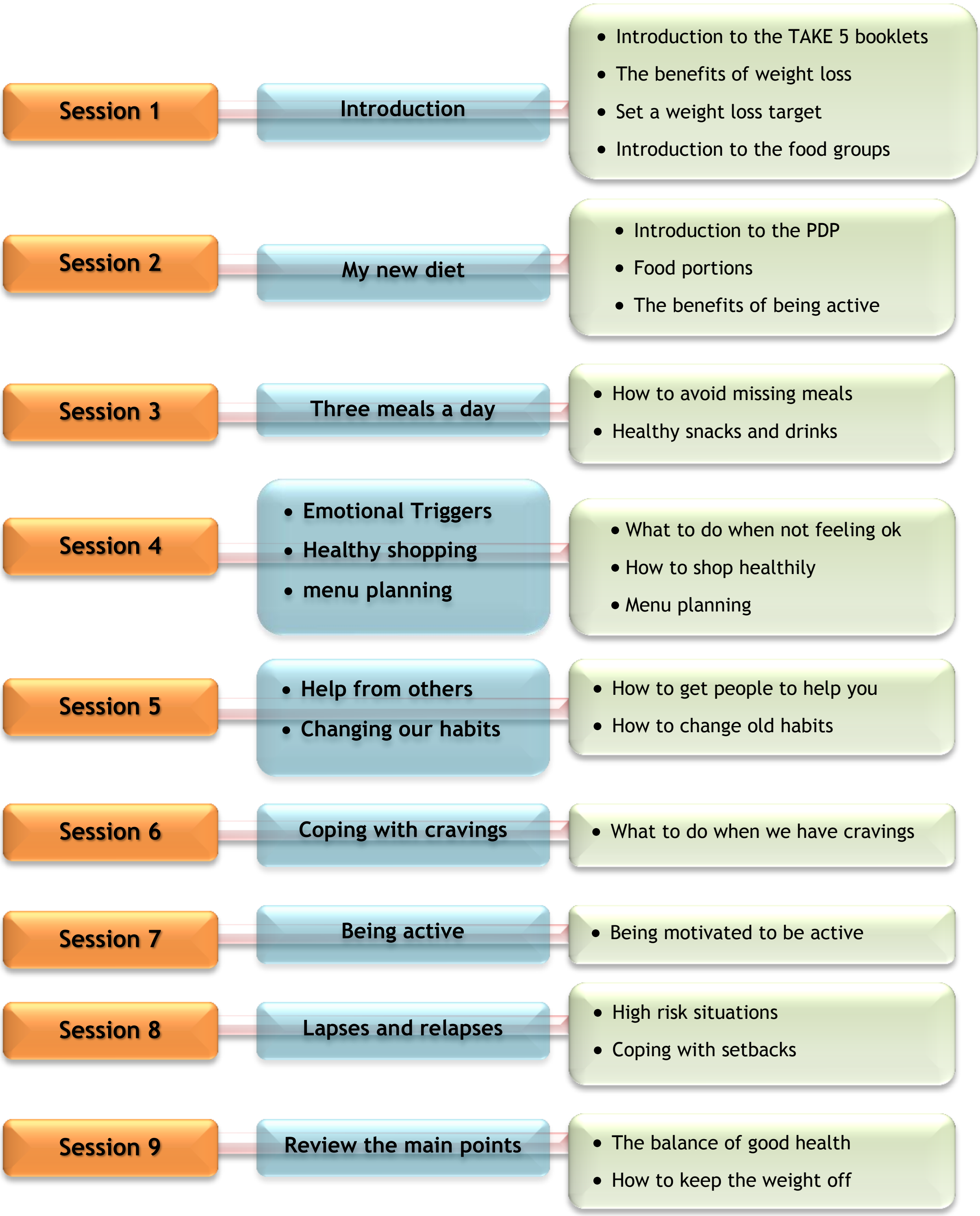
4.3.3 Phase 1: weight loss intervention

Unlike GCWMS that was delivered via groups, TAKE 5 was delivered individually in each participant's home. The intervention comprised of nine fortnightly sessions lasting 40-60 minutes (total duration approximately 16 weeks). Similar to the GCWMS, the TAKE 5 intervention fully incorporated the recommendations of current clinical guidelines (NICE 2006, SIGN 2010):

- Dietary change aiming for a daily energy deficit of 600 kilocalories per day
- Increasing levels of physical activity
- Behaviour change techniques to support change in eating and physical activity patterns.

The outline of the topics covered in TAKE 5 weight maintenance is illustrated in the figure 4.1.

Figure 4.1: Outline of sessions



4.3.3.1 Dietary intervention

Each participant was offered an individualised PDP. The PDP was a calorie and portion controlled diet aimed at weight loss of 0.5-1kg per week (Lean and James). The PDP calorie calculation was based on estimated total energy expenditure for each participant using the WHO (1985) equations for basal metabolic rate, combined with an activity factor adapted from WHO (1985). In more detail:

- Basal metabolic rate (BMR) was based on gender, age and weight and calculated using the Schofield equations (Schofield *et al.* 1985; NICE 2006) (Table 3.1)
- Total energy expenditure (TEE) was calculated by using BMR multiplied by a physical activity level (PAL) (Leslie *et al.* 2002). PAL values were adapted from WHO (1985) (Table 3.2). Following the evidence regarding the sedentary lifestyle of the adults with ID (Finlayson *et al.* 2011), the participants in the TAKE 5 study were categorised as inactive with a PAL value of 1.40.
- A deduction of 600 kilocalories led to the final energy deficit diet
- To avoid disturbance of the balance of good health a minimum and a maximum limit of PDP calorie prescription was defined as 1500 and 3000 calories per day.

PDP= (BMR x PAL) – 600

Table 4.1 Schofield equations for age and gender (Schofield *et al.* 1985)

AGE	SEX	BMR
18-30	MALE	15.3 W (Kg) + 679
	FEMALE	14.7 W (Kg) + 496
31-60	MALE	11.6 W (Kg) + 879
	FEMALE	8.7 W (Kg) + 829
>60	MALE	13.5 W (Kg) + 487
	FEMALE	10.5 W (Kg) + 596

Table 4.2 PAL values categories for males and females and examples for activities (adapted from WHO 1985).

	PAL Male	PAL Female	Examples of activities done on a daily basis
Extremely inactive	1.27	1.27	"totally inactive, dependent people" bed bound, minimal movement, no food preparation, "survival requirement"
Inactive	1.40	1.40	washing, dressing, short periods of standing, playing cards, inactive office work , driving, ironing and sewing, intermittent movement
Light	1.55	1.56	light housework, household shopping, snooker, bowls, active office work
Moderate	1.78	1.64	At least one hour a day, every day of one or a combination of the following activities: vigorous housework, gardening, light exercise e.g. slow swimming, walking, briskly walking the dog, cycling, dancing, or having a moderately active job e.g. post man, cleaner, nurse
Heavy	2.10	1.82	heavy exercise, very active jobs e.g. builder, labourer, athletes

Portions

The PDP provided daily caloric intake from a specified number of daily portions of foods based on the recommendations of the "eatwell plate" (http://www.food.gov.uk/scotland/scotnut/eatwellplate/). The "eatwell plate" that was previously called "Balance of Good Health" was based on the National Food Guidelines (1994). Therefore, the PDP was split up into six different food groups:

- starches (bread, other cereals and potatoes)
- fruit and vegetables (fresh, frozen, canned and dried)
- dairy (milk, cheese, yogurt)
- meat fish and alternatives (meat, poultry, fish, eggs, legumes and pulses)
- fat allowance (margarine, butter, olive oil and other spreads)
- extra allowance (foods and drinks containing sugar)

Starches made up the largest part of the diet (33%), followed by fruit and vegetables (33%), milk and dairy foods (15%), meat fish and alternatives (12%), foods and drinks high in sugar and fat (8%). Overall, the individualised PDP aimed to ensure that 50% of daily energy intake was from carbohydrates (with contributions from starchy foods, fruit and vegetables, and dairy products), less than 35% from fats and less than 20% from protein, and necessary micronutrients (Committee on the Medical Aspects of Food Policy 1991).

The daily prescription for fruit and vegetables was capped at five portions per day (www.eatwell.gov.uk) and for dairy three portions per day (Dietary Guidelines for Americans (DGA) 2010; Diabetes UK 2012). This aligned with government recommendations for fruit and vegetable consumption but also meant that participants were not overwhelmed in terms of the cost and practical implications of having more than this every day, although flexibility in increasing the intake could be achieved via use of extras or swaps. An example of a PDP can be found in Appendix 2.

4.3.3.2 Physical activity intervention

The aim of the physical activity component was to support participants to progressively increase their levels of physical activity to 45-60 minutes of moderate intensity exercise for five days per week (NICE 2006). The intervention also took into consideration the following recommendations (SIGN 2010):

- Physical activity can be accumulated over the course of the day in multiple small sessions of at least 10 minutes duration each
- Participants should also be encouraged to reduce the amount of time they spend inactive, such as watching television
- Sedentary individuals should be encouraged to increase their physical activity targets gradually, starting with 10-20 minutes of physical activity every other day during the early weeks of the programme, to minimise potential muscle soreness, fatigue and not compromise health

In each session goals for achieving recommended intensity levels were set based on individual’s current level of physical activity; physical ability level and an individual’s expressed preference. Examples included indoor activities e.g. housework and outdoor activities e.g. walking instead of using public transport.

According to a meta-analysis by Richardson *et al.* (2008), simple pedometers have been used in many walking programs aiming for an increase in step counts and resulting in a modest weight loss of 0.5kg in 10 weeks. The benefit of using a pedometer is dependent on its ability to provide an immediate visual record of the walking steps taken by a participant, enabling easy self-monitoring, and facilitating the process of goal setting (Lubans *et al.* 2009). Pedometers were given to each participant of TAKE 5 and training given on how to use these to measure daily steps taken. Based on the baseline average steps per day, individuals were encouraged to set walking targets in the TAKE 5 sessions, and progressively increase walking behaviours. Sport and exercise information were also given to each participant on local leisure facilities and clubs with accessible sports and exercise groups/classes.

4.3.3.3 Behaviour change techniques

In each session specific behaviour change techniques were used to support participants to make sustainable changes in eating and physical activity behaviours. These included:

a) Goal setting

At the end of each session participants were encouraged to set Specific, Measurable, Achievable, Relevant and Time specific (S.M.A.R.T) goals for dietary habits, physical activity patterns and behavior change. The overall aim for the goals was a realistic target weight loss of 5-10% from initial body weight achieved by losing 0.5-1kg per week. This is based on clinical recommendations for modest sustainable weight loss (NICE 2006; ADA 2009) and based on the evidence that expectations for unrealistic weight loss lead to poor weight loss outcomes and unsustainable weight loss maintenance (Grave *et al.* 2005; Teiheira *et al.* 2004).

b) Self-monitoring

Specially designed food diaries (user friendly) were developed for the participants with ID in TAKE 5.

c) Relapse prevention

Participants in TAKE 5 were prepared to face “high risk” situations and ways of coping with different types of lapses and relapses were rehearsed using role play.

d) Stimulus control

Participants were supported to identify internal and external cues that they identified as influencing their dietary intake and their physical activity patterns (Van Dorsten and Lindley 2008). This was facilitated by introducing ways of structuring their environment, preventing exposure to sedentary lifestyle and avoiding cues that would lead to overeating e.g. taking the stairs instead of the lift and not watching television while eating.

e) Assertiveness

The ability to be assertive against social pressure is regarded as important in weight management (Burke *et al*. 2005). The importance of understanding the differences between passive, aggressive, and assertive behaviour was explained to participants and they were introduced to a variety of assertiveness techniques to cope with pressure from others for them to eat. The importance of asking for support from the people from their internal (family and carers at home) and external environment (carers at day centres) was also discussed with participants, where relevant.

f) Problem solving

Participants in TAKE 5 were supported to identify their own “problematic” situations and to plan steps for solutions suitable to their needs and preferences.

g) Management of eating habits

The nine sessions included subjects for discussion that promoted specific changes in the participants' dietary patterns. These included: eating breakfast every day and how to avoid high calorie snacks.

4.3.3.4 Communication, adaptations and resources

The gap in provision of suitable methods and materials to enable people with ID to make healthy lifestyle choices is identified as a general problem (NHS Health Scotland 2004). Therefore, this study used appropriate methods and techniques such as augmentative communication ("Talking Mats") that aims to enable participants express their choices during the intervention (Brewster 2004) and used photos, food models and fat and muscle models to simplify information.

The supporting PowerPoint presentations used at the GCWMS service for each session were used as a base to develop hand-outs suitable for adults with ID by the author of this thesis DS. The hand-outs were provided at each session of the TAKE 5 weight loss intervention (examples of hand-outs can be found in appendix 3). The adaptations were appropriate to the developmental levels and the cognitive needs of the participants and were made by the author of this thesis who is an experienced researcher in adults with ID in consultation with other health professionals who work in this field. Adaptation was based on the recommendations of the Royal College of Nursing (2006) as to what form written and spoken information for people with ID ought to be made available.

Examples for written communication include:

- use simple language
- avoid abbreviations
- avoid using negatives e.g. say this afternoon rather than not this morning.
- avoid idioms or metaphors

In addition the author used photos from the Microsoft Office website photos and clip arts to provide a pictorial explanation for the information provided in each coloured printed hand out (http://office.microsoft.com/en-gb/images/?CTT=6&ver=14&app=winword.exe).

Examples for spoken communication include:

- if the person is not able to receive verbal information it may be necessary to approach the carer or a family member. Always seek permission to do this, and continue to include the person in the dialogue with eye contact
- if the person has to take a message, or take a further step in a process, use simple questions to ensure the person has understood. The person's capacity to repeat a phrase may not indicate understanding.

The intervention included four booklets that are not freely available, specially designed for this study only by a professional graphic designer, which provided weight loss information in a form appropriate to the cognitive needs of the participants. The title and the aims of each booklet are described below:

Booklet 1: Eat well- Feel well: The aim of the booklet was to provide basic information regarding healthy eating based on the "Eat Well" plate (http://www.nhs.uk/Livewell/Goodfood/Pages/eatwell-plate.aspx).

Booklet 2: You can do it: The aim of the booklet, accompanied by a DVD, aimed to motivate participants improve their physical activity

Booklet 3: How to help someone lose weight: The aim of the booklet was to motivate the carers support participants who try to lose weight

Booklet 4: Get help with losing weight: The aim of the booklet was to introduce the importance of losing weight and the need of involving other people in this difficult process

4.3.3.5 The role of the carers

Participants were invited to choose whether carers supported them during the intervention and assist with communication when needed, especially with the clarification of the messages of the hand-outs if a participant was unable to read. However, no specific role was set for the carers prior to their intervention.

4.3.4 Measures

4.3.4.1 Primary outcomes

- Weight change in Kg from baseline (Time 1) to post-intervention (Time 2)
- Weight loss of five per cent or more of initial body weight

4.3.4.2 Secondary outcomes

- Change in BMI (kg/m^2) and waist circumference (cm)
- Change of time (minutes) spend in moderate intensity physical activity per week
- Change of time (minutes) spent in sedentary behaviour per day

At baseline (Time 1) and on completion of the 16 week weight loss intervention (Time 2) a research assistant met with the participant and carers to complete the measures of outcome. The questionnaire used for this purpose can be found in appendix 4.

4.3.5 Anthropometric measurements

a) Weight

Measurements were made with the participant wearing light clothes without shoes. All measurements were made in duplicate. The final value was calculated as the mean of the two measurements. Weight (kg) was measured to the nearest 100 g, using Seca 877 scales (CE approval class III; Seca, Hamburg, Germany).

b) Height

Height (m) was measured to the nearest 1mm using the Seca Leicester stadiometer (Seca).

c) BMI

Height (m) and weight (kg) were used to calculate BMI using the WHO (1995) formula: BMI=Weight/Ht^2

d) Waist circumference

Waist measurements were made based on the protocol as recommended by the WHO (2008). Waist was measured at the midpoint between the top of the iliac crest and the lower margin of the last palpable rib in the mid auxiliary line. The measurement was made with a stretch resistant tape that was wrapped snugly around the participant, but not to the point that the tape was constricting. The tape was kept level and parallel to the floor at the point of measurement. The participants had removed any belts and heavy outer clothing. The measure was made directly over the skin. Two waist measurements were made and recorded. The final participant's waist measurement was calculated as the mean of the two observations.

4.3.6 Social support, ability and health status

Questionnaires were used at baseline (Time 1) and at the end of the 16 week intervention (Time 2). A purpose-designed data collection form was used to collect demographic and health data on participants. The form consisted of two sub-sections that covered the following:

Section A: Social support and ability
Section B: Physical health

Section A: Social support and ability

The environment that an individual lives in and the type of support provided to this person can play an important role in the prevalence and the treatment of obesity (Rimmer and Yamaki 2005; Emmerson *et al.* 2004). Therefore, the questionnaire included questions on the living arrangements of the participants e.g. if they lived with their parents or carers, if they had a part time or full time support, employment or education status (attending a college).

The level of ID was classified as mild, moderate, severe or profound. The assessment was based on a scores (5-25) obtained from five questions on the participants current ability levels in eating and drinking, in intimate care, personal safety, communication and decision making with or without support. Scoring and categorisation was:

- 5 - 8 = mild ID
- 9 – 13 = moderate ID
- 14 –19 = severe ID
- 20-25 = profound ID

This questionnaire has been used before by Cooper (1997) assessing the psychiatric epidemiology in adults with ID. It has been also compared and shown to have a good level of agreement with the Vineland's Adaptive Behaviour Scale which is a validated structured assessment of functioning and ability level (Sparrow *et al.* 1984).

Section B: Physical health

The questionnaire included questions on health problems known to be commonly experienced by people with ID and people with obesity. These included epilepsy high blood pressure, high cholesterol, sleep apnoea and impairments such as epilepsy, visual and hearing impairments (Emerson 2010). Prescribed medication was recorded based on the evidence that specific obesogenic medication can cause significant weight gain when used (Leslie *et al.* (2007).

4.3.7 Physical activity assessment

Physical activity was assessed in two different ways:

a) Objective assessment

Physical activity was measured objectively with use of Actigraph GT1M accelerometers (Manufacturing Technology, Inc., Fort Walton Beach, FL, USA).

Participants were invited to wear accelerometers for seven days before the start of the intervention (Time 1), and at the end of the intervention period (Time 2). The accelerometer was worn at the hip, attached to a belt worn round the waist. Wearing times included all waking hours, except when showering, bathing or swimming. The participants wore the accelerometers until they went to bed. The carers were asked to record the wearing times in a specific diary provided to them by the research assistant. In keeping with the guidelines on the validity of accelerometer data, the minimum data requirement was set at six hours of data on at least three days from seven.

The accelerometers were set to record activity over 15 seconds intervals (epochs). Activity counts of four consecutive epochs were summed to give activity counts/min. Published cut-offs were used to express the accelerometer data as three categories of activity intensity (Freedson *et al.* 1998):

(1) Sedentary behaviour 0–499 counts/min
(2) light-intensity activity 500–1951 counts/min
(3) moderate-to-vigorous-intensity activity > 1952 counts/ min.

b) Subjective assessment

Additional data on physical activity was collected using the International Physical Activity Questionnaire-short version (IPAQ-S). This type of self- report questionnaire has been used and validated in other studies and is positively accepted by investigators and respondents (Papathanasiou *et al.* 2009; Craig *et al.*2003). The original version is a seven day recall that was designed for adults (age over 18 years old) and focused on five activity domains asked independently (IPAQ core group 2012). For this study the short version was used and focused on only four generic items, collecting information on the time spent in vigorous and moderate intensity activity, walking and sitting. Knowing the barriers that the participants with ID may have in answering questions regarding time and frequency (Finlay and Lyons 2001), the carers were asked to assist the participant where appropriate.

4.3.8 The role of the researcher

The author of this thesis is a dietician with extensive experience in nutritional issues for adults with ID, and trained in the use of augmentative communication was involved in TAKE 5 in two major ways:

- As a “weight manager co-coordinator” assisting in the adaptation of the GWMS intervention and resources and the delivery of the intervention.
- As a “research assistant” assisting in the collection and analysis of data and assisting with manuscript writing and publication.

4.3.9 Results

4.3.9.1 Baseline characteristics

The mean age of the 54 participants (40.7% males and 59.3% females) that took part in the study was 48.3 (range 23–71, SD=12·01) years old. The majority of the participants were single (98%) and had a paid carer for support (61%). The level of ID was mild (31.5%), moderate (31.5%), severe (35.2%) and profound (1.9%). Only 13 participants had Down syndrome.

Participants reported having obesity related health problems such as high blood pressure (20.4%), high cholesterol (22.2%), Type 2 diabetes (9.3%) and problems with walking because of weight (35.2%).

The results on the primary and secondary outcomes of this study (Melville *et al.* 2011) for the 47 participants who completed the study have been described in the systematic review in chapter 3. An outline of the main results is:

4.3.9.2 Primary outcome

Weight change at 16 weeks

The mean weight loss at 16 weeks was 4.5kg (SD= 4·7 kg; 95% CI= -5·9, -3·03; P<0·0001). In addition, 36.5% participants lost 5% of their initial body weight.

4.3.9.3 Secondary outcome:

BMI and WC change at 16 weeks from baseline

There was a significant decrease in BMI (mean decrease=1.8 kg/m^2; 95% CI= -2.4, -1.3; P<0.0001) and in WC (mean decrease=6.3cm; 95% CI=-7.8, -4.7; P<0.0001).

4.3.9.4 Physical activity

Physical activity changes at 16 weeks from baseline

The accelerometer data showed a significant increase in the percentage of time spent in light-intensity physical activity (mean difference= +1.87%; 95% CI= 0.2, 3.5; P=0.027) and a significant decrease in the percentage of time (mean difference= -2.60%; 95% CI=-4.6,-0·6; P=0.012) spent in sedentary behaviour.

4.3.10 Conclusion

TAKE 5 is multi-component weight loss intervention for weight loss that can lead to a clinically significant weight loss in adults with ID and obesity and improve physical activity levels. However, in order to fully incorporate the clinical recommendations for the obesity management (NICE 2006; SIGN 2010) the intervention had to be followed by a second phase: a weight maintenance intervention to help participants sustain their lifestyle changes and maintain their weight loss.

Chapter 5: Methods

5.1 Study 2: Development and implementation of weight loss maintenance intervention for adults with intellectual disabilities

5.1.1 Study design

This is a 12 month pilot quasi experimental study following a 16 week weight loss intervention (TAKE 5) described in the general methods (Chapter 4). A flow chart of the methodology of the study is provided in figure 5.1.

The ethical approval from the TAKE 5 weight loss study was extended for the study 2. According to the Ethics Committee there was no need for procedures on obtaining a new approval for the rest of the studies since the methodologies did not include a randomisation and the studies were seen a continuation of the TAKE 5 weight loss study.

5.1.2 Participants

Participants were recruited from the TAKE 5 weight loss intervention. Forty seven participants who completed the weight loss intervention were provided information about the weight loss maintenance intervention at the end of the weight loss phase (Time 2).

5.1.2.1 Inclusion criteria

A weight loss of less than 5% of body weight is not considered clinically significant (NICE 2006), and a weight loss less than 3% of body weight is considered as a small weight fluctuation (Stevens *et al.* 2006). However, other studies have shown that weight losses as low as 2% can lead to a reduction in the risk of diabetes (Hamman *et al.* 2006) and weight losses 2-5% can lead to improvements of systolic blood pressure (SBP) and triglycerides (Wing *et al.* 2011). Taking the above into consideration participants were considered eligible for the weight loss maintenance intervention if they:

- Completed the TAKE 5: weight loss intervention
- Achieved a weight loss greater than 3% from initial body weight, after the TAKE 5: weight loss intervention
- Participants not planning further intentional weight loss at present

A total of 31 individuals that met the inclusion criteria were invited to participate in the weight loss maintenance phase. None of the participants that had lost greater than 3% from initial body weight wanted to pursue a further weight loss at the end of the weight loss intervention.

5.1.3 Measures

5.1.3.1 Primary outcomes

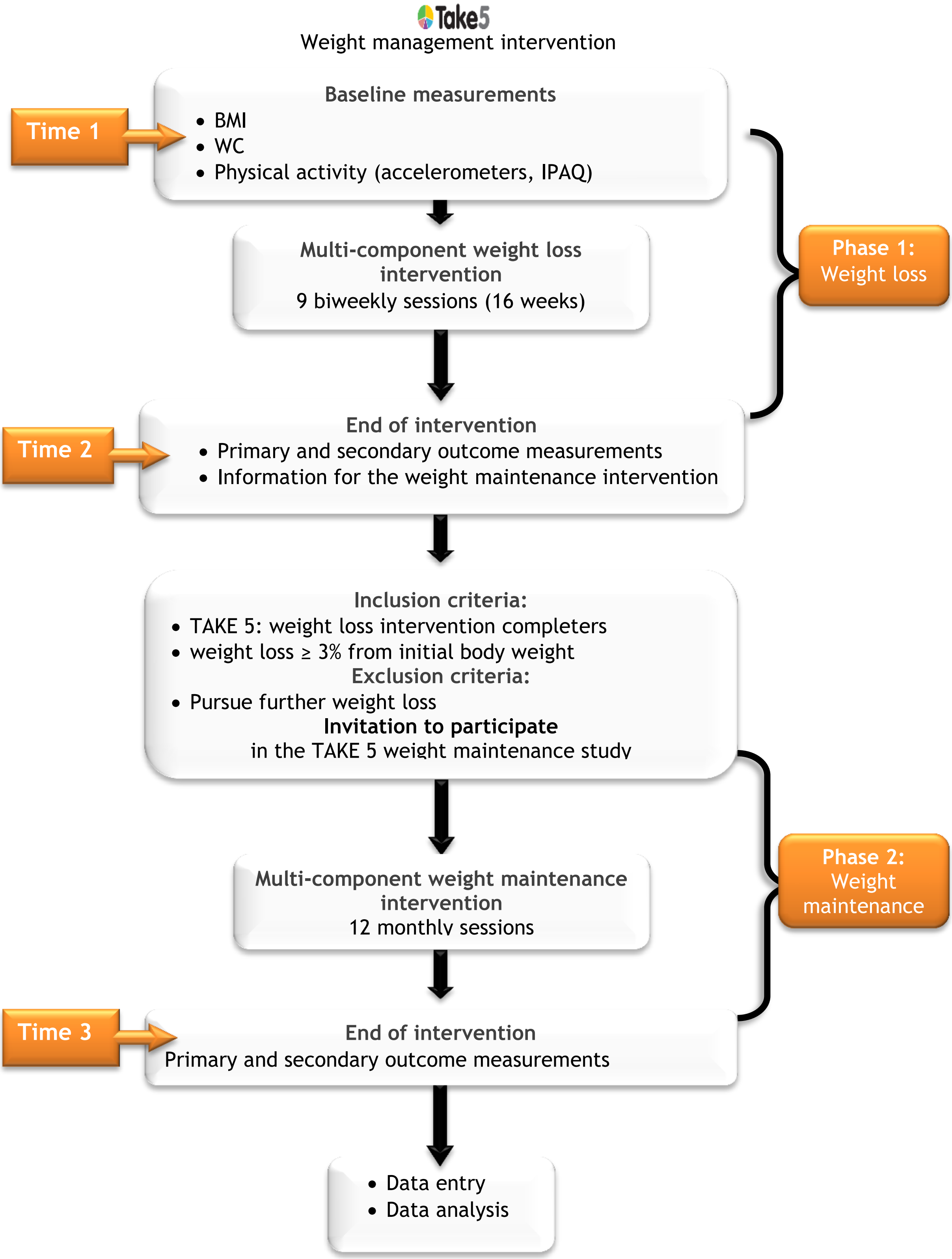
Weight change from end of 16 week weight loss phase (Time 2) to 12 months (Time 3)

- weight change (%) of less than ± 3% of body weight

5.1.3.2 Secondary outcomes

The secondary outcomes were the same with the ones described in the weight loss study but the differences were looked from the period Time 2 to Time 3 (section 4.3.9.3)

Figure 5.1: Flow Chart for methodology



5.1.4 Intervention

The TAKE 5 weight maintenance intervention was based on the structure used by the GCWMS described in the general methods and the principles of the National Weight Control Registry (NWCR) (Wyatt *et al.* 2005).

5.1.4.1 The National Weight Control Registry

One useful source of information for weight maintenance is the National Weight Control Registry established by Wing and Hill (1994) in US. The National Weight Control Registry aims to collect information regarding successful weight loss maintenance from a self-selected population of more than 4000 individuals who are age 18 or older and have lost at least 13.6 kg (30 lb) and maintained the weight loss for at least one year. The population is recruited from newspapers and magazine articles and is followed up annually. Answers from the registered sample (77% women, 82% college educated, 95% Caucasian, and 64% married) to a series of questionnaires focusing on ways of losing weight (support from a health professional or losing the weight on their own) and ways of maintaining the weight have shown that people who can keep their weight the same are the people who (Wing and Phelan 2005):

1. monitor their weight-at least once a week.
2. continue to eat a low fat or low calorie diet.
3. maintain a consistent eating pattern
4. eat breakfast every day
5. be active by watching less than 10 hours of TV per week and exercising for one hour per day.
6. avoid lapses and relapses

5.1.4.2 The TAKE 5 weight maintenance intervention

The above information from the National Weight Control Registry along with the information used by the GCWMS was used as the foundation for the development of TAKE 5: weight maintenance intervention.

The aim of the intervention was a weight change equal to ±3% from initial body weight (Stevens *et al*. 2006). Initial body weight was defined as the weight after the 16 weeks weight loss intervention (Time 2). The intervention comprised 12 monthly, individualized one to one sessions (40-50 minutes) that took place in the house of most participants. For two participants that due to lack of space the intervention was delivered at the day centre the participants attended.

The intervention also offered once monthly contact via telephone because evidence show that extended and frequent contact with individuals with obesity has been identified as an effective method for the prevention of weight regain after weight loss (Ross Middleton *et al*. 2011). The monthly telephone contacts were used to recap the main points of the previous sessions potentially missed due to lack of communication among the carers, to provide ongoing motivation and assist with problem solving. The contact was made with the participants or with the carers who supported them, depending on the ability levels of the participants.

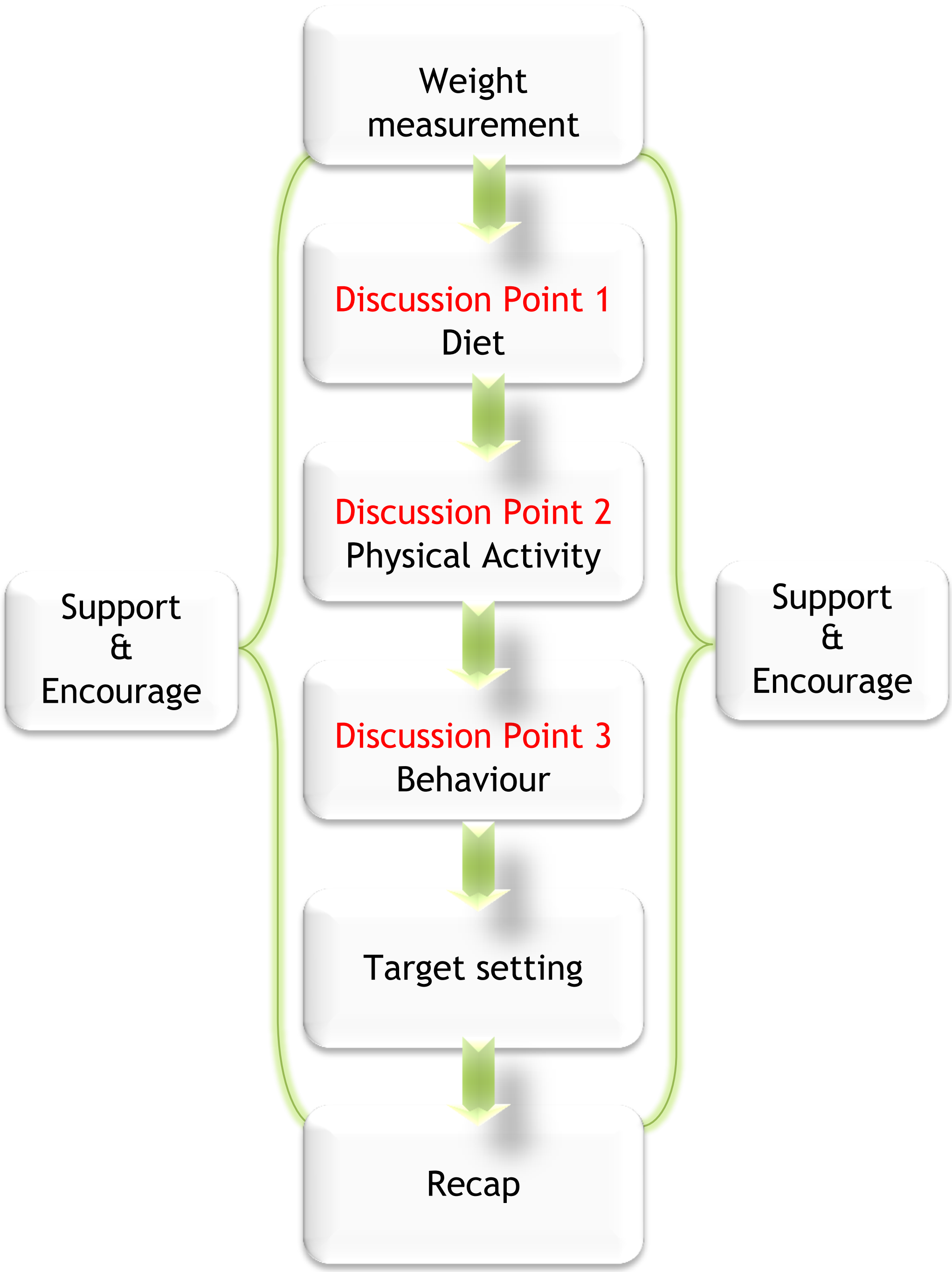
The whole intervention was delivered by DS the researcher for this thesis. The participants were offered one extra potential visit if needed every month. The content of the sessions delivered at the GWMS were adapted and changed to a great extent based on the ability levels of the participants with ID. In addition, the researcher used additional information obtained from the Food Standards Agency and the “Eat well, Be well” website. The website was a useful tool providing information and guidance on key issues such as healthy diet and food labels. The website was cancelled for a period of time but currently has been re-launched as the “eatwell site” for Scotland and can be accessed in: http://www.eatwellscotland.org/index.html. Example of hand-outs provided at each session can be found in appendix 5.

The outline of the topics covered in TAKE 5 weight maintenance is illustrated in the figure 5.2. The TAKE 5 weight maintenance intervention was multi-component focusing on the diet, physical activity and the behaviour of the participants. The overall approach followed during each session is illustrated in figure 5.3.

Figure 5.2: Outline of sessions

Session	Title	Content
Session 1	Keep the weight off	• My weight is important • The changes I have made • Set limits for my weight
Session 2	My new diet	• The balance of good health • The new PDP
Session 3	Control your weight and your diet	• Checking your weight • Keeping a food diary
Session 4	Let's get fit again	• How to become more active • My activity diary
Session 5	Regular eating	• Ideas for breakfast • Ideas for packed lunch • Ideas for healthy meals
Session 6	Becoming more active	• Finding time to be active
Session 7	Eating a healthy diet	• Not easy to eat a healthy diet and what to do
Session 8	Snacking	• Snacking the healthy way
Session 9	Lapses and relapses	• Not going back to old habits
Session 10	Evening meals	• Ideas for healthy evening meals • Eating at parties
Session 11	Eating out	• Eating out in a healthy way • Healthy drinks
Session 12	• Salt • Review	• How to eat less salt • How to maintain our weight

Figure 5.3: Multi-component approach followed in each session



5.1.5 Dietary advice

Each participant was offered a PDP following the same principles used in the TAKE 5 weight loss intervention and described in section 4.3.3.1 (dietary intervention). However, in the TAKE 5 weight loss maintenance intervention, the calorie and portion control diet did not aim for a 0.5-1kg weight loss per week.

The PDP was not an energy deficit diet and did not include a deduction of 600kcal. Individual PDPs ranged from a minimum of 1800kcal to a maximum of 3500kcal daily. Example of the PDP can be found in appendix 4.

Based on the evidence from Wing and Phelan (2005) and the recommendations of clinical guidelines (NICE 2006), a session was dedicated to the importance of having breakfast and ideas on eating healthy breakfast. The potential connection of having breakfast and weight maintenance may be attributed to the ability of breakfast to regulate our appetite better, feel less hungry between meals and eat less as a result (Timlin and Pereira 2007). The benefits could increase when breakfast includes foods that are rich in fibre increasing satiety (McCrory and Campbell 2011).

Ideas for healthy meals in session 5 and 10 were based on evidence on frequent meal consumption in UK from the market research firm Taylor Nelson Sofres (TNS) (http://www.tnsglobal.com)

5.1.6 Physical activity

There is no general agreement about the level and amount of physical activity for successful weight maintenance (Donnelly *et al.* 2004) and some studies report that weight control is a much more complicated process than just an issue of physical activity. However, research shows that being active can increase energy expenditure (Jakicic 2009) and this in turn can improve other health outcomes such as improvement of cardiovascular health (Cook and Schoeller 2011).

The advice on physical activity in TAKE 5 weight maintenance was based on the recommendations of clinical guidelines and studies supporting the importance of physical activity in the maintenance of reduced weight (NICE 2006; SIGN 2010; Catenacci and Wyatt 2007). Therefore, in addition to section 4.3.3.2:

- Individuals are more likely to maintain a healthy weight if they have an active lifestyle (30 minutes of moderate physical activity, five days per week).

- However, individuals who are overweight or obese may need to do more exercise during the day than the recommended amount of 30 minutes per day
- People who have been obese and who have lost weight should be advised that they may need to do at least 60 minutes of moderate-intensity activity a day to sustain their weight loss.

5.1.7 Behaviour change techniques

The behavioural approach techniques were the same as the ones outlined in section 4.3.3.3.

In addition to the behaviour approach techniques described in Phase 1, based on the evidence (Wing and Phelan, 2005) and the recommendations of SIGN (2010) participants were asked to record their weight once per week. Regular weight monitoring provides an opportunity for individuals to reflect on how lifestyle is affecting their weight and allows individuals to take action before weight changes significantly (Butryn *et al*. 2007). Therefore, in session 1 the participants were supported to set the limits of healthy weight fluctuation based on the definition of Stevens *et al*. (2006) and they were asked to aim not to surpass these limits.

5.1.8 The role of the carers

The carers prior and during to the TAKE 5 weight maintenance were asked:

1. To encourage and appreciate even minor changes in a participant's lifestyle
2. To ensure that a participant takes an active role in making lifestyle changes
3. To promote realistic changes in diet and activity if needed

5.1.9 Communication, adaptation and resources

The communication in TAKE 5 weight maintenance followed the same principles as described in the section 4.3.3.4.

Each session was accompanied by handouts illustrating the information of the session. The handouts were developed using the same principles described in section 4.3.3.4.

In addition, the intervention in Phase 2 of the TAKE 5 weight management had access to a photo-library developed and already used by ID specialists dieticians in health promotion projects of the Glasgow Learning Disability Partnership.

5.1.10 Anthropometric measurements

At the end of weight loss maintenance intervention (Time 3) participants were invited to have their height, weight and waist circumference measured in duplicate using a standard methodology as described in section 4.3.5.

5.1.11 Social support, ability and health status

For the assessment of support of the participants and their health status at the end of the weight maintenance intervention (Time 3), the study used the same questionnaires used in TAKE 5: weight loss intervention and described in section 4.3.6.

5.1.12 Physical activity assessment

The methodology for the physical activity assessment was the same with the one used in TAKE 5 weight loss intervention and described in section 4.3.7. To objectively measure the impact of Phase 2 on physical activity, participants were invited to wear accelerometers for one week post weight maintenance intervention (Time 3). Physical activity was also assessed with the use of IPAQS questionnaires. The validity of IPAQ questionnaires in adults with ID was assessed in the first phase of the TAKE 5 weight management programme showing limited agreement with the accelerometers in the assessment of moderate to vigorous physical actcvity and sedentary behaviour (Mathews *et al*. 2011). Therefore, the analysis in phase 2 (weight maintenance) focused only on time spent in walking following the evidence that suggest that this type of activity is one of the most important physical activities in adults with ID (Stanish *et al*. 2006; O'Hare and Black 2010).

5.1.13 Statistical analysis

All data management and statistics were performed using SPSS for windows version 18 (SPSS, Chicago, IL). Analysis of normality with Kolmogorov-Smirnov test showed that weight change was normally distributed.

Means, standard deviations (SD) for continuous variables e.g. weight, BMI, waist circumference at time 1, time 2 and at time 3 are reported in tables along with mean difference (95%CI) and corresponding *P* value at time 2 and time 3 in text. Categorical variables e.g. gender are reported in number and percentage in text and tables. Paired t-test analysis was used to examine within group differences of primary and secondary outcomes at time 2 and time 3. Physical activity measures were also analysed and reported in a similar manner to the above.

Weight changes at time 2 and time 3 were compared by patient characteristics using independent *t* tests. Mean changes for each group are provided along with the mean difference (95%CI) and the associated *P* value.

The identification of predictors of outcome of weight maintenance was based on the following steps (Chan 2004):

1. Linear regression analysis of continues variables. A value of "r" close to one would indicate that there is a strong relationship between the variables. A $p<0.05$ based on ANOVA test would indicate there is a statistically significant correlation between the two variables.
2. Cross tabulation was used for categorigal variables. A $P<0.05$ would indicate that the variable is contributing significantly to the outcome.
3. In case of identified factors ($p<0.05$) then a bivariate or multivariate logistic regression analysis would be used to identify possible correlations.

Study 3: Examining the effectiveness of a multi-component weight loss intervention

5.2 Study 3a: Comparing the effectiveness of a multi-component weight loss intervention in adults with and without intellectual disabilities-Methods

This section represents a body of work from which a paper has been published. Spanos *et al*. 2013 Journal of Human Nutrition and Dietetics; in press.

The ethical approval from the TAKE 5 weight loss study was extended for the study 3. According to the Ethics Committee there was no need for procedures on obtaining a new approval for the rest of the studies since the methodologies did not include a randomisation and the studies were seen a continuation of the TAKE 5 weight loss study.

5.2.1 Participants and matching

A "matching" process was used to identify two participants who completed the GCWMS to match with each participant who had completed TAKE 5 the weight management programme adapted to meet the needs of those with ID. Matching was considered an ideal method for the comparison of the two interventions because it eliminates differences in baseline variables that would interfere with the outcome of weight loss (Bland and Altman 1994).

The GCWMS provided an anonymous Excel list of 1421 patients to the author of this thesis. The list included information on gender, age, pre and post treatment weight and height and the weights of each patient at each weight management session. The researcher matched manually each participant with mild, moderate and profound ID who completed TAKE 5 (n=52) with two participants without ID from the top of the GCWMS list (n= 1421). The two population groups were matched according to three baseline criteria: 1) gender, 2) age within 1 year, 3) the same or BMI within ± 0.3 kg/m^2.

Both population groups were living in the area of Glasgow but the recruitment for the two interventions and the delivery of the two interventions took place in different periods. The GCWMS was developed in 2004 as an on-going specialist service within the NHS. From 2004 data from all referrals is routinely collected, stored and used to audit the service (Morrison *et al.* 2011). Recruitment and data collection for TAKE 5 study was completed between 2009 and 2010 (Melville *et al.* 2011).

5.2.2 Interventions

5.2.2.1 Similarities

Both multi-component interventions (16 week duration) have been described in detail previously in general methods (chapter 4; sections 4.2 and 4.3). Both interventions comprised nine sessions that incorporated the following recommendations for the management of obesity in adults without ID (NICE 2006; SIGN 2010):

- A prescription of a personalised diet calculated to achieve an energy deficit diet of 2510kJ/d (600kcal/d)
- Advice to improve physical activity (five days of moderate physical activity 45-60min)
- Behavioural approach techniques to facilitate changes in physical and dietary patterns

It has to be noted that both 16 week interventions aimed for a target weight loss of 5-10kg (11.5lbs to 21lbs). This should have been achieved at a steady weight loss of 0.5-1kg (1-2lbs) a week. This study used data from the 16 week weight loss period and not data from Phase 2 or weight maintenance. The reasons for not making comparisons with the participants finishing the weight maintenance phase include:

- The TAKE 5 weight maintance intervention included topic sessions that were not included in the GCWMS, making the two interventions different not only in the method of delivery (individuals vs. groups) but also in the content to a great extent.

- The GCWMS maintenance phase does not use a specific definition for weight maintenance in their aims but the TAKE 5 weight maintenance does (±3% weight change)
- The sample of participants in the weight maintenance phase (Phase 3) in the GCWMS can be heterogonous including participants that did not lose weight greater than 3% from initial body weight at phase 1 and participants that followed a LCD (Phase 2).

5.2.2.2 Differences

Even though the core methodology for the two interventions was the same, TAKE 5 and the GCWMS had four main differences:

- TAKE 5 was delivered to participants on a one to one basis while the GCWMS was delivered using group sessions
- The researcher for TAKE 5 delivered the sessions at the house of each participant but the dieticians in GCWMS delivered all the group sessions at a clinical setting
- In TAKE 5 participants were encouraged to have their carers present at the time of the sessions, and were asked to support participants were appropriate.
- The GCWMS offered optional ten structured supervised activity classes that participants could attend but TAKE 5 did not

5.2.2.3 Adaptations

The process of adapting the intervention of the GCWMS to develop the TAKE 5 intervention has been described in chapter 4 section 4.3.4.4

5.2.3 Primary Outcomes

The effectiveness of the two interventions at 16 weeks was compared in terms of:

- Total weight change (Kg)
- Total weight change (%)
- Total BMI change (kg/m^2)

Weight changes for both interventions were also compared in terms of expected weight loss using estimated energy requirements determined by Schofield equations (Schofield *et al.* 1985).

5.2.4 Anthropometric Measurements

The method of anthropometric measurements for weight and height in TAKE 5 has been described in Chapter 4 section 4.3.5. Anthropometric measurements in GCWMS are made by experienced dietitians working for the service following clinical protocols. The data from the TAKE 5 study and the GCWMS presented in this study were obtained at baseline, at each session and on completion of both interventions (16 week post intervention).

5.2.5 Health status

As described in chapter 4 section 4.3.6 in TAKE 5 study the researcher collected information on medical conditions including hypertension, heart disease, diabetes, arthritis, asthma and sleep apnoea. In GCWMS dietitians collect the same information as part of the referral process of patients to their service and they also have access to clinical information.

5.2.6 Statistical analysis

Data management and statistical analyses were performed using SPSS for windows version 18 (SPSS, Chicago, IL).

Medical conditions are reported in absolute numbers and proportions (%). Analysis of normality using the Shapiro-Wilk test showed that no continuous variables were normally distributed; therefore weight and BMI changes are reported as median values and ranges. Between groups comparisons with respect to weight and BMI change were performed using the nonparametric Mann

Whitney test. A *P* value of less than 0.05 indicated statistical significance for all comparisons.

5.3 Study 3b: Identification of socio-biological predictors for weight loss

5.3.1 Participants

Recruitment details and characteristics of the participants of the TAKE 5 study have been reported in the general methods. According to the study, 47 participants with ID and obesity completed 16 weeks of the weight loss intervention and five participants did not complete the intervention on time.

The TAKE 5 weight loss intervention examined the relationship of specific participant characteristics with weight loss but did not reveal any significant associations (Melville *et al*. 2011). However, the study did not include all the recruited participants in the analysis.

Study 2b obtained data from a total of 52 participants that completed the TAKE 5 study to repeat the regression analysis of variables assessed in Melville *et al*. (2011) and others.

5.3.2 Variables

The variables included in the analysis were the determinants of obesity in adults with ID, described in the introduction, variables initially assessed by Melville *et al*. (2011) and biological variables examined in adults without ID:

- Age (years)
- Baseline body weight (kg)
- Baseline BMI (kg/m^{-2})
- Down's syndrome
- Epilepsy seizures or fits
- Gender
- Family vs. paid carer

- Hearing impairment/ear problems
- Initial weight loss (4 weeks)
- Intellectual disabilities (mild/moderate v. severe/profound)
- Prescribed obesogenic medication
- Problems in walking because of weight
- Registered blind or partially sighted
- Type 2 diabetes

TAKE 5 did not assess knowledge of nutrition, did not provide assignments to the participants and did not report a high rate of attrition. Therefore the variables knowledge, self-reinforcement and adherence that have been examined in other studies in adults with ID were not examined as potential predictors for weight loss (Harris and Bloom 1984; Fox *et al*. 1985; Fisher *et al*. 1986; McCarran and Andrasik 1990; Mann *et al*. 2006; Moss 2009; Bazzano *et al*. 2009).

5.3.3 Statistical analysis

All data management and statistics were performed using SPSS for windows version 18 (SPSS,Chicago,IL) following the procedures as described in section 5.1.13

Chapter 6: Study 4 Qualitative Methods

Study 4: Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: a qualitative study

This chapter represents a body of work from which a paper has been published. Spanos *et al*. 2013 Journal of Intellectual Disability Research; **57**:90-102. (Appendix 8)

6.1 Introduction

Studies report that support from family or paid carers can have a positive impact on weight loss for adults with ID and obesity (Hamilton *et al*. 2007). Carer involvement can vary from offering support to the participants during sessions, to encouragement and reinforcement of healthy lifestyle messages (Harris and Bloom 1984; Fox *et al*. 1985; McCarran and Andrasik 1990; Bazzano *et al*. 2009). The systematic review in chapter 3 showed that no study to date has explored the role of carers in the weight loss process.

6.2 Study Design

The present study used a qualitative approach to explore carers' experiences and behaviour, with emphasis to their attitudes, interactions and views (Mays and Pope 1996; Silverman 2005). See figure 6.1 for the overall sequence of events followed in the methodology of this study.

The ethical approval from the TAKE 5 weight loss study was extended for the study 4. According to the Ethics Committee there was no need for procedures on obtaining a new approval for the rest of the studies since the methodologies did not include a randomisation and the studies were seen a continuation of the TAKE 5 weight loss study.

6.2.1 Sampling strategy

The study sample was recruited from the carers supporting adults (≥18 years) with ID and obesity (BMI ≥ $30kg^2$) already participating in a study of weight loss intervention (TAKE 5). Since, the TAKE 5 sample had already been identified and recruited before of the qualitative research, convenience sampling was chosen as the ideal technique that could be used to answer the research questions of this study. Convenience sample has been defined as the sample that "is found in one place, setting or source" (Bowling and Ebrahim 2005).

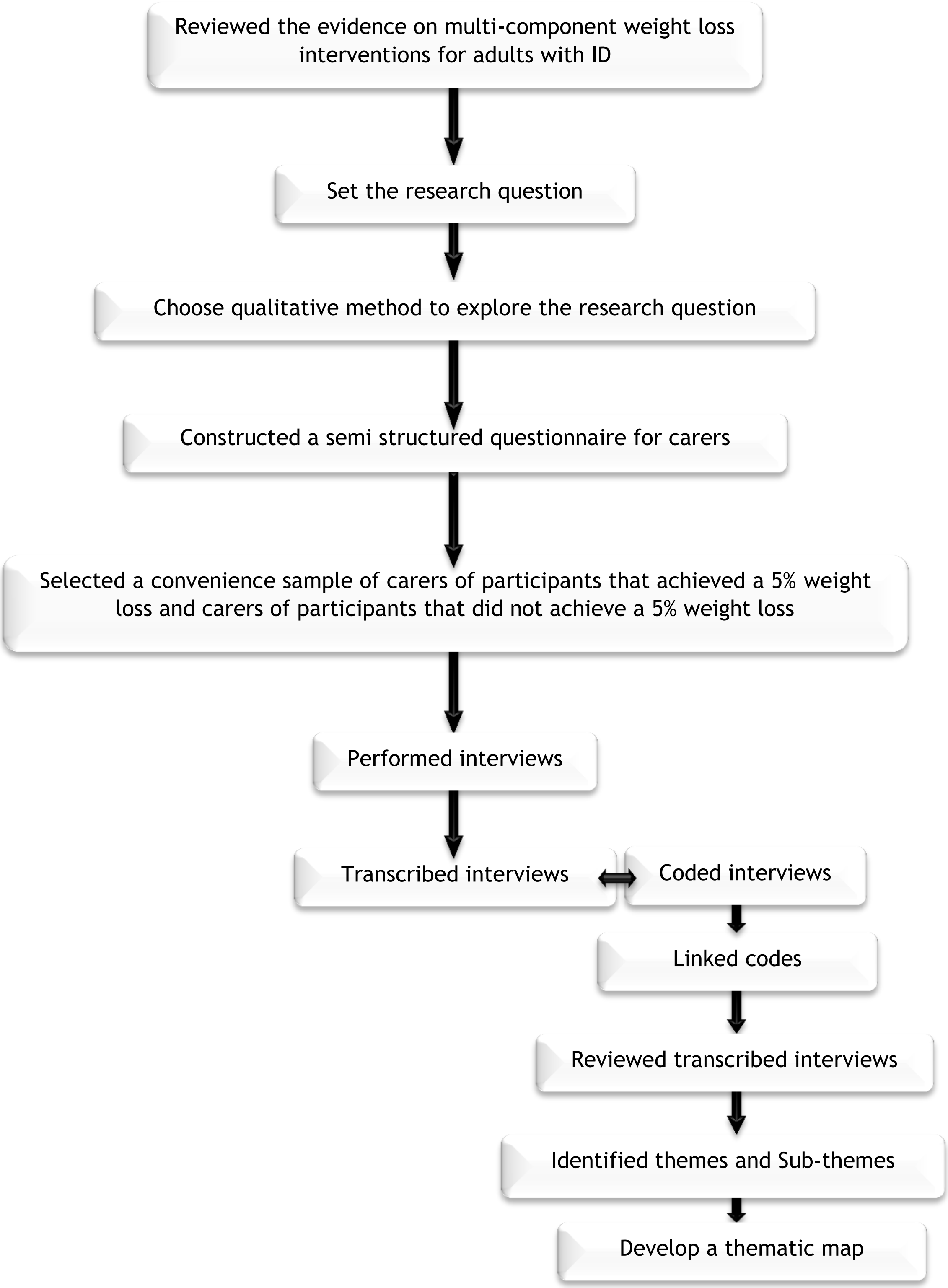
Contrary to quantitative research, there are no specific rules regarding sample sizes (Baum 2002). The sample size in qualitative research depends on several factors including: the research questions of the study, the time and the resources available (Patton 2002). These factors could determine whether the researcher will focus on the "breadth" (aimed in a large sample) or the "depth" (aimed in a small sample) of the data collected. Therefore, in this study the researcher decided to perform "in depth" interviews in a small sample describing a wide range of experiences.

In addition, the required number of participants can be determined by the saturation of the information collected from the interviews (Fade 2003). The saturation is reached when different respondents start reporting the same information and further interviews are not revealing new material. The researcher could then decide to stop the stage of the interviews without reaching the original estimated sampling (Glaser and Strauss 1967). According to Creswell (1998) saturation in qualitative studies that use grounded theory can be reached with a sample size ranging from 20 to 30 participants and Morse (1994) suggested a range of 30 to 50 for ethnographic studies.

Purposive sampling was also identified as the second suitable method of sampling for this study. Purposive sampling is a method that allows a case to be chosen because it illustrates some feature or process relevant to the questions in which the researchers are interested (Silverman 2005). This means that the researcher will select a sample that will provide specific information that will highlight the areas of interest (Patton 1990).

In this study the areas of interest included the role of paid and family carers in the support of adults with ID and obesity participating in a weight management intervention and the evaluation of this process based on their experiences. The researcher was looking for equal numbers of carers that supported participants that achieved a 5% weight loss and carers that supported participants that did not achieve a 5% weight loss at the end of the TAKE 5 weight loss intervention.

Figure 6.1: The sequence of events in the qualitative methodology



6.2.2 Interview schedule

The interview schedule comprised of a series of semi-structured questions; an initial set of open ended questions defined the areas to be explored. This allowed the interviewee and interviewer to deviate and explore comments in detail (Mays and Pope 1996). The interview schedule was developed based on the recommendations of Patton (1987), using questions based on behaviour or experience, on opinion or value, on feeling and on knowledge. The schedule was divided into three general topics:

1. Carers' perceptions of weight loss
2. Challenges faced while supporting participants to change his/her dietary and physical activity patterns
3. Carers' perceptions on the TAKE 5 weight loss intervention.

After reviewing three early interviews, the schedule was revised to include extra prompts to assist the researcher to explore the experiences of carers with the intervention. The set of semi structured questions can be found in the appendix 6.

6.2.3 Interviews

All the interviews were conducted on a one to one basis in participants' own homes by the researcher. All interviews lasted between 30-40 minutes. Interviews were audio-recorded digitally using Olympus DSS player 2300, to allow the review of interviewing quality. Carers were assured that their views would remain anonymous and confidential.

6.2.4 Data analysis

The main objective of the analysis was to explore the positive and negative experiences of carers supporting participants with ID during the process of a weight loss intervention. All data were anonymised and transcribed verbatim. Each interview was transcribed by a specific secretarial staff member. Each transcribed interview was checked against the original recording and made anonymous. The transcribed interviews were not shared with the carers. Although respondent validation is considered as the ultimate check (Lincoln and Guba 1985), the author believes that this method may rely on the false assumption that interviewees share the same critical ability as the researcher (textual reference) or can act as unbiased assessors (Murphy 1998).

Before analysis, each interview of a carer was identified with an interview number followed by the letters “CrN” for carers of participants that did not succeed 5% weight loss and “CrW” for carers of participants that did succeed 5% weight loss e.g. 1CrN and 2CrW.

The qualitative data software analysis package, ATLAS ti 5.2 software (Murf, Berlin, 2006) was used to organise the transcripts and analyze the data. The qualitative analytic method used was thematic analysis, which is a flexible method that can be used to explore experiences of participants and describe patterns within the qualitative data, without being influenced by other pre-existing theoretical frameworks. The analysis was an inductive process, since the categories and the themes, unlike the topics of interest, were not predetermined prior to the coding of the data (Ezzy 2002). It was performed in the following six steps as outlined by Braun and Clarke (2006):

1. The researcher listened to the audio recordings and read the transcripts several times to familiarise himself with the data. A list of ideas were produced and discussed with a second researcher (CM)
2. Identification of potential data driven codes. Extracts were matched with the listed codes;
3. Codes were collated to more general codes followed by the creation of potential sub-themes and broader concepts comprises the themes (example appendix 7)
4. Revision of the themes, collapsing the ones sharing relevant data and designing a thematic map;
5. Acceptance of the final themes and addition of descriptions;
6. The researcher chose extracts that were associated with the themes and the research questions for the report.

The process of coding and production of themes was an on-going process susceptible to changes following review and discussion with an additional researcher. As a measure of validity, the additional researcher (CM) reviewed the process of data analysis and analysed three randomly-selected transcripts and co-operated with the primary researcher in the linking of codes and the development of themes. As the same researcher gathered all data, continuity and consistency of approach and interpretation was preserved.

6.2.5 Confidentiality and anonymity

Data remained confidential with the recordings identified only by a research number and heard only by the interviewee and one secretarial staff member. Transcripts were read by the primary researcher and the two research supervisors. The participants were known only by the assigned research number. Copies of the anonymised transcribed interviews and the recorded interviews were stored and password protected as files in a computer stored safely in the department of Psychological Medicine. The participants' personal details were stored in a locked filing cabinet to be shredded at the end of the research period.

CHAPTER 7: Study 2 Results

7.1 Methods

The study design, setting, and method of data analysis have been described in chapter 5 (Methods), section 5.1.

7.2 Results

The results refer to three main points of the TAKE 5 weight management intervention:

Time 1: Baseline
Time 2: End of the 16 week weight loss intervention (end of Phase 2)
Time 3: End of 12 months weight maintenance intervention (end of Phase 3)

7.2.1 Participants

A total of 31 individuals were eligible and agreed to participate in Phase 2: weight maintenance. However one individual died eight months after initiating the intervention and two individuals dropped out of the study at Session 2 and Session 6 of the intervention, respectively. One participant decided to follow a commercial weight management programme and the second decided to take a break from weight management and planned to start again later.

The characteristics of the 28 participants of the weight maintenance intervention (Phase 2) are shown in table 7.1. A total number of 28 participants included 10 males (35.7%) and 18 females (64.3%). The mean age of the participants was 47.8 years (SD=10.7).

Table 7.1: Demographic and health characteristics of participants at the end of the 16 week weight loss intervention (time 2). (number of participants and percentages, n= 28)

Variable	n	%
Gender		
Male	10	35.7
Female	18	64.3
5% weight loss	18	64.3
3% to less than 5% weight loss	10	35.7
Ethnicity		
Caucasian	27	96.4
Other Asian background	1	3.6
Marital status		
Married/live with a partner	1	3.6
Single	27	96.4
Type of support		
Lives independently	1	3.6
Family carer	9	32.1
Paid carer	18	64.3
Down syndrome		
Yes	8	28.6
Level of intellectual disability		
Mild	10	35.7
Moderate	9	32.1
Severe	9	32.1
Epilepsy, seizures or fits		
Yes	9	32.1
Registered blind or partially sighted		
Yes	2	7.1
Hearing impairment		
Yes	5	17.9
*Hypertension or raised blood pressure		
Yes	7	25.0
*High cholesterol		
Yes	6	21.4
*Type 2 diabetes		
Yes	2	7.1
Obesogenic medication		
yes	7	25

*as reported by the carers based on diagnosis and prescribed medication from the GP

7.2.2 Primary outcomes

7.2.2.1 Weight change

The pattern of weight change from baseline (time 1) to the end of the weight management intervention (time 3) is illustrated in Figure 7.1. Table 7.2 shows mean weight in kg and standard deviation (SD) at time 1, time 2 and at time 3 and total mean weight change in kg at time 2 and time 3.

There was a statistically significant weight loss at the end of the weight loss intervention (Phase 1) (mean weight difference = -7.4kg; 95% CI= -5.6, -9.2; P <0.001). Mean weight change at the end of the weight maintenance intervention was -0.6kg (95% CI= -2.8, +1.5) and not statistically significant. Overall, from baseline to the end of weight management intervention participants lost -8kg (95% CI= -10.5, -5.5; P <0.001).

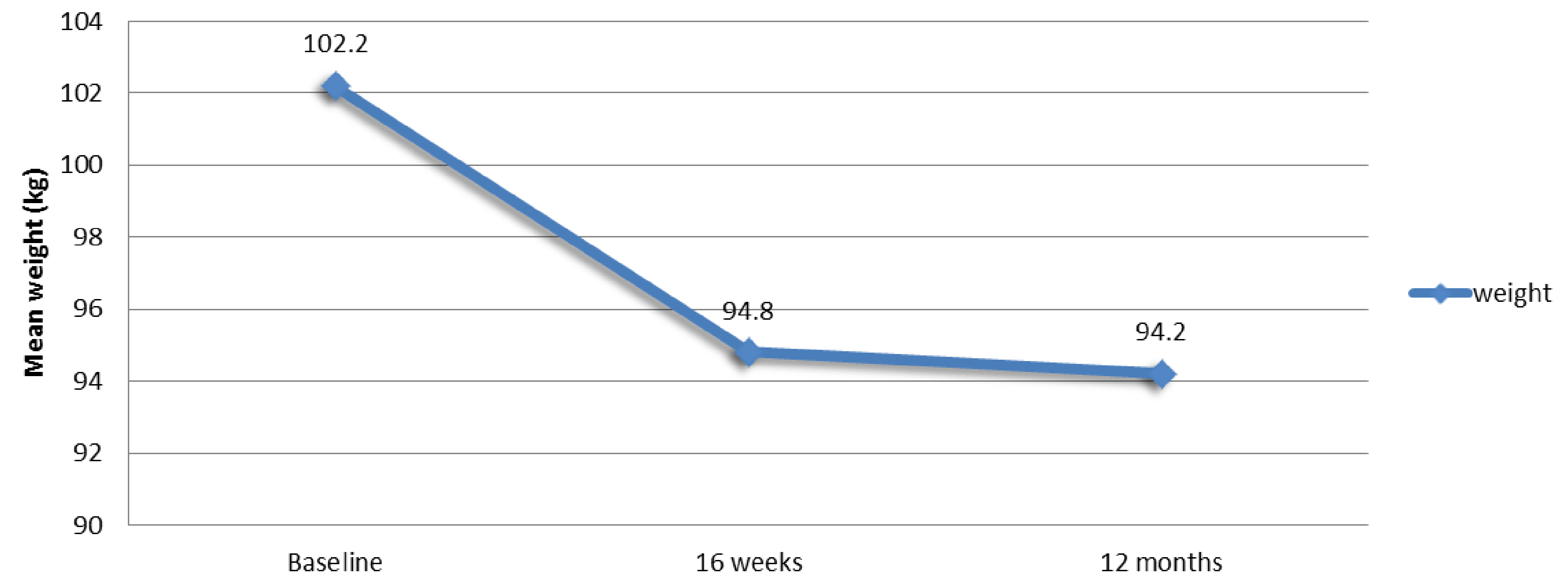
The mean percentage weight change between time 1 and time 2 was -7.4% (SD= 4.5) and between time 3 from time 2 was 0.4% weight loss (SD = 5.2).

Table 7.2: Weights (kg) at time 1 (baseline), time 2 (16 weeks) and time 3 (12 months) and weight changes (kg) at time 2, and at time 3 (analysis set; n=28) (Mean values, standard deviations)

	Time 1		Time 2		Time 3							
Outcome	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean diff. (time 2-time 1)**	**Mean diff. (time 3-time 2)**	**Mean diff. (time 3-time1)**	***P****	***P*****	***P******
Change in weight (kg)	102.2	22.7	94.8	22.2	94.2	21.6	-7.4	-0.6	-8.0	0.000	0.5	0.000

*Significant difference between time 2 and time 1
** Significant difference between time 3 and time 2
***Significant difference between time 3 and time 1

Figure 7.1 Weight changes for participants (n=28) at time 1 time 2 and time 3



7.2.2.2 Weight maintenance

Using the definition for weight loss maintenance by Stevens et al (2006), the participants were classified in three categories based on weight changes between time 2 and time 3:

- Participants that had a weight gain of > 3%
- Participants who maintained their weight
- Participants that had a weight loss of > 3%

Table 7.3 shows the numbers and percentages identified in each category with the mean weight change in kg and standard deviation (SD) at time 3.

Most of the participants (50.4%) maintained their weight (mean weight change=-0.5kg; SD= 2.2) within ± 3% from initial body weight at time 2, eight participants (28.7%) gained weight (mean weight gain= 5.4kg; SD= 2.2) and six participants lost weight (mean weight loss=-8kg; SD=3).

It should be noted that at the end of the weight maintenance intervention only one participant put on weight to an extent that he was heavier than his baseline weight at time 1 (+3.3kg over baseline weight) and three participants went back approximately to the same weight as they were at baseline (0.1 to 1.8kg difference from initial body weight).

Table 7.3: Categories of weight changes between time 2 (16 weeks) and time 3 (12 months) (analysis set; n=28) (Number of participants and percentages, mean values of weight change and standard deviation)

	Time 3			
Weight change	**n**	**%**	**Mean weight (kg) change at time 3**	**SD**
weight gain > 3%	8	28.7	+5.4	2.2
Weight maintenance	14	50.4	-0.5	1.8
weight loss >3%	6	21.6	-8.0	3.0

7.2.3 Secondary outcomes

7.2.3.1 Change in BMI

Table 7.4 shows the mean BMI in kg/m^2 and SD at time 1, time 2 and at time 3 and mean BMI change in kg/m^2 and SD at 16 weeks and at 12 months.

Mean change in BMI at 16 weeks was -2.9 kg/m^2 (95% CI=-3.6,-2.3; P<0.001). There was no statistically significant change in BMI at 12 months from BMI at the end of the 16 week weight loss intervention (mean BMI change= -0.06kg/m^2; 95% CI= -0.9, + 0.8). From baseline to the end of the weight management intervention, the BMI of the participants decreased by -3$kg/m^{2\,(}$95% CI=-3.9,-2.1; P<0.001).

7.2.3.2 Change in waist circumference

There were waist circumference data available for 27 participants. Table 7.4 shows the mean waist circumference in cm and SD at time 1, time 2 and at time 3 and mean waist circumference change at 16 weeks and 12 months.

The mean waist circumference change between time 1 and time 2 was -9.5cm (95% CI=-11.2,-7.7; P<0.001). There was no statistically significant change in waist circumference at 12 months from waist circumference at the end of the 16 week weight loss intervention (mean WC change= -0.4kg/m^2; 95% CI= -2.7, 1.9). The waist circumference of the 27 participants decreased from baseline to the end of the weight management intervention by 9.9 cm (95% CI=-11.2,-7.7; P<0.001).

Table 7.4: WC (cm) and BMI (kg/m^2) at time 1 (baseline), time 2 (16 weeks) and time 3 (12 months) and comparison of secondary anthropometric outcome measures at time 3 from time 2 (analysis set; n= 27 for WC and n= 28 for BMI) (Mean values, standard deviation)

	Time 1		Time 2		Time 3							
Outcome	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean diff. (Time 2- Time 1)**	**Mean diff. (Time 3 - Time 2)**	**Mean diff. (Time 3 - Time 1)**	***P****	***P*****	***P******
Change in WC (cm)	122.7	13.7	113.2	14.5	112.8	15.6	-9.5	-0.4	-9.9	0.000	0.7	0.000
Change in BMI (kg/m^2)	41.2	7.5	38.2	7.6	38.1	7.9	-2.9	-0.06	-3.0	0.000	0.8	0.000

*Significant difference between time 2 and time 1

** Significant difference between time 3 and time 2

***Significant difference between time 3 and time 1

7.2.4 Change in physical activity

7.2.4.1 Accelerometer data

Accelerometer data at time 1, time 2 and time 3 were available from 18 out of the 28 participants. At time 3, data from three participants were not included because the analysis showed no recordings or recordings for less than three days, four participants did not wear the accelerometers and three participants did not wear the accelerometers at time 2. A total of 18 participants were eligible for inclusion in the analysis.

The participants at time 1, time 2 and time 3 were asked to wear the accelerometers for seven days even though the minimum data requirement was set at six hour of data on at least three days from seven. Participants at the end of the 16 week weight loss intervention wore the accelerometers on more days (mean = 6.9 days; SD= 0.3) than at the end of the 12 months weight maintenance intervention (mean=6 days; SD= 6, 1.2) (P<0.05).

Figure 7.2 shows patterns of time change spent in different levels of physical activity. Table 7.5 shows mean time in minutes and SD spent in light, moderate to vigorous intensity and sedentary physical activity (as defined in the chapter 3, section 3.1.2.13) in previous seven days at time 1, time 2 and at time 3. The table also shows mean change of these variables and at time 2 and time 2.

Table 7.5: Physical activity at time 1(baseline), time 2 (16 weeks) and time 3 (12 months) and physical activity changes at time 2 and time 3 (analysis set – accelerometer; n=18) (Mean values, standard deviations)

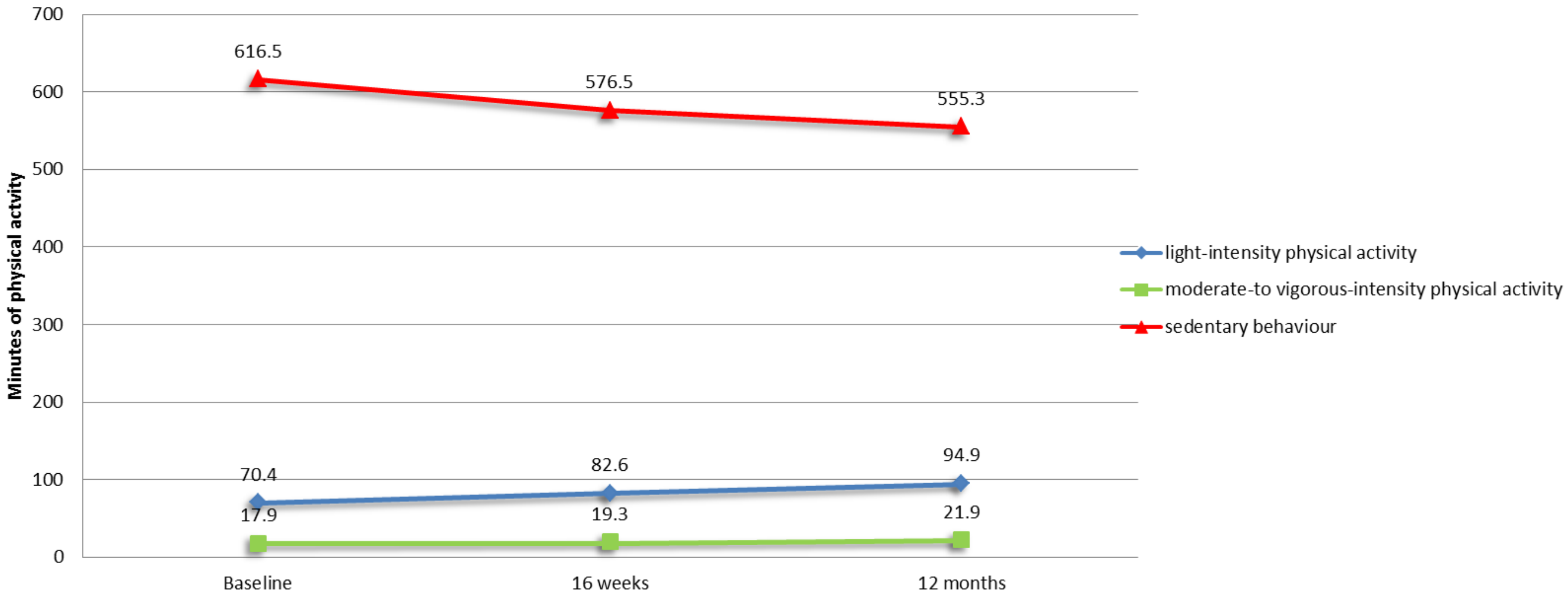
	Time 1		Time 2		Time 3							
Outcome	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean dif. (Time 2-Time 1)**	**Mean dif. (Time 3-Time 2)**	**Mean dif. (Time 3-Time 1)**	**P***	**P****	**P*****
Time spent (min) in light-intensity physical activity/d	70.4	37.5	82.6	38.2	94.9	38.8	12.1	12.4	24.5	0.2	0.09	0.002
Time spent (min) in moderate-to vigorous- Intensity physical activity/d	17.9	20.7	19.3	17.3	21.9	14.0	1.4	2.6	4.0	0.6	0.2	0.03
Time spent (min) in sedentary behaviour/d	616.5	136.6	576.5	145.9	555.3	139.6	-40.0	-21.2	-61.2	0.2	0.7	0.2
Percentage of time spent in light-intensity physical activity	10.0	5.2	12.6	6.2	12.7	4.5	2.5	0.03	2.6	0.05	0.9	0.01
Percentage of time spent in moderate-to-vigorous-intensity physical activity	2.8	3.8	3.2	3.6	2.8	1.7	0.4	-0.6	0.4	0.3	0.6	0.9
Percentage of time spent in sedentary physical behaviour	87.1	8.1	84.2	8.7	79.8	6.8	-2.9	-4.3	7.3	0.06	0.06	0.000

*Significant difference between time 2 and time 1

** Significant difference between time 3 and time 2

***Significant difference between time 3 and time 1

Figure 7.2 Changes in time (min) spent per day for participants (n=18) at time 1, time 2 and time 3 (accelerometer data)



Sedentary behaviour

Objective measurements collected from the accelerometers showed that participants continued to live sedentary lifestyles at the end of the 16 weeks of weight loss intervention (Phase 1) and at the end of the 12 months of the weight loss maintenance intervention (Phase 2). At the end of weight maintenance intervention participants were spending a mean of 555.3 (SD=139.6) min/d in sedentary activity or a 79.8% (SD=6.8) of the time spent wearing the accelerometers.

There was no statistically significant decrease in the percentage of time spent in sedentary behaviour between time 2 and time 3 but there was a statistically significant decrease in percentage of time spent in sedentary behaviour between baseline and time 3 (mean difference= -7.3%;SD=6.3; 95% CI=-10.4,-4.15).

Light physical activity

At the end of the weight loss maintenance intervention, participants were spending 94.9 (SD=38.8) minutes per day in light physical activity, equal to 12.6% of the monitored time. This means that participants spent more minutes in this type of physical activity than at the end of the weight loss intervention (mean=82.6 minutes; SD=38.2) but again the difference (12.4 minutes) was not significant.

However comparisons between time 3 and time 1 showed a statistically significant increase in time spent in light physical activity by 24.5 minutes per day (95% CI=9.9, 39.0), equal to a statistically significant increase of 7.3% of the percentage of monitored time ($P<0.001$).

Moderate to vigorous physical activity

There was no significant increase of time or percentage of time spent in moderate to vigorous physical activity at time 3 from time 2. Participants were spending only 2.8% (SD=1.7) of the recorded time in this type of physical activity. However, at time 3 participants were spending significantly more time in moderate to vigorous physical activity than in time 1 (mean difference=+4 minutes; SD=13.3; 95% CI=-2.6, 10.6).

7.2.4.2 IPAQ data

IPAQ data on walking were available for all participants (n=28) at time 1, time 2 and time 3.

Table 7.6 shows mean time (minutes) and SD spent in walking at time 1, 2 and time 3. The table also shows mean changes in this variable at time 2 and 3.

At time 3 participants spent less days (mean=4.5 days; SD=2.3) walking (at least 10 minutes) in the previous seven days than at time 2 (mean=5.5; SD= 2.1) (P<0.05). According to the bar chart (figure 6.3) less participants walked six (3.6%) or seven (39.3%) days at 12 months than at 16 weeks (7.1% and 57.1%, respectively).

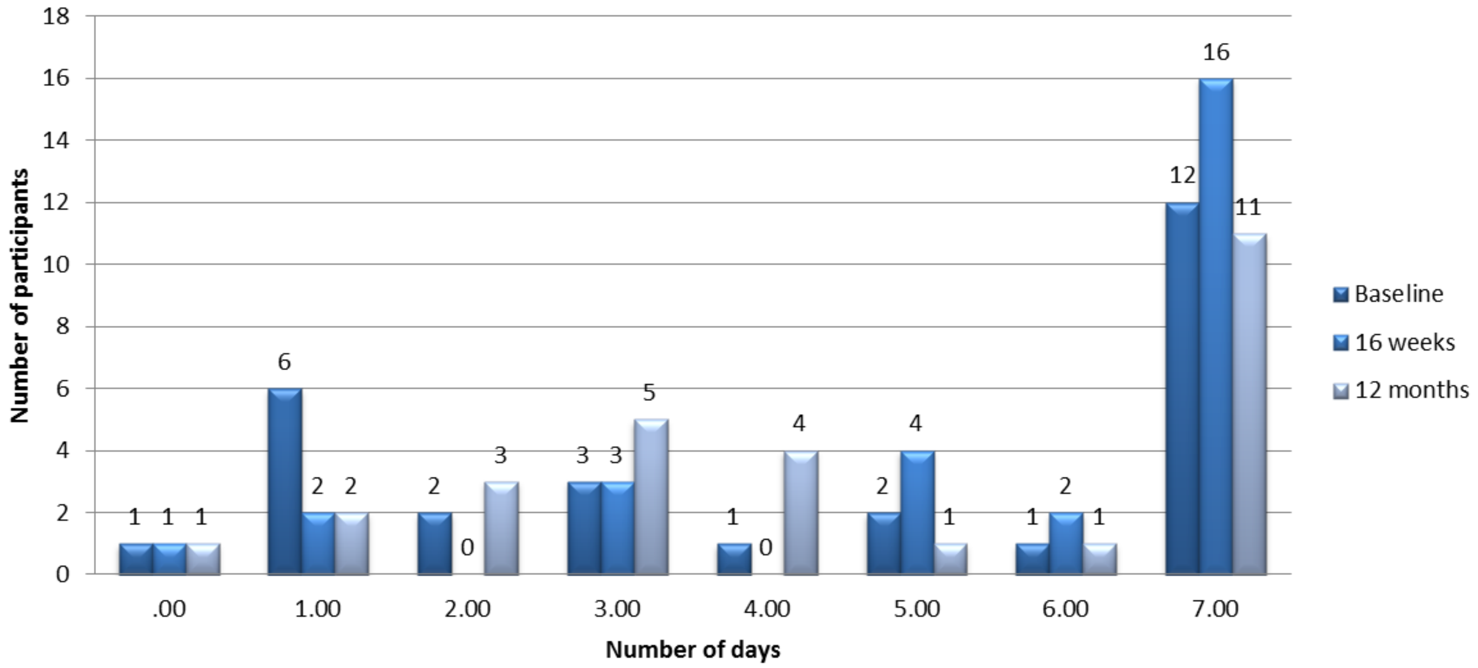
There was no statistically significant increase in the amount of minutes spent walking in one of those days at time 3 from time 1 or from time 2. At time 3 participants spent 75.5 minutes in walking in one of the 4.5 days.

Table 7.6: Walking at time 1 (baseline), time 2 (16 weeks) and time 3 (12 months) and comparison of time and days spent walking at time 3 from time 2 (analysis set- IPAQ; n=28) (Mean values, standard deviations)

	Time 1		**Time 2**		**Time 3**							
Outcome	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean diff.** (Time 2-Time 1)	**Mean diff.** (Time 3-Time 2)	**Mean diff.** (Time 3-Time 1)	***P****	***P*****	***P******
Number of days spent walking at least 10 minutes at a time in previous 7d	4.4	2.6	5.5	2.2	4.5	2.3	1.1	-1.0	0.1	0.01	0.04	0.7
Time spent (min) walking in one of these days	47.8	57.7	60.3	55.0	75.5	65.5	12.5	15.2	27.7	0.4	0.3	0.1

*Significant difference between time 2 and time 1
** Significant difference between time 3 and time 2
***Significant difference between time 3 and time 1

Figure 7.3 Number of participants by number of days walking at least 10 minutes at time 1, time 2, time 3



7.2.5 Predictors of weight maintenance

Table 7.8 shows correlations of potential individual predictors at time 2 and absolute weight change at time 3. None of the continuous variables were shown to be significant predictors.

Table 7.8: Simple correlation matrix between potential baseline individual predictors and absolute weight change at time 3 (correlation coefficients and *P*-values) (analysis set; n= 28)*

Correlation with weight loss	**r**	***P***
Age (years)	0.09	0.6
Absolute weight loss at time 2	0.18	0.3

Table 7.9 shows mean weights at time 2 and time 3 and mean weight changes at time 3 for each subgroup of potential predictors for weight maintenance at time 3. There was no significant weight change for males or females, participants with mild/moderate ID or severe ID, participants with paid support or family support, participants that achieved a 5% weight loss at time 2 or did not.

In addition, table 7.10 shows that there was no significant difference in weight change at time 3 between males and females, participants with mild to moderate ID and severe ID, participants with and without Down syndrome, participants living with family and paid carer support, participants that achieved and did not achieve a 5% weight loss at time 2.

Table 7.9: weight (kg) at time 2 (16 weeks) and time 3 and weight change (kg) at the end of 12 months (time 3) for each subgroup of potential predictors for weight loss maintenance (n=28) (mean values, standard deviations and 95% confidence intervals)

		Time 2		Time 3				
	n	**mean**	**SD**	**mean**	**SD**	**Mean diff. (Time 3-Time 2)**	**95% CI**	***P***
Gender								
Male	10	103.2	27.3	100.9	23.8	-2.2	-6.9, 2.5	0.3
female	18	90.1	17.9	90.4	19.9	0.3	-2.1, 2.7	0.8
ID								
Mild to moderate	19	95.5	25.7	94.4	24.9	-0.8	-3.9, 2.3	0.6
Severe	9	93.3	12.9	93.0	13.0	-0.2	-2.5,2.0	0.8
Down syndrome								
Present	8	83.7	19.0	83.7	23.0	-0.02	-5.8, 5.8	0.9
Not present	20	99.2	22.2	98.3	20.0	-0.8	-3.2,1.5	0.4
Type of support								
Family	10	100.2	19.3	99.9	21.7	-0.3	-5.6,4.9	0.9
Paid carers	18	91.7	23.6	90.9	21.4	-0.7	-2.9,1.4	0.5
Weight loss at time 2								
≥5% weight loss	18	90.6	21.7	90.9	21.9	0.3	-2.7, 3.4	0.8
<5% weight loss	10	102.2	22.1	99.9	20.7	-2.3	-5.0,0.4	0.08

Table 7.10: Comparison of weight change(kg) at time 3 (12 months) from time 2 (16 weeks) and patient characteristics (analysis set; n=28) (Mean values, standard deviations and 95% confidence intervals)

	Group 1		**Group 2**				
Variable	**mean**	**SD**	**mean**	**SD**	**Mean diff. weight change Time 3**	**95% CI**	***P***
Gender (group 1: male; group 2: female)	-2.2	6.5	0.3	4.9	-2.5	-6.9, 1.9	0.2
ID (group 1: mild/moderate; group 2: severe)	-0.8	6.5	-0.2	3.0	-0.6	-5.2,4.1	0.8
Down syndrome (group 1:yes; group 2: no)	0.01	6.7	-0.9	5.0	0.9	-3.9,5.7	0.7
Type of support (group 1: family; group 2: paid carer)	-0.3	7.4	-0.8	4.4	0.4	-4.1,4.9	0.8
Weight loss at time 2 (group 1: ≥5% weight loss; group 2: < 5% weight loss)	0.3	6.2	-2.3	1.2	2.6	-1.8,7.0	0.2
Obesogenic medication (group 1:yes; group 2:no)	-2.8	2.5	0.8	5.4	-3.6	-8.0,0.8	0.2

According to table 7.11, a greater number of participants with mild to moderate ID did not achieve weight maintenance than participants with severe ID (63% vs. 22%). Within those participants with mild to moderate ID that did not achieve weight maintenance, 58% put on weight significantly ($P<0.05$) (mean weight change= +5.1kg; SD=3.6; 95% CI=1.7, 8.5) and 42% lost weight significantly (mean weight change=-9.1kg; SD=3.8; 95% CI=-13.9, -4.3). The absolute mean weight change at time 3 for this group was not statistically significant (mean weight change:-0.8kg; SD=8.2; 95% CI=-6.0, 4.3)

In addition more participants that achieved a 5% weight loss at time 2 did not achieve weight maintenance than those that did not achieve a clinical significant weight loss at time 2 (66.7% vs. 20%). Within those participants that achieved a 5% weight loss at time 2 but not a weight maintenance, 66.7% put on weight significantly ($P<0.05$) (mean weight change=+5.2kg; SD=3.3, 95% CI=2.4, 8.0) and 33.3% lost weight significantly ($P<0.05$) (mean weight change = -8.6kg; SD=4.1; 95% CI=-15.2,-2.0). However, the absolute mean weight change for this group at time 3 was not statistically significant (mean weight change=+0.6; SD=7.6; 95% CI=-4.2, 5.4).

Table 7.12 shows associations of categorical variables at time 2 and weight loss maintenance (± 3% weight change) at time 3. Only 5% weight loss at time 2 was shown to be a significant predictor for weight loss maintenance ($P<0.05$) and with an odds ratio less than one indicated that participants that achieved a 5% weight loss are less likely to achieve a weight maintenance.

Table 7.11: Comparison of achievement of 3% weight maintenance at time 3 (12 months) and participant characteristics (analysis set; n=28)

	Group 1				**Group 2**				
	Yes 3% w.loss maintenance		**No 3% w.loss maintenance**		**Yes 3% w.loss maintenance**		**No 3% w.loss maintenance**		
Variable	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	***P***
Gender (group 1: male; group 2: female)	4	40	6	60	10	55.5	8	44.4	0.4
Intellectual disabilities (group 1: mild/moderate, group 2: severe)	7	36.8	12	63.1	7	77.7	2	22.3	0.04
Down syndrome (group 1:yes; group 2: no)	3	37.5	5	62.5	11	55	9	45	0.4
T. support (group 1:family; group 2: paid carer)	5	50	5	50	9	50	9	50	1
Weight loss at 16 weeks group 1: ≥ 5% weight loss; group 2: no 5% weight loss)	6	33.3	12	66.7	8	80	2	20	0.01

Table 7.12: Association between participants achieving a weight loss maintenance of 3% of their initial body weight and patient characteristics (analysis set; n=28)

Variable	**OR**[†]	**95% CI**	***P***
Gender (male v. female)	0.5	0.1,2.5	0.4
Intellectual disabilities (mild/moderate v. severe)	0.1	0.02,1.03	0.05
Down syndrome	0.5	0.09,2.6	0.4
Family v. paid carer	1	0.2,4.6	1
Weight loss at time 2 (≥5% weight loss v. <5% weight loss)	0.1	0.02,0.8	0.02

[†]Odds ratios and confidence intervals are for yes v. no for categorical variables, unless otherwise stated

7.3 Discussion

7.3.1 Key findings

The TAKE 5 weight management intervention for adults with ID and obesity is a multi-component intervention that incorporated a 16 week weight loss intervention and a 12 month weight maintenance intervention. The purpose of the weight maintenance intervention was to support participants to sustain their lifestyle changes in diet, physical activity and behaviour and maintain their weight loss for 12 months after the weight loss phase.

To facilitate the participants understanding of the definition of weight maintenance and to report robust results on weight changes, the present study accepted as weight maintenance only the weight changes within ± 3% from body weight at the end of the weight loss intervention. Following the weight maintenance intervention, the majority of the participants maintained their weight within those limits.

Objective measurements of physical activity (accelerometers) showed that the TAKE 5 weight maintenance intervention had no significant effect on sedentary behaviour, on light and moderate to vigorous physical activity level. Analysis of data from IPAQs showed a negative effect on number of days spent walking and no significant effect on time spent walking. Overall, the TAKE 5 weight management programme succeeded to improve the physical activity levels of the participants significantly but no participants in the current study met current physical activity recommendations after the weight loss maintenance intervention.

The identification of factors that can support individuals to maintain the weight they have lost is important for the development of strategies that can be used during a weight maintenance phase in research and in clinical settings (Elfhag and Rossner 2005). However, clinically significant weight loss at the end of Phase 1 was the only predictor for weight loss maintenance that this study identified.

7.3.2 Comparison with previous studies

7.3.2.1 Weight maintenance

It is difficult to compare the findings of this study with Saunders *et al.* (2011) the only multi-component weight loss intervention that provided a weight loss maintenance phase. The difficulty is related to the differences between the two studies, including the difference in the duration of the weight maintenance interventions (six months vs. 12 months), the type of the initial weight loss intervention (VLCD vs. 600kcal energy deficit diet) and the intensity of the weight maintenance intervention (monthly meetings with 24hr recalls vs. monthly meetings with extensive behavioral and health education).

Saunders *et al.* (2011) reported weight maintenance in reference to baseline weight but the present study reported maintenance in reference to the weight at the end of the weight loss phase. Saunders *et al.* (2011) did not use a definition for weight maintenance, reporting results as a mean of weight loss and weight gain. However, based on the definition for weight maintenance used by Stevens *et al.* (2006) both studies were effective in weight maintenance with Saunders *et al.* (2011) reporting an overall mean weight change of -2.8kg (≈2.94%) at six months follow up and this study of -0.62kg (-0.4%) at 12 months follow up. The weight changes in reference to baseline weight were -8.8kg for Saunders at al. (2011) and -8.05kg for this study.

Fox *et al.* (1984) was the only behavioural and physical activity intervention that included a five week weight maintenance intervention. Contrary to the weight loss intervention, the weekly meetings for maintenance were focused on behaviour change and not on physical activity. Similar to the TAKE 5 weight maintenance intervention, carers (parents) played an important role in encouraging and supporting the participants but also reviewing their progress. Fox *et al.* (1984) reported that participants continued to lose weight (1.8%) over the weight maintenance period. However, it has to be noted that unlike this study the weight loss maintenance intervention continued to actively promote further weight loss. Weight measurements at 12 months showed that the majority of the participants had put their weight on with only 37.5% maintaining a total weight loss of 5.8kg from baseline.

Other studies in adults with ID that included a weight loss maintenance phase were two behavioural therapy interventions (Fox *et al.* 1985; McCarran *et al.* 1990). The weight maintenance phase ranged from five weeks to three months, focusing on behaviour therapy. However, similar to Fox *et al.* (1984), Fox *et al.* (1985) reviewed the progress of the participants in adopting new dietary and physical activity behaviours and continued to promote further weight loss with the use of self-reward strategy for any changes in dietary habits or physical activity patterns.

The weight changes reported by Fox *et al.* (1985) after the weight maintenance phase were very small equal to + 0.7kg for the group of the participants that had support from their parents. The participants of the parent group maintained a total of 3.4% weight loss from pre-treatment. There was no significant difference in weight maintenance between the participants that had the support of their carers and those who did not (-1.5% weight loss). However, six months follow up measurements showed that participants in the group supported by parents gained weight (1.8kg) reducing the overall weight loss from baseline from 3.4kg to 1.9kg.

McCarran *et al.* (1990) provided overall post treatment measurements and it is not clear whether the post treatment measurements include the 14 week weight loss intervention only or plus the five week maintenance. Follow up measurements at 12 months showed weight gain leading to an overall weight loss of 1.5kg from baseline.

Three studies that did not include a weight maintenance intervention provided data from weight measurements at follow up after 12 months (Jakson and Thorbecke 1982; Harris and Bloom 1984; Chapman *et al.* 2005). Jackson and Thorbecke (1982) showed that after the weight loss intervention, participants from the intervention group continued to lose weight (1.58kg) leading to a total weight loss of 10.36% from baseline at 12 months. Chapman *et al.* (2005) did not report a significant reduction of BMI between baseline and at six months (end of weight loss intervention) but reported a significant reduction between baseline and at 12 months. However, Harris and Bloom (1984) reported weight gains at 12 months follow up, influencing the significance of the initial weight loss. This means that participants with ID may need more than six months of weight loss intervention to lose weight or that weight management interventions should provide a second structured weight maintenance phase to prevent weight gains. However, the findings are not enough to make strong conclusions from these studies.

7.3.2.2 Physical activity

Several studies and clinical guidelines provide evidence that physical activity plays an important role in the maintenance of reduced weight (Catenacci and Wyatt 2007; NICE 2006; SIGN 2010). Even though there is no general agreement about the level and amount of physical activity (Donnelly *et al*. 2004) and even though some studies suggest that weight control is a much more complicated process than just an issue of physical activity, research shows that being active can lead to health improvements including cardiovascular health (Cook and Schoeller 2011).

a) Moderate to vigorous physical activity

No weight management intervention for adults with ID that provided a weight maintenance intervention has assessed physical activity levels of the participants (Fox *et al*. 1984; Fox *et al*. 1985; McCarran and Andrasik 1990; Saunders *et al*. 2011). The studies did not provide information regarding advice on physical activity during the weight maintenance phase, with only Fox *et al*. (1985) reporting using reward systems to encourage changes in physical activity and Saunders *et al*. (2011) discontinuing self-recordings of physical activity from the participants.

From the three studies that did not provide a weight maintenance intervention but reviewed outcome measures at 12 months, only Harris and Bloom (1984) assessed fitness of the participants (Jakson and Thorbecke 1982; Harris and Bloom 1984; Chapman *et al*. 2005). The physical fitness assessment was based on time measurements while walking, jogging or running a half mile course. Even though there was a significant decrease in time spent to cover a half-mile at the end of the intervention (seven weeks) ($p<0.05$), the decrease was not significant at 12 months. No study that was classified as a "physical activity" intervention in the review of chapter 3 completed 12 month follow up measurements.

The TAKE 5 weight maintenance intervention did not include an exercise program but only promoted national guidelines (NICE 2006; SIGN 2010) on healthy physical activity levels. Two sessions out of the 12 sessions of the weight loss maintenance were exclusively dedicated to physical activity by providing information on how participants can become more active and ways of planning more activities during the day. Self-monitoring was also used in the form of an activity diary. In addition, as part of the goal setting process participants were encouraged to make changes relevant to physical activity. However, this method of physical activity promotion did not improve the levels of moderate to vigorous physical activity of the participants. This means that this aspect of the intervention may require a more intensive approach seen in other studies for adults without ID (Loveman *et al.* 2011) but also in the GCWMS such as including supervised group or individual exercise classes, prescribing a specific exercise regime of endurance or resistance training or of activities favorable for people with ID such as walking.

It is possible that the TAKE 5 weight maintenance intervention was unable to overcome commonly reported barriers to physical activity by people with ID and their carers including costs, participant's lack of knowledge of types of available physical activities and lack of understanding the benefits of physical activity (Hawkins and Look 2006; Mahy *et al.* 2010). However, the TAKE 5 aimed to improve the physical activity levels of the participants by providing advice on ways of overcoming potential barriers including advice to participate in suitable exercise programmes at the day centers and planning activities for their weekly routine. A systematic review by Bodde and Seo (2009) reported that modifiable barriers to physical activity for people with ID such as lack of social support because of limitations in planning, transportation and staffing is related to the lack of funding, policies and protocols of residential and day service programs. These barriers can be difficult to be addressed just by a weight maintenance intervention and may require the substantial contribution of managers of care plans for a holistic restructure of the support of an individual with ID. In addition, the high levels of inactivity identified in this population group (Mathews *et al*. 2011); can act as a barrier to significant increments in physical activity.

b) Walking

Walking is a common activity among people with ID (Stanish *et al*. 2006), with 80% of the participants in a survey of 470 people with ID in the East of Glasgow reporting that they would like to try walking as a physical activity (O'Hare and Black 2010). The promotion of walking in adults with ID can be seen as ideal for increasing physical activity because it can avoid some of the commonly reported barriers of becoming active including limited access to leisure centers and financial constraints (Hawkins and Look 2006). Walking is a cost effective physical activity, with low risk of injury and suitable for the most sedentary individuals that are motivated to increase their physical activity (WHO 2010; Ogilvie *et al*. 2007).

Several studies in adults without ID have reported that walking can prevent weight regain (Villanova *et al*. 2005; Nakade *et al*. 2012). For example successful weight maintainers from the National Weight Control Registry have reported energy expenditure equal to 2825 ± 2790kcal per week (11 830 ± 11 682 kJ per week) through physical activity (Klem *et al*. 1997). This is estimated as equivalent of walking 45.1 km per week (28 miles/wk).

According to a review of weight maintenance interventions in adults without ID, the effects of walking on weight control depend on the total duration of the exercise (Vortuba *et al*. 2000). Studies that reported exercise in excess of 3.7 MJ/wk (210 min/wk of brisk walking) were associated with 40% regain and 10 MJ/wk (600 min/wk of brisk walking) were associated with less than 15% weight regain. A second review of the evidence regarding physical activity and weight control suggested that weight maintenance as defined by Stevens *et al*. (2005) requires roughly 60 min walking per day (≈4 miles/day) at a moderate intensity (Donnelly *et al*. 2009).

National and international guidelines suggest that walking can lead to general health benefits when it is equivalent to 500–1000 MET-min per week of moderate to vigorous intensity activity or to 150–300 min/week of brisk walking (U.S guidelines; NICE 2006). The health benefits of walking include primary and secondary prevention of cardiovascular disease (Murtagh *et al*. 2007) and in some cases modest weight loss (Richardson *et al*. 2008). According to the IPAQ scoring protocol walking is classified as a moderate level of physical activity when individuals walk for at least 30 minutes per day or according to the compendium of physical activity (2000) when individuals walk at a pace of 5 km/hour (3 miles/hour). However, several studies have reported that the pace of walking in adults with ID is too low to lead to any health benefits (Stanish *et al*. 2006). Temple *et al*. (2000) highlighted the importance of discussing and demonstrating to people with ID a pace of walking that is more likely to promote health benefits.

The TAKE 5 weight maintenance did not succeed in increasing the time the participants spent in walking, with less participants reporting walking seven days per week. The lack of effect of TAKE 5 maintenance on walking can be attributed to one of the most commonly reported barriers to do this activity, the weather (Temple 2007). In a recent study by Caton *et al*. 2012, adults with ID reported joining walking clubs at day centres but the regularity doing the activity was uncertain and the lack of support from carers was identified as a barrier for the participants to go for a walk.

c) Sedentary behaviour

Sedentary behaviour has been defined as “a distinct class of activities that require low levels of energy expenditure in the range of 1.0–1.5 METs (multiples of the basal metabolic rate) and involve sitting during commuting, in the workplace and the domestic environment, and during leisure” (Thorp *et al*. 2011). Several studies report that sedentary behaviour can have a negative impact to health including low levels of metabolic energy expenditure and weight gain and inactivation of lipoprotein lipase affecting lipid metabolism (Thorp *et al*. 2011; Owen *et al*. 2011).

Proposed mechanisms for the contribution of sedentary behaviour to weight gain include less energy expenditure by spending more time in inactivity and increase of energy intake through food consumption triggered from watching television (TV) (Raynor *et al.* 2012). A systematic review by Pearson and Biddle (2011) that assessed the relationship between sedentary behaviour and dietary habits in adults showed that TV viewing was one of the most commonly assessed sedentary behaviors, and in 11 studies was positively associated with energy dense food and energy dense drink consumption. In addition, five out of seven studies that examined the effect of sedentary behaviour on energy intake reported a positive association between TV viewing and screening time and total energy intake. However, there is a limited evidence base assessing interventions that target the reduction of sedentary behaviour in adults (Owen *et al.* 2011).

The TAKE 5 weight maintenance intervention did not decrease the time participants spent in sedentary behaviour. However, it has to be noted that the overall TAKE 5 weight management programme had a significant effect on this type of activity, with less participants being sedentary than at baseline.

7.3.2.3 Predictors for weight maintenance

This is the first study that aimed to identify predictors for weight loss maintenance in adults with ID following a structured multi-component weight maintenance intervention.

a) Weight loss at the end of Phase 1

This study showed participants with ID that did not achieve a clinically significant weight loss (5%) at Phase 1 were more likely to maintain their weight at the end of the weight maintenance intervention than those that did reach this amount of weight loss.

The amount and rate of initial weight loss after a weight loss intervention have been examined as one of the predictive factors for successful long term weight loss maintenance in several studies for adults without ID (Elfhag and Rossner 2005). It is believed that greater weight loss achieved during a weight loss phase and followed by a multi-component weight loss maintenance intervention can lead to improved sustained weight maintenance (Astrup and Rossner 2000). However according to Bogers *et al*. (2010), percentage of weight maintenance is not dependant on initial weight loss and according to Nackers *et al*. (2010), individuals that achieve a greater weight loss in a faster pace are not in a higher risk of regaining the lost weight.

Contrary to above studies, McGuire *et al*. (1999) reported that weight losses greater than 30% from initial body weight can act as a risk factor for weight regain. This was supported by Curioni and Lurenco (2005) and Sbrocco *et al*. (1999) that also observed that greater weight loss is more difficult to sustain.

b) Level of intellectual disabilities

Even though the Chi-square test showed more participants with mild to moderate level of ID not maintaining their weight than participants with profound ID, further analysis showed no association.

One possible explanation to the first finding is that participants with mild to moderate ID are more independent and autonomous, and may therefore have to rely on their own self-motivation and efforts to maintain their lifestyle changes. On the other hand people with severe to profound ID have to rely on the efforts of their carers and the plans they have set for them to prevent significant relapses and weight gains.

7.3.3 Limitations

This is a study with a small sample and the results should be treated with a degree of caution. Similar to many studies in weight management (Loveman *et al*. 2011) no statistical power analysis was undertaken to calculate a sample size for the 16 week weight loss intervention, restricting the number of participants that could continue and take part in Phase 2 (the weight maintenance intervention). However, the TAKE 5 weight loss intervention study was a feasibility study, first of its nature that would provide the evidence to justify a larger RCT (Melville *et al*. 2011).

This limitation in sample size could have also affected the power of identifying any correlations between socio-clinical characteristics and weight maintenance. Underpowered studies with small samples cannot lead to real predictors of outcome (Van Voorhis *et al.* 2007, Stubbs *et al.* 2011). Texeira *et al.* (2004) explained the difficulty of reviewing the evidence behind weight loss predictors because the majority of the studies reviewed had a low level of power to detect significant moderate associations (*r* around 0.2 and around 0.3), because of the small sample size.

As with any study, a RCT would provide strength of the findings of the TAKE 5 weight maintenance study. A control group that did not receive an intervention could provide a robust evaluation of the weight maintenance intervention (Stanley 2007). In addition, the study did not examine the feasibility of the weight management programme in relation to cost effectiveness, an important aspect to show the potentials of this intervention in real community or clinical settings (Loveman *et al.* 2012). This could be also examined by randomising participants into the TAKE 5 weight management intervention and to a control group receiving "care as usual" as defined by the local health services.

Seven participants did not want to wear the accelerometers to assess their physical activity. However, no specific reasons were given by the participants or their carers of why they did not want to wear the devices. This could have been further investigated to explore other methods of objective assessment of physical activity for those participants that feel uncomfortable with wearing an accelerometer.

For the assessment of walking the researcher used IPAQ allowing potential errors due to under or over estimation of walking activity from the carers. It is possible that carers may have underestimated the walking frequency of the participants because of lack of information from the rest of the carers who supported the participants in the previous seven days. In addition, even though the TAKE 5 intervention in phase 1 and phase 2 discussed the importance of the walking pace by describing the characteristics of moderate intensity (NICE 2006), the study did not collect any information regarding the pace of the walk e.g. brisk walking or the distance achieved each day. Walking can be assessed with the use of pedometers but in adults that walk in a slow pace, measurements of steps can be inaccurate (Cyarto *et al*. 2004).This means that walking needs to be assessed with recent and potentially more valid methods such as a combination of physical activity diaries, accelerometers and global positioning systems (GPS) (Bassett 2012; Butte *et al*. 2012).

Pedometers can be used as a motivator for individuals to walk more (Lubans 2009). It has to be noted that pedometers were provided to the participants of the TAKE 5 weight loss intervention. Even though the participants were advised to continue to use the pedometers as part of the weight maintenance intervention, no data were recorded on how many participants still had these pedometers and how many continued to use them. This investigation could provide more information on the poor of effects of the weight maintenance intervention on physical activity.

This study highlighted the importance of providing a service that is suitable to the cognitive and communication needs of people with ID. Therefore, the materials used in this study were designed based on recommendations on simplification of information by using pictorial explanations (Van Schrojenstein Lantman-de Valk 2005). In addition the researcher was trained in the use of augmentative communication (Murphy *et al*. 2008) and used a photo-library specially developed for people with ID allowing the participants to express their feelings and show their knowledge. It would be valuable for the study if advocacy groups and service users or accessible information workers were approached at an early stage to evaluate the construction and layout of the materials used in the intervention (Ward and Townsley 2005). However, the technique used in the materials and the technique of communication in the weight maintenance intervention was already tested during the TAKE 5 weight loss intervention.

One limitation of this study is the lack of information on the participants' socioeconomic status. The only sociological information collected was on social support and type of employment of the carer or the participant. The researcher assessed the impact of type of support on weight loss but not the impact of the type of employment on weight loss. The researcher did not use the second question because it was not extensive enough to provide valid information. Information like these can be very important in weight management and have been extensively investigated in the general population with valid questionnaires but not in adults with ID. For example, evidence from the general population show that participants from lower socioeconomic background are more likely to not attend a health service or to stop attending a health service early (Reid 2009). The reasons for this are not clear. This thesis could have used the Scottish Index of Multiple Deprivation (SENS 2006).The SIMD is an area-based index that uses current income, employment, health, education, skills and training, geographic access to services, housing, and crime to describe the level of deprivation in small geographic areas. Morrison et al. (2011) used the SIMD and showed that participants without ID of the GWMS that where from deprived areas were less likely to succeed a 5kg weight loss.

The TAKE 5 weight management study included eight questions from the Scottish Health Survey (2010) Food Frequency Questionnaire (FFQ) to collect pre and post intervention information on the dietary habits of the participants. However, the data were not analysed because information on dietary habits were not part of the research questions. In addition, the answers to the FFQ were reported mainly from the carers and not from the participants decreasing the reliability and validity of the questionnaire significantly. It has to be noted that some of the carers were not confident with their answers on diet because they did not always know what the participant was eating and drinking when supported by other carers. However, a new study that will focus on the dietary habits of the participants could provide more on information on this under-researched area by using more valid methods at baseline including seven day weighed dietary records. Post intervention data will not be useful since the weighed dietary records would be time consuming for the carers and would affect their on-going support to the participants to follow the TAKE 5 portion controlled diet.

CHAPTER 8: Study 3 Results

8.1 Study 3a

Comparing the effectiveness of a multi-component weight loss intervention in adults with and without intellectual disabilities

8.1.1 Methods

The study design, setting and methods for data analysis have been described in Chapter 5 (Methods) section 5.2

8.1.2 Results

Analysis of normality using the Shapiro-Wilk test showed that no continuous variables were normally distributed; therefore weight and BMI changes are reported as median values and ranges.

8.1.2.1 Participants

All TAKE 5 participants (n=52), median age 51 (range: 26, 73) years and median BMI 38.4 (range: 31.7, 62.8) kg/m^2 were matched with 104 GCWMS participants without ID (Table 8.1). The entire sample (n=156) comprised 61 males (39.1%) and 95 females (60.9%).

Table 8.1. Demographic characteristics of participants with ID and matched participants with no ID at baseline (median, range).

	ID† (n=52)		NID† (n=104)	
Characteristics	**Median**	**Range**	**Median**	**Range**
Age (years)	51	(26,73)	51	(28,73)
Weight (Kg)	96.5	(67.6, 185.8)	107.5	(77,187.6)
Height (m)	1.54	(1.31,1.88)	1.65	(1.37, 1,86)
BMI (kg/m^2)	38.4	(31.7, 62.8)	37.8	(31.5,63.4)

† participants with intellectual disabilities (ID), participants with no intellectual disabilities (NID)

8.1.2.2 Health Characteristics

The baseline health characteristics of both population groups are reported in table 8.2. The incidence of heart disease and diabetes was significantly higher in GCWMS participants with arthritis, and asthma was significantly higher in TAKE 5 participants ($p<0.05$). Both groups were similar with respect to the occurrence of high blood pressure and apnoea.

Table 8.2 Comparison of health characteristics of the participants from both population groups at baseline (number of participants and percentages).

	ID† (n=52)		NID† (n=104)		
Characteristic	**n**	**%**	**n**	**%**	**P***
Raised BP	10	19.2	10	9.6	0.091
Heart Disease	-	-	13	12.5	0.008†
Diabetes	4	7.7	22	21.2	0.034†
Arthritis	5	9.6	2	2.0	0.029†
Asthma	8	15.4	1	1.0	0.000†
OS Apnoea	1	1.9	1	1.0	0.616

† participants with intellectual disabilities (ID), participants with no intellectual disabilities (NID)
*Differences between ID and NID group
† $p<0.05$

8.1.2.3 Attendance

Participants with ID had significantly higher attendance at all nine sessions than the participants with no ID (88.5% vs. 18% *P*<0.05). Some participants (36%) with no ID attended a total of 8 sessions, the rest attended 5 to 7 sessions.

8.1.2.4 Comparison of weight change outcomes

This study presents the results of the participants from both matched population groups that attended all nine sessions (ID n=46 and no ID n=19). Participants of both interventions did not differ with respect to the absolute amount of weight lost (median:-3.6 vs. -3.8; *P*=0.4) or the change in BMI (median: -1.5 vs.-1.4; *P*=0.9, (table 8.3).

Table 8.3 Comparison of anthropometric outcome measures at 16 weeks from baseline for nine sessions completers (median, range).

	ID† (n=46)		**NID† (n=19)**		
Outcome at 16 weeks	**Median**	**Range**	**Median**	**Range**	**P***
Total weight change (kg)	-3.6	(-18.5,3.0)	-3.8	(-23.5,3.2)	0.4
Total weight change (%)	-3.8	(-16.9,2.6)	-3.6	(-18.2,2.0)	0.9
Total BMI change (kg/m^2)	-1.5	(-5.9, 1.0)	-1.4	(-7.9,1.1)	0.9

†participants with intellectual disabilities (ID), participants with no intellectual disabilities (NID)
*Differences between ID and NID group

The proportion of each group achieving 5% weight loss did not differ (38.5% for TAKE 5 and 36.5% for GCWMS participants (*P*=0.9).

Rate of weight change at each session and at 16 weeks

Participants of both programmes did not differ with respect to the amount of weight lost at each session but failed to achieve the total weight loss predicted using estimated energy requirements (see table 4). Both groups of participants achieved significantly lower weight loss after session 4 than the expected weight loss (2 pounds/week or 0.9kg/week) based on the energy deficit diet (*P*<0.05), see table 8.4 and figure 8.1).

Table 8.4. Comparison of weight change from session 1 at 16 weeks (median, range).

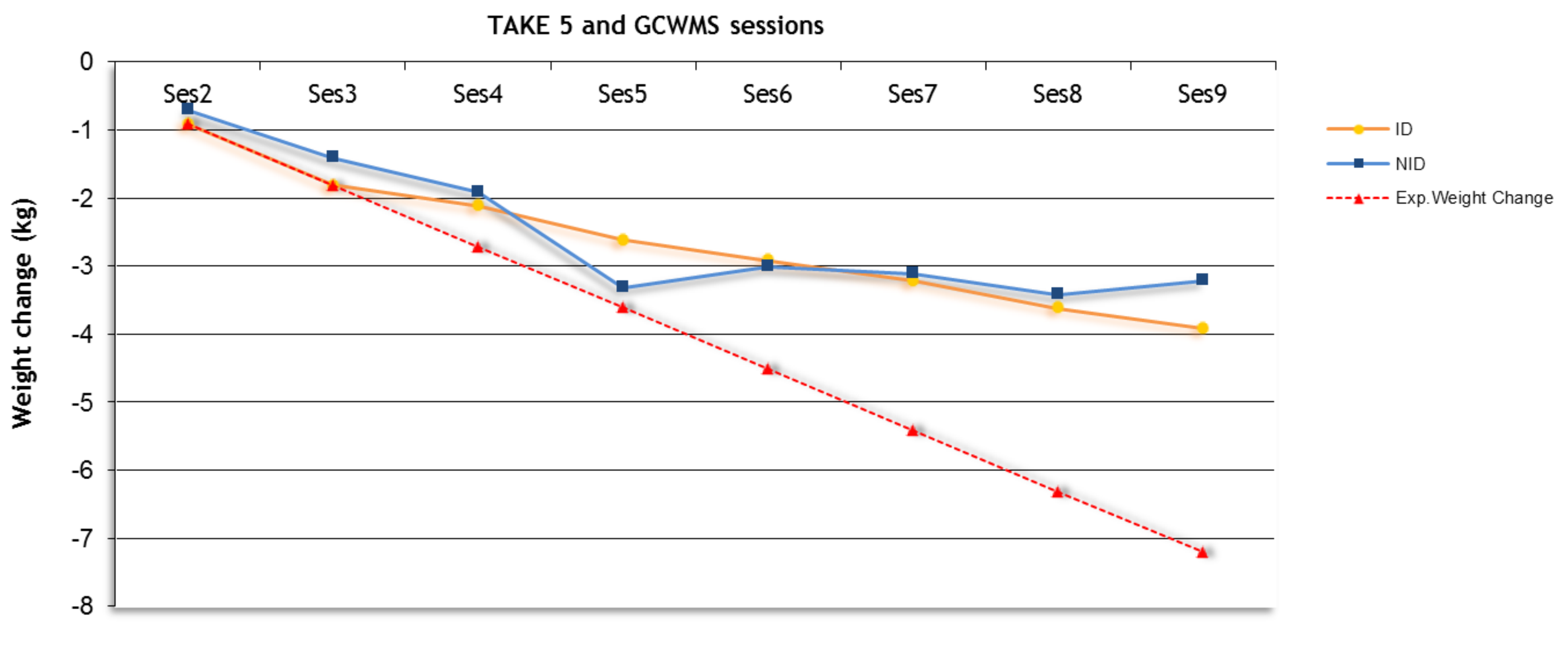
	ID† (n=46)		NID† (n=19)		Exp. Weight change		
Sessions	**Median**	**Range**	**Median**	**Range**	**Median**	**P***	**P****
Session 2	-0.9	(-2.9, 1.5)	-0.9	(-8.9, 1.8)	-0.9	0.6	0.9
Session 3	-1.8	(-15.1, 4.3)	-1.7	(-10.7, 1.8)	-1.8	0.7	0.9
Session 4	-2.0	(-15.5, 4.5)	-2.1	(-12.3, 2.6)	-2.7	0.5	0.1
Session 5	-2.6	(-15.5, 4.3)	-2.8	(-12.3, 2.6)	-3.6	0.5	0.02
Session 6	-2.6	(-18.1, 5.3)	-3.2	(-17.5, 2.8)	-4.5	0.4	0.003
Session 7	-2.9	(-18.3, 4.4)	-3.25	(-17.5, 2.3)	-5.4	0.3	0.000
Session 8	-3.3	(-18.9, 3.4)	-3.6	(-17.5, 3.2)	-6.3	0.8	0.000
Session 9	-3.6	(-18.5, 1.07)	-3.8	(-23.5, 3.2)	-7.2	0.9	0.000

† participants with intellectual disabilities (ID), participants with no intellectual disabilities (NID)

*Differences between ID and NID group

**Differences between median weight loss and expected weight loss

Figure 8.1 Rate of weight change for each group and expected weight change



8.2 Study 3b: Results

8.2.1 Methods

The study design, setting and methods for data analysis have been described in Chapter 5 (Methods), section 5.3

8.2.2 Results

8.2.2.1 Associations between socio-biological variables and absolute weight loss at time 2 (16 weeks)

Analysis of data for the 52 completers of the TAKE 5 weight loss intervention showed a mean weight loss of -4.2kg (SD=4.8) and a -4.3% (SD=4.7) weight loss at time 2.

Table 8.5 shows the mean values and standard deviation for the continuous biological variables that were examined as predictors for weight loss at time 2.

Table 8.5: Mean and standard deviation for continuous biological variables. (n= 52)

Variable	mean	SD
Age (years)	48.9	25.5
Baseline weight (kg)	100.7	25.5
Baseline BMI (kg/m^2)	40.9	7.7
Weight loss at 4 weeks (kg)	-2.2	2.6

Table 8.6 shows correlations and *P* values between baseline individual predictors and absolute weight loss at 16 weeks. Changes in age, baseline body weight and baseline BMI were not correlated with changes in weight at the end of the 16 week weight loss intervention. Only, initial weight loss at four weeks (-2.2kg) was positively correlated with weight loss at 16 weeks. The correlation was statistically significant.

Table 8.6: Simple correlation matrix between potential biological predictors and absolute weight loss at time 2 (correlation coefficients and *P* values) (analysis set; n= 52)

Correlation with weight loss	**r**	***P***
Age (years)	0.01	0.91
Baseline body weight (kg)	0.06	0.64
Baseline BMI (kg/m^{-2})	0.02	0.8
Initial weight loss (4 weeks)	0.68	0.000*

Analysis obtained from linear regression

*P≤0.05

Table 8.7 shows mean weights (kg) at time 1 and time 2 and mean weight changes at time 2 for each subgroup of potential categorical socio-biological predictors for weight loss at time 2. There was significant weight loss for each subgroup of each category except for the participants that were prescribed obesogenic medication, diagnosed with Type 2 diabetes and participants that were partially or registered blind.

However, according to table 8.8 there were no significant between group differences in weight loss (Kg) at the end of the weight loss intervention. Therefore, the analysis did not proceed to further steps of multivariate analysis.

Table 8.7: weight (kg) at time 1 (baseline) and time 2 (16 weeks) and weight change (kg) at the end time 2 for each subgroup of potential predictors for weight loss (n=52) (mean values, standard deviations and 95% confidence intervals)

		Time 1		Time 2				
	n	**mean**	**SD**	**mean**	**SD**	**Mean diff. (Time 2-Time 1)**	**95% CI**	***P***
Gender								
Male	21	111.9	32.5	107.1	33.4	-4.8	-7.8,-1.9	0.003
female	31	93.0	15.9	89.2	15.7	-3.8	-5.0,-2.6	0.000
ID								
Mild to moderate	33	105.5	29.4	100.6	30.3	-4.9	-6.8,-2.9	0.000
Severe/profound	19	92.2	13.9	89.0	12.0	-3.1	-4.6,-1.6	0.000
Down syndrome								
Present	13	90.3	16.8	85.0	16.2	-5.2	-7.3,-3.1	0.000
Not present	39	104.1	27.2	100.2	27.3	-3.9	-5.6,-2.2	0.000
Type of support								
Family	17	105.5	28.4	100.6	28.8	-4.8	-7.7,-1.9	0.003
Paid carers	35	98.3	24.1	94.4	24.2	-3.9	-5.5,-2.4	0.000
Obesogenic medication								
Prescribed	11	91.4	12.4	88.0	15.7	-3.3	-6.9,0.2	0.065
Not prescribed	41	103.2	27.6	98.7	27.5	-4.5	-5.9,-3.0	0.000
Type 2 diabetes								
Present	4	119.4	43.4	117.6	46.7	-1.8	-7.1,3.5	0.359
Not present	48	99.1	23.6	94.6	23.1	-4.5	-5.8,-2.9	0.000
Epilepsy								
Present	13	98.1	13.3	93.9	13.1	-4.2	-5.8,-2.6	0.000
Not present	39	101.5	28.5	97.3	28.8	-4.3	-6.0,-2.5	0.000
Hearing impairment								
Yes	12	94.4	15.9	90.2	14.4	-4.2	-6.4,-2.0	0.001
No	40	102.5	27.7	98.4	28.1	-4.2	-5.8,-2.5	0.000
Blind/ partially sighted								
yes	4	96.7	18.6	89.5	10.3	-7.1	-23.2,8.9	0.254
no	48	101.0	26.2	96.9	26.5	-4.0	-5.2,-2.8	0.000
***Walking problems**								
Yes	18	111.1	28.5	106.8	27.1	-4.3	-7.3,-1.3	0.008
No	34	95.1	22.4	90.9	23.5	-4.2	-5.6,-2.8	0.000

*walking problems due to weight

Table 8.8: Comparison of weight change (kg) at time 2 from time 1 and participant characteristics (n=52) (Mean values and 95% confidence intervals)

	Group 1	**Group 2**			
Variable (Group 1 vs. Group 2)	**Mean weight loss**	**Mean weight loss**	**Mean diff. (group 2-group 1)**	**95% CI**	***P***
Gender (Male vs. female)	-4.8	-3.8	-1.0	-3.7, 1.7	0.461
Level of ID (Mild/moderate vs. severe/profound)	-4.9	-3.1	-1.8	-4.5,0.9	0.198
Down syndrome (yes vs. no)	-5.2	-3.9	-1.2	-4.4,1.8	0.422
Support (Family carer vs. paid carer)	-4.8	-3.9	-0.8	-3.7,2.0	0.561
obesogenic medication vs. no obesogenic medication	-3.3	-4.5	1.1	-2.1,4.5	0.488
Type 2 diabetes (yes vs. no)	-1.8	-4.5	2.6	-2.4,7.7	0.296
Epilepsy (yes vs. no)	-4.2	-4.3	0.07	-3.0,3.2	0.964
Hearing impairment (yes vs. no)	-4.5	-4.2	-0.3	-3.5,2.9	0.858
Registered blind vs.no	-7.1	-4.0	-3.1	-8.1,1.9	0.222
Problems in walking vs. no problems with walking*	-4.3	-4.2	-0.1	-2.9,2.7	0.940

Analysis was performed using two-sample t test

8.2.2.2 Associations between baseline socio-biological variables and 5% weight loss at the end of 16 weeks (time 2)

The analysis showed that 36.5% of the participants achieved a clinically significant weight loss. Table 8.9 shows odds ratio (OR), 95% CI and P values indicating associations between baseline individual predictors and 5% or more weight loss at 16 weeks. No biological and sociological predictors were identified for a clinically significant weight loss (5% weight loss from baseline body weight). Therefore, the analysis did not proceed to further steps of multivariate analysis.

Table 8.9: Association between participants achieving a weight loss of 5% or more of their initial body weight at time 2 and patient characteristics (n= 52)

Variables	OR	95% CI	*P*
Gender (Male vs. female)	0.8	0.25,2.5	0.7
Mild/moderate vs. severe/profound	2.06	0.6,7.07	0.25
Down syndrome (yes vs. no)	2.6	0.72,9.5	0.14
Support (Family carer vs. paid carer)	1.9	0.6,6.3	0.28
Prescribed obesogenic medication (yes vs. no)	0.58	0.13,2.5	0.5
Type 2 diabetes (yes vs. no)	0.5	0.05,5.7	0.62
Epilepsy (yes vs. no)	1.11	0.3, 4.07	0.87
Hearing impairment (yes vs. no)	2.07	0.56,7.7	0.27
Registered blind or partially sighted	1.8	0.23,14.12	0.57
Problems in walking vs. no problems with walking*	0.36	0.09,1.32	0.12

Analysis obtained from cross tabulation
*because of weight

8.3 Discussion

8.3.1 Key findings

The purpose of the studies 3a and 3b was to identify factors that could influence the effectiveness of the TAKE 5 weight loss intervention.

Study 3a showed that the two population groups in TAKE 5 and GCWMS had different health characteristics, with participants with ID having a lower incidence of diabetes and heart disease. This may reflect the differing referral criteria to each programme, general practitioners or hospital consultants refer patients to the GWMS when they have a BMI over 35 kg/m^2 or a BMI over 30 kg/m^2 but patients could also have other co-morbidities.

Contrary to the participants without ID, most of the participants with ID attended all of the nine sessions of the weight loss intervention. Attendance in weight management is crucial and studies have shown it is usually associated with greater weight losses (Moroshko *et al.* 2011; Stubbs *et al.* 2012). It is possible that the one to one delivery of the sessions in TAKE 5 were crucial in ensuring maximal attendance of the participants with ID and ensuring a good level of understanding of the programme. Group based interventions can sometimes offer attractive cost savings often being at least as effective in terms of weight loss as one to one individual interventions, by requiring less health professional hours (Paul-Ebhohimhen and Avenell 2009). However, we suggest that participants with ID would be less able to succeed at weight loss in group treatment setting, and that the one to one delivery of TAKE 5 made the intervention accessible to the participants. An estimate of cost effectiveness is justified to warrant the use of the intervention in community settings.

Our comparison has shown that both the interventions appeared equally effective in terms of actual weight loss, success in achieving 5% weight loss and rate of weight loss over the intervention period. These findings suggest that TAKE 5 in its current adapted form and multi-component structure overcame potential barriers such as communication, accessibility and difficulties to encourage behavioural change and effectively supported individuals with ID to lose weight.

However, both population groups did not achieve the expected weight loss at the end of weight loss intervention, which can be attributed to the difficulty in achieving weight loss. It is a process that requires sustained motivation, social support and time to improve dietary practices and physical activity (Teixeira *et al.* 2012; Byrne *et al.* 2012). Such variables cannot be taken into consideration within prediction equations used to calculate the expected weight loss.

Study 3b repeated the statistical analysis of Melville *et al.* (2011) but this time included all the completed participants of the TAKE 5 weight loss intervention and added variables that were not previously examined, showing again no correlation between any sociological or biological predictors and weight loss at the end of the 16 week intervention. A new examination of weight loss at each stage of the intervention showed that initial weight loss at four weeks was correlated with total weight at the end of the intervention. No predictors were correlated with clinically significant weight loss at the end of the 16 weeks weight loss intervention.

8.3.2 Comparisons with previous studies

8.3.2.1 Effectiveness

The effectiveness of a multi-component weight management intervention in people with and without ID has been examined in only one study by Ewing *et al.* (2004). Ewing *et al.* (2004) evaluated the impact of the Health Education Learning Programme (HELP) for people with mild to moderate ID (n=97) and people without ID (n=97). The eight week programme was designed to educate participants to improve their physical activity levels, make healthier dietary choices and reduce their levels of stress. The study found a statistically significant difference in BMI reduction (P<0.001) between the two groups, with more participants without ID (44.3%) decreasing BMI by ≥ 0.75 units than the participants without ID (18.5%). However, the study did not follow the recommendations for the use of three to six month weight management intervention (NICE 2006; SIGN, 2010; NHLBI 2010), did not use the matching process and contrary to this study did not show total clinically significant weight reduction for both population groups.

The effectiveness of multi-component weight management services delivered in primary care in UK for adults without ID such as the GCWMS and the Counterweight programme have been assessed and reported in studies (Morrison *et al.* 2011; Counterweight Project Team 2008). For example evaluation of the GCWMS at 16 weeks showed that 35.5% of the service users lost five kg and an evaluation of the Counterweight programme at six months showed 38.0% of the service users lost ≥5% of their initial body weight.

There is no published audit assessing the clinical effectiveness of multi-component weight management services in the UK for adults with ID that follow current national clinical guidelines for the general population (NICE 2006; SIGN 2010) and are delivered by health professionals. It has to be noted that an audit of the existing obesity services for adults with ID in Surrey has shown that the provision of weight management services in the community and in primary care for this population group is insufficient (Smallman *et al.* 2011). However, Smallman *et al.* (2011) did not evaluate the effectiveness of the service provided.

The health and lifestyle differences between those with and without ID may affect how specific weight management programmes are implemented, e.g. individuals with ID and autism or individuals with Down syndrome may take longer to accept a lifestyle change that is not part of their routine than those without ID (Emerson and Baines 2010; Mahy *et al.* 2010). This means that proposed lifestyle changes such as challenging poor dietary habits and pronounced inactivity, may lead to a different pattern and rate of weight change in those with ID. However, the findings of this study suggest that the changes implemented were sufficient to lead to weight loss, a loss of clinical importance for around one third of participants and at the same rate as in adults without ID.

8.3.2.2 Predictors for weight loss

a) Baseline weight/BMI

This is the second study to examine the relationship between baseline weight or BMI and weight loss in adults with ID and showed no correlations. Geller and Crowley (2009) reported that the higher the starting weight of the participants the greater the amount of weight loss but the association was borderline significant (P=0.054).

In adults without ID a review of studies by Texeira *et al.* (2005) identified 16 studies that examined the associations between initial weight or BMI and change in weight or BMI after treatment. The majority of the studies (n=8) showed no associations, six studies reported that higher initial BMI was associated with larger weight loss and two studies reported negative association. The review identified that the relationship between baseline weight and weight changes was influenced by the degree of obesity and the duration of the study. This means that studies that showed a positive association included participants with a higher BMI (mean BMI: 37 kg/m^2) than studies that showed negative or no association (mean BMI: 31 kg/m^2) and they were studies of shorter duration.

Wadden *et al.* (1992) aimed to identify biological predictors for weight loss in participants (n=76) with obesity (mean BMI: 39.4 ± 0.8 kg/m^2) that followed three types of weight management: 1) VLCD 2) behaviour therapy and energy deficit diet 3) a combination of both. Initial body weight was strongly associated with weight loss at the end of treatment and at one year follow-up ($p<0.05$). This was supported by Hainer *et al.* (2008) that mainly examined hormonal determinants (e.g. insulin, pancreatic polypeptide) of weight loss in 67 women (BMI: 32.4 ± 4.4 kg) following a four week in-patient comprehensive weight reduction program with diet and physical activity under the strict control. The study also showed that baseline weight was correlated with absolute weight loss.

In a larger sample of participants (n=505) with obesity (BMI: 30 ± 45 kg/m^2) treated with sibutramine and an energy deficit diet (600kcal energy deficit) for six months, baseline body weight was found as one of the strongest predictors for weight loss ($p<0.001$) (Hansen *et al.* (2001)). This was supported by Stevens *et al.* (2001) that showed that with every ten kg of higher baseline weight, weight loss increased by 0.8kg ($P<0.0001$).

However, a RCT that assessed the effectiveness of a 26 week self-help weight loss intervention versus a structured commercial programme for 423 overweight and obese participants (BMI of 27 to 40 kg/m^2) did not find a significant correlation between initial weight and weight loss (Heshka *et al.* 2000).

According to Stubbs *et al.* (2010), positive correlations between pre-treatment weight or BMI and weight loss in heavier participants is associated with the intensity of the intervention. This means that studies with very obese participants provide more intensive weight loss interventions, having a positive influence on initial weight loss. However, according to Hansen *et al.* (2001) heavier participants lose more weight simply due to higher energy expenditure.

b) Initial weight loss

This is the first study in adults with ID that investigated the potential relationship between initial weight loss during an intervention and absolute weight loss. Similar to other studies in the general population early weight loss was associated with total weight loss at six months (Wadden *et al.* 1992; Handjieva-Darlenska *et al.* 2010; Guaraldi *et al.* 2011). This study demonstrated that an early weight loss at week four of 2.2kg could predict a weight loss outcome of at least four kg during a 16 week multi-component weight loss intervention.

According to Wadden *et al.* (1992) successful weight loss early in treatment is associated with successful weight at the end of the treatment. The study showed that weight loss (3.6kg) in the first month of the treatment following a 1200kcal/day diet can be a strong predictor for weight loss at six months and at year one follow up. This was supported by the Diogenes study that specifically examined the impact of initial weight loss on total weight loss success in 932 participants following an 800kcal diet for eight weeks (Handjieva-Darlenska *et al.* 2010). The study reported that a weight loss of 2.6 kg at week 1 was the optimal cut-off predictor for at least ten kg weight loss at week eight.

Elfhag *et al.* (2010) examined potential predictors of outcome for weight loss by offering to 247 participants with obesity (mean BMI=41.1kg/m^2) a two phase intervention: phase I (five weeks): lectures on lifestyle behaviours and phase II (4-5 months): group treatment aiming lifestyle changes. The study found that a pre-treatment weight loss and weight loss following the weekly lectures of the five week Phase I could act as predictors for weight loss. In more detail a 1kg weight loss during phase I was strong predictor for a 13% of the variation in Phase II weight loss.

The positive correlation between early weight loss and total weight loss has been also shown in studies that administer sibutramine in individuals with weight problems, with diabetes or without diabetes. A review of this type of studies showed that early weight loss in the first four weeks of treatment was a strong positive predictor of weight loss (Guaraldi *et al*. 2011).

According to Stotland and Larocque (2005) early weight loss during a weight loss intervention indicates a stronger motivation from the participants to lose weight and can be potentially related to early changes in diet and physical activity. However, it is possible for individuals that lose weight at a slower rate to still lose the same or greater amount of weight at the end a weight loss intervention (Handjieva-Darlenska *et al*. 2010).

c) Gender

Gender differences in weight loss have been examined in several studies for adults with ID and without ID. This study showed that gender was not a significant predictor for weight loss at the end of the 16 weeks of weight loss intervention.

The findings from studies in adults with ID are not consistent with studies like Marshall *et al*. (2003) showing no differences between men and women and other studies like Geller and Crowley (2009) showing a significant weight loss for women but not for men and Mann *et al*. (2006) reporting that female gender was a significant predictor of BMI reduction of 0.8 or greater. Geller and Crowley (2009) reported that female participants benefited more from the weight management programme than men because they were supported by female staff that acted as role models to them. On the other hand, Fox *et al*. (1985) showed greater per cent weight loss in males than in females but no correlations were examined (5.25% vs. 4.25%, respectively).

According to Stubbs *et al.* (2011) gender could act as a predictor for weight loss, with some studies in adults without ID showing that women have less success with rate of weight loss than men. This difference between genders in rate of weight loss can be attributed to the different ways that men and women are motivated to lose weight. For example men are more likely than women to try to control their weight and achieve a better initial weight loss because of a medical event e.g. heart attack (Gorin *et al.* 2004). On the other hand, women are more likely than men to perceive themselves as overweight and report attempting to lose weight (Lemon *et al.* 2009).

Specific psychological factors can have a different impact on weight loss in men and women (Presnell *et al.* 2008). For example higher depressive symptoms promote greater weight loss in men than in women because men are more likely to take active coping strategies (Presnell *et al.* 2008). In addition, an American study of weight loss expectations in a sample of overweight and obese adults (n=658) showed that women had significantly ($P < 0.0001$) greater weight loss expectations than men (9.1 ± 6.6% vs. 6.7 ± 5.8%), as well as greater goals (19.7 ± 8.5% vs. 13.4 ± 9.7%) (Fabricatore *et al.* 2008). Higher weight loss expectations lead to higher attrition rates in weight loss programs (Moroshko *et al.* 2011) and poorer weight loss outcomes (Texeira *et al.* 2005).

The difference in weight loss between men and women can be attributed to biological differences (Sartorio *et al.* 2005; Handjieva-Darlenska *et al.* 2010) including the effect of menstrual cycle on overconsumption in women (Dye and Blundell 1997) and the difference in body composition and energy expenditure, with women having more subcutaneous fat and slower rate of lipolysis than men (Boutcher and Dunn 2009).

d) Living arrangements

The type of living arrangement of an individual with ID provides important information about the type of his/her social support and the level of restrictive environment that he/she lives in. Social support is very important in weight management and can have the form of emotional, instrumental, informational and appraisal support (Verheijden *et al.* 2005). This support can come from family members, friends and colleagues and in the case of people with ID sometimes from paid carers. It is suggested that families may facilitate psychological support for people with ID in weight management interventions better than paid carers (Geller and Crowley 2009).

It is also believed that people with ID that live in family homes have a greater access to food availability than those who live in restrictive accommodations supported by paid carers (Geller and Crowley 2009). However, there is no evidence to show that weight loss in people with ID is influenced by the type of living arrangement e.g. living with natural carers (families) vs. living with paid carers.

This study after repeating the analysis of Melville *et al.* (2011) but including all the completed participants of the TAKE 5 intervention showed again no associations between five per cent weight loss or absolute weight loss and type of family or carer support at home. This follows the findings of Harris and Bloom (1984) that showed that participants living with families did not lose significantly more weight than those in group homes (mean weight loss: -3.86kg vs. -2.35kg, respectively). Another study by Geller and Crowley (2009) also showed no significant difference in weight loss between these two types of living arrangements.

e) Down syndrome

Similar to Marshall *et al.* (2003), Melville *et al.* (2011) and this study reported no associations between five per cent weight loss and Down syndrome.

People with Down syndrome may have difficulties in losing weight because of non-modifiable physiological factors causing them gain weight including decreased resting metabolic rate, hypotonicity leading to hyperactivity and defects in the secretion of leptin (Allison *et al.* 1995; Luke *et al.* 1994; Mendoca *et al.* 2010; Proto *et al.* 2007).

f) Level of intellectual disabilities

This study showed no statistically significant association between level of ID and weight loss. This is similar to the findings of Geller and Crowley (2009) that also showed no association between levels of ID versus weight loss.

However, Harris and Bloom (1984) found a significant positive correlation between the amount of weight lost and the IQ of the participants (r=0.86)). This was supported by Wu *et al.* (2010) that showed that participants with mild disability level lost more weight (4.98kg) during a six month of intervention than the rest of the participants with severe ID. Ewing *et al.* (2011) found significant differences between BMI change and presence of ID.

8.3.3 Limitations

8.3.3.1 Study 3a

Even though the two populations in this study were matched, several factors make the two population groups in this short report different. These include differences in social background (education, employment), which can impact on weight loss (Siu *et al.* 2011). Individuals with ID are more susceptible to social exclusion in terms of education and employment than adults without ID (Emerson *et al.* 2011). These distinctive differences in socioeconomic background would not allow appropriate matching between the two population groups. It would not be suitable to define the socioeconomic background of adults with ID by using the same definition for adults without ID when access to income, to a residence in a specific geographical area and to education (if any) depends on different factors for the two population groups. For example residence for adults with ID may depend on availability, type of support care plan and amount of available economic benefits. However, the researcher could have matched the populations based on their ethnicity, another potentially important determinant to weight management (zapka *et al.* 2009).

An important difference between the two interventions was the inclusion of the carers during the TAKE 5 intervention. The carers were present at the sessions to support participants in communication and understanding but also played an active role in social support during weight management as close members of the participants providing encouragement (Spanos *et al*. 2013). Even though this type of close and direct support was potentially missing from the participants treated by the GCWMS, group sessions like the ones in GCWMS do provide some type of social support by including members who share the same weight problems, experiences and encourage each other (Verheijden *et al*. 2005; Reider and Ruderman 2007).

An important difference between GCWMS and the TAKE 5 intervention is the inclusion of structured supervised physical activity classes for the participants without ID but not for the participants with ID. The TAKE 5 weight loss intervention did not include an exercise program but only promoted the recommendations of national clinical guidelines (NICE 2006; SIGN 2010) on healthy physical activity levels and focused on reducing sedentary behaviour. The intervention included advice and information to encourage participants to attend appropriate activity classes at the day centre they attended. The researcher also advised the carers to support the participants to plan activities as part of the daily activity routines. Both interventions encouraged activity to be part of the goal setting process and part of the self-monitoring process. The effect of TAKE 5 on physical activity successfully decreasing sedentary behaviour of participants has been published elsewhere (Melville *et al*. 2011) but the impact of the GCWMS has not been assessed.

However, regardless of the differences in the mode of delivery, group or one to one, supervised exercise classes or general information on physical activity, both the TAKE 5 and GCWMS programmes followed the same design principles, provided the same information and had the same planned outcomes.

8.3.3.2 Study 3b

The barrier of the TAKE 5 study to identify a predictor for weight loss is probably related to the lack of calculation of statistical power analysis that has been previously examined in the limitations in Chapter 7 section 7.3.3.

One of the limitations of the study 3a was that lack of investigation of common variables assessed as potential weight loss predictors in adults with ID. These include:

a) Self-reinforcement

Three weight loss interventions for adults with ID asked participants to complete homework as part of behavioural change strategy and to ensure subject involvement assessed correlations between completion of assignments and weight loss (Fox *et al.* 1985; Fisher *et al.* 1986; McCarran and Andrasik 1990). Fox *et al.* (1985) found that assignment completion was highly correlated to weight loss ($r=0.83$) and reported that participants who had their parents involved in the weight loss intervention completed slightly more homework assignments than the group that did not have their parents involved. However, McCarran and Andrasik (1990) found no correlations between weight change and compliance measures on the "eating habits" records ($r=0.02$). Fisher *et al.* (1986) also reported no significant relationship between completion of homework and weight loss.

b) Knowledge of nutrition

The positive effects of a health education programme on healthy eating knowledge was found to be a strong predictor of successful BMI reduction equal to 0.8 or greater ($p=0.004$) (Mann *et al.* 2006). However, Harris and Bloom (1984) did not find a correlation between the amount of weight lost and changes in knowledge of behaviour management or nutrition.

c) Adherence

A physical activity intervention study looked at associations between adherence to the walking programme provided and changes in coronary risk factors (Moss 2009). The authors reported that participants with less than 50% adherence had greater reduction in percentage of body fat than those who adhered more than 50-70% or more than 70%. The authors stated that people who adhered more than 70% were also highly active at the beginning of the intervention. The authors state that sedentary people could modify risk factors for coronary heart disease with only 50% increase of activity. However, this finding remains unclear and possibly could be explained further by exploring other confounding factors such as possible changes in the diet of the participants. Bazzano *et al.* (2009) found no association between attendance rate and changes in weight or BMI.

However, self-reinforcement, knowledge and adherence were not assessed in this study because the primary aims were focused on the feasibility of the TAKE 5 weight loss intervention and not on the identification of predictors for weight loss.

CHAPTER 9: Study 4 Results

9.1 Methods

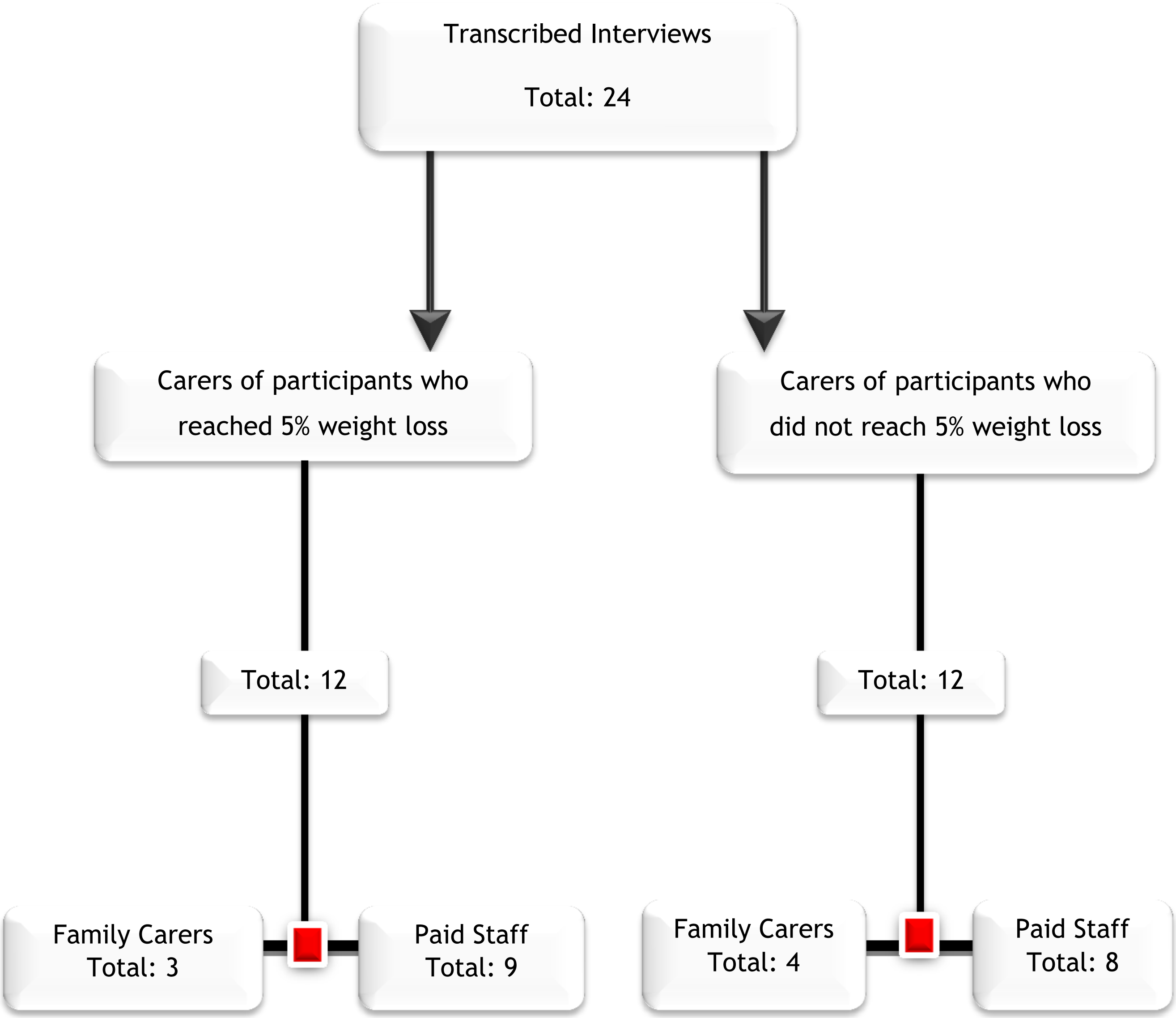
The study design, setting and methods of data analysis have been described in Chapter 5 (qualitative methods), section 5.1

9.2 Results

9.2.1 Participants

Each carer, representing one participant from the TAKE 5 weight management study, was invited to participate in a research interview at the end of the weight loss study. The researcher felt that saturation was reached by the 24th interview. By the 24^{th} interview the answers provided from the carers were similar and could clearly be categorised to the emerging themes. The carers provided full or part time support (1-24hr) to the participants at home. Therefore, a purposive sample of 24 carers took part: 16 paid and eight family carers who supported participants who had achieved a 5% weight loss (n=12) or not (n=12) (see figure 8.1). The carers supported participants that lived independently, in cluster care, in supported settings such as shared tenancies, or in family homes in the catchment area of NHS Greater Glasgow and Clyde, UK.

Figure 9.1: Flowchart of sample distribution in this study



9.2.2 Themes

Thematic analysis led to the identification of three master themes:

- Carers' perceptions of participants' health
- Barriers and facilitators to weight loss
- Carers' perceptions of the multi-component weight loss intervention.

A thematic map is illustrated in figure 9.2. Each theme was, subdivided into smaller sub-themes and represented by verbatim extracts from the interviews.

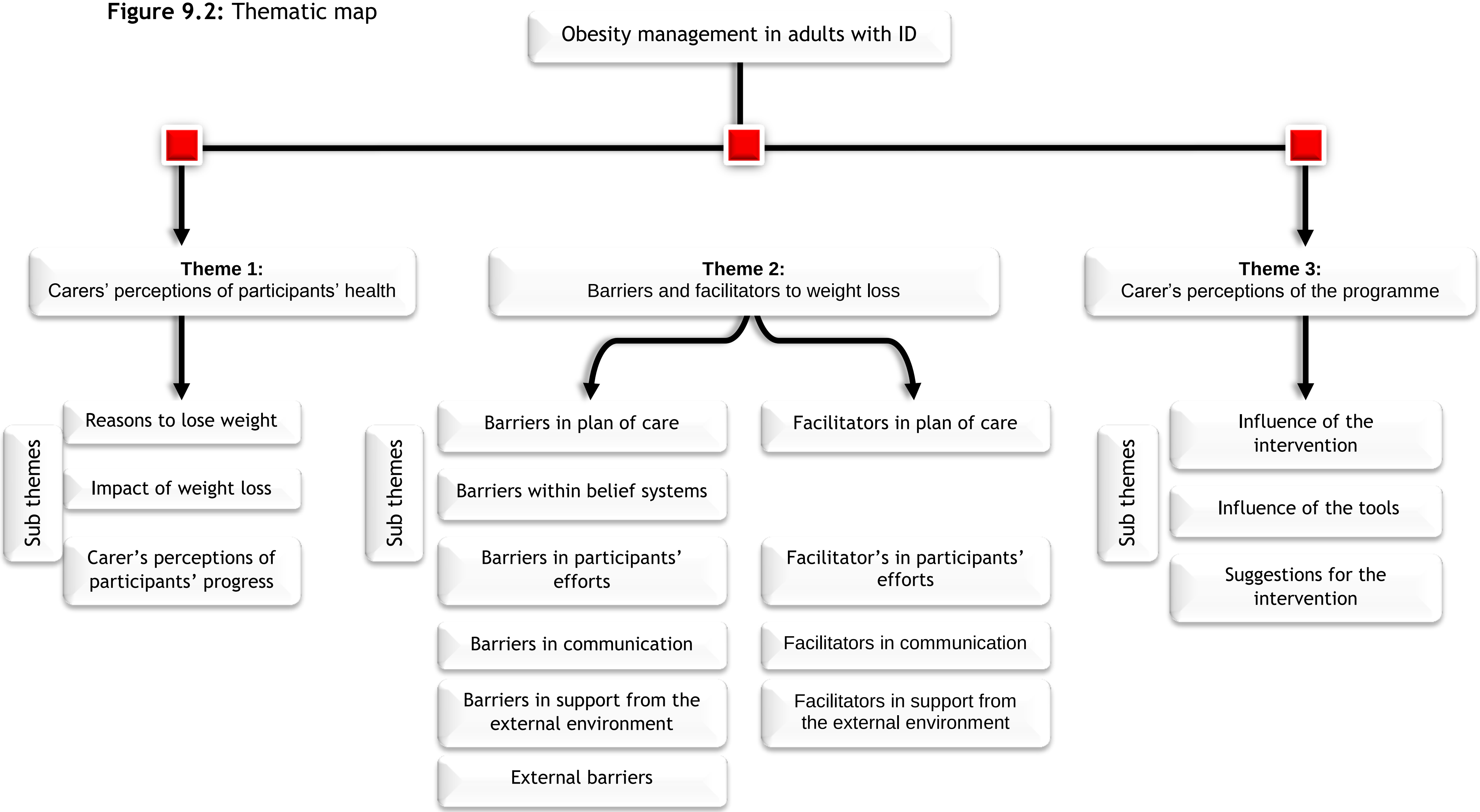
Extracts were chosen from paid and family carers of:

1) participants who lost weight (at least 5% weight loss from initial body weight)
2) participants who did not lose weight (<5% weight loss from initial body weight)

For purposes of confidentiality all names from the extracts have been changed. When providing extracts from the interviews the following transcripts conventions are used:

…Short pause
(…) Words omitted to shorten quote
[Text] explanatory information included by author
C-Comment provided by the carer
I-Comment made by interviewer

Figure 9.2: Thematic map



9.2.3 Theme 1: Carers' perceptions of participants' health

9.2.3.1 Reasons to lose weight

The carers from both groups identified three main reasons they felt a participant should try to lose weight: health, mobility and psychosocial reasons. According to most of the carers, participants should lose weight to improve their health in general. When asked to be more specific they reported that weight loss can prevent heart problems, prevent diabetes and increase life expectancy. Psychosocial reasons such as increased independence, possibilities of employment and emotional benefits were also identified to a lesser extent.

> C: Long term health benefits … and obviously health risks and things like that have been reduced. I: When you say health risks, what do you mean? C: Diabetes and heart disease, any other illnesses caused by obesity and things

> "It speaks for itself doesn't it you know, hopefully live longer, his health. "(Paid carer of a participant who lost weight)

9.2.3.2 Impact of weight loss on participants

Carers from both groups described mainly the noticeable impact of weight loss on participants' appearance. Other impacts of weight loss described were improvement in mobility e.g. walking, improvement in sleeping patterns and breathing. Changes in confidence and emotional benefits were also reported:

> "There has obviously been a good weight loss and that in turn has probably made her a bit more confident because when we were buying clothes she didn't always like to go in and try them on, now she can't wait to try them on." (Paid carer of a participant who lost weight)

> "She is less tired, she is sleeping better so we seem to have less negative self-talk as well."(Paid carer of a participant who lost weight)

9.2.3.3 Carers' perceptions of participants' progress

Overall, carers reported feeling satisfied with the participants' progress in changing their diet and physical activity patterns and amount of weight lost. Only one carer reported not being worried about a participant's current weight but other carers reported that the participants would benefit more from greater weight loss:

> "She's done well so far, she's done very well so far but you know it's only the tip of the iceberg for Anne." (Family carer of participant who lost weight)

9.2.4 Theme 2: Barriers and facilitators to weight loss

9.2.4.1 Barriers in plan of care

The carers of participants who did not lose weight explained having difficulties supporting the participants when other care staff did not follow the support plan for weight loss or did not comply with the recommendations of the PDP. For example offering too many foods high in fat and in larger than recommended portions. In addition, limited cooking skills, less healthy cooking methods or frequent dining out was reported in several interviews. Carers from both groups spoke about the need for motivated staff who can work in a "consistent" way to facilitate the support of a participant during the weight loss process:

> "We tried to follow the guidelines (…) but again it's the consistency, it has to be everybody." (Paid carer of a participant who did not lose weight)

> "you don't really get the consistency you know as you've seen, because at the last care meeting we talked about putting the consistency in, whereas I've had to fight and scream to get more consistency in" (Family carer of a participant who lost weight)

Carers from both groups reported that big teams and "new staff" replacing permanent staff for short periods cannot provide appropriate support for the participants. It is more difficult to sustain effective communication in big teams and new staff may provide less efficient weight loss support than carers that have worked with a participant for longer periods:

> "If there are too many people there it gets lost, the communication gets lost, it breaks down." (Family carer of a participant who lost weight)

> "You get somebody in who is just new and ach [oh well] I'll just do that for quickness and doesn't know what they've been through." (Paid carer of a participant who lost weight)

Carers from both groups expressed the need for more time to support participants during the weight loss intervention. In particular, family carers had difficulties offering support to participants and deal with their own "busy" life at the same time:

> "I've got a very busy life as well, my mum passed away as well and my dad wasn't well either so it's quite a busy household, my husband, my kids, myself - I've got a daughter in care so I find it quite hard." (Family carer of a participant who lost weight)

> "Yes I'm just busy too, it is just life really I think. I suppose you know, I mean time obviously is there if you find it but it is just, it is hard" (Family carer of a participant who lost weight)

Paid carers reported that instability with the support shifts acted as a barrier to their efforts to support participants during the weight loss intervention. They requested more time with the specific client to be able to offer appropriate support with menu planning and to ensure that the rest of the staff and the client followed the intervention.

> "That was my whole stress and my whole aggravation was the fact that I wasn't getting enough time with Sofia and I had to battle with that, because that was just about how they make the rotas up which is just a

practical thing, its no even a big deal. " (Paid carer of a participant who lost weight)

In addition, poor staffing levels and supporting more than one person in the same accommodation acted as a barrier to the carers' efforts to provide a better support to a participant taking part in a weight loss intervention. In some cases carers had to support and to prepare meals for two people who had two different dietary requirements (high calorie diet for an undernourished client and low calorie diet for an obese TAKE 5 participant) but lived in the same accommodation.

> "It was too much to take in for the one client when we were looking after 13 you know. We know that each person's individual needs are very important and we understand that and we did try but all I'm saying is that it did fall by the wayside quite often you know" (Paid carer of a participant who did not lose weight)

> "In this house we've two clients in here and one is the complete opposite from the other dietary requirements, so basically one's been losing weight and with the other one we're trying to build up, so we having to basically sometimes make two different meals" (Paid carer of a participant who lost weight)

9.2.4.2 Facilitators in plan of care

Carers from both groups suggested that small teams with established staff can provide better support to a participant in a weight loss intervention. The benefits of a small stable team include better communication, ensuring that the weight loss plan is followed better and a consistent environment, essential for some adults with ID, is provided:

> "We are a stable team, we're able to talk to each other; we can see each other on a regular basis, (…) so we can pass any information on as far as dietary requirements are." (Paid carer of a participant who lost weight)

> "They [small team] would build up a routine with Anne, so therefore Anne would get used to going out on x day with so and so (…)." (Family carer that provides support with paid carers to a participant who lost weight)

Two carers spoke about the importance of involving participants with activities that could facilitate the weight loss process and can have a positive impact on their confidence such as healthy cooking and healthy shopping:

> "There's no point just saying "Look there's your dinner, that's all you are getting", I think you've got to involve them. They are looking to lose weight and if you can involve them as much as possible and includes prepare it [meal]." (Paid carer of a participant who lost weight)

> "She'll not know the difference, say it was like she picked up a jelly for instance and it's sugar in it and picking up another one and saying "Oh that one not got any sugar (…)"and just basically prompting and reminding her and giving her a healthier alternative." (Paid carer of a participant who lost weight)

The carers of participants who lost weight described praising and giving positive encouragement to a participant as a successful strategy to support participants to reach their targets during the weight loss process:

> "At the beginning it was hard for him, like everybody else it's hard when you go on a diet, but we'd always praised him and gave him that support." (Paid carer of a participant who lost weight)

9.2.4.3 Barriers within belief systems

It was acknowledged, mainly by the carers of participants who lost weight, that not all the carers or family members shared the same view of the benefits of weight loss for obese adults with ID. Some carers felt that there was lack of understanding from other carers or family members who frequently perceived their efforts as actions of "deprivation". They also reported that their colleagues would not consider weight loss as a priority for an adult with ID or they would empathise with the person having an ID and regard it as a justification for not restricting food choice:

> "It's obviously a social thing and it's very difficult to overcome it, especially when the person has a handicap (…) they think "Oh goodness let him have it"". (Family carer of a participant who lost weight)

Both groups of carers stated that "Freedom of choice" was consistently debated between carers and other support staff at participants home and at resource centres. For some support staff, adults with ID are responsible for their own choices. However, a carer explained that there is a need for supporting people with ID to make an informed choice in relation to healthy lifestyles:

> "Some carers saying "Well she's an adult she's got a choice" (…) we've got to help her make - still give her choices but help her to make healthier choices." (Paid carer of a participant who lost weight)

9.2.4.4 Barriers in participants' efforts to adopt healthy lifestyles

Carers of participants who did not lose weight reported having difficulties when participants were unwilling to increase their physical activity levels autonomously or not making healthy food choices when unsupported. A mother of a participant expressed her strong concerns about her son's ability or motivation to make healthy food choices when he is not at home:

> "We obviously are a big influence with him staying at home, but we would eventually hope that he does go somewhere and the thought terrifies me from the point of view of if he can then eat whenever and whatever." (Family carer of a participant who lost weight)

The participants' level of ID acted as a barrier during the process of weight loss for both groups of carers. Some participants were not able to understand the principles of weight loss, including following a healthy diet and increasing physical activity patterns:

"She doesn't understand the contents of food and portioning, (…), she doesn't understand a small loaf shouldn't just last a day." (Paid carer of a participant who did not lose weight)

"Sometimes you've got to over it a couple of times but I think the majority of clients you'd need to do that. The problems that we had in here right at the beginning, we needed to talk about them more than once you know what I mean." (Paid carer of a participant who lost weight)

ID or cognitive difficulties were seen as having an impact to a participant's motivation to lose weight. Carers did try to explain the health benefits of weight loss to participants but it was described as a challenging process. Discussion or experience of the health risks associated with obesity did not have an impact on participants:

"Her health doesn't motivate her, because she doesn't have that understanding or concept." (Family carer of a participant who lost weight)

9.2.4.5 Facilitators in participants' efforts to adopt healthy lifestyles

According to the views of both groups of carers, weight loss can be successful when a participant is motivated to lose weight and willing to make changes in his/her diet and physical activity patterns:

"You've always got to have a client that is willing to lose weight; if the clients aren't willing to lose weight it ain't going happen." (Paid carer of a participant who lost weight)

"You need to motivate Jim; (…) Jim will not come of his own willingness to do these things" (Paid carer of a participant who did not lose weight)

Carers highlighted the ability and the efforts of some participants to make changes with their diet and physical activity independently. This helped the carers to build a relationship of "trust" with the participants.

> “He actually helped himself and made sure it was a small portion, so that way I can trust him as well now, so I know he won’t go more that - small portions. I hope he is taking more of a responsibility now.” (Paid carer of a participant who lost weight)

9.2.4.6 Barriers in communication

Communication between carers in a team was mainly through the use of written reports, known as the “communication book”. Matters of concern were discussed during staff meetings. One of the barriers highlighted by both groups of carers was a lack of communication between staff in a team supporting a participant. Transfer of information through the use of a “communication book” was often unsuccessful particularly for the carers of participants who did not lose weight:

> “Mary [carer] was good at writing everything up, but does everybody read it?” (Paid carer of a participant who did not lose weight)

Carers from both groups reported difficulties with establishing communication with the external environment of a participant such as the staff at resource centres they attended. The carers at home explained that the main communication route with the key workers at resource centres was annual reviews and they felt that there was lack of information provided by the support staff at centres.

> “In regards to his eating it’s very little communication. We had tried sending a book with Anne for them to write down - that never happened” (Paid carer of a participant who lost weight)

9.2.4.7 Facilitators in communication

Carers of participants who lost weight ensured communication with the participants by encouraging them to make lifestyle changes and discussing the benefits of weight loss. A carer reported that a client’s ability to communicate and express his feelings to them was also important to allow better individual support:

> "He was able to talk to us and we were able to understand it to help him. And that's all it is, is for us to understand it so we can help the client." (Paid carer of a participant who lost weight)

Only two carers of participants who lost weight used direct communication with other staff or family members of the supported individuals to ensure consistency with the weight loss intervention.

9.2.4.8 Barriers in support from the external environment: resource centres and respite units

A majority of carers from both groups reported that they felt there was insufficient support from resource centres to facilitate changes in a participant's diet or physical activity. They reported that resource centres would take their attendees for meals in fast food outlets; did not support participants to make healthier food choices and they would not follow the advice given by the participant's main carers:

> "She was getting McDonald's every week definitely, every time she went bowling with the Centre she was getting McDonald's." (Paid carer of a participant who did not lose weight)

Two carers of participants who lost weight were disappointed with respite units or resource centres not offering a healthy diet. They tried to take control by providing the healthy foods needed for the specific participant at respite or preparing packed lunches for the participant to take to the centre.

> "I was actually giving him the stuff in (Respite), I give them the sachets of the sugar-free jelly and the diluting juice and his Weight Watchers crisps were actually physically in his bag, so that they don't need to" (Family carer of a participant who lost weight)

9.2.4.9 Facilitators in support from the external environment

External support from resource centres was provided by promoting healthy lifestyles through specific projects or clubs that participants took part in. These included walking clubs or sessions on achieving healthy eating habits. Only two carers from both groups were satisfied with the meals and foods provided at resource centres.

9.2.4.10 External barriers

Carers from both groups reported two main external factors that acted as barriers to their efforts to support participants with the weight loss. One was the weather, which during the winter prevented participants from doing one of their main physical activities, walking. The second reported factor was safety. Some carers did not feel that participants were safe to do activities outdoors without support:

> “I wouldn’t let him go a walk on his own which is a key thing you know, so therefore you have to have somebody with him at all time.” (Family carer of a participant who lost weight)

9.2.5 Theme 3: Carers’ perceptions of the weight loss intervention

9.2.5.1 Influence of the intervention

The TAKE 5 intervention was recognised as improving the knowledge of the participants and the carers. The aspects of each consultation cited as the most beneficial were checking the participant’s weight and reviewing the progress of the participant and the carers.

The targets set at the end of each consultation were regarded by both groups of carers as suitable and achievable for both carers and participants. Participants enjoyed setting targets at the end of the consultation and reported liking the process of aiming for something. Carers reported supporting their client to achieve their targets but also described the importance of being flexible regarding the time needed to reach a target because the result would still be of benefit:

> "I think the targets were really attainable; they were fine they weren't overstretching anybody, worker or the person." (Paid carer of a participant who lost weight)

However a carer reported that the intervention was not always easy to follow:

> "I did struggle for the first couple and it was trying to get a routine for me and trying to get time for Sally". (Paid carer of a participant who lost weight)

9.2.5.2 Influence of the resources

Carers described the PDP as a good illustration of a healthy balanced diet, helping the carers to identify the food groups and the appropriate daily amounts that needed to be offered to a participant:

> "It [PDP] gave staff an idea of a balanced diet which I didn't think Louise had (…) if we were completing that and see where it was falling short in certain areas, try and encourage a change of diet to reflect the amount of carbohydrates, fruit and vegetables." (Paid carer of a participant who lost weight)

However, some carers of participants who lost and did not lose weight thought the PDP was too complicated for them and for their colleagues and unsuitable to the cognitive needs of participants.

> "I thought when they said that it was going to be one made for specialist for people with learning disabilities cos the mainstream one is complicated, I thought it would be really simple, it wasn't." (Paid carer of a participant who did not lose weight)

> "I mean the first half of it was really, really difficult to take everything in and measure everything and count everything." (Paid carer of a participant who lost weight)

"I certainly understood it. I would say a couple of the staff I don't think understood it." (Paid carer of a participant who did not lose weight)

Several carers from both groups described the booklets as a good source of information and had a suitable format for the needs of people with ID. Carers mainly praised the inclusion of pictures in the booklets that allowed participants who could not read text to use them:

"Mary can't read, Mary can see pictures and work out - that means that and that means this, (…) and she could see the pictures and went "oh that's right, that's what I should be eating and that's what I shouldn't be eating"". (Paid carer of a participant who lost weight)

Carers of participants who lost weight explained that using a food diary was another useful tool as long as there was consistency in completion. The food diary was used to illustrate a participant's daily intake, allowing the carers to understand how close the participant's intake was to the principles of a balanced diet.

"The best thing I found was the diary, keeping a written note religiously every day of every single thing we had eaten and had to drink, because until you see it in black and white you don't appreciate just what you're actually consuming in a day" (Family carer of a participant who lost weight)

However some carers reported that the intervention provided too much information to them and the participants.

"Well as I say there's lots, and lots of paperwork, a lot is not appropriate for Sally, but it could work for somebody else…" (Paid carer of a participant who did not lose weight)

"To be honest with you - there were quite a lot leaflets, I had to skim sort of through them" (Paid carer of a participant who lost weight)

A carer reported having difficulties at the beginning of the programme. The difficulties were related to getting used to the amount of information given at the beginning of the intervention.

> “There was lot information given as well which at the start was a lot to take in.” (Paid carer of a participant who lost weight)

9.2.5.3 Suggestions for the intervention

Most carers from both groups were satisfied with the intervention but some carers suggested the intervention should be simplified and adapted more for the needs of the participants. Recommendations included the use of simpler language, to make the intervention “less complicated”, develop strategies to motivate participants and provide set menus.

Several, carers of participants who did not lose weight suggested the use of training for staff that would focus on the principles of a healthy balanced diet and cooking:

> “I think definitely will be good to give them [Carers] some kind of training (…). I mean quite a lot of people cook at home but you know that maybe be 10 out of 30.” (Paid carer of a participant who did not lose weight)

The carers reported that there is a need for on-going support for the carers and the participants regarding their lifestyle. The support could be provided by a health professional that could have an impact on their knowledge and on the participant’s motivation to lose weight.

> “Coming once a month, it's basically “no” for John it will be for us more than anything I think that would be, it gives the information that we need.” (Paid carer)

9.3 Discussion

9.3.1 Carers' perceptions of the health effects of obesity on the participants

The results indicated that carers involved in the multi-component weight loss intervention had a general knowledge on the health risks associated with obesity. The carers correctly identified the major health benefits of weight loss, but less often described the improvements in terms of quality of life, such as a participant becoming more independent or confident. Similar findings have been reported, where carers recognised the health benefits of healthier lifestyles for adults with ID more readily than self-image or quality of life benefits (Melville *et al*. 2009).

9.3.2 The role of carers supporting adults with ID in a weight loss intervention

It is well known that carers can have a positive impact upon the health and wellbeing of people with ID but their role in assisting weight loss in obese individuals is unclear. In this study, the carers highlighted that they facilitated weight loss when they supported and involved participants with ID in practical issues such as healthy cooking and shopping. This means that individuals with ID should not just be passive recipients of healthy living messages but should be encouraged to take an active role in implementing a healthier lifestyle (Pownall 2010).

Successful weight loss interventions have frequently incorporated behavioural techniques to promote changes in diet and physical activity (Norris *et al*. 2005). The carers in this study used behaviour change techniques such as social encouragement and praise, which is similar to the findings from previous weight loss studies (Hamilton *et al*. 2007), but they were also involved in setting dietary targets based on the participants' preferences. In addition, carers promoted realistic physical activity targets based on the ability of both the participant and carer, with walking reported as one of the most common activities. Temple *et al*. (2000) described walking as a low cost opportunity for moderate physical activity and advocated the promotion of the health benefits of intensive walking in adults with ID.

9.3.3 Strategies that carers and participants adopted to overcome barriers to change lifestyle habits, whilst participating in a weight loss intervention

This study identified similarities in the barriers the two groups of carers reported experiencing while supporting participants to lose weight. For all carers, the level of organization of a service provided to an adult with ID was an important factor during weight loss. The carers expressed the need for a care plan that incorporated small established staff teams that can follow the weight loss plan consistently, and establishing better communication and cooperation between the staff within the same support team. In addition, the findings suggest that carers who support an adult with ID during the weight loss process would benefit from having consistent shift patterns and more one to one time allocated with the person they support.

Barriers in communication and cooperation were also identified between the carers from the internal and external service. Annual reviews were not seen as sufficient or effective as a communication method to support the weight loss of the participants. A future qualitative research study assessing the perspectives of the carers working in the external environment could potentially reveal more information about the principles of the services provided at resource centres but also could reveal mechanisms to establish better communication with the carers at the home of the individuals with ID.

The majority of the carers at home described how the unhealthy dietary patterns of the participants at resources centres inhibited their efforts to lose weight and less carers described the positive influence of resource centres on weight loss through health promotion projects. Some carers at home identified some of the positive steps in day centres in improving physical activity. Carers and people with ID have reported in the past the need for placements in resource centres or daytime opportunities to improve their physical activity (Finlayson *et al.* 2009) and it seems that these centres can promote physical activity through specific projects such as walking clubs. However, according to the findings of this study the efforts of the resources centres to improve the diet of people with ID are not the same.

The determinants of obesity in adults with ID are multi-factorial and can be associated with genetic predispositions or metabolic abnormalities but more often are associated with environmental factors (Melville *et al*. 2007). The environment can affect health by asserting a multi-institutional (family, resource centres, local communities) influence on the behaviour (Baranowski *et al*. 2003). Therefore, solutions may require an ecological approach to address the complex behavioural influences. This means that future research could explore the interrelationships among internal and external environmental influences and provide information essential to the management of obesity in adults with ID.

The poor staffing levels described by the paid carers as a barrier to their efforts to support weight loss have been reported in other studies where staff could not support participants to improve their physical activity levels (Messent *et al*. 1999; Temple and Walkey 2007). In contrast, and similar to other studies, family carers described difficulties while supporting participants and also meeting their own needs (Burton 2008; Kerston *et al*. 2001). Thus, a weight loss intervention, as for any other health service, should be flexible and aim to accommodate the needs of the adults with ID, along with the needs of the carers who support them.

According to current policies, carers should assist people with ID to increase control of their own lives by supporting and respecting their choices (Department of Health 2009). The findings of this study suggest that this aspect of policies has caused uncertainty among carers supporting people with ID to lose weight. Adults with ID may lack the cognitive ability to assess the consequences of long term unhealthy food choices (Smyth and Bell 2006). Therefore, some carers believe that individuals should be supported to make informed choices. Other carers may decide to act passively, following the recommendations of public policies and expressing respect to the rights of people with ID. A qualitative study on barriers to physical activity has shown that sometimes carers could even promote sedentary behaviour and give negative messages in order to protect the people they support from “overdoing it” (Frey *et al*. 2005).

However, it has to be noted that "health" is a multi-dimensional and relative term which can be perceived by people in different ways (Blaxter 1990). This means that even if carers are trained to help people with ID to make their own choices based on their abilities, "as long as these choices are not detrimental to their health" (as recommended by Bannerman *et al.* 1990), they may still act based on what their own beliefs are about a "healthy lifestyle" or "quality of life".

Cognitive impairments were recognised by the carers as having an impact on the participants' understanding and motivation to lose weight. "Lack of understanding" of the health benefits of physical activity is rated as one of the most significant barriers in adults with ID (Hawkins and Look, 2006). Reinforcement of healthy living messages in this study was seen as a partial solution to this difficulty, and discussion of the health benefits of weight loss was used as a mechanism to motivate participants. However, the latter was generally described as unsuccessful. It is therefore, important that motivational goals are pertinent to each individual participant and may be related more to day to day priorities rather than the overriding health benefits of weight loss.

Similar difficulties with a perceived lack of motivation of people with ID in adopting healthy lifestyle patterns, and especially in engaging in physical activities, have been also reported in other studies (Messent *et al.* 1998). However, motivation to make lifestyle changes can be influenced by different factors (Georgiadis *et al.* 2006) and may be only partially relevant to cognitive impairments. A study has shown that improved self-image is a greater motivator in women than in men and personal health has a bigger influence on the motivation of older people, and men (Satia *et al.* 2001). This type of study to investigate which factors motivate involving adults with ID during a weight loss process has not been reported in the literature.

According to the findings of the present study, the carers reported barriers similar to the external barriers reported from adults with ID in other qualitative studies including weather and safety (Temple 2007, Frey *et al.* 2005). This means that weight loss interventions should include extra information on alternative solutions to external barriers which prevent or limit lifestyle changes. For example, to promote solutions when bad weather conditions or safety issues prevent improvement of physical activity.

The weight loss intervention was described by carers as successful when participants were able to make lifestyle changes independently. This suggests that, where possible, a weight loss intervention should aim to empower a participant's ability in decision making, goal setting and attainment, and self-regulation. The successful impact of interventions on the self-determination of adults with ID and subsequently on their quality of life has been explored (Algozzine *et al.* 2001) but it has not been examined in weight loss interventions.

9.3.4 Carers' perceptions of the acceptability and utility of TAKE 5

Overall, the carers were satisfied with the TAKE 5 multi-component weight loss intervention, including the behavioural techniques used, and they praised the adapted resources used to promote a healthy lifestyle. Marshall *et al.* (2003) also used adapted health promotion materials in a health promotion intervention, leading to weight loss in adults with ID. However in the study reported here, the carers of participants who did not lose weight described barriers associated with the complexity of some aspects of the intervention. Therefore, the prescription of the energy deficit diet, necessary for successful weight loss according to clinical guidelines, may require further simplification and adaption to meet the needs of people with ID and their carers. It has to be noted that the carers found it difficult to adapt to the recommendations of the intervention especially at the start of the programme and criticised the amount of information provided to them and the participants.

All carers stressed the need for on-going support, and opportunities for carer training from health professionals, to facilitate appropriate healthy lifestyles for individuals with ID. Previous studies have shown that carer training on health promotion and on models of active support can influence healthy eating practices and improve activity levels of people with ID (Kneringer and Page 1999; Jones *et al.* 2001). Therefore, health promotion and training initiatives should target not only individuals with ID but also carers involved in supporting healthy lifestyle choices (Melville *et al*. 2009; McGuire *et al*. 2007).

9.4 Limitations

Reflexivity can be defined as the potential influence of the researcher's background or knowledge to the collection of the data and to the shaping of the data analysis (Murphy 1998). In this study, the interviewer (DS) was the weight management coordinator who delivered the sessions with each participant during the weight loss study. This could have been a potential source of bias and the researcher was aware that this could have an impact on the data collection process and its quality. Therefore, prior to each interview carers were informed that reporting their experiences and personal beliefs would provide important information relevant to the development of any future weight loss services for adults with ID. In addition, to eliminate the impact of the researcher on the quality of the data, for initial interviews "peer de-briefing" sessions were used. These sessions allowed the researcher to discuss the circumstances of the data collection with a second researcher with experience in qualitative research (CM) but not closely involved with the data collection process (Guba and Lincoln 1989). One of the strengths of the study is the inclusion of a variety of carers (e.g. paid carers, family carers) minimizing influences from one specific type of carer to the analysis.

This qualitative study reported the experiences and opinions of the carers only and not of the participants with ID. It has to be noted that the researcher developed qualitative questionnaires and carried out interviews with only two participants with ID. Communication difficulties have led to the exclusion of adults with ID from research. However, techniques such as "Talking mats" or pictorial representation of subjects to be discussed have been identified as a useful method of improving the participation of people with ID in qualitative studies. The author of this thesis used this type of augmentative communication together with a structured questionnaire to explore the participants' perception about the influence of family, carers and resources in weight management. However, the two interviews did not produce data of high quality. This means that the questionnaire used was probably not suitable for the cognitive needs of the participants or that the researcher was lacking considerable skills needed for this type of qualitative interviews. The level of the ability of the participant to go through the process of the interview was not assessed or scored by a valid assessment tool but it was based on the primary researchers' judgment. Finally, the presence of the carers during the interview and the fact that the interviewer was the same person that delivered the intervention made the participants feel that the interview was a process of assessment instead of a method of exploring their beliefs and opinions. A new qualitative study should use an experienced researcher in this area of qualitative research that will be not involved with the development and delivery of the intervention. The interviewer should use questionnaires and methods of interview reviewed and validated by a group of individuals with ID. Carers should not be present in the interviews because they could affect the quality of the information collected.

CHAPTER 10: General discussion

10.1 Adults with ID and research

Obesity is an important health issue for adults with ID and the prevalence is increasing. The health risks of obesity in adults with ID are similar to the ones identified in the general population but the evidence for the effectiveness of different methods of treatment in this population group is minimal. It is essential for the development of a weight management service to have an adequate and valid evidence base. The national clinical guidelines (NICE 2006; SIGN 2010), previous systematic reviews of weight management interventions in adults with ID (Hamilton *et al.* 2007; Jinks *et al.* 2011) and this thesis have identified only a minimal research infrastructure in this area of research.

Over the years, people with ID have had a minimal involvement in research (Iacono 2006) even though they have expressed their interest in participating (Ham *et al.* 2004). There is no research which has examined the reasons why exclusion of individuals with ID from weight management studies has taken place. This may reflect the already identified challenges in developing research for adults with ID, especially in relation to ethical processes for vulnerable adults. Several studies and ethics committees have looked at the ethical issues related to the types of interventions provided to people with ID, reporting that it is necessary for the interventions to be tailored to the needs of the participants and highlighted the importance of principles and procedures that need to be followed when individuals with ID do not have the capacity to consent participation in a given study (McDonald and Kidney 2012).

An important issue that probably challenges researchers to initiate research in ID include the risks of under recruitment. A review of 20 studies in this population group showed that lack of direct contact when inviting individuals with ID to participate in a study, inclusion of invasive procedures such as blood testing and the procedures of taking consent lead to a poor participation in the studies for adults with ID (Cleaver *et al.* 2010).

This thesis aimed to overcome or avoid these barriers, initiating research by researchers with clinical experience in ID. This thesis adhered to ethical standards by delivering an intervention suitable to the needs of adults with ID, and minimised elements that are known to limit recruitment of those with ID, such as bloodletting and other invasive elements, in the study.

10.2 Clinical and research implications

There is numerous evidence and recommendations to guide practice in weight loss, however much less is known about how people can sustain intentional weight loss and avoid regain over the long term (Sciamanna *et al.* 2011). This lack of evidence for weight maintenance in adults has led to insufficient evidence for clinical guidelines to provide detailed recommendations (SIGN 2010). There are even less data to guide the development of weight maintenance interventions for adults with ID.

The assessment of the weight loss and the weight maintenance intervention was a part of a quasi-experimental pilot study without a control group. Quasi experimental designs are usually used for the evaluation of an intervention pre and post and can be very useful when a control group is part of the study. However, the TAKE 5 weight loss intervention was a small pilot study that was used to help the development of a further larger confirmatory study.

Even though the assessment of the TAKE 5 weight management programme did not follow the principles of a RCT, the evidence provided in this study may have clinical and research relevance for the development of weight management for adults with ID. The following section provides recommendations in the area of research or clinical services based on the strengths and the limitations of this thesis. Two flow-charts were developed following these recommendations using photographs specially designed for adults with ID by Photo-Symbols © Ltd (2013).

10.2.1 Multi-component weight maintenance intervention for adult with ID

10.2.1.1 The weight loss phase

The level of success of long term weight maintenance depends largely on the type of weight loss intervention provided as part of a weight management programme. For example studies that have used VLCD as part of their weight loss intervention have reported a 40% to 50% regain of the weight lost in the first two years following treatment (Tsai and Wadden 2006) and studies that have used diet and exercise have reported a 20% greater sustained weight loss in the first year following treatment than studies that have used diet alone (Curioni and Lourenco 2005). In addition, a systematic review by Franz *et al.* (2007) found that multi-component weight loss interventions that incorporate diet, physical activity and behaviour led to weight loss maintenance of 8.5% compared to 4.6% in single dietary interventions at 12 months.

The long term effectiveness of a multi-component weight loss intervention may rely on the holistic approach of the programme to promote changes to all crucial areas of weight management. It is recommended that these changes must be simple and acceptable by individuals in order to be sustainable. For example, the diet should include all the food groups with a tolerable energy deficit, physical activity recommendations should take into consideration the sedentary lifestyle of the individual and promote small and slow changes and finally at the end of the weight loss programme individuals must be prepared to face behaviours that trigger a relapse (Stubbs and Lavin 2013). This means that the TAKE 5 weight loss programme by following the above recommendations for a holistic approach to weight loss and simple and tolerable lifestyle changes had set a good foundation for supporting participants to follow a sustainable lifestyle. This subsequently led to a sustainable weight loss.

10.2.1.2 The weight maintenance phase

The number of studies that have investigated the type of weight loss maintenance intervention that should be provided to individuals with obesity after weight loss is limited and inconclusive (Loveman *et al.* 2011). For example Cox *et al.* (2007) suggested that prevention of weight regain is just a case of a calorie intake not exceeding the daily energy requirement but for Tate *et al.* (2007) physical activity is the major contributor to weight maintenance.

Akers *et al.* (2010) identified that studies examining weight maintenance interventions have limitations in relation to reporting information affecting their implementation into actual practice settings. The review evaluated studies of weight maintenance interventions using the “RE_AIM” framework: Reach, Efficacy/effectiveness, Adoption, Implementation, and Maintenance. The authors identified two studies that focused on diet, three studies that focused on diet and behaviour, one study on physical activity and behaviour change and 13 multi-component weight loss maintenance interventions. The review reported that among all the studies (single and multi-component) the group based behaviour therapy was found to be most effective in reporting information in relation to influence of the intervention on outcomes, weight regain, and attrition. However, this was an overall evaluation of the quality of the studies in terms of reporting information and not of actual effectiveness in terms of mean weight loss and weight regain.

Further research in adults with ID and without ID is needed to investigate multi-component weight maintenance interventions leading to specific recommendations for each component of the intervention e.g. calorie intake, type and amount of physical activity prescribed and type of behaviour change techniques used. However, the TAKE 5 weight maintenance intervention was based on the principles of a multi-component approach, followed the recommendations of the NWCR, the largest database on successful maintainers, and provided a well-structured intervention that led to weight maintenance.

10.2.1.3 A need for ongoing support

Weight loss maintenance is a very difficult process and according to some studies, the difficulty is related to the natural process of the body to regain the lost weight (Rosenbaum *et al.* 2005). These physiological responses to weight loss include decrease in metabolic rate and total energy expenditure (Redman *et al.* 2009). Weight loss will also lead to a decrease in levels of leptin and increase of ghrelin, orexigenic and anorexigenic hormones involved with the regulation of food intake and body weight (Wadden *et al.* 2004, Crujeiras *et al.* 2010).

In addition, psychological challenges for an individual to sustain new healthy behaviours and resist relapsing to previous unhealthy dietary and activity patterns make weight loss maintenance even more difficult (Wing 2001). Negative emotions such as feelings of failure, stigma and self-criticism are known for triggering a relapse, acting as a barrier to weight maintenance (Gilbert 2009).

It should be noted that individuals that are motivated to maintain their weight loss have to face the above difficulties. They also have to resist the less likely modified determinants of weight gain such as the obesogenic environments and the deleterious effects of the food industry (Stubbs and Lavin 2013).

This means that individuals with obesity that have lost weight may need ongoing support from health professionals to overcome the barriers and maintain their weight losses (Wadden *et al.* 2004). The idea of extended care on the long term maintenance was investigated by a recent meta-analysis (Ross Middleton *et al.* 2012) showing that prolonged support in the form of individual sessions or phone calls providing social support lead to the maintenance of an additional weight loss of 3.2kg for a period of 17.6 months.

TAKE 5 incorporated this type of support as part of the weight maintenance intervention, with the majority of participants achieving weight loss maintenance showing that future interventions may need to adopt these principles of extended care, especially for adults with ID that may find it difficult to reach weight maintenance targets without on-going support.

10.2.1.4 Recommendation 1

This thesis follows the findings of other studies in the general population and adds more evidence in the development of weight maintenance interventions in adults with ID showing that a weight maintenance intervention may be effective when the intervention provides extended care for 12 months and is a part of a multi-component weight management intervention that:

1. provides a personalised 600kcal energy deficit diet for 16 weeks followed by a 12 month healthy balanced diet (50% of daily energy intake was from carbohydrates, less than 35% from fats and less than 20% from protein)
2. provides advice on improving physical activity levels
3. uses behaviour change techniques that support weight loss and long term maintenance of lifestyle changes

A future RCT following the same principles as TAKE 5 could provide more valid conclusions about the effectiveness of a multi-component weight maintenance intervention by making comparisons with single component weight management interventions or care as usual.

10.2.2 Weight maintenance definition

There is no universal definition of weight maintenance, with several studies choosing different limits of healthy weight fluctuation or defining weight maintenance as a reference for baseline weight or weight after a weight loss intervention (Stevens *et al.* 2005). The use of a specific definition for weight maintenance having as a reference the weight at the end of the weight loss intervention and not the weight at baseline allowed this thesis to provide a valid interpretation of the effectiveness of a weight maintenance intervention.

It has to be noted that national clinical guidelines in UK do not provide a definition for weight maintenance (NICE 2006; SIGN 2010). Weight maintenance can be defined “either in relation to weight losses previously achieved or in terms of absolute or percentage weight change at points successively more distant in time” (Jeffery *et al.* 2000). Time points usually used to evaluate success in weight loss maintenance include 18 months to 30 months after weight loss therapy (six months).

Examples of studies that have defined weight maintenance differently include Jeor *et al.* (1997) and Sherwood *et al.* (2000) that defined weight maintenance as a change of less than 2.3 kg and the NHLBI (2000) that defined weight maintenance as regain of weight less than three kg in two years and a sustained reduction in waist circumference of at least 1.6 inches (four cm). Weight maintenance has also been defined as a loss of at least 5% of body weight, or a reduction in BMI of at least one unit, and keeping weight below this minimum amount for at least one year post weight loss (The institute of Medicine 1995). Other studies have defined weight maintenance as a 5-10% weight loss from baseline body weight maintaining this for one year or two years (Elfhag and Rossner 2005; Wing and Phelan 2005; Kraschnewski *et al.* (2010)).

In this thesis weight maintenance was defined based on the recommendations of Stevens *et al.* (2005). Stevens *et al.* (2005) explained that body weight measurements at different time points may not be the same and researchers may need to be aware of specific measurements errors. These include: the natural weight changes from body fluid fluctuations (e.g. during menstrual cycle or after a physical activity), different clothing worn by the participants at the different points of measurement and because of meal consumption prior to the measurements. Stevens *et al.* (2005) is the only evidence based study that has described potential errors in measurements in detail and has provided a detailed explanation of potential natural fluctuations of weight. Therefore, this thesis used the definition of Stevens *et al.* (2005) and defined weight maintenance as "a weight change of less than 3% of a designated body weight under standardized conditions".

The use of a specific definition for weight maintenance in the thesis may have had a potentially a positive effect on the measured outcome. Using upper and lower limits for weight fluctuation may have helped the participants and their carers to prepare and take suitable action when the weight increased to an unhealthy level. This was reported by the carers of the participants to the researcher but it was not formal part of qualitative assessment of the study.

10.2.2.1 Recommendation 2

Using a definition of weight maintenance will prevent studies from reporting mixed results from the weight loss period and the weight maintenance period, overestimating the effectiveness of the weight management programme. This will also allow systematic reviews to make valid comparisons among studies. In addition, will allow participants to understand the limits of a healthy weight change and act when unhealthy weight gain occurs.

10.2.3 The health effects of weight loss and weight maintenance in adults with ID and obesity

Previous research in the general population has reported that a five to 10% weight loss from initial body weight can lead to important clinical health benefits including improvement of lipid profiles (Tzotzas *et al*. 2011), reduction of blood pressure (Perez *et al*. 2007) and reduction of plasma blood glucose (Anderson *et al*. 2003). However, there is a need for maintenance of this weight loss to sustain those health benefits (Ferland and Eckel 2011).

There are no weight management studies that have assessed the effect of clinically significant weight loss and weight maintenance on obesity related risks in adults with ID. Only, Bertoli *et al*. (2006) a single component weight loss intervention showing a clinically significant weight loss at 12 months for six participants who were overweight or obese and assessed the effects of weight loss on biochemical parameters, blood pressure and metabolic syndrome. The study reported no effects on plasma glucose, plasma lipids and blood pressure but complete recovery from metabolic syndrome was observed for two participants. However, these results are difficult to interpret as Bertoli *et al*. (2006) reported results for adults with ID and without ID and the study findings were assessed for the effects of total weight loss for all the completers of the intervention and not specifically for those individuals that achieved clinically significant weight loss.

This thesis assessed the effectiveness of TAKE 5 weight management intervention and showed that a weight management programme for adults with ID based on multi-component principles, can lead to clinically significant weight loss, followed by successful weight maintenance for 12 months. This means that even though clinical outcomes were not assessed in this thesis, the weight loss at 16 weeks and weight maintenance at 12 months achieved by the participants of the TAKE 5 intervention may have led to health benefits. A new study could use non-invasive methods and explore the health benefits of weight loss in adults with ID.

A clinically significant weight loss and long term weight loss maintenance can have a positive impact on the impaired health related quality of life of adults with obesity (Blissmer *et al*. 2006; Karrlson *et al*. 2007). Health related quality of life can be assessed in relation to physical health, emotional well-being and psychosocial functioning (Kolotkin *et al*. 2001). For this reason studies use validated and reliable assessment tools that focus on multiple areas of health related quality of life. For example, a study by Engel *et al*. (2003) used a 31 item questionnaire (Impact of weight on quality of life - IWQOL-Lite) in adults without ID focusing on physical function, self-esteem, sexual Life, public distress and work. The study showed that weight loss had a positive impact on the health related quality of life of the participants and each unit of weight regained having a negative impact on the measured outcome.

Similar to other studies of weight management interventions for adults with ID, this thesis did not assess the impact of weight loss on the health related quality of life of the participants. The already busy format of the pre and post assessment of the pilot TAKE 5 weight management programme including anthropometric measurements, physical activity measurements and collecting socio-clinical information made the researcher hesitant to investigate this outcome. Even though the concept of quality of life has been investigated in adults with ID for many years there is a lack of validated reliable assessment tools accessible to this population group (Townsend-White *et al*. 2012).

An example of assessment tool that could be used in a new study assessing the impact of weight changes on health related quality of life in adults with ID is the Multifaceted Lifestyle Satisfaction Scale (MLSS) (Harner and Heal 1993). This questionnaire can be answered by individuals with ID without the support of a carer. A second example of an assessment tool that can be answered by individuals with ID or by two people that know the participant very well is the QOL-Q (Schalock and Keith 1993). This type of assessment of the impact of a weight management intervention on the quality of life of an individual may be more appealing in adults with ID that are discouraged by the invasive clinical procedures e.g. blood testing.

Weight management and subsequent weight loss can have a positive impact on the participants' self-esteem (Kolotkin *et al.* 2001). This means that the effectiveness of a multi-component weight management intervention could be assessed not only in relation to weight changes but also in relation to specific psychological benefits. Even though this was not assessed in this thesis, valid and reliable measurement tools for adults with ID could be used in future research. Examples include the use of the Rosenberg Self-Esteem Scale, a commonly used assessment tool in weight management interventions for the general population (Vieira *et al.* 2012) that has been also adapted and tested in adults with ID (Davis *et al.* 2009).

10.2.3.1 Recommendation 3

There is a need for studies in adults with ID that can evaluate the impact of weight loss on the quality of their life. The assessment should focus on clinical, sociological and psychological improvements after weight loss. However, researchers will need to focus on reliable methods and valid tools suitable for adults with ID.

10.2.4 Accessible weight management services for adults with ID

The TAKE 5 weight management intervention provides new evidence that could be used to support the development of accessible weight management services for adults with ID.

There is a worldwide concern about the gap in accessible health services suitable to the needs of adults with ID (WHO 2007). Based on the health care policies in UK, people with ID have the same access to primary and secondary health care and in some complicated health issues (epilepsy, disphagia, and mental health problems) they can have access to specialised services (Redley *et al.* 2012). This means that for health conditions like obesity, diabetes and heart problems individuals with ID will be provided treatment from the same secondary health care services as the general population. However, lack of adaptations of these services to the communication and cognitive needs of people with ID make the treatment provided inaccessible and ineffective.

The gap in provision of suitable methods and materials to enable people with ID to make healthy lifestyle choices is identified as a large scale problem (NHS Health Scotland, 2004) with communication reported as a crucial barrier to the effective health care of people with ID (Krahn *et al*. 2006). Individuals with ID have expressed the need for improved communication with health professionals, in order to rely less on the carers who support them (Murphy 2006). The TAKE 5 weight management intervention provides the methodological evidence that could be used to reduce the disparities in weight management services for this population group. In 2009, the department of health published a policy (Valuing People Now) reporting the plans for services and information accessible to people with ID. This means that research that involves adults with ID can follow current guidelines or resources from reliable sources such as Mencap, a charity working with learning disability services, to make the interventions more accessible to the participants.

The point of view of participants involved in research concerning the methods, information and resources used is important and should be explored (McDonald *et al*. 2012). This is possible with the use of qualitative research that will reveal the meanings, attitudes, interactions and views of participants in a study (Mays *et al*.). The study of the TAKE 5 weight management intervention explored the beliefs and experiences of the carers supporting adults with ID but did not investigate the opinions of the participants with ID. The use of “user friendly” techniques such as “photovoice” (Booth and Booth 2003), “life story” approaches (Atkinson 2004) or augmentative communication (Brewster 2004), could help participants with ID to express their views about a specific study and make this type of qualitative research feasible.

10.2.4.1 Recommendation 4

The TAKE 5 weight management programme followed the principles of an accessible intervention using resources and communication techniques suitable to the needs of the participants. Similar methods should be followed by other studies and health services but with a greater involvement of adults with ID and other specialised services in the planning and construction process of the intervention. Qualitative interviews with the participants at the end of an intervention will provide more information on the delivery of accessible information.

10.2.5 Carers and weight management for adults with ID

The role that carers have in the reduction of health inequalities experienced by people with ID has been highlighted by UK policies (Redley *et al*. 2012). Family or paid carers have an understanding of the needs of the people they support and as recommended by the DOH (Health care for all 2008) they should be involved in the design and the delivery of a health service. This thesis described in detail for the first time the important role the carers can have in weight management. The carers can provide social support, they can be involved in the process of behaviour change and they can ensure that people with ID play an active role when they make healthy lifestyle changes. By this way, the carers can contribute to the overall effectiveness of a weight management intervention. However, this role should be sustained in the weight loss phase and in the weight maintenance phase. In a new study, the design of the weight management intervention should be based on the barriers and experiences of carers supporting people with ID to lose weight and similarly to the TAKE 5 weight management intervention, they should be actively involved in the delivery by having the role well defined.

However, the carers identified their own weaknesses and highlighted their need to be skilled and trained. This is a perception that follows the findings on the identified needs for carers to improve their dietary knowledge (Melville *et al*. 2009). The Scottish Government (2003) agrees with the above and highlights the importance of training the carers in understanding of how to support people with ID. The carers should have access to available community training schemes such as the accredited training in nutrition for carers, provided by The Royal Environmental Health Institute Scotland or the Edexcel National Vocational Qualifications (NVQs) that provides training for health and social care services.

A study by Jenkins and McKenzie (2011) described the utility of applying the 'Theory of Planned Behaviour' to predict the intention of carers to support adults with ID to make changes with their diet. The theory is based on the idea that individuals' intentions to change behaviour are affected by attitudes, subjective norms and perceived behavioural control. The study suggested that that training of carers could be based on this theory and can have a positive impact on the adults with ID that they support, by teaching the carers to have a positive attitude and hence an intention to increase healthy behaviour around food and eating (Jenkins and McKenzie 2011). The utility of the theory was also tested for predicting the intentions of carers to support people with ID to make changes with their physical activity (Martin *et al.* 2011).

This thesis also showed that the effectiveness of weight management for adults with ID is not only dependent on the structure of the intervention but also on the structure of the care plan provided to the participant at that period. This situation is common in several types of support for people with ID attributed to lack of guidelines and policies from social care commissionaires and service providers and no guidance to carers on what kind of support they should provide to people with ID (Messent *et al.* 1999). Policies for the support of people with ID should acknowledge the communication and co-ordination barriers reported by the carers. The policies should demand from support plans to include well-co-ordinated communication between care agencies, day centres and family carers, especially when a health care service such as weight management requires a shared support by the internal and external environment.

10.2.5.1 Recommendation 5

The BDA (2011) agrees that supporting systems for adults with ID can be quite complex and inconsistencies can occur. It is recommended that "having a schematic of key people involved in the health and wellbeing of the client is a critical factor in increasing the success of any prevention or intervention" (BDA p8; 2011).Therefore, a weight management intervention for adults with ID should be based on the following principles:

1. the carers play in important role in weight management in the form of social support, therefore they should be part of the intervention
2. the level of skills and knowledge of the carers can be limited, therefore training should be provided
3. potential barriers to the aims of a weight management intervention can emerge from the poorly designed care plans for adults with ID. Therefore individuals that are important to the development of these care plans are responsible to co-ordinate a well-structured support for the individuals that want to lose weight.

10.2.6 Cost effectiveness of multi-component weight management intervention

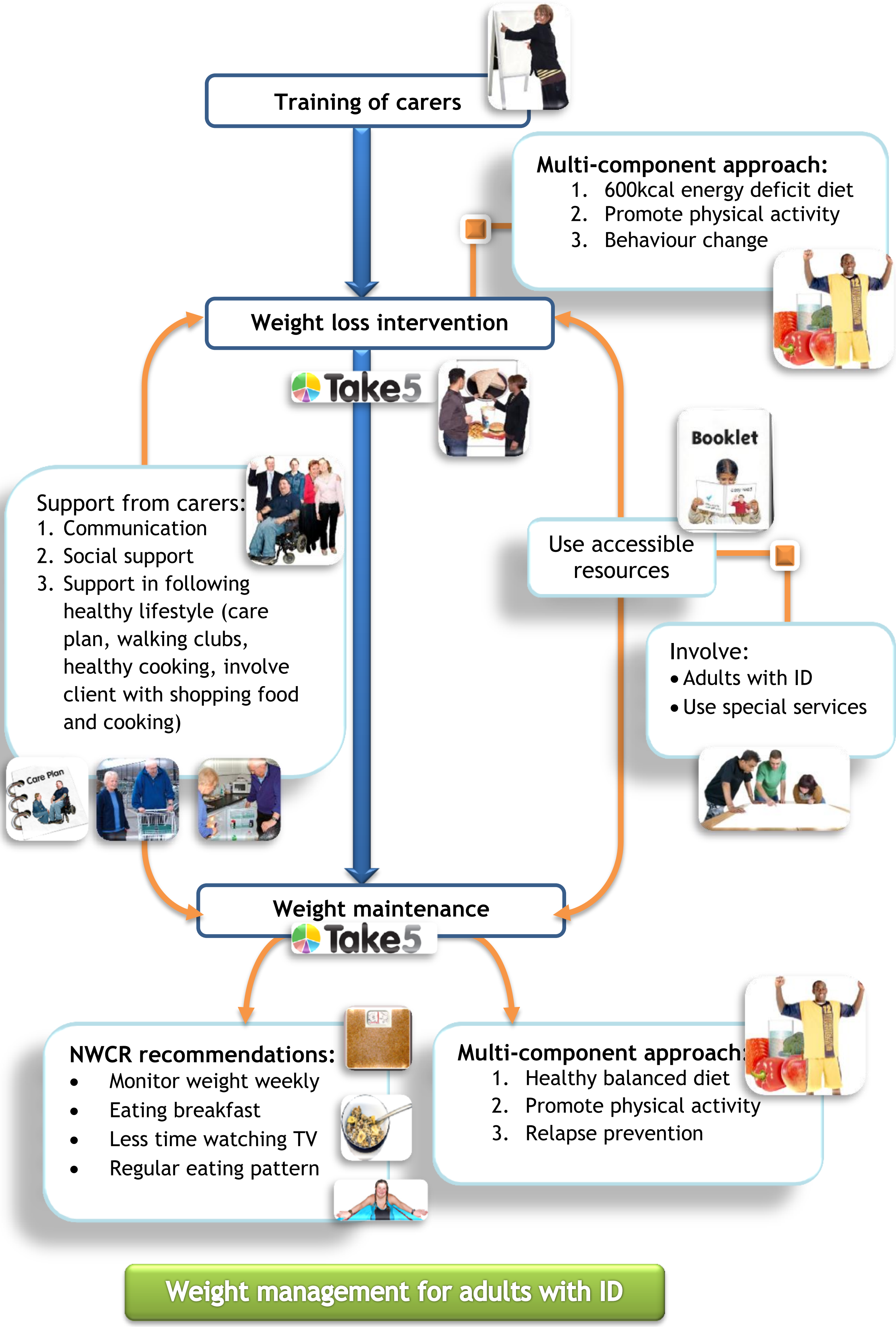
The growing prevalence of obesity in UK requires the development of cost-effective multi-component weight management services that will not affect the already financially depleted National Health Service (Haynes *et al.* 2010). In 2008 national clinical guidelines (NICE 2008) approved the use of the EQ-5D for the economic evaluation of health services by assessing their cost per quality adjusted life year (QALY). Loveman *et al.* (2011) indentified only two multi-component studies that met the inclusion criteria of the systematic review, a study using the EQ-5D (Trueman *et al.* 2010) and one using micro-costing techniques (Roux *et al.* 2006). The analysis showed that long term multi-component weight management interventions (follow up of more than 18 months) in adults without ID are more cost-effective than care as usual and single component interventions. However, limitations of the economic evaluation in both studies, the difference in the estimated costs for treatment in USA and UK and the use of antiobesity drugs in one study (Trueman *et al.* 2010); make the evidence less reliable and inconclusive. In addition, the economic evaluation of weight loss maintenance interventions is even more limited in current literature (Akers *et al.* 2010)

There is no similar information published for weight management interventions in adults with ID and the validity of the EQ-5 has not been assessed in adults with ID, indicating the need for a study assessing the economic feasibility of a long term weight management intervention for this population group.

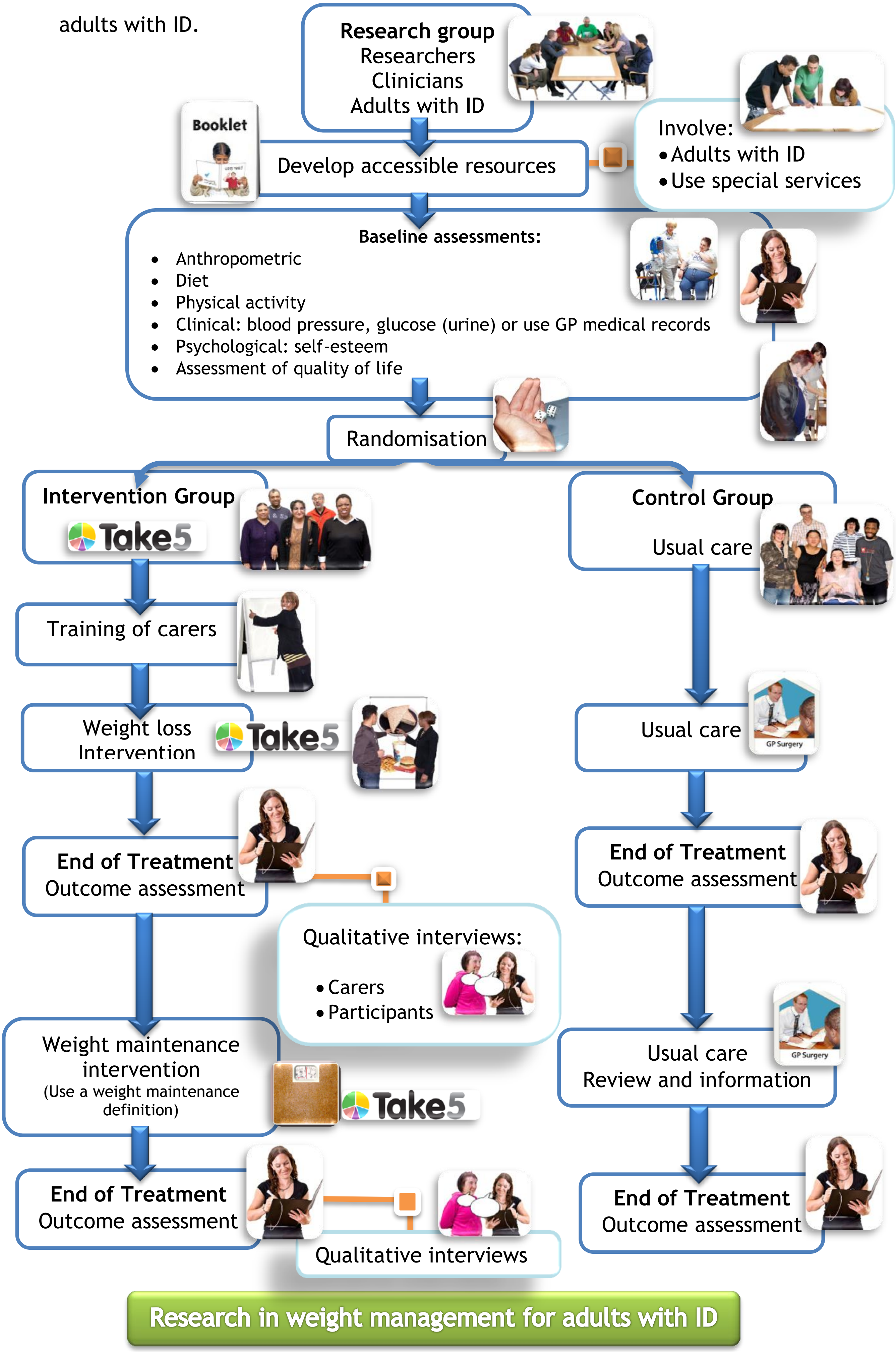
10.2.6.1 Recommendation 6

The economic evaluation of a weight management service similar to the TAKE 5 weight management programme should focus on principles and strategies that may be necessary for the effectiveness of such intervention in this population group. These include a long term continuous contact of 12 monthly contacts, the inclusion of individual consultations instead of group sessions and the development and use of user friendly recourses.

Flow chart 10.1: Recommendations for weight management service for adults with ID.



Flow chart 10.2: Recommendations for research in weight management for adults with ID.



10.3 Conclusions

This thesis was devised to answer the following research questions:

1. What components are included in weight loss interventions for adults with ID?
2. Are weight loss interventions for adults with ID associated with a clinically significant weight loss (5-10% weight loss from initial body weight)?
3. Do interventions include a weight loss maintenance component?

A systematic review of weight management interventions for adults with ID from 1983 to 2011 identified only eight studies out of the 22 that followed the recommendations of national clinical guidelines (NICE 2006, 2010) on the use of multi-component weight loss interventions. In comparison with the weight management studies in adults without ID, the quality of the research in adults with ID was poor, with inadequate descriptions of the components of the interventions and strong methodological limitations. This did not allow robust comparisons and conclusions about the effectiveness of the weight loss interventions in relation to clinically significant weight loss in adults with ID. Similar to the weight management interventions in adults without ID, research of weight maintenance interventions in adults with ID is minimal.

4. Do participants in a multi-component weight maintenance intervention achieve to maintain their weight loss (a weight change of less than 3%)?
5. Does the multi-component weight loss maintenance intervention decrease the time spent in sedentary behaviour per day to a statistically significant level?
6. Does the multi-component weight loss maintenance intervention increase physical activity to a statistically significant level?
7. Are there statistically significant associations between socio-clinical variables and success of the weight maintenance intervention?

The multi-component weight maintenance intervention of the TAKE 5 weight management programme successfully supported participants to maintain their weight for 12 months. The weight maintenance intervention did not succeed to improve the levels of physical activity of the participants to a statistically significant level. The part of the intervention focusing on the improvement of physical activity needs to be reviewed. It was difficult to make robust comparisons with other studies because this is the only study that has used a specific definition for weight maintenance, delivered a structured multi-component weight maintenance intervention, and assessed physical activity levels at the end of the intervention. A larger well powered study using valid methods could provide more information on baseline dietary patterns of adults with ID but also information on socio-biological pre and post treatment predictors for weight maintenance. An evaluation of the cost effectiveness of the TAKE 5 weight management intervention is justified.

8. Is a multi-component weight loss intervention adapted to the needs of adults with ID and obesity as effective in this population group as it was in those without ID?
9. Are there statistically significant associations between socio-clinical variables at baseline, and the likelihood of participants achieving the target weight loss of 5% or more of initial body weight?

TAKE 5 a multi-component weight loss intervention adapted for adults with ID and obesity can be as effective as the same intervention as the one for adults without ID. This means that TAKE 5 can be used in its current structure by a weight management service to reduce the disparities in weight management services for this population group. The only predictor for weight loss identified was initial weight loss of 1.8kg at four weeks. The small sample size of this study may have prevented the analysis to detect significant correlations between socio-biological variables and weight loss. Well powered studies that analyse the evidence in an efficient way are needed to reveal predictors for weight loss in adults with ID during a multi-component weight loss intervention.

10. What were the carers' perceptions of the impact of obesity and perceived benefits of weight loss on participants' health?
11. What role do carers supporting adults with ID and obesity play in implementing a weight loss intervention?

12. What strategies did carers and participants adopt to overcome barriers to change in lifestyle habits during a weight loss intervention?
13. What were carers' perceptions of the acceptability and utility of the multi-component weight loss intervention?

This thesis showed that carers supporting adults with ID to lose weight associated weight loss mainly to the clinical and physical health benefits. Carers can play an important role in supporting adults with ID in multi-component weight loss interventions in the form of social support. The support provided to adults with ID needs to be part of a holistic and well-coordinated service to help to ensure that carers from the external and internal environment have the same aims. Weight management services would maximize their effectiveness by using information and materials adapted to the needs of adults with ID, and employ strategies to improve self-determination and motivation, whilst considering the barriers that could challenge the carers who support individuals.

10.4 Future research topics

The possible future research generated by this thesis:

1 A RCT comparing the effectiveness of a multi-component weight loss intervention with care as usual
2 What is the effect of weight loss on health related quality of life in adults with ID?
3 Is a structured multi-component weight management intervention in adults with ID cost-effective in comparison with treatment as usual?
4 What are the perceptions of adults with ID of the acceptability, accessibility and utility of a multi-component weight management intervention?
5 In a RCT assessing the effectiveness of a multi-component weight loss intervention are there significant bivariate or multivariate associations between socio-biological variables at baseline, and whether participants achieve weight maintenance?

10.5 Research Skills developed within this thesis

- Critical appraisal of research literature
- Systematic review methodology
- Development of qualitative research
- Development of weight maintenance interventions for adults with ID
- Evaluation of weight loss and weight maintenance interventions for adults with ID
- Designing intervention materials for adults with ID
- Intervention implementation and study management
- Preparation of manuscripts and submission for publication
- Preparation and delivery of presentations at national and International conferences

References

Agurs-Collins, T. D., Kumanyika, S. K., Ten Have, T. R. & Adams-Campbell, L. L. 1997. A randomized controlled trial of weight reduction and exercise for diabetes management in older African-American subjects. *Diabetes care,* 20, 1503-11.

Akers, J. D., Estabrooks, P. A. & Davy, B. M. 2010. Translational research: bridging the gap between long-term weight loss maintenance research and practice. *J Am Diet Assoc,* 110, 1511-22, 1522 e1-3.

Alborz, A., McNally, R. & Glendinning, C. 2005. Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *Journal of health services research & policy,* 10, 173-82.

Algozzine, B., Browder, D., Karvonen, M., Test, D. W. & Wood, W. M. 2001. Effects of Interventions to Promote Self-Determination for Individuals with Disabilities. *Review of Educational Research,* 71, 219-277.

Allison, D. B., Gomez, J. E., Heshka, S., Babbitt, R. L., Geliebter, A., Kreibich, K. & Heymsfield, S. B. 1995. Decreased resting metabolic rate among persons with Down Syndrome. *Int J Obes Relat Metab Disord,* 19, 858-61.

Aman, M. G., Burrow, W. H. & Wolford, P. L. 1995. The Aberrant Behavior Checklist-Community: factor validity and effect of subject variables for adults in group homes. *Am J Ment Retard,* 100, 283-92.

American Psychiatric Association (2000) *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). American Psychiatric Association, Washington, DC.

American Association on Intellectual and Developmental Disabilities: Definition of intellectual Disability. [http://www.aaidd.org/content_100.cfm?navID=21]

Anderson, J. W., Kendall, C. W. & Jenkins, D. J. 2003. Importance of weight management in type 2 diabetes: review with meta-analysis of clinical studies. *J Am Coll Nutr,* 22, 331-9.

Anderson, M.L., Matsa, D.A. 2011.Are Restaurants Really Supersizing America? *Am Econ J: App Econ*, 3, 152–188

Anderssen, S. A., Hjermann, I., Urdal, P., Torjesen, P. A. & Holme, I. 1996. Improved carbohydrate metabolism after physical training and dietary intervention in individuals with the "atherothrombogenic syndrome'. Oslo Diet and Exercise Study (ODES). A randomized trial. *J Intern Med,* 240, 203-9.

Antal, M., Zajkas, G., Rajhathy, B., Nagy, K., Szanto, E., Thur, M., Dworschak, E., Gergely, A., Bedo, M. & Biro, G. 1988. Longitudinal examinations in the course of dietotherapy of mentally retarded obese in-patients. *Z Ernahrungswiss,* 27, 101-8.

Arem, H. & Irwin, M. 2011. A review of web-based weight loss interventions in adults. *Obes Rev,* 12, e236-43.

Astrup, A. & Rossner, S. 2000. Lessons from obesity management programmes: greater initial weight loss improves long-term maintenance. *Obesity reviews : an official journal of the International Association for the Study of Obesity,* 1, 17-9.

Atkinson *, D. 2004. Research and empowerment: involving people with learning difficulties in oral and life history research. *Disability & Society,* 19, 691-702.

Atkinson, R. L. 1989. Low and very low calorie diets. *Med Clin North Am,* 73, 203-15.
Atlantis, E. & Baker, M. 2008. Obesity effects on depression: systematic review of epidemiological studies. *International journal of obesity,* 32, 881-91.
Avenell, A., Broom, J., Brown, T. J., Poobalan, A., Aucott, L., Stearns, S. C., Smith, W. C., Jung, R. T., Campbell, M. K. & Grant, A. M. 2004a. Systematic review of the long-term effects and economic consequences of treatments for obesity and implications for health improvement. *Health technology assessment,* 8, iii-iv, 1-182.
Avenell, A., Brown, T. J., McGee, M. A., Campbell, M. K., Grant, A. M., Broom, J., Jung, R. T. & Smith, W. C. 2004b. What are the long-term benefits of weight reducing diets in adults? A systematic review of randomized controlled trials. *J Hum Nutr Diet,* 17, 317-35.
Baker, S., Jerums, G. & Proietto, J. 2009. Effects and clinical potential of very-low-calorie diets (VLCDs) in type 2 diabetes. *Diabetes Res Clin Pract,* 85, 235-42.
Ball, K. & Crawford, D. 2006. Socio-economic factors in obesity: a case of slim chance in a fat world? *Asia Pac J Clin Nutr,* 15 Suppl, 15-20.
Ball, K., Mishra, G. & Crawford, D. 2002. Which aspects of socioeconomic status are related to obesity among men and women? *Int J Obes Relat Metab Disord,* 26, 559-65.
Bandura, A. 1986. *Social foundations of thought and action : a social cognitive theory,* Englewood Cliffs, N.J., Prentice-Hall.
Bannerman, D. J., Sheldon, J. B., Sherman, J. A. & Harchik, A. E. 1990. Balancing the right to habilitation with the right to personal liberties: the rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of applied behavior analysis,* 23, 79-89.
Baranowski, T., Cullen, K. W., Nicklas, T., Thompson, D. & Baranowski, J. 2003. Are current health behavioral change models helpful in guiding prevention of weight gain efforts? *Obesity research,* 11 Suppl, 23S-43S.
Barte, J. C., ter Bogt, N. C., Bogers, R. P., Teixeira, P. J., Blissmer, B., Mori, T. A. & Bemelmans, W. J. 2010. Maintenance of weight loss after lifestyle interventions for overweight and obesity, a systematic review. *Obesity reviews : an official journal of the International Association for the Study of Obesity,* 11, 899-906.
Bartlo, P. & Klein, P. J. 2011. Physical activity benefits and needs in adults with intellectual disabilities: systematic review of the literature. *Am J Intellect Dev Disabil,* 116, 220-32.
Bassett, D. R. 2012. Device-based monitoring in physical activity and public health research. *Physiological measurement,* 33, 1769-83.
Baum, F. (2002) *The new public health,* 2nd ed., South Melbourne, Victoria, Australia ; New York: Oxford University Press.
Bazzano, A. T., Zeldin, A. S., Diab, I. R., Garro, N. M., Allevato, N. A. & Lehrer, D. 2009. The Healthy Lifestyle Change Program: a pilot of a community-based health promotion intervention for adults with developmental disabilities. *American journal of preventive medicine,* 37, S201-8.
Beales, P. L., Elcioglu, N., Woolf, A. S., Parker, D. & Flinter, F. A. 1999. New criteria for improved diagnosis of Bardet-Biedl syndrome: results of a population survey. *J Med Genet,* 36, 437-46.
Bertoli, S., Battezzati, A., Merati, G., Margonato, V., Maggioni, M., Testolin, G. & Veicsteinas, A. 2006. Nutritional status and dietary patterns in disabled people. *Nutr Metab Cardiovasc Dis,* 16, 100-12.

Bertoli S, Spadafranca A, Merati G, Testolin G, Veicsteinas A,Battezzati A. Nutritional counselling in disabled people: effects on dietary patterns, body composition and cardiovascular risk factors. *Eur J Phys Rehabil Med* 2008;44:149-58.
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. *J Intellect Disabil Res,* 52, 287-98.
Biswas, A. B., Vahabzadeh, A., Hobbs, T. & Healy, J. M. 2010. Obesity in people with learning disabilities: possible causes and reduction interventions. *Nursing times,* 106, 16-8.
Bland, J. M. & Altman, D. G. 1994. Matching. *BMJ,* 309, 1128.
Blaxter, M. 1990. *Health and lifestyles,* London, Tavistock/Routledge.
Blissmer, B., Riebe, D., Dye, G., Ruggiero, L., Greene, G. & Caldwell, M. 2006. Health-related quality of life following a clinical weight loss intervention among overweight and obese adults: intervention and 24 month follow-up effects. *Health Qual Life Outcomes,* 4, 43.
Blumenthal, J. A., Sherwood, A., Gullette, E. C., Babyak, M., Waugh, R., Georgiades, A., Craighead, L. W., Tweedy, D., Feinglos, M., Appelbaum, M., Hayano, J. & Hinderliter, A. 2000. Exercise and weight loss reduce blood pressure in men and women with mild hypertension: effects on cardiovascular, metabolic, and hemodynamic functioning. *Archives of internal medicine,* 160, 1947-58.
Bodde, A. E. & Seo, D. C. 2009. A review of social and environmental barriers to physical activity for adults with intellectual disabilities. *Disability and health journal,* 2, 57-66.
Bokszanska, A., Martin, G., Vanstraelen, M., Holt, G., Bouras, N. & Taylor, D. 2003. Risperidone and olanzapine in adults with intellectual disability: a clinical naturalistic study. *Int Clin Psychopharmacol,* 18, 285-91.
Booth, T. I. M. & Booth, W. 2003. In the Frame: Photovoice and mothers with learning difficulties. *Disability & Society,* 18, 431-442.
Boutcher, S. H. and Dunn, S. L. (2009) 'Factors that may impede the weight loss response to exercise-based interventions', *Obesity reviews : an official journal of the International Association for the Study of Obesity,* 10(6), 671-80.
Bowling A: *Research methods in health: investigating health and health services*. 2nd ed. Buckingham: Open University Press, 2002.
Bowman, S. A. & Vinyard, B. T. 2004. Fast food consumption of U.S. adults: impact on energy and nutrient intakes and overweight status. *J Am Coll Nutr,* 23, 163-8.
Brand-Miller, J. C., Holt, S. H., Pawlak, D. B. & McMillan, J. 2002. Glycemic index and obesity. *Am J Clin Nutr,* 76, 281S-5S.
Braun, V. & Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3, 77-101.
Braunschweig, C. L., Gomez, S., Sheean, P., Tomey, K. M., Rimmer, J. & Heller, T. 2004. Nutritional status and risk factors for chronic disease in urban-dwelling adults with Down syndrome. *Am J Ment Retard,* 109, 186-93.
Bray, G. A. 2003. Risks of obesity. *Endocrinol Metab Clin North Am,* 32, 787-804, viii.
Bray, G. A. & Champagne, C. M. 2005. Beyond energy balance: there is more to obesity than kilocalories. *J Am Diet Assoc,* 105, S17-23.

Brewster, S. J. 2004. Putting words into their mouths? Interviewing people with learning disabilities and little/no speech. *British Journal of Learning Disabilities,* 32, 166-169.
British Dietetic Association-The Learning Disabilities Obesity Group (LDOG) (2011).Weight management in adults with learning disability living in the Community. (http://www.bda.uk.com/publications/statements/WeightManagementAdultsLearningDisabilities.pdf)
Brownell, K. D., Brownell, K. D. & LEARN Education Center. 2000. *The LEARN program for weight management 2000 : lifestyle, exercise, attitudes, relationships, nutrition,* Dallas, Tex., American Health Pub. Co. : LEARN Education Center distributor.
Bryan, F., Allan, T. & Russell, L. 2000. The move from a long-stay learning disabilities hospital to community homes: a comparison of clients' nutritional status. *Journal of Human Nutrition and Dietetics,* 13, 265-270.
Buckland, G., Bach, A. & Serra-Majem, L. 2008. Obesity and the Mediterranean diet: a systematic review of observational and intervention studies. *Obes Rev,* 9, 582-93.
Burgers, J. S., Bailey, J. V., Klazinga, N. S., Van Der Bij, A. K., Grol, R., Feder, G. & Agree, C. 2002. Inside guidelines: comparative analysis of recommendations and evidence in diabetes guidelines from 13 countries. *Diabetes Care,* 25, 1933-9.
Burke, L. E., Wang, J. & Sevick, M. A. 2011. Self-monitoring in weight loss: a systematic review of the literature. *J Am Diet Assoc,* 111, 92-102.
Burke, L. E., Warziski, M., Styn, M. A., Music, E., Hudson, A. G. & Sereika, S. M. 2008. A randomized clinical trial of a standard versus vegetarian diet for weight loss: the impact of treatment preference. *International journal of obesity,* 32, 166-76.
Burke, V., Beilin, L. J., Cutt, H. E., Mansour, J., Williams, A. & Mori, T. A. 2007. A lifestyle program for treated hypertensives improved health-related behaviors and cardiovascular risk factors, a randomized controlled trial. *Journal of clinical epidemiology,* 60, 133-41.
Burton, M. 2008. Grounding Constructions of Carers: Exploring the Experiences of Carers through a Grounded Approach. *British Journal of Social Work,* 38, 493-506.
Butland, B., Jebb, S.A., Kopelman, P., McPherson, K., Thomas, S., Mardell, J., Parry, V. *Foresight. Tackling obesities: future choices – project report.* London, UK: Government Office for Science; 2007
Butler, J. V., Whittington, J. E., Holland, A. J., Boer, H., Clarke, D. & Webb, T. 2002. Prevalence of, and risk factors for, physical ill-health in people with Prader-Willi syndrome: a population-based study. *Developmental medicine and child neurology,* 44, 248-55.
Byrne, S., Barry, D. & Petry, N. M. 2012. Predictors of weight loss success. Exercise vs. dietary self-efficacy and treatment attendance. *Appetite,* 58, 695-8.
Campbell, M. & Martin, M. 2010. Reducing health inequalities in Scotland: the involvement of people with learning disabilities as national health service reviewers. *British journal of learning disabilities,* 38, 49-58.
Carver, C. S. & Scheier, M. F. 1982. Control theory: a useful conceptual framework for personality-social, clinical, and health psychology. *Psychol Bull,* 92, 111-35.

Catenacci, V. A. & Wyatt, H. R. 2007. The role of physical activity in producing and maintaining weight loss. *Nature clinical practice. Endocrinology & metabolism,* 3, 518-29.

Caterson, I. D., Hubbard, V., Bray, G. A., Grunstein, R., Hansen, B. C., Hong, Y., Labarthe, D., Seidell, J. C. & Smith, S. C., Jr. 2004. Prevention Conference VII: Obesity, a worldwide epidemic related to heart disease and stroke: Group III: worldwide comorbidities of obesity. *Circulation,* 110, e476-83.

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, 248-259.

Centre for reviews and Dissemination (2009) Systematic reviews. CRD's guidance for undertaking reviews in health care. http://www.york.ac.uk/inst/crd/SysRev/!SSL!/WebHelp/SysRev3.htm (accessed 21.03.2012)

Chandler, K. E., Kidd, A., Al-Gazali, L., Kolehmainen, J., Lehesjoki, A. E., Black, G. C. & Clayton-Smith, J. 2003. Diagnostic criteria, clinical characteristics, and natural history of Cohen syndrome. *J Med Genet,* 40, 233-41.

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 : JOID,* 9, 131-44.

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 : JOID,* 12, 309-23.

Chief Medical Officer (CMO) (2011) *Start Active, Stay Active: A report on physical activity for health from the four home countries' Chief Medical Officers*, London: DH.

Chodzko-Zajko, W. J., Proctor, D. N., Fiatarone Singh, M. A., Minson, C. T., Nigg, C. R., Salem, G. J. & Skinner, J. S. 2009. American College of Sports Medicine position stand. Exercise and physical activity for older adults. *Med Sci Sports Exerc,* 41, 1510-30.

Christensen, R., Bartels, E. M., Astrup, A. & Bliddal, H. 2007. Effect of weight reduction in obese patients diagnosed with knee osteoarthritis: a systematic review and meta-analysis. *Ann Rheum Dis,* 66, 433-9.

Clark, M., Hampson, S. E., Avery, L. & Simpson, R. 2004. Effects of a tailored lifestyle self-management intervention in patients with type 2 diabetes. *British journal of health psychology,* 9, 365-79.

Cleaver, S., Ouellette-Kuntz, H. & Sakar, A. 2010. Participation in intellectual disability research: a review of 20 years of studies. *Journal of intellectual disability research : JIDR,* 54, 187-93.

Colditz, G. A., Willett, W. C., Rotnitzky, A. & Manson, J. E. 1995. Weight gain as a risk factor for clinical diabetes mellitus in women. *Annals of internal medicine,* 122, 481-6.

Cook, C. M. & Schoeller, D. A. 2011. Physical activity and weight control: conflicting findings. *Current opinion in clinical nutrition and metabolic care,* 14, 419-24.

Cooper, C., Snow, S., McAlindon, T. E., Kellingray, S., Stuart, B., Coggon, D. & Dieppe, P. A. 2000. Risk factors for the incidence and progression of radiographic knee osteoarthritis. *Arthritis Rheum,* 43, 995-1000.

Cooper, S.-A., Smiley, E., Finlayson, J., Jackson, A., Allan, L., Williamson, A., Mantry, D. & Morrison, J. 2007. The Prevalence, Incidence, and Factors Predictive of Mental Ill-Health in Adults with Profound Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities,* 20, 493-501.

Cooper, S. A. 1997. Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *The British journal of psychiatry : the journal of mental science,* 170, 375-80.

Corbett, F. Dobbie, M. Doig, J. D'Souza, L. Given, L. Gray, L. Leyland, A. Macgregor, L. Marryat, T. Maw, M. Miller, J. Mindell, R. Ormston, R. Roth, C. Sharp The Scottish Health Survey Volume 1: Main Report. The Scottish Government, Edinburgh (2010)

Cox, T. L., Malpede, C. Z., Desmond, R. A., Faulk, L. E., Myer, R. A., Henson, C. S., Heimburger, D. C. & Ard, J. D. 2007. Physical activity patterns during weight maintenance following a low-energy density dietary intervention. *Obesity (Silver Spring),* 15, 1226-32.

Craig R, Mindell J. *Health Survey for England 2010. Leeds: NHS Information Centre; 2011.*

Creswell, J. W. (1998) *Qualitative inquiry and research design : choosing among five traditions,* Thousand Oaks, Calif.: Sage Publications.

Crujeiras, A. B., Goyenechea, E., Abete, I., Lage, M., Carreira, M. C., Martínez, J. A. & Casanueva, F. F. 2010. Weight Regain after a Diet-Induced Loss Is Predicted by Higher Baseline Leptin and Lower Ghrelin Plasma Levels. *Journal of Clinical Endocrinology & Metabolism,* 95, 5037-5044.

Cuijpers, P., van Straten, A. & Warmerdam, L. 2007. Problem solving therapies for depression: a meta-analysis. *Eur Psychiatry,* 22, 9-15.

Cunningham, K., Gibney, M. J., Kelly, A., Kevany, J. & Mulcahy, M. 1990. Nutrient intakes in long-stay mentally handicapped persons. *Br J Nutr,* 64, 3-11.

Curioni, C. C. & Lourenco, P. M. 2005. Long-term weight loss after diet and exercise: a systematic review. *International journal of obesity,* 29, 1168-74.

Cyarto, E. V., Moorhead, G. E. & Brown, W. J. 2004. Updating the evidence relating to physical activity intervention studies in older people. *Journal of science and medicine in sport / Sports Medicine Australia,* 7, 30-8.

D'Zurilla, T. J. & Goldfried, M. R. 1971. Problem solving and behavior modification. *J Abnorm Psychol,* 78, 107-26.

Davis, C., Kellett, S. & Beail, N. 2009. Utility of the Rosenberg self-esteem scale. *Am J Intellect Dev Disabil,* 114, 172-8.

Deakin, T. A., Cade, J. E., Williams, R. & Greenwood, D. C. 2006. Structured patient education: the diabetes X-PERT Programme makes a difference. *Diabetic medicine : a journal of the British Diabetic Association,* 23, 944-54.

Delrue, M. A. & Michaud, J. L. 2004. Fat chance: genetic syndromes with obesity. *Clin Genet,* 66, 83-93.

Demark-Wahnefried, W., Rock, C. L., Patrick, K. & Byers, T. 2008. Lifestyle interventions to reduce cancer risk and improve outcomes. *Am Fam Physician,* 77, 1573-8.

Department of Health. Dietary Reference Values for Food Energy, Nutrients for the United Kingdom. Department of Health: *Report of the Panel on Dietary Values of the Committee on Medical Aspects of Food Policy*. 8th edition. HMSO, London; 1996.

Department of Health (2009) *Valuing People Now: A new three-year strategy for people with learning disabilities*. HMSO, London.
Deshpande, A. D., Harris-Hayes, M. & Schootman, M. 2008. Epidemiology of diabetes and diabetes-related complications. *Physical therapy,* 88, 1254-64.
Dixon, J. B. 2010. The effect of obesity on health outcomes. *Molecular and cellular endocrinology,* 316, 104-8.
Dixon, J. B., Dixon, M. E. & O'Brien, P. E. 2003. Depression in association with severe obesity: changes with weight loss. *Archives of internal medicine,* 163, 2058-65.
Djuric, Z., DiLaura, N. M., Jenkins, I., Darga, L., Jen, C. K., Mood, D., Bradley, E. & Hryniuk, W. M. 2002. Combining weight-loss counseling with the weight watchers plan for obese breast cancer survivors. *Obesity research,* 10, 657-65.
Dombrowski, S. U., Avenell, A. & Sniehott, F. F. 2010. Behavioural interventions for obese adults with additional risk factors for morbidity: systematic review of effects on behaviour, weight and disease risk factors. *Obes Facts,* 3, 377-96.
Donnelly, J. E., Blair, S. N., Jakicic, J. M., Manore, M. M., Rankin, J. W., Smith, B. K. & American College of Sports, M. 2009. American College of Sports Medicine Position Stand. Appropriate physical activity intervention strategies for weight loss and prevention of weight regain for adults. *Med Sci Sports Exerc,* 41, 459-71.
Donnelly, J. E., Smith, B., Jacobsen, D. J., Kirk, E., Dubose, K., Hyder, M., Bailey, B. & Washburn, R. 2004. The role of exercise for weight loss and maintenance. *Best practice & research. Clinical gastroenterology,* 18, 1009-29.
Dossus, L., Rinaldi, S., Becker, S., Lukanova, A., Tjonneland, A., Olsen, A., Stegger, J., Overvad, K., *et al.* R. 2010. Obesity, inflammatory markers, and endometrial cancer risk: a prospective case-control study. *Endocr Relat Cancer,* 17, 1007-19.
Douketis, J. D., Macie, C., Thabane, L. & Williamson, D. F. 2005. Systematic review of long-term weight loss studies in obese adults: clinical significance and applicability to clinical practice. *Int J Obes (Lond),* 29, 1153-67.
Draheim, C. C. 2006. Cardiovascular disease prevalence and risk factors of persons with mental retardation. *Mental retardation and developmental disabilities research reviews,* 12, 3-12.
Draheim, C. C., Williams, D. P. & McCubbin, J. A. 2002. Physical activity, dietary intake, and the insulin resistance syndrome in nondiabetic adults with mental retardation. *Am J Ment Retard,* 107, 361-75.
Drewnowski, A. 2004. Obesity and the food environment: dietary energy density and diet costs. *Am J Prev Med,* 27, 154-62.
Drewnowski, A. & Darmon, N. 2005. The economics of obesity: dietary energy density and energy cost. *Am J Clin Nutr,* 82, 265S-273S.
Dubnov-Raz, G. & Berry, E. M. 2008. The dietary treatment of obesity. *Endocrinol Metab Clin North Am,* 37, 873-86.
Dye, L. and Blundell, J. E. (1997) 'Menstrual cycle and appetite control: implications for weight regulation', *Human reproduction,* 12(6), 1142-51.
Dyson, P. A. 2010. The therapeutics of lifestyle management on obesity. *Diabetes Obes Metab,* 12, 941-6.
Edelman, D., Oddone, E. Z., Liebowitz, R. S., Yancy, W. S., Jr., Olsen, M. K., Jeffreys, A. S., Moon, S. D., Harris, A. C., Smith, L. L., Quillian-Wolever,

R. E. & Gaudet, T. W. 2006. A multidimensional integrative medicine intervention to improve cardiovascular risk. *Journal of general internal medicine*, 21, 728-34.

Elfhag, K. & Rossner, S. 2005. Who succeeds in maintaining weight loss? A conceptual review of factors associated with weight loss maintenance and weight regain. *Obes Rev*, 6, 67-85.

Elfhag, K. and Rossner, S. 2010. 'Initial weight loss is the best predictor for success in obesity treatment and sociodemographic liabilities increase risk for drop-out', *Patient education and counseling*, 79(3), 361-6.

Elmer, P. J., Obarzanek, E., Vollmer, W. M., Simons-Morton, D., Stevens, V. J., Young, D. R., Lin, P. H., Champagne, C., & *et al*. 2006. Effects of comprehensive lifestyle modification on diet, weight, physical fitness, and blood pressure control: 18-month results of a randomized trial. *Annals of internal medicine*, 144, 485-95.

Emerson, E. 2005. Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *J Intellect Disabil Res*, 49, 134-43.

Emerson, E. & Baines, S. (2010b) Health inequalities and people with learning disabilities in the UK: 2010. Improving Health and Lives: Learning Disabilities Observatory. http://www.improvinghealthandlives.org.uk/publications.

Emerson, E. & Baines, S. (2010) The estimated prevalence of autism among adults with learning disabilities in england. http://www.improvinghealthandlives.org.uk/publications (Accessed 18/06/2012)

Engel, S. G., Crosby, R. D., Kolotkin, R. L., Hartley, G. G., Williams, G. R., Wonderlich, S. A. & Mitchell, J. E. 2003. Impact of weight loss and regain on quality of life: mirror image or differential effect? *Obes Res*, 11, 1207-13.

Esfahani, A., Wong, J. M., Mirrahimi, A., Srichaikul, K., Jenkins, D. J. & Kendall, C. W. 2009. The glycemic index: physiological significance. *J Am Coll Nutr*, 28 Suppl, 439S-445S.

Esfahani, A., Wong, J. M., Mirrahimi, A., Villa, C. R. & Kendall, C. W. 2011. The application of the glycemic index and glycemic load in weight loss: A review of the clinical evidence. *IUBMB Life*, 63, 7-13.

Esposito, K., Kastorini, C. M., Panagiotakos, D. B. & Giugliano, D. 2011. Mediterranean diet and weight loss: meta-analysis of randomized controlled trials. *Metab Syndr Relat Disord*, 9, 1-12.

Evans, P. D., McIntyre, N. J., Fluck, R. J., McIntyre, C. W. & Taal, M. W. 2012. Anthropomorphic measurements that include central fat distribution are more closely related with key risk factors than BMI in CKD stage 3. *PLoS One*, 7, e34699.

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 : the official publication of the Society for Public Health Education*, 31, 77-87.

Fabricatore, A. N. 2007. Behavior therapy and cognitive-behavioral therapy of obesity: is there a difference? *J Am Diet Assoc*, 107, 92-9.

Fabricatore, A. N., Wadden, T. A., Rohay, J. M., Pillitteri, J. L., Shiffman, S., Harkins, A. M. and Burton, S. L. (2008) 'Weight loss expectations and goals in a population sample of overweight and obese US adults', *Obesity*, 16(11), 2445-50.

Fade, S. A. (2003) 'Communicating and judging the quality of qualitative research: the need for a new language', *Journal of human nutrition and dietetics : the official journal of the British Dietetic Association,* 16(3), 139-49.

Faith, M. S., Butryn, M., Wadden, T. A., Fabricatore, A., Nguyen, A. M. & Heymsfield, S. B. 2011. Evidence for prospective associations among depression and obesity in population-based studies. *Obesity reviews : an official journal of the International Association for the Study of Obesity,* 12, e438-53.

Faith, M. S., Matz, P. E. & Jorge, M. A. 2002. Obesity-depression associations in the population. *Journal of psychosomatic research,* 53, 935-42.

Farooqi, I. S. & O'Rahilly, S. 2005. New advances in the genetics of early onset obesity. *Int J Obes (Lond),* 29, 1149-52.

Faulkner, G. E., Gorczynski, P. F. & Cohn, T. A. 2009. Psychiatric illness and obesity: recognizing the "obesogenic" nature of an inpatient psychiatric setting. *Psychiatr Serv,* 60, 538-41.

Ferland, A. & Eckel, R. H. 2011. Does sustained weight loss reverse the metabolic syndrome? *Curr Hypertens Rep,* 13, 456-64.

Finlayson, J., Jackson, A., Cooper, S.-A., 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,* 22, 236-247.

Finlayson, J., Turner, A. & Granat, M. H. 2011. Measuring the Actual Levels and Patterns of Physical Activity/Inactivity of Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities,* 24, 508-517.

Fishbein, M. & Ajzen, I. 1975. *Belief, attitude, intention, and behavior : an introduction to theory and research,* Reading, Mass., Addison-Wesley Pub. Co.

Fisher, E. 1986. Behavioral weight reduction program for mentally retarded adult females. *Perceptual and motor skills,* 62, 359-62.

Flegal, K. M., Carroll, M. D., Ogden, C. L. & Curtin, L. R. 2010. Prevalence and trends in obesity among US adults, 1999-2008. *JAMA,* 303, 235-41.

Flegal KM, Carroll MD, Kit BK, Ogden CL. 2012.Prevalence of obesity and trends in the distribution of body mass index among US adults, 1999–2010. JAMA. 307(5):491–7.

Flegal KM, Shepherd JA, Looker AC, et al. Comparisons of percentage body fat, body mass index, waist circumference, and waist-stature ratio in adults. *AmJ Clin Nutr*. 2009;89(2):500-508.

Fleischhacker, S. E., Evenson, K. R., Rodriguez, D. A. & Ammerman, A. S. 2011. A systematic review of fast food access studies. *Obes Rev,* 12, e460-71.

Ford, E. S., Kohl, H. W., 3rd, Mokdad, A. H. & Ajani, U. A. 2005. Sedentary behavior, physical activity, and the metabolic syndrome among U.S. adults. *Obes Res,* 13, 608-14.

Foreyt, J. P. & Poston, W. S., 2nd 1998. What is the role of cognitive-behavior therapy in patient management? *Obes Res,* 6 Suppl 1, 18S-22S.

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,* 5, 69-79.

Fox, R. A., Rosenberg, R. & Rotatori, A. F. 1985. Parent involvement in a treatment program for obese retarded adults. *Journal of behavior therapy and experimental psychiatry,* 16, 45-8.

Franz, M. J., VanWormer, J. J., Crain, A. L., Boucher, J. L., Histon, T., Caplan, W., Bowman, J. D. & Pronk, N. P. 2007. Weight-loss outcomes: a systematic review and meta-analysis of weight-loss clinical trials with a minimum 1-year follow-up. *J Am Diet Assoc,* 107, 1755-67.

Friedenreich, C. M. & Orenstein, M. R. 2002. Physical activity and cancer prevention: etiologic evidence and biological mechanisms. *J Nutr,* 132, 3456S-3464S.

Frost, G. 2007. Commentary on Frost, G., Masters, K., King, C., Kelly, M., Hasan, U., Heavens, P., White, R. & Stanford, J. (1991) A new method of energy prescription to improve weight loss. Journal of Human Nutrition and Dietetics; 4, 369-373. *J Hum Nutr Diet,* 20, 157-8.

Frost, G., Masters, K., Kin, C., Kelly, M., Hasan, U., Heavens, P., White, R. & Stanford, J. 1991. A new method of energy prescription to improve weight loss. *Journal of Human Nutrition and Dietetics,* 4, 369-373.

Frost, G., Masters, K., King, C., Kelly, M., Hasan, U., Heavens, P., White, R. & Stanford, J. 2007. A new method of energy prescription to improve weight loss. *J Hum Nutr Diet,* 20, 152-6.

Fujiura, G. T., Park, H. J. & Rutkowski-Kmitta, V. 2005. Disability Statistics in the Developing World: A Reflection on the Meanings in our Numbers. *Journal of Applied Research in Intellectual Disabilities,* 18, 295-304.

Gale, L., Naqvi, H. & Russ, L. 2009. Asthma, smoking and BMI in adults with intellectual disabilities: a community-based survey. *J Intellect Disabil Res,* 53, 787-96.

Gariepy, G., Wang, J., Lesage, A. D. & Schmitz, N. 2010. The longitudinal association from obesity to depression: results from the 12-year National Population Health Survey. *Obesity,* 18, 1033-8.

Garrow, J.S., James W.P.T., Ralph A. (Eds.), Human Nutrition and Dietetics (10th ed.), Churchill Livingston, Edinburgh (2000), pp. 515–526

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.

Georgiadis, M. M., Biddle, S. J. & Stavrou, N. A. 2006. Motivation for weight-loss diets: A clustering, longitudinal field study using self-esteem and self-determination theory perspectives. *Health Education Journal,* 65, 53-72.

Gilbert, P. (2009). The Compassionate Mind. A New Approach to the Challenges of Life: London: Constable & Robinson.

Giskes, K., Avendano, M., Brug, J. & Kunst, A. E. 2010. A systematic review of studies on socioeconomic inequalities in dietary intakes associated with weight gain and overweight/obesity conducted among European adults. *Obes Rev,* 11, 413-29.

Giskes, K., van Lenthe, F., Avendano-Pabon, M. & Brug, J. 2011. A systematic review of environmental factors and obesogenic dietary intakes among adults: are we getting closer to understanding obesogenic environments? *Obes Rev,* 12, e95-e106.

Glaser, B. G. and Strauss, A. L. (1967) *The discovery of grounded theory; strategies for qualitative research, Observations,* Chicago,: Aldine Pub. Co.

Glasgow, R. E., Strycker, L. A., Toobert, D. J. & Eakin, E. 2000. A social-ecologic approach to assessing support for disease self-management: the Chronic Illness Resources Survey. *J Behav Med,* 23, 559-83.

Goldstone, A. P., Holland, A. J., Hauffa, B. P., Hokken-Koelega, A. C., Tauber, M. & speakers contributors at the Second Expert Meeting of the Comprehensive Care of Patients with, P. W. S. 2008. Recommendations for the diagnosis and management of Prader-Willi syndrome. *J Clin Endocrinol Metab,* 93, 4183-97.

Gonzalez, C. A. & Riboli, E. 2010. Diet and cancer prevention: Contributions from the European Prospective Investigation into Cancer and Nutrition (EPIC) study. *European journal of cancer,* 46, 2555-62.

Goodrick, G. K., Poston, W. S., 2nd, Kimball, K. T., Reeves, R. S. & Foreyt, J. P. 1998. Nondieting versus dieting treatment for overweight binge-eating women. *Journal of consulting and clinical psychology,* 66, 363-8.

Gorin, A. A., Phelan, S., Hill, J. O. and Wing, R. R. (2004) 'Medical triggers are associated with better short- and long-term weight loss outcomes', *Preventive medicine,* 39(3), 612-6.

Greaves, C. J., Sheppard, K. E., Abraham, C., Hardeman, W., Roden, M., Evans, P. H. & Schwarz, P. 2011a. Systematic review of reviews of intervention components associated with increased effectiveness in dietary and physical activity interventions. *BMC public health,* 11, 119.

Greaves, C. J., Sheppard, K. E., Abraham, C., Hardeman, W., Roden, M., Evans, P. H., Schwarz, P. & Group, I. S. 2011b. Systematic review of reviews of intervention components associated with increased effectiveness in dietary and physical activity interventions. *BMC Public Health,* 11, 119.

Grimshaw, J., Campbell, M., Eccles, M. & Steen, N. 2000. Experimental and quasi-experimental designs for evaluating guideline implementation strategies. *Family practice,* 17 Suppl 1, S11-6.

Grol, R. & Grimshaw, J. 2003. From best evidence to best practice: effective implementation of change in patients' care. *Lancet,* 362, 1225-30.

Grotle, M., Hagen, K. B., Natvig, B., Dahl, F. A. & Kvien, T. K. 2008. Obesity and osteoarthritis in knee, hip and/or hand: an epidemiological study in the general population with 10 years follow-up. *BMC musculoskeletal disorders,* 9, 132.

Guaraldi, F., Pagotto, U. and Pasquali, R. 2011. 'Predictors of weight loss and maintenance in patients treated with antiobesity drugs', *Diabetes, metabolic syndrome and obesity : targets and therapy,* 4, 229-43.

Guba, E. G. & Lincoln, Y. S. 1989. *Fourth generation evaluation,* Newbury Park, Calif. ; London, Sage.

Hainer, V., Hlavata, K., Gojova, M., Kunesova, M., Wagenknecht, M., Kopsky, V., Parizkova, J., Hill, M. and Nedvidkova, J. 2008. 'Hormonal and psychobehavioral predictors of weight loss in response to a short-term weight reduction program in obese women', *Physiological research / Academia Scientiarum Bohemoslovaca,* 57 Suppl 1, S17-27.

Ham, M., Jones, N., Mansell, I., Northway, R., Price, L. & Walker, G. 2004. 'I'm a researcher!' Working together to gain ethical approval for a participatory research study. *Journal of Learning Disabilities,* 8, 397-407.

Hamilton, M. & Greenway, F. 2004. Evaluating commercial weight loss programmes: an evolution in outcomes research. *Obes Rev,* 5, 217-32.

Hamilton, S., Hankey, C. R., Miller, S., Boyle, S. & Melville, C. A. 2007. A review of weight loss interventions for adults with intellectual disabilities. *Obes Rev,* 8, 339-45.

Han, T. S., Richmond, P., Avenell, A. & Lean, M. E. 1997. Waist circumference reduction and cardiovascular benefits during weight loss in women. *Int J Obes Relat Metab Disord,* 21, 127-34.

Handjieva-Darlenska, T., Handjiev, S., Larsen, T. M., van Baak, M. A., Jebb, S., Papadaki, A., Pfeiffer, A. F., Martinez, J. A., Kunesova, M., Holst, C., Saris, W. H. and Astrup, A. 2010 'Initial weight loss on an 800-kcal diet as a predictor of weight loss success after 8 weeks: the Diogenes study', *European journal of clinical nutrition,* 64(9), 994-9.

Hansen, D., Astrup, A., Toubro, S., Finer, N., Kopelman, P., Hilsted, J., Rossner, S., Saris, W., Van Gaal, L., James, W. and Goulder, M. 2001. 'Predictors of weight loss and maintenance during 2 years of treatment by sibutramine in obesity. Results from the European multi-centre STORM trial. Sibutramine Trial of Obesity Reduction and Maintenance', *International journal of obesity and related metabolic disorders : journal of the International Association for the Study of Obesity,* 25(4), 496-501.

Hardcastle, S., Taylor, A., Bailey, M. & Castle, R. 2008. A randomised controlled trial on the effectiveness of a primary health care based counselling intervention on physical activity, diet and CHD risk factors. *Patient education and counseling,* 70, 31-9.

Harner, C. J. & Heal, L. W. 1993. The Multifaceted Lifestyle Satisfaction Scale (MLSS): psychometric properties of an interview schedule for assessing personal satisfaction of adults with limited intelligence. *Res Dev Disabil,* 14, 221-36.

Haslam, D. W. & James, W. P. 2005. Obesity. *Lancet,* 366, 1197-209.

Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S. & Strydom, A. 2010. Major Health Risks in Aging Persons With Intellectual Disabilities: An Overview of Recent Studies. *Journal of Policy and Practice in Intellectual Disabilities,* 7, 59-69.

Havercamp, S. M., Scandlin, D. & Roth, M. 2004. Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Rep,* 119, 418-26.

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

Healy, L. A., Ryan, A. M., Rowley, S., Boyle, T., Connolly, E., Kennedy, M. J. & Reynolds, J. V. 2010. Obesity increases the risk of postmenopausal breast cancer and is associated with more advanced stage at presentation but no impact on survival. *The breast journal,* 16, 95-7.

Heller, T., McCubbin, J. A., Drum, C. & Peterson, J. 2011. Physical activity and nutrition health promotion interventions: what is working for people with intellectual disabilities? *Intellectual and developmental disabilities,* 49, 26-36.

Henderson, A., Lynch, S. A., Wilkinson, S. & Hunter, M. 2007. Adults with Down's syndrome: the prevalence of complications and health care in the community. *Br J Gen Pract,* 57, 50-5.

Heshka, S., Greenway, F., Anderson, J. W., Atkinson, R. L., Hill, J. O., Phinney, S. D., Miller-Kovach, K. and Xavier Pi-Sunyer, F. (2000) 'Self-help weight loss versus a structured commercial program after 26 weeks: a randomized controlled study', *The American journal of medicine,* 109(4), 282-7.

Hession, M., Rolland, C., Kulkarni, U., Wise, A. & Broom, J. 2009. Systematic review of randomized controlled trials of low-carbohydrate vs. low-fat/low-calorie diets in the management of obesity and its comorbidities. *Obes Rev,* 10, 36-50.

Hill, J. O. 2006. Understanding and addressing the epidemic of obesity: an energy balance perspective. *Endocr Rev,* 27, 750-61.

Hogg, J. & Tuffrey-Wijne, I. 2008. Cancer and Intellectual Disability: A Review of Some Key Contextual Issues. *Journal of Applied Research in Intellectual Disabilities,* 21, 509-518.

Holland, K. (2011) *British Institute of Learning Disabilities Fact Sheet: Learning Disabilities* (Kidderminster: British Institute of Learning Disabilities).
Hove, O. 2004. Weight survey on adult persons with mental retardation living in the community. *Res Dev Disabil,* 25, 9-17.
Iacono, T. 2006. Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability,* 31, 173-179.
International Obesity Task Force. (2009) Obesity: Understanding and challenging the global epidemic. 2009-2010 report. Available at http://www.iaso.org/site_media/uploads/IASO_Summary_Report_2009.pdf(Accessed 18/06/2012)
Ismail, I., Keating, S. E., Baker, M. K. & Johnson, N. A. 2012. A systematic review and meta-analysis of the effect of aerobic vs. resistance exercise training on visceral fat. *Obes Rev,* 13, 68-91.
Jackson-Leach, R. & Lobstein, T. 2006. Estimated burden of paediatric obesity and co-morbidities in Europe. Part 1. The increase in the prevalence of child obesity in Europe is itself increasing. *Int J Pediatr Obes,* 1, 26-32.
Jackson, H. J. & Thorbecke, P. J. 1982. Treating obesity of mentally retarded adolescents and adults: an exploratory program. *American journal of mental deficiency,* 87, 302-8.
Jacob, J. J. & Isaac, R. 2012. Behavioral therapy for management of obesity. *Indian J Endocrinol Metab,* 16, 28-32.
Jakicic, J. M. & Otto, A. D. 2005. Physical activity considerations for the treatment and prevention of obesity. *Am J Clin Nutr,* 82, 226S-229S.
Janssen, S., Ramaswami, G., Davis, E. E., Hurd, T., Airik, R., Kasanuki, J. M., Van Der Kraak, L., Allen, S. J., Beales, P. L., Katsanis, N., Otto, E. A. & Hildebrandt, F. 2011. Mutation analysis in Bardet-Biedl syndrome by DNA pooling and massively parallel resequencing in 105 individuals. *Hum Genet,* 129, 79-90.
Jeevanandam, L. 2009. Perspectives of intellectual disability in Asia: epidemiology, policy, and services for children and adults. *Curr Opin Psychiatry,* 22, 462-8.
Jeffery, R. W., Drewnowski, A., Epstein, L. H., Stunkard, A. J., Wilson, G. T., Wing, R. R. & Hill, D. R. 2000. Long-term maintenance of weight loss: current status. *Health Psychol,* 19, 5-16.
Jeffery, R. W. & Wing, R. R. 1995. Long-term effects of interventions for weight loss using food provision and monetary incentives. *Journal of consulting and clinical psychology,* 63, 793-6.
Jeffery, R. W., Wing, R. R., Thorson, C. & Burton, L. R. 1998. Use of personal trainers and financial incentives to increase exercise in a behavioral weight-loss program. *Journal of consulting and clinical psychology,* 66, 777-83.
Jenkins, C. M. & McKenzie, K. 2011. The Application of the Theory of Planned Behaviour to Diet in Carers of People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities,* 24, 237-246.
Jenny, Z., Nicholas, L., Heather, A., Michael, L. & Chris Del, M. 2004. Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. *Journal of Intellectual & Developmental Disability,* 29, 211-225.
Jinks, A., Cotton, A. & Rylance, R. 2011. Obesity interventions for people with a learning disability: an integrative literature review. *Journal of advanced nursing,* 67, 460-71.

Johnson, F., Cooke, L., Croker, H. & Wardle, J. 2008. Changing perceptions of weight in Great Britain: comparison of two population surveys. *BMJ,* 337, a494.
Jolly, K., Lewis, A., Beach, J., Denley, J., Adab, P., Deeks, J. J., Daley, A. & Aveyard, P. 2011. Comparison of range of commercial or primary care led weight reduction programmes with minimal intervention control for weight loss in obesity: lighten Up randomised controlled trial. *BMJ,* 343, d6500.
Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Gallagher, B. & Roper, A. 2001. Evaluation of the dissemination of active support training in staffed community residences. *Am J Ment Retard,* 106, 344-58.
Kac, G., Velasquez-Melendez, G., Schlussel, M. M., Segall-Correa, A. M., Silva, A. A. & Perez-Escamilla, R. 2012. Severe food insecurity is associated with obesity among Brazilian adolescent females. *Public Health Nutr,* 15, 1854-60.
Kandel, I., Morad, M. & Merrick, J. 2004. Health Needs Assessment Report: People with Learning Disabilities in Scotland. *Journal of Policy and Practice in Intellectual Disabilities,* 1, 113-114.
Kanfer, F. H. & Goldstein, A. P. 1991. *Helping people change : a textbook of methods,* New York, Pergamon Press.
Karlsson, J., Taft, C., Ryden, A., Sjostrom, L. & Sullivan, M. 2007. Ten-year trends in health-related quality of life after surgical and conventional treatment for severe obesity: the SOS intervention study. *Int J Obes,* 31, 1248-1261.
Katzmarzyk, P. T. & Lear, S. A. 2012. Physical activity for obese individuals: a systematic review of effects on chronic disease risk factors. *Obes Rev,* 13, 95-105.
Kersten, P., McLellan, L., George, S., Mullee, M. A. & Smith, J. A. E. 2001. Needs of carers of severely disabled people: are they identified and met adequately? *Health and Social Care in the Community,* 9, 235-243.
Key, T. J., Appleby, P. N., Reeves, G. K., Roddam, A., Dorgan, J. F., Longcope, C., Stanczyk, F. Z., Stephenson, H. E., Jr., Falk, R. T., Miller, R., Schatzkin, A., Allen, D. S., & *et al*. 2003. Body mass index, serum sex hormones, and breast cancer risk in postmenopausal women. *Journal of the National Cancer Institute,* 95, 1218-26.
Keyserling, T. C., Samuel-Hodge, C. D., Ammerman, A. S., Ainsworth, B. E., Henriquez-Roldan, C. F., Elasy, T. A., Skelly, A. H., Johnston, L. F. & Bangdiwala, S. I. 2002. A randomized trial of an intervention to improve self-care behaviors of African-American women with type 2 diabetes: impact on physical activity. *Diabetes care,* 25, 1576-83.
Kiernan, C. 1999. Participation in Research by People with Learning Disability: Origins and Issues. *British Journal of Learning Disabilities,* 27, 43-47.
Kirk, S. F., Penney, T. L. & McHugh, T. L. 2010. Characterizing the obesogenic environment: the state of the evidence with directions for future research. *Obes Rev,* 11, 109-17.
Kirk, S. F., Penney, T. L., McHugh, T. L. & Sharma, A. M. 2012. Effective weight management practice: a review of the lifestyle intervention evidence. *Int J Obes (Lond),* 36, 178-85.
Kirkman, M. S., Weinberger, M., Landsman, P. B., Samsa, G. P., Shortliffe, E. A., Simel, D. L. & Feussner, J. R. 1994. A telephone-delivered intervention for patients with NIDDM. Effect on coronary risk factors. *Diabetes care,* 17, 840-6.

Kissela, B. M., Khoury, J., Kleindorfer, D., Woo, D., Schneider, A., Alwell, K., Miller, R., Ewing, I., Moomaw, C. J., Szaflarski, J. P., Gebel, J., Shukla, R. & Broderick, J. P. 2005. Epidemiology of ischemic stroke in patients with diabetes: the greater Cincinnati/Northern Kentucky Stroke Study. *Diabetes care,* 28**,** 355-9.

Kneringer, M. J. & Page, T. J. 1999. Improving staff nutritional practices in community-based group homes: evaluation, training, and management. *Journal of applied behavior analysis,* 32**,** 221-4.

Knowler, W. C., Barrett-Connor, E., Fowler, S. E., Hamman, R. F., Lachin, J. M., Walker, E. A. & Nathan, D. M. 2002. Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *The New England journal of medicine,* 346**,** 393-403.

Kodama, S., Saito, K., Tanaka, S., Horikawa, C., Fujiwara, K., Hirasawa, R., Yachi, Y., Iida, K. T., Shimano, H., Ohashi, Y., Yamada, N. & Sone, H. 2012. Effect of Web-based lifestyle modification on weight control: a meta-analysis. *Int J Obes (Lond),* 36**,** 675-85.

Koh-Banerjee, P., Wang, Y., Hu, F. B., Spiegelman, D., Willett, W. C. & Rimm, E. B. 2004. Changes in body weight and body fat distribution as risk factors for clinical diabetes in US men. *American journal of epidemiology,* 159**,** 1150-9.

Kolotkin, R. L., Crosby, R. D., Williams, G. R., Hartley, G. G. & Nicol, S. 2001. The relationship between health-related quality of life and weight loss. *Obes Res,* 9**,** 564-71.

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

Kraschnewski, J. L., Boan, J., Esposito, J., Sherwood, N. E., Lehman, E. B., Kephart, D. K. & Sciamanna, C. N. 2010. Long-term weight loss maintenance in the United States. *Int J Obes (Lond),* 34**,** 1644-54.

Kwak, L., Proper, K. I., Hagstromer, M. & Sjostrom, M. 2011. The repeatability and validity of questionnaires assessing occupational physical activity--a systematic review. *Scand J Work Environ Health,* 37**,** 6-29.

Laddu, D., Dow, C., Hingle, M., Thomson, C. & Going, S. 2011. A review of evidence-based strategies to treat obesity in adults. *Nutrition in clinical practice : official publication of the American Society for Parenteral and Enteral Nutrition,* 26**,** 512-25.

Laitinen, J. H., Ahola, I. E., Sarkkinen, E. S., Winberg, R. L., Harmaakorpi-Iivonen, P. A. & Uusitupa, M. I. 1993. Impact of intensified dietary therapy on energy and nutrient intakes and fatty acid composition of serum lipids in patients with recently diagnosed non-insulin-dependent diabetes mellitus. *Journal of the American Dietetic Association,* 93**,** 276-83.

Lancaster, T. & Stead, L. F. 2005. Individual behavioural counselling for smoking cessation. *Cochrane Database Syst Rev***,** CD001292.

Lau, D. C., Douketis, J. D., Morrison, K. M., Hramiak, I. M., Sharma, A. M. & Ur, E. 2007. 2006 Canadian clinical practice guidelines on the management and prevention of obesity in adults and children [summary]. *CMAJ,* 176**,** S1-13.

Lavie, C. J., Milani, R. V. & Ventura, H. O. 2009. Obesity and cardiovascular disease: risk factor, paradox, and impact of weight loss. *Journal of the American College of Cardiology,* 53**,** 1925-32.

Lawes, C. M., Vander Hoorn, S. & Rodgers, A. 2008. Global burden of blood-pressure-related disease, 2001. *Lancet,* 371**,** 1513-8.

Lean, M. E., Han, T. S. & Morrison, C. E. 1995. Waist circumference as a measure for indicating need for weight management. *BMJ,* 311, 158-61.

Lean, M. E. & James, W. P. 1986. Prescription of diabetic diets in the 1980s. *Lancet,* 1, 723-5.

Leitzmann, M. F., Moore, S. C., Koster, A., Harris, T. B., Park, Y., Hollenbeck, A. & Schatzkin, A. 2011. Waist circumference as compared with body-mass index in predicting mortality from specific causes. *PLoS One,* 6, e18582.

Lemon, S. C., Rosal, M. C., Zapka, J., Borg, A. and Andersen, V. (2009) 'Contributions of weight perceptions to weight loss attempts: differences by body mass index and gender', *Body image,* 6(2), 90-6.

Leslie, W. S., Hankey, C. R. & Lean, M. E. 2007. Weight gain as an adverse effect of some commonly prescribed drugs: a systematic review. *QJM,* 100, 395-404.

Leslie, W. S., Lean, M. E., Baillie, H. M. & Hankey, C. R. 2002. Weight management: a comparison of existing dietary approaches in a work-site setting. *Int J Obes Relat Metab Disord,* 26, 1469-75.

Lincoln, Y. S. & Guba, E. G. 1985. *Naturalistic inquiry,* Beverly Hills, Calif. ; London, SAGE.

Linde, J. A., Simon, G. E., Ludman, E. J., Ichikawa, L. E., Operskalski, B. H., Arterburn, D., Rohde, P., Finch, E. A. & Jeffery, R. W. 2011. A randomized controlled trial of behavioral weight loss treatment versus combined weight loss/depression treatment among women with comorbid obesity and depression. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine,* 41, 119-30.

Lindstrom, J., Louheranta, A., Mannelin, M., Rastas, M., Salminen, V., Eriksson, J., Uusitupa, M. & Tuomilehto, J. 2003. The Finnish Diabetes Prevention Study (DPS): Lifestyle intervention and 3-year results on diet and physical activity. *Diabetes care,* 26, 3230-6.

Locke, E. A. & Latham, G. P. 2002. Building a practically useful theory of goal setting and task motivation. A 35-year odyssey. *Am Psychol,* 57, 705-17.

Logue, E., Sutton, K., Jarjoura, D., Smucker, W., Baughman, K. & Capers, C. 2005. Transtheoretical model-chronic disease care for obesity in primary care: a randomized trial. *Obesity research,* 13, 917-27.

Logue, J. & Scottish Intercollegiate Guidelines Network 2010. *Management of Obesity: A National Clinical Guideline*, NHS Quality Improvement Scotland.

Lopez, A. D., Mathers, C. D., Ezzati, M., Jamison, D. T. & Murray, C. J. L. 2006. Measuring the Global Burden of Disease and Risk Factors, 1990-2001. *In:* Lopez, A. D., Mathers, C. D., Ezzati, M., Jamison, D. T. & Murray, C. J. L. (eds.) *Global Burden of Disease and Risk Factors*. Washington (DC).

Loveman, E., Frampton, G. K., Shepherd, J., Picot, J., Cooper, K., Bryant, J., Welch, K. & Clegg, A. 2011. The clinical effectiveness and cost-effectiveness of long-term weight management schemes for adults: a systematic review. *Health technology assessment,* 15, 1-182.

Lubans, D.R., Foster, C., Biddle, S.J.H. 2008. A review of mediators of behavior in interventions to promote physical activity among children and adolescents. *Prev Med*, 47:463-470.

Ludman, E., Simon, G. E., Ichikawa, L. E., Operskalski, B. H., Arterburn, D., Linde, J. A., Jeffery, R. W., Rohde, P. & Finch, E. A. 2010. Does depression reduce the effectiveness of behavioral weight loss treatment? *Behav Med,* 35, 126-34.

Ludwig, D. S. 2002. The glycemic index: physiological mechanisms relating to obesity, diabetes, and cardiovascular disease. *JAMA,* 287, 2414-23.

Luke, A., Roizen, N. J., Sutton, M. & Schoeller, D. A. 1994. Energy expenditure in children with Down syndrome: correcting metabolic rate for movement. *J Pediatr,* 125, 829-38.
Luppino, F. S., de Wit, L. M., Bouvy, P. F., Stijnen, T., Cuijpers, P., Penninx, B. W. & Zitman, F. G. 2010. Overweight, obesity, and depression: a systematic review and meta-analysis of longitudinal studies. *Archives of general psychiatry,* 67, 220-9.
Lyon, C. J., Law, R. E. & Hsueh, W. A. 2003. Minireview: adiposity, inflammation, and atherogenesis. *Endocrinology,* 144, 2195-200.
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 : JIDR,* 54, 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 of mental retardation : AJMR,* 111, 62-73.
Marinou, K., Tousoulis, D., Antonopoulos, A. S., Stefanadi, E. & Stefanadis, C. 2010. Obesity and cardiovascular disease: from pathophysiology to risk stratification. *International journal of cardiology,* 138, 3-8.
Markowitz, S., Friedman, M. A. & Arent, S. M. 2008. Understanding the Relation Between Obesity and Depression: Causal Mechanisms and Implications for Treatment. *Clinical Psychology: Science and Practice,* 15, 1-20.
Marlatt, G. A. & George, W. H. 1984. Relapse prevention: introduction and overview of the model. *Br J Addict,* 79, 261-73.
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, 147-53.
Matthews, L., Hankey, C., Penpraze, V., Boyle, S., Macmillan, S., Miller, S., Murray, H., Pert, C., Spanos, D., Robinson, N. & Melville, C. A. 2011. Agreement of accelerometer and a physical activity questionnaire in adults with intellectual disabilities. *Preventive medicine,* 52, 361-4.
Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T. & Saxena, S. 2011. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Res Dev Disabil,* 32, 419-36.
Mays N. & Pope C. (1996) *Qualitative research in health care*: BMJ Books, London.
McAllister, C. J., Whittington, J. E. & Holland, A. J. 2011. Development of the eating behaviour in Prader-Willi Syndrome: advances in our understanding. *Int J Obes (Lond),* 35, 188-97.
McAllister, E. J., Dhurandhar, N. V., Keith, S. W., Aronne, L. J., Barger, J., Baskin, M., Benca, R. M., Biggio, J., Boggiano, M. M., Eisenmann, J. C., Elobeid, M., Fontaine, K. R., Gluckman, P., Hanlon, E. C., Katzmarzyk, P., Pietrobelli, A., Redden, D. T., Ruden, D. M., Wang, C., Waterland, R. A., Wright, S. M. & Allison, D. B. 2009. Ten putative contributors to the obesity epidemic. *Crit Rev Food Sci Nutr,* 49, 868-913.
McCarran, M. S. & Andrasik, F. 1990. Behavioral weight-loss for multiply-handicapped adults: assessing caretaker involvement and measures of behavior change. *Addictive behaviors,* 15, 13-20.
McCloughen, A. & Foster, K. 2011. Weight gain associated with taking psychotropic medication: an integrative review. *Int J Ment Health Nurs,* 20, 202-22.

McDonald, K. E. & Kidney, C. A. 2012. What Is Right? Ethics in Intellectual Disabilities Research. *Journal of Policy and Practice in Intellectual Disabilities,* 9, 27-39.

McGee, D. L. 2005. Body mass index and mortality: a meta-analysis based on person-level data from twenty-six observational studies. *Annals of epidemiology,* 15, 87-97.

McGuire, B. E., Daly, P. & Smyth, F. 2007a. Lifestyle and health behaviours of adults with an intellectual disability. *Journal of intellectual disability research : JIDR,* 51, 497-510.

McGuire, L. C., Strine, T. W., Okoro, C. A., Ahluwalia, I. B. & Ford, E. S. 2007b. Healthy lifestyle behaviors among older U.S. adults with and without disabilities, Behavioral Risk Factor Surveillance System, 2003. *Prev Chronic Dis,* 4, A09.

McGuire, M. T., Wing, R. R., Klem, M. L., Lang, W. & Hill, J. O. 1999. What predicts weight regain in a group of successful weight losers? *Journal of consulting and clinical psychology,* 67, 177-85.

McTigue, K. M., Harris, R., Hemphill, B., Lux, L., Sutton, S., Bunton, A. J. & Lohr, K. N. 2003. Screening and interventions for obesity in adults: summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med,* 139, 933-49.

Mefferd, K., Nichols, J. F., Pakiz, B. & Rock, C. L. 2007. A cognitive behavioral therapy intervention to promote weight loss improves body composition and blood lipid profiles among overweight breast cancer survivors. *Breast cancer research and treatment,* 104, 145-52.

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. *The British journal of nutrition,* 105, 1553-62.

Melville, C. A., Cooper, S. A., McGrother, C. W., Thorp, C. F. and Collacott, R. 2005.'Obesity in adults with Down syndrome: a case-control study', *Journal of intellectual disability research : JIDR,* 49(Pt 2), 125-33.

Melville, C. A., Cooper, S. A., Morrison, J., Smiley, E., Allan, L., Jackson, A., Finlayson, J. & Mantry, D. 2008. The prevalence and incidence of mental ill-health in adults with autism and intellectual disabilities. *J Autism Dev Disord,* 38, 1676-88.

Melville, C. A., Hamilton, S., Hankey, C. R., Miller, S. & Boyle, S. 2007. The prevalence and determinants of obesity in adults with intellectual disabilities. *Obes Rev,* 8, 223-30.

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.

Menard, J., Payette, H., Baillargeon, J. P., Maheux, P., Lepage, S., Tessier, D. & Ardilouze, J. L. 2005. Efficacy of intensive multitherapy for patients with type 2 diabetes mellitus: a randomized controlled trial. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne,* 173, 1457-66.

Mendonca, G. V., Pereira, F. D. and Fernhall, B. 2010. 'Reduced exercise capacity in persons with Down syndrome: cause, effect, and management', *Therapeutics and clinical risk management,* 6, 601-10.

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.
Mendoza, J. A., Drewnowski, A. & Christakis, D. A. 2007. Dietary energy density is associated with obesity and the metabolic syndrome in U.S. adults. *Diabetes Care,* 30**,** 974-9.
Messent, P. R., Cooke, C. B. & Long, J. 1998. Daily physical activity in adults with mild and moderate learning disabilities: is there enough? *Disability and rehabilitation,* 20**,** 424-7.
Messent, P. R., Cooke, C. B. & Long, J. 1999. Primary and secondary barriers to physically active healthy lifestyles for adults with learning disabilities. *Disabil Rehabil,* 21**,** 409-19.
Mitri, J., Hamdy, O. 2009.Diabetes medications and body weight. Expert Opin Drug Saf.;8:573-584
Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G. & Group, P. 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ,* 339**,** b2535.
Mokdad, A. H., Ford, E. S., Bowman, B. A., Dietz, W. H., Vinicor, F., Bales, V. S. & Marks, J. S. 2003. Prevalence of obesity, diabetes, and obesity-related health risk factors, 2001. *JAMA : the journal of the American Medical Association,* 289**,** 76-9.
Moran, R., Drane, W., McDermott, S., Dasari, S., Scurry, J. B. & Platt, T. 2005. Obesity among people with and without mental retardation across adulthood. *Obes Res,* 13**,** 342-9.
Moroshko, I., Brennan, L. & O'Brien, P. 2011. Predictors of dropout in weight loss interventions: a systematic review of the literature. *Obesity reviews : an official journal of the International Association for the Study of Obesity,* 12**,** 912-34.
Morrison, D. S., Boyle, S., Morrison, C., Allardice, G., Greenlaw, N. & Forde, L. 2012. Evaluation of the first phase of a specialist weight management programme in the UK National Health Service: prospective cohort study. *Public health nutrition,* 15**,** 28-38.
Morse, J. M. (1994) *Critical issues in qualitative research methods,* Thousand Oaks: Sage Publications.
Moss, S. J. 2009. Changes in coronary heart disease risk profile of adults with intellectual disabilities following a physical activity intervention. *Journal of intellectual disability research : JIDR,* 53**,** 735-44.
Murawski, M. E., Milsom, V. A., Ross, K. M., Rickel, K. A., DeBraganza, N., Gibbons, L. M. & Perri, M. G. 2009. Problem solving, treatment adherence, and weight-loss outcome among women participating in lifestyle treatment for obesity. *Eat Behav,* 10**,** 146-51.
Murphy, E., Dingwall, R., Greatbatch, D., Parker, S. & Watson, P. 1998. Qualitative research methods in health technology assessment: a review of the literature. *Health technology assessment,* 2**,** iii-ix, 1-274.
Murphy, J. 2006. Perceptions of communication between people with communication disability and general practice staff. *Health expectations : an international journal of public participation in health care and health policy,* 9**,** 49-59.
Murphy, M. H., Nevill, A. M., Murtagh, E. M. & Holder, R. L. 2007. The effect of walking on fitness, fatness and resting blood pressure: a meta-analysis of randomised, controlled trials. *Preventive medicine,* 44**,** 377-85.
Murugan, A. T. & Sharma, G. 2008. Obesity and respiratory diseases. *Chronic respiratory disease,* 5**,** 233-42.

Mustajoki, P. & Pekkarinen, T. 2001. Very low energy diets in the treatment of obesity. *Obes Rev,* 2, 61-72.
Nackers, L. M., Ross, K. M. & Perri, M. G. 2010. The association between rate of initial weight loss and long-term success in obesity treatment: does slow and steady win the race? *International journal of behavioral medicine,* 17, 161-7.
Nakade, M., Aiba, N., Suda, N., Morita, A., Miyachi, M., Sasaki, S., Watanabe, S. & Group, S. 2012. Behavioral change during weight loss program and one-year follow-up: Saku Control Obesity Program (SCOP) in Japan. *Asia Pacific journal of clinical nutrition,* 21, 22-34.
National Guideline Clearing house. http://www.guideline.gov/.
National Heart Lung and Blood Institute. & National Institute of Diabetes and Digestive and Kidney Diseases (U.S.) 1998. *Clinical guidelines on the identification, evaluation, and treatment of overweight and obesity in adults : the evidence report,* Bethesda,(Md): National Institutes of Health, National Heart, Lung, and Blood Institute.
National Health Service, Health Scotland (NHS) (2004) *Health Needs Assessment Report. People with Learning Disabilities in Scotland*. NHS Health Scotland.
National Institute of Health (USA). *Third Report of the National Cholesterol Education Program Expert Panel on Detection, Evaluation and Treatment of High Blood Cholesterol in adults (Adult Treatment Panel III)*. NIH Publication 01-3670. NIH, Bethesda, Md, 2001.
National Institutes of Health (NIH) National Heart, Lung, and Blood Institute (NHLBI) North American Association for the Study of Obesity (NAASO). (2000) *The Practical Guide: Identification, Evaluation, and Treatment of Overweight and Obesity in Adults*. NIH Publication Number 00–4084. Rockville, MD: NIH
National Institute for Health and Clinical Excellence (NICE) (2006) *Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children*. NICE, London.
National Institute for Health and Clinical Excellence CG43 Obesity: full guideline, section 5b - management of obesity in clinical settings (adults): evidence statements and reviews.
Nelson M, Erens B, Bates B, Church S & Boshier T (2007) Low Income Diet and Nutrititon Survey. Volume 1. Background, Methods, Sample Characteristics. London: The Stationery Office.
Nield, L., Summerbell, C. D., Hooper, L., Whittaker, V. & Moore, H. 2008. Dietary advice for the prevention of type 2 diabetes mellitus in adults. *Cochrane Database Syst Rev,* CD005102.
Nihalani, N., Schwartz, T. L., Siddiqui, U. A. & Megna, J. L. 2011. Weight gain, obesity, and psychotropic prescribing. *J Obes,* 2011, 893629.
Nihira, K., Leland, H., & Lambert, N. (1993). *Adaptive Behavior Scale - Residential and Community (2nd Edition)*. Pro-Ed: Austin, TX
Nolan, C. J., Damm, P. & Prentki, M. 2011. Type 2 diabetes across generations: from pathophysiology to prevention and management. *Lancet,* 378, 169-81.
Nordmann, A. J., Nordmann, A., Briel, M., Keller, U., Yancy, W. S., Jr., Brehm, B. J. & Bucher, H. C. 2006. Effects of low-carbohydrate vs low-fat diets on weight loss and cardiovascular risk factors: a meta-analysis of randomized controlled trials. *Arch Intern Med,* 166, 285-93.

Norris, S. L., Zhang, X., Avenell, A., Gregg, E., Schmid, C. H. & Lau, J. 2005. Long-term non-pharmacological weight loss interventions for adults with prediabetes. *Cochrane database of systematic reviews,* CD005270.

Office for National Statistics. Family Food. The Stationery Office: London, 2010.

O'Gorman, D. J. & Krook, A. 2008. Exercise and the treatment of diabetes and obesity. *Endocrinol Metab Clin North Am,* 37, 887-903.

O'Regan, P. & Drummond, E. 2008. Cancer information needs of people with intellectual disability: a review of the literature. *European journal of oncology nursing : the official journal of European Oncology Nursing Society,* 12, 142-7.

Ogden, C. L., Carroll, M. D., Kit, B. K. & Flegal, K. M. 2012. Prevalence of obesity in the United States, 2009-2010. *NCHS Data Brief,* 1-8.

Ogilvie, D., Foster, C. E., Rothnie, H., Cavill, N., Hamilton, V., Fitzsimons, C. F. & Mutrie, N. 2007. Interventions to promote walking: systematic review. *BMJ,* 334, 1204.

Oldroyd, J. C., Unwin, N. C., White, M., Mathers, J. C. & Alberti, K. G. 2006. Randomised controlled trial evaluating lifestyle interventions in people with impaired glucose tolerance. *Diabetes research and clinical practice,* 72, 117-27.

Organisation for Economic Co-Operation and Development: Health at a Glance 2011: OECD Indicators Paris: OECD Publishing; 2011.

Owen, N., Sugiyama, T., Eakin, E. E., Gardiner, P. A., Tremblay, M. S. & Sallis, J. F. 2011. Adults' sedentary behavior determinants and interventions. *Am J Prev Med,* 41, 189-96.

Paeratakul, S., Lovejoy, J. C., Ryan, D. H. & Bray, G. A. 2002. The relation of gender, race and socioeconomic status to obesity and obesity comorbidities in a sample of US adults. *Int J Obes Relat Metab Disord,* 26, 1205-10.

Papas, M. A., Alberg, A. J., Ewing, R., Helzlsouer, K. J., Gary, T. L. & Klassen, A. C. 2007. The built environment and obesity. *Epidemiol Rev,* 29, 129-43.

Parker, E. D. & Folsom, A. R. 2003. Intentional weight loss and incidence of obesity-related cancers: the Iowa Women's Health Study. *International journal of obesity and related metabolic disorders : journal of the International Association for the Study of Obesity,* 27, 1447-52.

Patja, K., Iivanainen, M., Vesala, H., Oksanen, H. & Ruoppila, I. 2000. Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of intellectual disability research : JIDR,* 44 (Pt 5), 591-9.

Patton, M. Q. 1987. *How to use qualitative methods in evaluation,* Newbury Park, Calif., SAGE Publications.

Patton, M. Q. (1990) *Qualitative evaluation and research methods,* 2nd ed., Newbury Park, Calif.: Sage Publications.

Patton, M. Q. (2002) *Qualitative research and evaluation methods,* 3 ed., Thousand Oaks, Calif.: Sage Publications.

Paul-Ebhohimhen, V. & Avenell, A. 2009. A systematic review of the effectiveness of group versus individual treatments for adult obesity. *Obesity facts,* 2, 17-24.

Pawlak, D. B., Ebbeling, C. B. & Ludwig, D. S. 2003. Spirited critique of glycaemic index (GI) and its role in the treatment of obesity. *Obes Rev,* 4, 73-4.

Pearson, E. S. 2012. Goal setting as a health behavior change strategy in overweight and obese adults: a systematic literature review examining intervention components. *Patient Educ Couns,* 87, 32-42.

Pérez Pérez, A., Ybarra Muñoz, J., Blay Cortés, V. & de Pablos Velasco, P. 2007. Obesity and cardiovascular disease. *Public health nutrition,* 10, 1156-1163.
Pi-Sunyer, F. X. 2000. Weight loss and mortality in type 2 diabetes. *Diabetes care,* 23, 1451-2.
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Poirier, P., Giles, T. D., Bray, G. A., Hong, Y., Stern, J. S., Pi-Sunyer, F. X. & Eckel, R. H. 2006. Obesity and cardiovascular disease: pathophysiology, evaluation, and effect of weight loss. *Arterioscler Thromb Vasc Biol,* 26, 968-76.
Pottie, P., Presle, N., Terlain, B., Netter, P., Mainard, D. & Berenbaum, F. 2006. Obesity and osteoarthritis: more complex than predicted! *Ann Rheum Dis,* 65, 1403-5.
Poulain, M., Doucet, M., Major, G. C., Drapeau, V., Series, F., Boulet, L. P., Tremblay, A. & Maltais, F. 2006. The effect of obesity on chronic respiratory diseases: pathophysiology and therapeutic strategies. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne,* 174, 1293-9.
Pownall, J. D. 2009. *Health knowledge and expected outcomes of risky behaviour : a comparative study of non-disabled adolescents and young people with intellectual and physical disabilities.* Thesis (Ph D), University of Glasgow.
Prentice, A. M. 2006. The emerging epidemic of obesity in developing countries. *Int J Epidemiol,* 35, 93-9.
Prentice, A. M. & Jebb, S. A. 2003. Fast foods, energy density and obesity: a possible mechanistic link. *Obes Rev,* 4, 187-94.
Presnell, K., Pells, J., Stout, A. and Musante, G. 2008. 'Sex differences in the relation of weight loss self-efficacy, binge eating, and depressive symptoms to weight loss success in a residential obesity treatment program', *Eating behaviors,* 9(2), 170-80.
Pritchard, J. E., Nowson, C. A. & Wark, J. D. 1997. A worksite program for overweight middle-aged men achieves lesser weight loss with exercise than with dietary change. *J Am Diet Assoc,* 97, 37-42.
Prochaska, J. O., Norcross, J. C. & DiClemente, C. C. 1994. *Changing for good : the revolutionary program that explains the six stages of change and teaches you how to free yourself from bad habits,* New York, W. Morrow.
Proper, K. I., Singh, A. S., van Mechelen, W. & Chinapaw, M. J. 2011. Sedentary behaviors and health outcomes among adults: a systematic review of prospective studies. *Am J Prev Med,* 40, 174-82.
Proto, C., Romualdi, D., Cento, R. M., Romano, C., Campagna, G. & Lanzone, A. 2007. Free and total leptin serum levels and soluble leptin receptors levels in two models of genetic obesity: the Prader-Willi and the Down syndromes. *Metabolism,* 56, 1076-80.
Ratliff, J.C., Barber, J.A., Palmese, L.B., Reutenauer, E.L., Tek, C. 2010. Association of prescription H1 antihistamine use with obesity: results from the National Health and Nutrition Examination Survey Obesity (Silver Spring), 18, pp. 2398–2400
Raynor, H. A., Bond, D. S., Freedson, P. S. & Sisson, S. B. 2012. Sedentary behaviors, weight, and health and disease risks. *Journal of obesity,* 2012, 852743.

Redley, M., Banks, C., Foody, K. & Holland, A. 2012. Healthcare for men and women with learning disabilities: understanding inequalities in access. *Disability & Society,* 27, 747-759.

Redman, L. M., Heilbronn, L. K., Martin, C. K., de Jonge, L., Williamson, D. A., Delany, J. P. & Ravussin, E. 2009. Metabolic and behavioral compensations in response to caloric restriction: implications for the maintenance of weight loss. *PLoS One,* 4, 9.

Reeves, G. K., Pirie, K., Beral, V., Green, J., Spencer, E. & Bull, D. 2007. Cancer incidence and mortality in relation to body mass index in the Million Women Study: cohort study. *BMJ,* 335, 1134.

Reeves, R. S., McPherson, R. S., Nichaman, M. Z., Harrist, R. B., Foreyt, J. P. & Goodrick, G. K. 2001. Nutrient intake of obese female binge eaters. *Journal of the American Dietetic Association,* 101, 209-15.

Renehan, A. G., Roberts, D. L. & Dive, C. 2008. Obesity and cancer: pathophysiological and biological mechanisms. *Archives of physiology and biochemistry,* 114, 71-83.

Renjilian, D. A., Perri, M. G., Nezu, A. M., McKelvey, W. F., Shermer, R. L. & Anton, S. D. 2001. Individual versus group therapy for obesity: effects of matching participants to their treatment preferences. *Journal of consulting and clinical psychology,* 69, 717-21.

Rennie, K. L. & Jebb, S. A. 2005. Prevalence of obesity in Great Britain. *Obes Rev,* 6, 11-2.

Rieder, S. & Ruderman, A. 2007. The development and validation of the weight management support inventory. *Eat Behav,* 8, 39-47.

Rimmer, J. H. 1999. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Phys Ther,* 79, 495-502.

Rimmer, J. H., Heller, T., Wang, E. & Valerio, I. 2004. Improvements in physical fitness in adults with Down syndrome. *American journal of mental retardation : AJMR,* 109, 165-74.

Rimmer, J. H., Rubin, S. S., Braddock, D. & Hedman, G. 1999. Physical activity patterns of African-American women with physical disabilities. *Med Sci Sports Exerc,* 31, 613-8.

Rimmer, J. H. & Yamaki, K. 2006. Obesity and intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews,* 12, 22-27.

Robertson, J., Emerson, E., Gregory, N., Hatto, C., Turner, S., Kessissoglou, S. & Hallam, A. 2000. Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Res Dev Disabil,* 21, 469-86.

Rodgers, J. 1998. 'Whatever's on her Plate': Food in the Lives of People with Learning Disabilities. *British Journal of Learning Disabilities,* 26, 13-16.

Rollnick, S., Butler, C. C., Kinnersley, P., Gregory, J. & Mash, B. 2010. Motivational interviewing. *BMJ,* 340, c1900.

Rosenbaum, M., Goldsmith, R., Bloomfield, D., Magnano, A., Weimer, L., Heymsfield, S., Gallagher, D., Mayer, L., Murphy, E. & Leibel, R. L. 2005. Low-dose leptin reverses skeletal muscle, autonomic, and neuroendocrine adaptations to maintenance of reduced weight. *J Clin Invest,* 115, 3579-86.

Ross, H. M., Laws, R., Reckless, J., Lean, M. & Counterweight Project, T. 2008. Evaluation of the Counterweight Programme for obesity management in primary care: a starting point for continuous improvement. *British Journal of General Practice,* 58, 548-554.

Ross Middleton KM, Patidar SM, Perri MG: The impact of extended care on the long-term maintenance of weight loss: a systematic review and meta-analysis. Obes Rev 2011, 13(6):509–517.

Ross, R. & Janssen, I. 2001. Physical activity, total and regional obesity: dose-response considerations. *Med Sci Sports Exerc,* 33, S521-7; discussion S528-9.

Rotatori, A. F. & Fox, R. 1981. *Behavioral weight reduction program for mentally handicapped persons : a self-control approach,* Baltimore, University Park Press.

Roux, L., Kuntz, K. M., Donaldson, C. & Goldie, S. J. 2006. Economic evaluation of weight loss interventions in overweight and obese women. *Obesity (Silver Spring),* 14, 1093-106.

Royal College of Nursing. (2006) *Meeting the Health Needs of People with Learning Disabilities: Guidance for Nursing Staff.* London: RCN.

Ryan, D. 2005. Risks and benefits of weight loss: challenges to obesity research. *European Heart Journal Supplements,* 7, L27-L31.

Sacks, F. M., Bray, G. A., Carey, V. J., Smith, S. R., Ryan, D. H., Anton, S. D., McManus, K., Champagne, C. M., Bishop, L. M., Laranjo, N., Leboff, M. S., Rood, J. C., de Jonge, L., Greenway, F. L., Loria, C. M., Obarzanek, E. & Williamson, D. A. 2009. Comparison of weight-loss diets with different compositions of fat, protein, and carbohydrates. *N Engl J Med,* 360, 859-73.

Sailer, A., Miltenberger, R., 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, 15-28.

Salome, C. M., King, G. G. & Berend, N. 2010. Physiology of obesity and effects on lung function. *Journal of applied physiology,* 108, 206-11.

Saris, W. H., Blair, S. N., van Baak, M. A., Eaton, S. B., Davies, P. S., Di Pietro, L., Fogelholm, M., Rissanen, A., Schoeller, D., Swinburn, B., Tremblay, A., Westerterp, K. R. & Wyatt, H. 2003. How much physical activity is enough to prevent unhealthy weight gain? Outcome of the IASO 1st Stock Conference and consensus statement. *Obes Rev,* 4, 101-14.

Sartorio, A., Maffiuletti, N. A., Agosti, F. and Lafortuna, C. L. 2005. 'Gender-related changes in body composition, muscle strength and power output after a short-term multidisciplinary weight loss intervention in morbid obesity', *J Endocrinol Invest,* 28(6), 494-501.

Satia, J. A., Kristal, A. R., Curry, S. & Trudeau, E. 2001. Motivations for healthful dietary change. *Public health nutrition,* 4, 953-9.

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,* 49, 103-12.

Sbrocco, T., Nedegaard, R. C., Stone, J. M. & Lewis, E. L. 1999. Behavioral choice treatment promotes continuing weight loss: preliminary results of a cognitive-behavioral decision-based treatment for obesity. *Journal of consulting and clinical psychology,* 67, 260-6.

Schaar, B., Moos-Thiele C, Platen P. Effects of exercise, diet, and a combination of exercise and diet in overweight and obese adults—a meta-analysis of the data. *Open Sports Med J* 2010;4:17-28.

Schalock R. L. & Keith K. D. (1993) Quality of Life Questionnaire. IDS Publishing Corporation, Worthington,OH.

Schalock R. L., Borthwick-Duffy S. A., Bradley V. J., Buntinx W. H. E., Coulter D. L., Craig E. M. et al. (2010) Intellectual Disability: Definition, Classification, and System of Supports (Eleventh Edition). AAID, Washington DC.

Schoeller, D. A. & Buchholz, A. C. 2005. Energetics of obesity and weight control: does diet composition matter? *J Am Diet Assoc,* 105**,** S24-8.

Schofield, W. N. 1985. Predicting basal metabolic rate, new standards and review of previous work. *Human nutrition. Clinical nutrition,* 39 Suppl 1**,** 5-41.

Scottish Centre for Social Research –National Statistics-The Scottish Health Survey: Volume 1: Main Report http://www.scotland.gov.uk/Resource/Doc/358842/0121284.pdf (Accessed 20/01/13)

Scottish Intercollegiate Guideline Network (SIGN). (2010) *Management of obesity: a national clinical guideline*. Edinburgh: SIGN.

Schwartz, T. L., Nihalani, N., Virk, S., Jindal, S. & Chilton, M. 2004. Psychiatric medication-induced obesity: treatment options. *Obes Rev,* 5**,** 233-8.

Sciamanna, C. N., Kiernan, M., Rolls, B. J., Boan, J., Stuckey, H., Kephart, D., Miller, C. K., Jensen, G., Hartmann, T. J., Loken, E., Hwang, K. O., Williams, R. J., Clark, M. A., Schubart, J. R., Nezu, A. M., Lehman, E. & Dellasega, C. 2011. Practices associated with weight loss versus weight-loss maintenance results of a national survey. *Am J Prev Med,* 41**,** 159-66.

Scientific Advisory Committee on Nutrition (SACN) *(*2011*)* Dietary Reference Values for Energy. *The Stationery Office: London.*

Seagle, H. M., Strain, G. W., Makris, A. & Reeves, R. S. 2009. Position of the American Dietetic Association: weight management. *J Am Diet Assoc,* 109**,** 330-46.

Sharma, A.M., Pischon, T., Hardt, S., Kunz, I., Luft, F.C. 2001.Hypothesis: β-adrenergic receptor blockers and weight gain: A systematic analysis. Hypertension; 37: 250–254

Shaw, J. E., Sicree, R. A. & Zimmet, P. Z. 2010. Global estimates of the prevalence of diabetes for 2010 and 2030. *Diabetes research and clinical practice,* 87**,** 4-14.

Shaw, K., O'Rourke, P., Del Mar, C. & Kenardy, J. 2005. Psychological interventions for overweight or obesity. *Cochrane database of systematic reviews***,** CD003818.

Shekelle, P. G., Ortiz, E., Rhodes, S., Morton, S. C., Eccles, M. P., Grimshaw, J. M. & Woolf, S. H. 2001. Validity of the Agency for Healthcare Research and Quality clinical practice guidelines: how quickly do guidelines become outdated? *JAMA,* 286**,** 1461-7.

Sherwood, N. E., Jeffery, R. W., French, S. A., Hannan, P. J. & Murray, D. M. 2000. Predictors of weight gain in the Pound of Prevention study. *Int J Obes Relat Metab Disord,* 24**,** 395-403.

Silverman, D. 2005. *Doing qualitative research : a practical handbook,* London, Sage Publications.

Simila, S. & Niskanen, P. 1991. Underweight and overweight cases among the mentally retarded. *J Ment Defic Res,* 35 (Pt 2)**,** 160-4.

Simon, G. E., Rohde, P., Ludman, E. J., Jeffery, R. W., Linde, J. A., Operskalski, B. H. & Arterburn, D. 2010. Association between change in depression and change in weight among women enrolled in weight loss treatment. *Gen Hosp Psychiatry,* 32**,** 583-9.

Siu, J., Giskes, K. & Turrell, G. 2011. Socio-economic differences in weight-control behaviours and barriers to weight control. *Public health nutrition,* 14, 1768-78.

Smallman, S., Engel, B. & Nelson, J. 2011. Obesity services for adults with learning disabilities. *Journal of Human Nutrition and Dietetics,* 24, 304-305.

Smyth, C. M. & Bell, D. 2006. From biscuits to boyfriends: the ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities,* 34, 227-236.

Sode-Carlsen, R., Farholt, S., Rabben, K. F., Bollerslev, J., Schreiner, T., Jurik, A. G., Frystyk, J., Christiansen, J. S. & Hoybye, C. 2011. Growth hormone treatment for two years is safe and effective in adults with Prader-Willi syndrome. *Growth Horm IGF Res,* 21, 185-90.

Southard, B. H., Southard, D. R. & Nuckolls, J. 2003. Clinical trial of an Internet-based case management system for secondary prevention of heart disease. *Journal of cardiopulmonary rehabilitation,* 23, 341-8.

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. Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: a qualitative study. *Journal of intellectual disability research : JIDR,* 57, 90-102.

Spiegelman, B. M. & Flier, J. S. 2001. Obesity and the regulation of energy balance. *Cell,* 104, 531-43.

St Jeor, S. T., Brunner, R. L., Harrington, M. E., Scott, B. J., Daugherty, S. A., Cutter, G. R., Brownell, K. D., Dyer, A. R. & Foreyt, J. P. 1997. A classification system to evaluate weight maintainers, gainers, and losers. *J Am Diet Assoc,* 97, 481-8.

Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Bershadsky, J., Taub, S., Fortune, J. & Ticha, R. 2011. Overweight and obesity among adults with intellectual disabilities who use intellectual disability/developmental disability services in 20 U.S. States. *American journal on intellectual and developmental disabilities,* 116, 401-18.

Stanish, H. I., Temple, V. A. & Frey, G. C. 2006. Health-promoting physical activity of adults with mental retardation. *Mental retardation and developmental disabilities research reviews,* 12, 13-21.

Stanley, K. 2007. Design of randomized controlled trials. *Circulation,* 115, 1164-9.

Stedman, K. V. & Leland, L. S. 2010. Obesity and intellectual disability in New Zealand. *J Intellect Dev Disabil,* 35, 112-5.

Stein, Q. P., Mroch, A. R., De Berg, K. L. & Flanagan, J. D. 2011. The influential role of genes in obesity. *S D Med,* Spec No, 12-5, 17.

Stevens, J., Truesdale, K. P., McClain, J. E. & Cai, J. 2006. The definition of weight maintenance. *International journal of obesity,* 30, 391-9.

Stevens, V. J., Corrigan, S. A., Obarzanek, E., Bernauer, E., Cook, N. R., Hebert, P., Mattfeldt-Beman, M., Oberman, A., & *et al.* 1993. Weight loss intervention in phase 1 of the Trials of Hypertension Prevention. The TOHP Collaborative Research Group. *Archives of internal medicine,* 153, 849-58.

Stevens, V. J., Obarzanek, E., Cook, N. R., Lee, I. M., Appel, L. J., Smith West, D., Milas, N. C., Mattfeldt-Beman, M.,& *et al.* 2001. Long-term weight loss and changes in blood pressure: results of the Trials of Hypertension Prevention, phase II. *Annals of internal medicine,* 134, 1-11.

Stotland, S. C. and Larocque, M. (2005) 'Early treatment response as a predictor of ongoing weight loss in obesity treatment', *Br J Health Psychol,* 10(Pt 4), 601-14.

Straetmans, J. M., van Schrojenstein Lantman-de Valk, H. M., Schellevis, F. G. & Dinant, G. J. 2007. Health problems of people with intellectual disabilities: the impact for general practice. *The British journal of general practice : the journal of the Royal College of General Practitioners,* 57, 64-6.

Strasser, B., Siebert, U. & Schobersberger, W. 2010. Resistance training in the treatment of the metabolic syndrome: a systematic review and meta-analysis of the effect of resistance training on metabolic clustering in patients with abnormal glucose metabolism. *Sports Med,* 40, 397-415.

Strazzullo, P., D'Elia, L., Cairella, G., Garbagnati, F., Cappuccio, F. P. & Scalfi, L. 2010. Excess body weight and incidence of stroke: meta-analysis of prospective studies with 2 million participants. *Stroke,* 41, e418-26.

Stubbs, J., Whybrow, S., Teixeira, P., Blundell, J., Lawton, C., Westenhoefer, J., Engel, D., Shepherd, R., McConnon, A., Gilbert, P. & Raats, M. 2011. Problems in identifying predictors and correlates of weight loss and maintenance: implications for weight control therapies based on behaviour change. *Obesity reviews : an official journal of the International Association for the Study of Obesity,* 12, 688-708.

Stubbs, R. J., Brogelli, D. J., Pallister, C. J., Whybrow, S., Avery, A. J. & Lavin, J. H. 2012. Attendance and weight outcomes in 4754 adults referred over 6 months to a primary care/commercial weight management partnership scheme. *Clinical Obesity,* 2, 6-14.

Swinburn, B., Egger, G. & Raza, F. 1999. Dissecting obesogenic environments: the development and application of a framework for identifying and prioritizing environmental interventions for obesity. *Prev Med,* 29, 563-70.

Tate, D. F., Jeffery, R. W., Sherwood, N. E. & Wing, R. R. 2007. Long-term weight losses associated with prescription of higher physical activity goals. Are higher levels of physical activity protective against weight regain? *The American journal of clinical nutrition,* 85, 954-9.

Teixeira, P. J., Palmeira, A. L., Branco, T. L., Martins, S. S., Minderico, C. S., Barata, J. T., Silva, A. M. and Sardinha, L. B. .2004. 'Who will lose weight? A reexamination of predictors of weight loss in women', *The international journal of behavioral nutrition and physical activity,* 1(1), 12.

Teixeira, P. J., Going, S. B., Sardinha, L. B. & Lohman, T. G. 2005. A review of psychosocial pre-treatment predictors of weight control. *Obesity reviews : an official journal of the International Association for the Study of Obesity,* 6, 43-65.

Teixeira, P. J., Silva, M. N., Mata, J., Palmeira, A. L. & Markland, D. 2012. Motivation, self-determination, and long-term weight control. *The international journal of behavioral nutrition and physical activity,* 9, 22.

Temple, C. A., Jeff W Walkley, Viviene 2000. Physical activity levels of individuals living in a group home. *Journal of Intellectual and Developmental Disability,* 25, 327-341.

Temple, V. A. 2007. Barriers, enjoyment, and preference for physical activity among adults with intellectual disability. *Int J Rehabil Res,* 30, 281-7.

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 & developmental disability,* 32, 28-38.

Teucher, B., Rohrmann, S. & Kaaks, R. 2010. Obesity: focus on all-cause mortality and cancer. *Maturitas,* 65, 112-6.

The NHS Information Centre for Health and Social Care- National Statistics. The Health Survey for England 2008 Physical Activity and fitness: Full report https://catalogue.ic.nhs.uk/publications/public-health/surveys/heal-surv-phys-acti-fitn-eng-2008/heal-surv-phys-acti-fitn-eng-2008-rep-v2.pdf (Accessed 20/01/13)

The NHS Information Centre for Health and Social care T-National Statistics. Statistics on obesity, physical activity and diet: England 2012: Full report http://www.aso.org.uk/wp-content/uploads/downloads/2012/03/2012-Statistics-on-Obesity-Physical-Activity-and-Diet-England.pdf (Accessed 20/01/13)

Thomas, D. E., Elliott, E. J. & Baur, L. 2007. Low glycaemic index or low glycaemic load diets for overweight and obesity. *Cochrane Database Syst Rev*, CD005105.

Thorogood, A., Mottillo, S., Shimony, A., Filion, K. B., Joseph, L., Genest, J., Pilote, L., Poirier, P., Schiffrin, E. L. & Eisenberg, M. J. 2011. Isolated aerobic exercise and weight loss: a systematic review and meta-analysis of randomized controlled trials. *Am J Med*, 124, 747-55.

Thorp, A. A., Owen, N., Neuhaus, M. & Dunstan, D. W. 2011. Sedentary Behaviors and Subsequent Health Outcomes in Adults: A Systematic Review of Longitudinal Studies, 1996–2011. *American Journal of Preventive Medicine*, 41, 207-215.

Toobert, D. J., Glasgow, R. E. & Radcliffe, J. L. 2000. Physiologic and related behavioral outcomes from the Women's Lifestyle Heart Trial. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*, 22, 1-9.

Toobert, D. J., Strycker, L. A., Glasgow, R. E., Barrera Jr, M. & Angell, K. 2005. Effects of the mediterranean lifestyle program on multiple risk behaviors and psychosocial outcomes among women at risk for heart disease. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*, 29, 128-37.

Townsend-White, C., Pham, A. N. T. & Vassos, M. V. 2012. Review: A systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours. *Journal of Intellectual Disability Research*, 56, 270-284.

Trichopoulou, A. & Lagiou, P. 1997. Healthy traditional Mediterranean diet: an expression of culture, history, and lifestyle. *Nutr Rev*, 55, 383-9.

Trueman, P., Haynes, S. M., Felicity Lyons, G., Louise McCombie, E., McQuigg, M. S., Mongia, S., Noble, P. A., Quinn, M. F., Ross, H. M., Thompson, F., Broom, J. I., Laws, R. A., Reckless, J. P., Kumar, S., Lean, M. E., Frost, G. S., Finer, N., Haslam, D. W., Morrison, D., Sloan, B. & Counterweight Project, T. 2010. Long-term cost-effectiveness of weight management in primary care. *Int J Clin Pract*, 64, 775-83.

Tsai, A. G. & Wadden, T. A. 2005. Systematic review: an evaluation of major commercial weight loss programs in the United States. *Ann Intern Med*, 142, 56-66.

Tsai, A. G. & Wadden, T. A. 2006. The evolution of very-low-calorie diets: an update and meta-analysis. *Obesity (Silver Spring)*, 14, 1283-93.

Tudor-Locke, C. & Bassett, D. R., Jr. 2004. How many steps/day are enough? Preliminary pedometer indices for public health. *Sports Med*, 34, 1-8.

Tuffrey-Wijne, I., Bernal, J., Hubert, J., Butler, G. & Hollins, S. 2009. People with learning disabilities who have cancer: an ethnographic study. *Br J Gen Pract*, 59, 503-9.

Tyrer, F. & McGrother, C. 2009. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *Journal of intellectual disability research : JIDR,* 53, 898-904.

Tzotzas, T., Evangelou, P. & Kiortsis, D. N. 2011. Obesity, weight loss and conditional cardiovascular risk factors. *Obesity reviews : an official journal of the International Association for the Study of Obesity,* 12, e282-9.

Van Dongen, J. M., Proper, K. I., van Wier, M. F., van der Beek, A. J., Bongers, P. M., van Mechelen, W. & van Tulder, M. W. 2011. Systematic review on the financial return of worksite health promotion programmes aimed at improving nutrition and/or increasing physical activity. *Obes Rev,* 12, 1031-49.

Van Dorsten, B. & Lindley, E. M. 2008. Cognitive and behavioral approaches in the treatment of obesity. *Endocrinol Metab Clin North Am,* 37, 905-22.

van Schrojenstein Lantman-de Valk, H. M. J. 2005. Health in People with Intellectual Disabilities: Current Knowledge and Gaps in Knowledge. *Journal of Applied Research in Intellectual Disabilities,* 18, 325-333.

Van Voorhis C.R.W., Morgan, B.L. Understanding power and rules of thumb for determining sample sizes. Tutorials in Quantitative Methods for Psychology, 3 (2007), pp. 43–50

Verheijden, M. W., Bakx, J. C., van Weel, C., Koelen, M. A. & van Staveren, W. A. 2005. Role of social support in lifestyle-focused weight management interventions. *European journal of clinical nutrition,* 59 Suppl 1, S179-86.

Verweij, L. M., Coffeng, J., van Mechelen, W. & Proper, K. I. 2011. Meta-analyses of workplace physical activity and dietary behaviour interventions on weight outcomes. *Obes Rev,* 12, 406-29.

Vieira, P. N., Silva, M. N., Mata, J., Coutinho, S. R., Santos, T. C., Sardinha, L. B. & Teixeira, P. J. 2012. Correlates of health-related quality of life, psychological well-being, and eating self-regulation after successful weight loss maintenance. *J Behav Med.*

Villanova, N., Pasqui, F., Burzacchini, S., Forlani, G., Manini, R., Suppini, A., Melchionda, N. & Marchesini, G. 2006. A physical activity program to reinforce weight maintenance following a behavior program in overweight/obese subjects. *International journal of obesity,* 30, 697-703.

Villareal, D. T., Apovian, C. M., Kushner, R. F., Klein, S., American Society for, N. & Naaso, T. O. S. 2005. Obesity in older adults: technical review and position statement of the American Society for Nutrition and NAASO, The Obesity Society. *Obes Res,* 13, 1849-63.

Villareal, D. T., Banks, M., Sinacore, D. R., Siener, C. & Klein, S. 2006. Effect of weight loss and exercise on frailty in obese older adults. *Archives of internal medicine,* 166, 860-6.

Virk, S., Schwartz, T. L., Jindal, S., Nihalani, N. & Jones, N. 2004. Psychiatric medication induced obesity: an aetiologic review. *Obes Rev,* 5, 167-70.

Votruba, S. B., Horvitz, M. A. & Schoeller, D. A. 2000. The role of exercise in the treatment of obesity. *Nutrition,* 16, 179-88.

Wadden, T.A., Letizia, K.A. Predictors of attrition and weight loss in patients treated by moderate and severe caloric restriction. In: Wadden TA, VanItallie TB, eds. Treatment of the Seriously Obese Patient. New York: Guilford Press; 1992:383-410.

Wadden, T. A., Butryn, M. L. & Byrne, K. J. 2004. Efficacy of lifestyle modification for long-term weight control. *Obes Res,* 12 Suppl, 151S-62S.

Wadden, T. A., Butryn, M. L. & Wilson, C. 2007. Lifestyle modification for the management of obesity. *Gastroenterology,* 132, 2226-38.

Wadden, T. A., Stunkard, A. J. & Berkowitz, R. I. 2005. *Obesity : a guide for mental health professionals,* Philadelphia, Saunders.

Wallace, R. A. & Schluter, P. 2008. Audit of cardiovascular disease risk factors among supported adults with intellectual disability attending an ageing clinic. *J Intellect Dev Disabil,* 33, 48-58.

Ward, L. & Townsley, R. 2005. 'It's about a dialogue...'1 Working with people with learning difficulties to develop accessible information. *British Journal of Learning Disabilities,* 33, 59-64.

Weinheimer, E. M., Sands, L. P. & Campbell, W. W. 2010. A systematic review of the separate and combined effects of energy restriction and exercise on fat-free mass in middle-aged and older adults: implications for sarcopenic obesity. *Nutr Rev,* 68, 375-88.

Weinstock, C., Konig, D., Harnischmacher, R., Keul, J., Berg, A. & Northoff, H. 1997. Effect of exhaustive exercise stress on the cytokine response. *Medicine and science in sports and exercise,* 29, 345-54.

Westerterp, K. R. 2009. Assessment of physical activity: a critical appraisal. *European journal of applied physiology,* 105, 823-8.

Whitlock, G., Lewington, S., Sherliker, P., Clarke, R., Emberson, J., Halsey, J., Qizilbash, N., Collins, R. & Peto, R. 2009. Body-mass index and cause-specific mortality in 900 000 adults: collaborative analyses of 57 prospective studies. *Lancet,* 373, 1083-96.

Willner, P. 2004. Brief cognitive therapy of nightmares and post-traumatic ruminations in a man with a learning disability. *The British journal of clinical psychology / the British Psychological Society,* 43, 459-64.

Wing, R. R., Epstein, L. H., Nowalk, M. P., Koeske, R. & Hagg, S. 1985. Behavior change, weight loss, and physiological improvements in type II diabetic patients. *Journal of consulting and clinical psychology,* 53, 111-22.

Wing, R. R. & Hill, J. O. 2001. Successful weight loss maintenance. *Annu Rev Nutr,* 21, 323-41.

Wing, R. R. & Phelan, S. 2005. Long-term weight loss maintenance. *Am J Clin Nutr,* 82, 222S-225S.

Wing, R. R., Venditti, E., Jakicic, J. M., Polley, B. A. & Lang, W. 1998. Lifestyle intervention in overweight individuals with a family history of diabetes. *Diabetes care,* 21, 350-9.

Wing, R.R., Lang, W., Wadden, T.A., Safford, M., Knowler, W.C., Bertoni,A.G.,Hill, J.O. Brankati, F.L., Peters, A., WagenKnecht, L. 2011. Benefits of modest weight loss in improving cardiovascular risk factors in overweight and obese individuals with type 2 diabetes. Diabetes Care 2011;34:1481–1486

Withrow D, Alter DA. The economic burden of obesity worldwide: a systematic review of the direct costs of obesity. *Obesity Reviews*. 2011;12(2):131–141

Wood, P. D., Stefanick, M. L., Dreon, D. M., Frey-Hewitt, B., Garay, S. C., Williams, P. T., Superko, H. R., Fortmann, S. P., Albers, J. J., Vranizan, K. M. & et al. 1988. Changes in plasma lipids and lipoproteins in overweight men during weight loss through dieting as compared with exercise. *N Engl J Med,* 319, 1173-9.

World Cancer Research Fund and American Institute for Cancer Research. Food, Nutrition and the Prevention of Cancer: A Global Perspective. Washington, DC: World Cancer Research Fund and American Institute for Cancer Research; 2009.

World Health Organization (WHO). International classification of diseases 9th revision (ICD-9). Geneva: WHO, 1977

WHO. Physical status: the use and interpretation of anthropometry. Report of a WHO Expert Committee. WHO Technical Report Series 854. Geneva: World Health Organization, 1995

WHO. Obesity: preventing and managing the global epidemic. Report of a WHO Consultation. WHO Technical Report Series 894. Geneva: World Health Organization, 2000.

WHO. *The International Classification of Functioning, Disability and Health* (ICF). WHO, Geneva; 2001.

WHO. Appropriate body-mass index for Asian populations and its implications for policy and intervention strategies. The Lancet, 2004; 157-163.

WHO. Atlas on country resources in intellectual disabilities. Geneva: World Health Organization; 2007

WHO. Waist Circumference and Waist–Hip Ratio: Report of a WHO Expert Consultation. Geneva;2008.

Wu, C. L., Lin, J. D., Hu, J., Yen, C. F., Yen, C. T., Chou, Y. L. & Wu, P. H. 2010. The effectiveness of healthy physical fitness programs on people with intellectual disabilities living in a disability institution: six-month short-term effect. Research in developmental disabilities, 31, 713-7.

Wyatt, H.R., Phelan, S., Wing, R.R., Hill, J.O. (2005). Lessons from patients who have successfully maintained weight loss. Obesity Managament, 1, 56-61.

Wynne, K., Stanley, S., McGowan, B. & Bloom, S. 2005. Appetite control. The Journal of endocrinology, 184, 291-318.

Yamaki, K. 2005. Body weight status among adults with intellectual disability in the community. Ment Retard, 43, 1-10.

Yamaki, K. & Taylor, S. J. 2005. Body Weight Status Among Adults With Intellectual Disability in the Community. *Mental Retardation,* 43, 1-10.

Yang, Q., Rasmussen, S. A. & Friedman, J. M. 2002. Mortality associated with Down's syndrome in the USA from 1983 to 1997: a population-based study. *Lancet,* 359, 1019-25.

York, D. A., Rossner, S., Caterson, I., Chen, C. M., James, W. P., Kumanyika, S., Martorell, R. & Vorster, H. H. 2004. Prevention Conference VII: Obesity, a worldwide epidemic related to heart disease and stroke: Group I: worldwide demographics of obesity. *Circulation,* 110, e463-70.

You, T., Yang, R., Lyles, M. F., Gong, D. & Nicklas, B. J. 2005. Abdominal adipose tissue cytokine gene expression: relationship to obesity and metabolic risk factors. *American journal of physiology. Endocrinology and metabolism,* 288, E741-7.

Zamboni, M., Mazzali, G., Zoico, E., Harris, T. B., Meigs, J. B., Di Francesco, V., Fantin, F., Bissoli, L. & Bosello, O. 2005. Health consequences of obesity in the elderly: a review of four unresolved questions. *Int J Obes (Lond),* 29, 1011-29.

Zhao, G., Ford, E. S., Li, C., Tsai, J., Dhingra, S. & Balluz, L. S. 2011. Waist circumference, abdominal obesity, and depression among overweight and obese U.S. adults: National Health and Nutrition Examination Survey 2005-2006. *BMC psychiatry,* 11, 130.

Ziviani J, Lennox N, Allison H, Lyons M, Del Mar C: Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. *Intellect Dev Disabil* 2004, **3**: 211-25.

Appendix 1

Search Terms Medline Searched in OVID 1985 - 2011		**Citations Returned**
1.	exp Mental Retardation/	
2.	exp Learning Disorders/	
3.	exp Mentally Disabled Persons/	
4.	exp Developmental Disabilities/	
5.	((Mental$ or learning or cognitive or intellect$) and (retard$ or handicap$ or disab$ or difficult$ or impair$)).	
6.	Or / 1-5	
7.	exp Obesity/	
8.	Obes$.tw.	
9.	exp Weight Gain/	
10.	exp Weight Loss/	
11.	exp Body Mass Index/	
12.	bmi.mp.	
13.	(bmi or body mass index).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]	
14.	(Overweight or over weight or overeat$ or over eat$).af.	
15.	Or / 7-13	
16.	exp Behaviour Therapy/	
17.	exp Cognitive Therapy/	
18.	exp Social Support/	
19.	exp Family Therapy/	
20.	exp Life Style/	
21.	lifestyle.mp.	
22.	Support group.mp. or exp Self-Help Groups/	
23.	Low fat diet.mp. or exp Diet, Fat-Restricted/	
24.	low calorie diet.mp. or exp Caloric Restriction/	
25.	diet restriction.mp. or exp Diet, Reducing/	
26.	(diet or diets or dieting).tw.	
27.	exp Exercise/	
28.	Physical education.mp. or exp "Physical Education and Training"/	
29.	physical activity.mp. or exp Motor Activity/	
30.	exp Health Promotion/	
31.	exp Health Education/	
32.	Nutrition education.mp.	
33.	Or/15-30	
34.	6 and 15 and 33	
35.	Limit 34 to humans , adults, English language	
36.	Excluding Prader-Willi syndrome	
37.	Excluding through titles and abstracts	

Data Extraction Form
General Information
Title: **Authors:** **Country of Origin:** **Year:** **Type of publication:**
Study Characteristics
Research Question:
Aims:
Study design:
Inclusion Exclusion criteria:
Randomization:
Sample Characteristics
Number and presence of power calculation:
Age:
Gender:
Level ID and diagnosis:
BMI:
WC:
Extra:
Outcome Measures
Intervention
Duration:
General Description and locations:
Components:
Diet Description:
Physical activity Description
Behaviour Description:
Extra:
Group or individual:
Results/outcomes/values
Weight:
BMI:
Other (WC):
Physical activity:
Health related:
Drop outs:
Follow UP:
Conclusion

Quality Check list			
Please tick as appropriate and provide comments in each section	**Yes**	**No**	**Comments**
Clear research question			
Ethics			
External validity **(based on the presence of generalisability)**			
Sampling bias (e.g. power, heterogeneity)			
Control groups			
Randomization-Clear explanation of the process			
Blinding			
Confounding factors			
All 3 components :diet, physical activity, behavior			
Clinically effective -5% to 10% weight loss			
Replicable			
Explanation of attrition rate			
Follow up			
Weight maintenance intervention			
Relevant			
Overall evaluation:			

Appendix 2

Scotland A Research Ethics Committee

Secretariat
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9026
Fax 0131 536 9346
www.corec.org.uk

NHS SCOTLAND

Dr Craig Melville
Senior Lecturer in Learning Disabilities
Psychiatry
University of Glasgow
Section of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Date: 7 January 2009
Your Ref.:
Our Ref.: 08/MRE00/97

Enquiries to: Walter Hunter
Extension: 89026
Direct Line: 0131 536 9026
Email: walter.hunter@lhb.scot.nhs.uk

RECEIVED - 9 JAN 2009

Dear Dr Melville

Study title: **A pilot study of a weight loss intervention for adults with learning disabilities and obesity**

REC reference: **08/MRE00/97**

Thank you for your letter of 16 December 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman together with D r Quigley and Mrs A Macpherson.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Adults with Incapacity (Scotland) Act 2000

I confirm that the Committee has approved this research project for the purposes of the Adults with Incapacity (Scotland) Act 2000. The Committee is satisfied that the requirements of section 51 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

WEIGHT LOSS AND LEARNING DISABILITIES

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a research study. The information sheet tells you about the study. Please read the information sheet, or ask someone to read it with you. This information sheet is for you to keep. It is also available on a CD.

You can talk to your family and friends about the study. Ask them what they think about it.

What will the research study find out?

This research study will see if a new treatment helps people lose weight. The treatment will try to help people make changes to their diet and be more active. We hope that 30 people will take part in the study.

Why do you want me to take part?

We are inviting you to take part because you are using the learning disabilities services of NHS Greater Glasgow and Clyde. A worker who knows you thinks you are overweight.

What will the study involve?

A researcher will contact you and ask to visit you. You do not have to meet the researcher. Please let us know if you do not want to see the researcher.

You can ask the researcher questions about the study. The researcher will invite you to decide if you want to take part in the research study. If you say yes, you will be asked to sign a form. You can keep a copy of the consent form.

If you choose to take part, the researcher will visit you twice over six months. The meetings will be at a place that is suitable for you. Each one will last about one hour. The researcher will ask questions about:

- ✓ Yourself and the things you do
- ✓ Your diet and physical activity
- ✓ Problems caused by being overweight.

We would like to ask a carer who knows you questions about your health, and your lifestyle. We will ask your permission to speak to a carer and which carer you would like us to speak to.

You will also be asked to wear a special belt for one week at the beginning of the study, and one week at the end. This measures how active you are.

We will ask you if we can tell your GP that you are taking part in the study. We will also ask if we can look at your medical notes. This will provide us with information about your health, and the help you have received.

What does the treatment involve?

A dietitian from the clinical service will arrange to meet you at your home once every two weeks. There will be a total of nine sessions, over a six month period. These sessions are to help you find ways to lose weight. You will talk about your current diet and activities. Then the dietitian will help you to choose ways to make changes to help you lose weight.

A carer will support you in these sessions. The carer will help you make a note of your diet and activities, and help you plan the changes you want to make.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this if you wish to complain about any aspect of the way you have been treated during the course of this study, the normal National Health Service complaints mechanism will be available to you.

Has ethical approval been granted for this study?

This study has been granted ethical approval by the MREC for Scotland, Committee A, and the local research ethics committee for NHS Greater Glasgow and Clyde.

When will the study take place?

This study will take place during 2009 - 2010 but your involvement would be for only six months.

Will taking part in the study help me?

If you decide to take part in the study it might help you lose weight. However, taking part might not help. Nobody has used this treatment before. We do not know if it works.

What will happen if I decide not to take part in the study?

You do not have to take part in this research study. It is OK to say no. If you don't want to take part, this will not affect the care and support you receive.

What if I change my mind and do not want to take part during the study?

You can change your mind about taking part, or stop, at any time. You do not have to give a reason. If you change your mind this will not affect the care and support you receive.

Where would the interviews take place?

If it is OK with you, the researcher will arrange to see you at your home. If you want the researcher can arrange to see you somewhere else.

What will happen to the information the researcher collects?

All the information about you is kept safe. It will be treated with strict confidence. It will be kept secret. The research team will not tell anyone your name. The information will be kept very safely on a computer. The Data Protection Act will be followed at all times.

What will happen to the results of the study?

When the research study is finished, the research team will write to you about the research findings. They will also write reports about the research. Your name will not be used in the reports. No one will be able to tell from the reports if you took part in the research.

Who is organising and funding the research?

This study is organised by the Learning Disabilities Research Group, at the University of Glasgow. The money to pay for the study was provided by the Chief Scientist's Office, of the Scottish Government.

How can I find out more about the study?

You can ask the researcher questions about the study. The name and telephone number of the researcher are shown below. The names of the members of the research team are below. You can contact them at any time to ask questions.

Thank you for reading this information sheet.

Researcher

Susan Macmillan
Section of Psychological Medicine,
Division of Community Based Sciences
Academic Centre, Gartnavel Royal
Hospital, 1055 Great Western Road,
Glasgow, G12 0XH.
Telephone: 0141 211 3878

Specialist Learning Disabilities Dietitian

Dimitrios Spanos
Section of Psychological Medicine,
Division of Community Based Sciences
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Hospital, 1055 Great Western Road,
Glasgow, G12 0XH.
Telephone: 0141 211 3878

Alternative contact

Dr. Craig Melville, Senior Lecturer in Learning Disabilities, University of Glasgow. Telephone: 0141 211 3878

WEIGHT LOSS AND LEARNING DISABILITIES

PARTICIPANT CONSENT FORM

This form asks if I will take part in a research study.

A researcher will ask me questions about my diet and physical activity.
I will work with a dietitian to try and lose weight.

The treatment might help me lose weight.

The researchers will keep my information confidential (secret) and safe.

Please tick the box if you agree with what it says.

I have been given an information sheet about the study.

YES ☐

I have asked all the questions I want to.

YES ☐

I have been given enough answers to my questions.

YES ☐

I know it is OK to say 'No' to taking part in the study. I don't have to takepart. I don't have to say why.

YES ☐

Saying 'No' will not affect my future health care or support in any way.

YES ☐

I know I can change my mind and say 'No' later on.

YES ☐

I know that the researcher will measure my height, weight and waist.

YES ☐

This will happen before and after I take part in the weight loss intervention.

I know the research team will write about the study results. I know the results will not include my name. No one will be able to identify me from the results.

YES ☐

I agree to taking part in the research study

YES ☐

Signed

……………………………………………………………………………………………….

Name

………………………………………………………………………………………………..

Date

…………………………………………………………………………………………………

WEIGHT LOSS AND LEARNING DISABILITIES

CARER CONSENT FORM

This form asks if I will support the person named below to take part in a research study of a weight loss intervention. I know that I am not providing consent for the person with learning disabilities I support to take part in the study.

Name of participant……………………………………………………………………………….

I am completing this form as the carer that the participant has chosen to support them during the weight loss study. Other carers will also support the individual.

My relationship to the participant is (please tick):

family carer ☐
paid carer ☐
other, please specify……………………………………………………………………………...

I know that I am not a participant in the study so I will not be asked for information about my own lifestyle, or invited to try and lose weight.

A researcher will ask me questions about the health and lifestyle of the person I support. I will be asked to support the participant to collect information about their diet, physical activity and lifestyle. I will also be involved in supporting the participant to make changes to their diet, levels of activity and lifestyle in order to try and lose weight.

The researchers will keep all the information confidential. Only members of the research team will have access to the information I discuss.

I understand that participation in the research study might help the person with learning disabilities I support.

Please tick the box that you believe applies to each statement

I have been given an information sheet about the study

YES ☐

I have asked all the questions I want to ☐

YES

I am satisfied that my questions have been thoroughly answered ☐

YES

I know it is OK to say 'no' to supporting the person to take part in the study.
I don't have to take part. I don't have to say why. ☐

YES

If I say 'no', I know it will not affect the future health care, or support, that the person I support receives ☐

YES

I know the research team will write about the study results. However, the results will not include my name, or the name of the person I support.
No one will be able to identify me, or the person with learning disabilities I support, from the results. ☐

YES

I agree to supporting the person I support to take part in the research study YES ☐

Signed

…………………………………………………………………………………………….

Name

……………………………………………………………………………………………..

Date

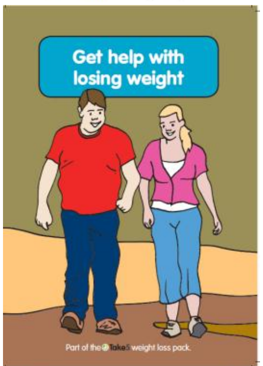
………………………………………………………………………………………………

Appendix 3 Resources used in TAKE 5 weight loss phase

Booklets offered to participants at TAKE 5 weight loss intervention

Booklet 1: Eat Well-Feel Well

Booklet 2: You can do it



Booklet 3: Get help with losing weight

Booklet 4: How to help someone lose weight

Prescribed diet form

Name

Date

Personalised Dietary Prescription of 1800 calories per day

Food Group	Portions recommended per day	Current number of portions per day
 Starches (bread, cereals, potatoes, rice, pasta)	**8**	
 Fruit and vegetables	5	
 Dairy	3	
 Meat, fish , peas, lentils, beans	3	
 Fats (butter, low fat, oil, mayonnaise, salad cream)	1	
 Extras (sweet foods, extra portions, dessert, crisps)	160 calories	Calories

Take5

Appendix 4

Participant DOB: --

Date of Appointment ------------ / ------------- / --------------

Name of assessor --

Location of Assessment (e.g. participant's home) ---

Details of informant: ***(please tick one***

No informant	
Family carer	
Paid carer	
Friend or other	

Informant name: --

Length of time informant has known participant: Years Months

Name of key worker: --

Name of key worker at day centre: ---

Contact details: --

--

ANTHROPOMETRIC MEASUREMENTS

1(a) Height, without shoes (in meters and centimetres)

(1) **……….............m**

(2) **……….............m**

Mean height ……….............m

(b) Weight, without shoes and in light clothing (kg)

(1) **……….............kg**

(2) **……….............kg**

Mean weight ……….............kg

(c) Body Mass Index = Weight (kg) / Height $(m)^2$ **……………………..**

(d) Waist circumference on full expiration

(1) **……….............cm**

(2) **……….............cm**

Mean waist circumference ……….............cm

(e) Knee Height

(1) **……….............cm**

(2) **……….............cm**

Mean knee height……….............cm

SECTION A: INITIATING THE INTERVIEW: GENERAL BACKGROUND INFORMATION

<u>Instructions</u>: meet the participant and where appropriate the informant. Explain to them that you want to find out how the person with learning disabilities speaks to someone new. The informant should help with answering only if the person with learning disabilities has difficulty giving information. If an informant is present he / she can give the person some support, for example by providing a reminder of an activity. Information provided by informant should be recorded within brackets (..........)

Interviewer Hello, my name is *[Interviewer's name]*...

I am pleased to meet you. What is your name?

Respondent

....

Interviewer I would like to know about you. Tell me what you like doing.
(Do you listen to music? Do you watch television? Do you like shopping? Do you enjoy eating? What do you like best?)

Respondent

....

Interviewer You like…….. *[Repeat the list of activities reported spontaneously].*
What do you like doing with other people? (Do you go to a club? Do you go to church, (mosque, etc)?) *[Other examples: job, visiting neighbours, pub, sport, leisure activity, parties]*

Respondent

....

Interviewer Tell me about people that you are close to.
If respondent only mentions family also ask Do you have friends?

Respondent

....

Interviewer Tell me about anyone special. Are you married? Do you have a boy friend or a girl friend? How do you get on? Do you look forward to meeting him/her?

Respondent

....

Interviewer What do you like doing with friends/ family?
Do you visit people? Do people visit you? *[Other examples: shopping, talking, meals together, trips out, cinema, games, other leisure activity]*

Respondent

....

Interviewer Tell me about things you do where you pay attention. Do you have a job? Do you go to College?
[Other examples: work, any other educational activity, story on television, reading, puzzles, jig-saws , cooking, darts, pool, dominoes or other games, travelling]

Respondent

....

....

Interviewer You have told me about …..*[Repeat the full list of activities mentioned in previous answer]*

Thank you for telling me about yourself.

I will now ask you some questions about the place you live

A1. PERSONAL DETAILS

1. First language……………………………………………………………………………

2. Gender *(Please tick)*

Male	1	[ ]
Female	2	[ ]

3. Marital status *(Please tick)*

Married / live in partner	1	[ ]
Separated / divorced	2	[ ]
Single	3	[ ]
Widow/er	4	[ ]

4. Ethnicity *(Please tick)*

Indian	1	[ ]
Pakistani	2	[ ]
Bangladeshi	3	[ ]
Chinese	4	[ ]
Caucasian	5	[ ]
Black Caribbean	6	[ ]
Black African	7	[ ]
Black other	8	[ ]
Other Asian background	9	[ ]
Mixed background	10	[ ]

Other & specify…………………………………...………………………………… [ ]

A2. SOCIAL SUPPORTS

1. **Tell me about the place you live. Is this your own home? Who else lives here with you?**
   (Please tick)

Parents home	1	[ ]
Other family carers home	2	[ ]
Lives independently +/- children, without any paid support	3	[ ]
Lives independently with spouse / partner +/- children, without any paid support	4	[ ]
Supported group living (shared tenancy, with paid support)	5	[ ]
Supported living – individual (single tenancy, with paid support)	6	[ ]
Residential care (registered home)	7	[ ]
Nursing home	8	[ ]
NHS accommodation	9	[ ]
Other & specify…………………………………………………………....		[ ]

2. If accommodation type = 5 - 7, ask **How much support do you get each week? Is there someone here overnight?** specify **level of support** at accommodation. *(Please tick)*

Part-time support (less than daily)	1	[ ]
Part-time support (daily)	2	[ ]
24 hour support, sleep-in nights	3	[ ]
24 hour support, including wake at night	4	[ ]

Organisation providing support package………………………………………………………..

3. **Do you/ Does the person** have a job? Do you/ Does the person go to college or a day centre? What **employment type/s** does the person have? *(Please tick as many as required)*

None	0	[ ]
Part time paid employment (30 hours / week or less)	1	[ ]
Full time paid employment (more than 30 hours / week)	2	[ ]
Paid employment with paid support / employment training	3	[ ]
Employed, but only paid up to the subscribed limit	4	[ ]
Voluntary work	5	[ ]
College	6	[ ]

Day centre & specify name………………………………………………...… 7 [ ]

Extra 1:1 support to access a day centre & specify centre……………….…8 [ ]

1:1 paid support for day opportunity (as part of 24 hour support package) 9 [ ]

1:1 paid support for day opportunity

(separate from support package at home) 10 [ ]

Looking after home and family 11 [ ]

Retired from paid work 12 [ ]

School 13 [ ]

Other & specify……………………..………………………………….. [ ]

A3. ABILITY AND DEVELOPMENT

I would like to ask the person who supports you some questions about areas of your life you need support with.

1. How much support does the person need with **eating and drinking**? (*Please tick*)

Totally independent 1 [ ]

Minimum assistance 2 [ ]

Regular prompting / supervision 3 [ ]

1:1 support required 4 [ ]

1:1 support required and special equipment

/ positioning or PED feeding 5 [ ]

2. How much support does the person need with **intimate care** e.g. bathing, dressing? (*Please tick*)

Fully independent 1 [ ]

Minimum assistance 2 [ ]

Regular prompting / supervision 3 [ ]

1:1 support required, but able to contribute in a limited way - 4 [ ]
may require special lifting equipment

1:1 support required, unable to contribute and totally dependent – 5 [ ]
requires special lifting equipment

3. How much support does the person need with **personal safety**? (*Please tick*)

Aware of personal safety and acts accordingly 1 [ ]

Minimum assistance 2 [ ]

Some awareness / appropriate action, but requires some supervision 3 [ ]

Requires constant supervision to ensure safety	4	[ ]
Total dependency for personal safety	5	[ ]

4. How much support does the person require with **communication**? (*Please tick*)

Communicates clearly and independently	1	[ ]
Communicates reasonably clearly, including using signs / aids	2	[ ]
Requires staff support with communication	3	[ ]
Much time is required to understand and facilitate the person's communication	4	[ ]
Communication skills are extremely limited	5	[ ]

5. How much support does the person require with **decision making**? (*Please tick*)

Makes own decisions in an informed way	1	[ ]
Minimum support to make own decisions	2	[ ]
Can make some choices / decisions	3	[ ]
Support required for even simple decisions	4	[ ]
Total dependence on others for decision making / choices	5	[ ]

6. **Add up** the sum of scores in 2 – R6 [ ] [ ]

SECTION B: PHYSICAL AND MENTAL HEALTH

B1. OVERVIEW

What **health problems do you/ is the person known to have**, or receives treatment for? For each named problem ask if it limits the person's activities or lifestyle in any way eg. accessing community resources

Health problem or diagnosis	Does this limit your activities in any way?
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1
	No **[ ]** 2 Yes **[ ]** 1

Code *For coding purposes only, do not ask participant or carers*

	Health problem or diagnosis	Does this limit your activities in any way?	
B1.1	Certain infectious and parasitic diseases	No [ ] 2	Yes [ ] 1
B1.2	Neoplasms	No [ ] 2	Yes [ ] 1
B1.3	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	No [ ] 2	Yes [ ] 1
B1.4	Endocrine, nutritional and metabolic diseases	No [ ] 2	Yes [ ] 1
B1.5	Mental and behavioural disorders	No [ ] 2	Yes [ ] 1
B1.6	Diseases of the nervous system	No [ ] 2	Yes [ ] 1
B1.7	Diseases of the eye and adnexa	No [ ] 2	Yes [ ] 1
B1.8	Diseases of the ear and mastoid process	No [ ] 2	Yes [ ] 1
B1.9	Diseases of the circulatory system	No [ ] 2	Yes [ ] 1
B1.10	Diseases of the respiratory system	No [ ] 2	Yes [ ] 1
B1.11	Diseases of the digestive system	No [ ] 2	Yes [ ] 1
B1.12	Diseases of the skin and subcutaneous tissue	No [ ] 2	Yes [ ] 1
B1.13	Diseases of the musculoskeletal system and connective tissue	No [ ] 2	Yes [ ] 1
B1.14	Diseases of the genitourinary system	No [ ] 2	Yes [ ] 1
B1.15	Pregnancy, childbirth and the puerperium	No [ ] 2	Yes [ ] 1
B1.16	Certain conditions originating in the perinatal period	No [ ] 2	Yes [ ] 1
B1.17	Congenital malformations, deformations and chromosomal abnormalities	No [ ] 2	Yes [ ] 1
B1.18	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	No [ ] 2	Yes [ ] 1
B1.19	Injury, poisoning and certain other consequences of external causes	No [ ] 2	Yes [ ] 1
B1.20	External causes of morbidity and mortality	No [ ] 2	Yes [ ] 1
B1.21	Factors influencing health status and contact with health services	No [ ] 2	Yes [ ] 1
B1.22	Codes for special purposes	No [ ] 2	Yes [ ] 1

B2. EPILEPSY

1. Has the person ever experienced **seizures, epilepsy or fits**? **YES [ ] 1**

NO [ ] 2

If yes, who does the person see about their epilepsy…………………………………………………………?

B3. VISION

1. Does the person have a **visual impairment or problem** in her / his eye/s e.g. cataract, short sighted? **YES [ ] 1**

NO [ ] 2

If **YES**, specify

……………………………………………………………………………………...

……………………………..…………………………….………………………………
……………..

……………………………..…………………………….………………………………
……………..

2. Is the person **registered blind or partially sighted?**
   YES [ ] 1

NO [ ] 2

B4. HEARING

1. Does the person have a **hearing impairment or problem with her / his ear/s** e.g. repeated ear infections, deaf? **YES [ ] 1**

NO [ ] 2

If **YES**, specify

……………………………………………………………………………………...

………………………....……………………………………………………………………
……………..

B5. Does the person have any of the health problems listed below?

Health problem or diagnosis	
High blood pressure	No [ ] 2 Yes [ ] 1
High cholesterol	No [ ] 2 Yes [ ] 1
Heart disease	No [ ] 2 Yes [ ] 1
Asthma	No [ ] 2 Yes [ ] 1
Arthritis	No [ ] 2 Yes [ ] 1
Osteoporosis	No [ ] 2 Yes [ ] 1
Problems breathing whilst asleep (OSA)	No [ ] 2 Yes [ ] 1
Diabetes	No [ ] 2 Yes [ ] 1
Problems walking because of their weight	No [ ] 2 Yes [ ] 1

B6A. MEDICATION

1. Ask to see all the **medications** the person is currently taking, and list them. Ask why the person is prescribed each medication. Include non-prescription medications such as those bought over the counter e.g. antihistamines, and complementary medications.

Drug name	**Dose mg**	**Frequency**	**Reason for prescription**
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			

For coding purposes only, do not ask participant or carers

B6B. Is the person taking any obesenogenic, psychotropic or antiepileptic drugs?

No **2** [ ]

Yes **1** [ ]

B7. BINGE EATING AND PURGING

1. Has the person you support eaten an unusually large amount of food very quickly, even after being asked to slow down the pace of their eating?

No	**2**	[ ]
Yes	**1**	[ ]

2. If you answered "yes" to Q1, how often do they do this?

Less than once a month	A few times a month	About once a week	About three times a week	Every day
☐	☐	☐	☐	☐

3. Has the person ever made themselves sick after eating, or taken medicine to make them go to the toilet, to control their weight?

No	**2**	[ ]
Yes	**1**	[ ]

4. If you answered "yes" to Q3, how often have they do you do this?

Less than once a month	A few times a month	About once a week	About three times a week	Every day
☐	☐	☐	☐	☐

B8. OVERVIEW OF MENTAL HEALTH

1. Does the person have any mental health needs, emotional or psychological problems, dementia or other psychiatric ill health?

No	**2**	[ ]
Yes	**1**	[ ]
Not sure		[ ]

2. Has the person received a diagnosis?

No	**2**	[ ]
Yes	**1**	[ ]
Not sure		[ ]

If YES**, specify the diagnosis……………………………………………………………..............……………**
……………………………………………………………………………………………….…….
..

3. Does the person already see a learning disabilities psychiatrist?

Yes & specify whom……	**1**	**[ ]**
No	**2**	**[ ]**
Not sure		**[ ]**

4. Does the person already see a learning disabilities psychologist?

Yes & specify whom………………………………………………..	**1**	**[ ]**
No	**2**	**[ ]**
Not sure		**[ ]**

B9. PROBLEM BEHAVIOURS –use problem behaviour checklist.

1. Does the person have any **problem behaviours**, challenging behaviour, or special needs related to behaviour?

No	**2**	**[ ]**
Yes	**1**	**[ ]**

If YES, specify type of problem and any support the person receives

……………………….......……………………………………………………………………
……………………..…………………………………………………………………………
……………………………….…………………………………………………………………
……………………………………………………………….

If there is a suggestion that the person has undiagnosed mental ill-health, suggest that you will discuss referral with UCEDD psychiatrist.

B9.2 – for coding only – summary of Problem Behaviour Checklist

	Behaviour present?	**Does Behaviour meet DC-LD criteria?**	**meets Criteria A**	**meets Criteria B**	**meets Criteri a C**	**meets Criteria D**
Verbally aggressive behaviour	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**
Physically aggressive behaviour	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**
Destructiveness to property	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**
Self-injurious behaviour	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**
Sexually inappropriate behaviour	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**
Oppositional behaviour	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**
Wandering behaviour	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**
Faecal smearing	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**
Pica	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes [ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**	**No [ ] 2** **Yes[ ] 1**

SECTION C1: LIFESTYLE HABITS

In this section, you will be asked questions about the eating habits of the person you support.

Please answer by ticking the appropriate box for each question. Please answer ALL questions.

LH1 On average, how many hours does the person you support spend watching TV, DVDs or videos?

Does not watch TV	1-3 hours a month	1 hour a week	2-4 hours a week	5-6 hours a week	1 hour a day	2–3 hours a day	4-5 hours a day	6+ hoursday
☐	☐	☐	☐	☐	☐	☐	☐	☐

LH2 On average, how many hours does the person you support spend using computers?

Include hours spent playing computer games on PC, X-Box, Playstation etc.

Does not use computer	1-3 hours a month	1 hour a week	2-4 hours a week	5-6 hours a week	1 hour a day	2–3 hours a day	4-5 hours a day	6+ hoursday
☐	☐	☐	☐	☐	☐	☐	☐	☐

LH3 On average, how many cigarettes, if any, does the person you support smoke?

None, does not smoke	less than 1 cigarette a month	1-3 cigarettes a month	1-6 cigarettes a week	1-3 cigarettes a day	4-10 cigarettes a day	11-20 cigarettes a day	21-39 cigarettes a day	40+ cigarettes a day
☐	☐	☐	☐	☐	☐	☐	☐	☐

LH4 On average, how much alcohol does the person you support usually drink during a typical week?

Type of Alcohol **Amount** **Units**

LH5
Units Total =

Section C2: Food & Drink

In this section, you will be asked questions about the eating habits of the person you support

Please answer by ticking the appropriate box for each question. Please answer ALL questions.

FD1 How many main meals does the person you support usually have each day?

1	2	3	4+
☐	☐	☐	☐

FD2 How often does the person you support eat breakfast?

Never	Occasionally	Most Days	Always
☐	☐	☐	☐

FD3 On average, how many portions of fruit and vegetables does the person you support eat each day? *Can include one glass of fruit juice a day.*

None	1-2	3-4	5-6	7-8	9 or more
☐	☐	☐	☐	☐	☐

FD4 How often does the person you support eat chocolate, crisps or biscuits? *Include savoury biscuits such as cream crackers.*

Never, or less than 1 a month	1-3 times a month	Once a Week	2-4 times a week	5-6 times a week	Once a Day	2–3 times a day	4–5 times a day	6+ times a day
☐	☐	☐	☐	☐	☐	☐	☐	☐

FD5 **How often does the person you support eat cakes, scones, sweet pies or puddings?**

Never, or less than 1 a month	1-3 times a month	Once a Week	2-4 times a week	5-6 times a week	Once a Day	2–3 times a day	4–5 times a day	6+ times a day
☐	☐	☐	☐	☐	☐	☐	☐	☐

FD6 **How often does the person you support drink soft drinks, not including diet or low-calorie drinks?** ***Include squashes and fizzy drinks. Include cans, bottles and mixers. Do not include fresh fruit juice.***

Never, or less than 1 a month	1-3 times a month	Once a Week	2-4 times a week	5-6 times a week	Once a Day	2–3 times a day	4–5 times a day	6+ times a day
☐	☐	☐	☐	☐	☐	☐	☐	☐

FD7 **How often does the person you support eat carry out food? Include chip shop, Chinese or Indian food**

Never, or less than 1 a month	1-3 times a month	Once a Week	2-4 times a week	5-6 times a week	Once a Day	2–3 times a day	4–5 times a day	6+ times a day
☐	☐	☐	☐	☐	☐	☐	☐	☐

FD8 **How often does the person you support eat food from a fast food outlet? Give examples of McDonalds, Burger King or KFC**

Never, or less than 1 a month	1-3 times a month	Once a Week	2-4 times a week	5-6 times a week	Once a Day	2–3 times a day	4–5 times a day	6+ times a day
☐	☐	☐	☐	☐	☐	☐	☐	☐

For coding purposes only do not ask participants.

FD9 Does the person eat five or more portions of fruit and vegetables a day?

Yes (1) No (2)

☐ ☐

FD10 Does the person eat chocolate, crisps or biscuits once a day or more?

Yes (1) No (2)

☐ ☐

FD11 Does the person eat cakes, scones, sweets, pies or puddings once a day or more?

Yes (1) No (2)

☐ ☐

FD12 Does the person drink sugary soft drinks once a day or more?

Yes (1) No (2)

☐ ☐

FD13 Does the person eat carry out food two or more times a week?

Yes (1) No (2)

☐ ☐

FD14 Does the person eat fast food two or more times a week?

Yes (1) No (2)

☐ ☐

Section C3: Physical Activity Levels

In this section, you will be asked questions about the physical activity levels of the person you support.

INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

I am interested in finding out about the kinds of physical activities the person you support does as part of their everyday life. The questions will ask you about the time he/she spent being physically active in the **last 7 days**. Please try and answer each question even if you do not consider the person you support to be an active person. Please think about activities they do at work, as part of housework, to get from place to place, and in spare time for recreation, exercise or sport. I am going to ask about walking and moderate exercise later. First I would like to ask about vigorous activities.

VIGOROUS
Think about all the **vigorous** activities that the person you support did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Vigorous: Gasping! Muscles aching, breathing fast and very heavy. Difficulty catching breath. Things like running, competitive sports, martial arts or other exercise classes.

We are interested in any physical activities that they did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did the person you support do **vigorous** physical activity?

   _____ days per week

   ☐ No vigorous physical activities → ***Skip to question 3***

2. How much time did he/ she usually spend doing **vigorous** physical activities on one of those days?

   _____ hours per day

   _____ minutes per day

   ☐ Don’t know/Not sure

MODERATE
Think about all the **moderate** activities that the person you support did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did the person you support do **moderate** physical activities like playing sports for fun, cycling or dancing? Moderate activities make people feel comfortably breathless. Can still talk and feel slightly sweaty.

   Do not include walking.

   _____ **days per week**

   ☐ No moderate physical activities → ***Skip to question 5***

4. How much time did he/she usually spend doing **moderate** physical activities on one of those days?

   _____ **hours per day**

   _____ **minutes per day**

   ☐ Don't know/Not sure

WALKING
Think about the time the person you support spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you might do solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did they **walk** for at least 10 minutes at a time?

   _____ **days per week**

   ☐ No walking → ***Skip to question 7***

6. How much time did they usually spend **walking** on one of those days?

   _____ **hours per day**

   _____ **minutes per day**

   ☐ Don't know/Not sure

The last question is about the time the person you support spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, on a bus, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did the person you support spend **sitting** on a **week day**?

_____ hours per day

_____ minutes per day

☐ Don't know/Not sure

This is the end of the questionnaire, thank you for answering the questions

Appendix 5 Resources used in TAKE 5 weight loss maintenance phase

Name ____________ Date ____________

Personalised Dietary Prescription of 2300 calories per day

	Food Groups	**Weight loss**	**Weight maintenance**
		Portions for 1900 calories per day	Portions for 2300 calories per day
	Starches (bread, cereals, potatoes, rice, pasta)	**9**	**12**
	Fruit and vegetables	**5**	**5**
	Dairy	**3**	**3**
	Meat, fish , eggs, beans and lentils	**3**	**3**
	Fats (butter, low fat, oil, mayonnaise, salad cream)	**2**	**2**
	Treats (sweet foods, extra portions, dessert, crisps)	**70 Calories**	**230Calories**

Take5

<u>Handout session 4:</u>

How to become more active

Start with small targets

It is easier if you start with activities that you are already able to do.

Then do more

- **This is not a good target**

  Walk for 60 minutes everyday

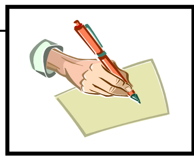
- **This is a good target**

  Walk for 10 minutes twice per day

At the end of the week check what you did.

Do you feel pleased?

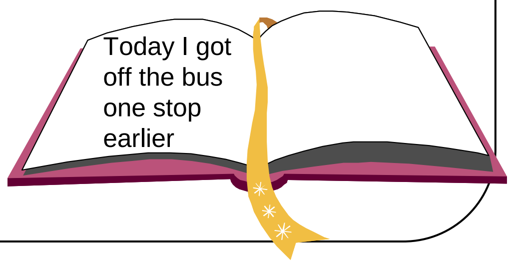
Now, how can you do more?



Write your activities in a diary

People who write their activities in a dairy can control their weight better. You can do this with a friend together.

- Write what you did
- What can you change?
- Can you do more?



Remember your activities

Find ways to remember your activities

- Choose to go for a walk after the TV programme you like.
- Leave your swim suit or your gym clothes on the top of your drawer, to remind you to do your activity.

You are active – feel happy

Sometimes we do not want to go for a walk.

Try to think why being active is good for you.

Going for a walk can help you keep your weight the same.

I did too much at the centre today. I do not want to dance today at home.

If I do my dance then I will feel better. I will have fun, my weight will not go up and I will feel pleased.

Try and make it have a purpose

- If you have to go to the shops, walk. Do not take the bus or taxi
- If you take the bus, get off a stop earlier
- Take the stairs and not the escalators when shopping

<u>**Handout session 5:**</u>

Pack a healthy lunch

Many people choose to take a packed lunch to work, the day centre or college.

A packed lunch is a great idea because

- It saves money
- You can decide what is in your meal

Packed lunches do not have to be boring.

Ideas for packed lunches

Bread, pasta and rice

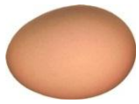
- Try different types of bread. Try sliced bread, bread rolls, pita breads, bagels, baguettes.

- Try wholemeal or granary brown bread.

- Use rice or pasta for a salad. Try the recipes that we gave you.

Fillings

- Use lean meat or chicken or fish or hard boiled eggs in sandwiches or salads.

- If you use bacon, choose lean bacon.

  Cut the fat off and grill it.

- Try mashed sardines with vinegar or tomato.

- Make a sandwich with ham or cheese and salad.

- If you use cheese, choose a low fat variety and the right portion.

- Use less butter, spread, mayonnaise or other dressing if the filling is moist.

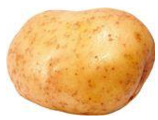
- If you do have mayonnaise, choose a low fat variety when you can.

Soups

- Soups count as one of your five a day fruit and vegetable portions. Use chunky vegetables.

- Avoid cans of soup because they can be high in salt. Try one of the recipes that we gave you and make your own soup.

- Potatoes can also give soups a thick and creamy texture without having to add butter or cream.



- To make your soup more filling have it with a bread roll.

Other ideas

- Add colour to your lunch with chopped raw vegetables.

Try carrot or pepper sticks or cherry tomatoes with cottage cheese.

- Have fruit canned in natural juice after your lunch. It can be very refreshing.

- Do not forget your low fat yoghurt.

What about treats?

Choose carefully the treats for your packed lunch

- low fat crisps

- plain biscuits

- a scone

- a sugar free jelly

What about drinks?

Try

- Water

- A glass of low fat milk

- Sugar free squash

- Low calorie hot chocolate drink

- Sugar free drinks

Store your lunch safely

- Store your lunch in the fridge or in a cool place.

Handout session 9:

Not going back to old habits

Everyone makes mistakes, we are only human. When people are trying to lose weight they may go back to old habits – this is common. Although this sounds gloomy, the good news is that there is something you can do if this happens.

You have to be prepared to take action.

High risk situations

- Being alone at home, with the chance to eat whatever is in the cupboards
- At a buffet when there is lots of different types of food on offer
- On holiday, when you have always seen it as a treat to eat a lot
- Feeling low or depressed 
- Being bored 
- Feeling angry or upset 
- Having an argument
- Wanting to celebrate good news 
- Feeling relieved about something that has been worrying you

Ask yourself these questions:

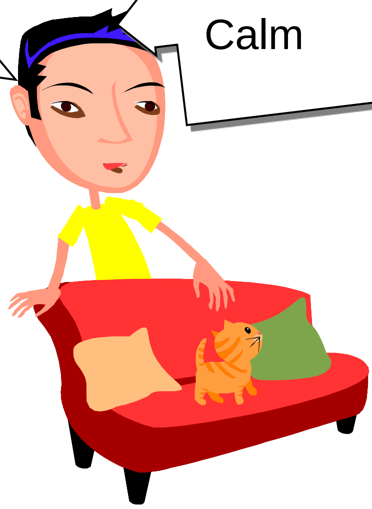
- Was I feeling tired, lonely or frustrated?
- Was I angry, stressed or bored?
- Did I have to deal with a particular person or situation?
- Did I find it difficult to say no when someone offered me food?
- Did it happen when I was alone?

What to do

- **Stop- stay calm -think**

Stay

Calm



Have a cake

- Think **why ?**

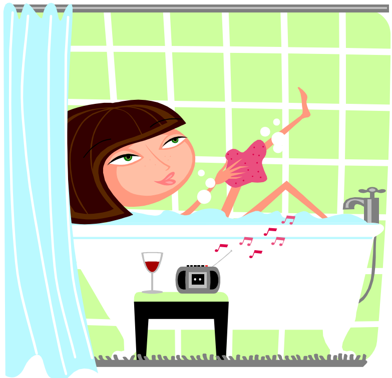
Why

Deal with it: Make a list of alternative activities

Make sure the list contains enjoyable activities that are not food related:

Ring a friend

Have a relaxing bath



Go for a walk

Recall your reasons for wanting to lose weight.

I want to lose weight because

1……………………….

- **Get support**. Other people can be a great source of support when you do not feel strong enough to rely on yourself.

Appendix 6

Carers' semi-structured interview schedule:

As you already know my name is D_ and I am a dietitian working for NHS and University of Glasgow. We are here today to chat with you about how L_ coped with the changes in her diet and physical activity and of course to talk about your experiences assisting L_ to cope with these changes. We hope the information will help us and other people with learning disabilities to understand the principles regarding weight loss and obesity.

All the information which is collected from you during the course of the interview will be kept strictly confidential. With your agreement we would like to record the interview.

This will mean we won't have to write anything down and would allow us to talk more freely. There is no right or wrong answer to any of the questions.

It is helpful to be honest about the things that you like and the things that you don't like so much. I can explain any questions that are unclear.

If there is any question that you do not want to answer it is okay, we can move onto the next question. Thank you for your help.

2. As you know, X has been trying to make changes to his diet and physical activity over the last few months, so I would like to begin by asking you how you feel about these changes. [Can I ask you to tell me some of these changes? – only if necessary]
3. Were there any difficulties you faced while trying to support X to lose weight? How did you deal with these? Prompts: sufficient information, enough support.
4. Was it difficult to communicate with the rest of the staff in the house?
5. Was it difficult to change X's routine,

6. What about communication with staff at the resource centre or college?
7. Do you think that there were specific things that helped X lose weight? Can you tell me a bit more about them? Prompt: extra things that could be discussed are the support that the carers offer to the client, the regular visits of the health professional or the resources used, PDP, increasing physical activity.
8. If the client hasn't lost weight- Do you have any thoughts of why this happened?
9. How did you find the "How to help someone lose weight" booklet and the rest of the booklets? Did you learn anything new? How about the recipes and the pedometers?
10. In previous sessions, we set 2-3 targets for the next 2 weeks. What do you think about these targets? Do you think that these targets were achievable? Suitable for your client?
11. Can you give me a feedback regarding the PDP's? Was it easy for you to follow the PDP? What aspects of the PDP you found difficult?
12. Do you plan what X will eat? If yes, do you think that this helps other staff to prepare healthy foods? if no does this make it more difficult for the staff to follow the recommendations? What do you suggest?
13. How do you think X is coping with the changes to his diet?
14. What about X's physical activity?
15. Would you like to see X continue to receive help with his diet and activity? What kind of help? Why?
16. Is there anything that would help you support X better in adopting healthier eating and activity patterns?
17. Are there any suggestions you would like to make regarding the "Take 5"programme?

Appendix 7

Example of Clustering Codes	
Clustered Codes	**Codes**
Reasons to lose wt: Health	Reasons to lose wt: breathing Reasons to lose wt: health Reasons to lose wt: heart Reasons to lose wt: live longer Reasons to lose wt: planned operation Reasons to lose wt: tiredness
Reasons to lose wt: Psychosocial	Reasons to lose wt: confidence Reasons to lose wt: career Reasons to lose wt: mental health Reasons to lose wt: Independence
Impact of wt loss: Health	Impact of weight loss: breathing Impact of weight loss: health
Impact of wt loss: Psychosocial	Impact of weight loss: confidence Impact of weight loss: mental state
Carer’s efforts-diet: Healthy diet	Carer's efforts-diet: cut down foods-fat/sugar Carer's efforts-diet: use of low fat/sugar foods Carer's efforts-diet: less snacking Carer's efforts-diet: avoid unhealthy meals Carer's efforts-diet: fruit and veg Carer's efforts-diet: replace unhealthy foods Carer's efforts-diet: use of low cal ready-made meals Carer's efforts-diet: variety
Carer’s efforts-diet: Healthy skills	Carer's efforts-diet: healthy cooking Carer's efforts-diet: homemade cooking Carer's efforts-diet: food labeling Carer's efforts-diet: food shopping Carer's efforts-diet: availability of healthy foods Carer's efforts-diet: avoid meals out Carer's efforts-diet: avoid take-away
Carer’s efforts-diet: Allowance	Carer's efforts-diet: offer healthy choices Carer's efforts-diet: allowance of fatty foods Carer's efforts-diet: allowance of treats
Carer’s efforts-diet: Control	Carer's efforts-diet: cut down money Carer's efforts-Diet: packed lunches Carer's efforts: being assertive Carer's efforts-diet: No allowance of treats
Client’s efforts-diet: Healthy diet	Client's efforts-diet: eating more fruit and veg Client's efforts-diet: eats healthy foods Client's efforts-diet: not eating foods high in sugar/ fat Client's efforts-diet: not eating snacks
Client’s efforts-diet: Healthy dietary habits	Client's efforts-diet: makes better food choices Client's efforts-diet: not eating at night Client's efforts-diet: not buying foods from outside Client's efforts-diet: not buying sweets from outside Client's efforts-diet: not eating out Client's efforts-diet: eating less

Client’s efforts-PA: indoors	Client's efforts-PA: housework Client's efforts-PA: use of dice
Client’s efforts-PA: outdoors	Client's efforts-PA: dancing Client's efforts-PA: swimming Client's efforts-PA: gym Client's efforts-PA: walking
Client not complying: unhealthy diet	Client not complying: eats foods high in sugar/ fat Client not complying: eating food Client not complying: eating treats Client not complying: snacking Client not complying: drinking alcohol Client not complying: general
Client not complying: unhealthy dietary habits	Client not complying: eating when staff not present Client not complying: buying food from outside Client not complying: eating during the night

Appendix 8

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Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: a qualitative study

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Abstract

Background To date, no studies have explored the role of carers in supporting adults with intellectual disabilities (ID) and obesity during a weight loss intervention. The present study explored perceptions of carers supporting adults with ID, as they participated in a 6-month multi-component weight loss intervention (TAKE 5).
Methods Semi-structured interviews were used to explore the experiences of 24 carers. The transcripts were analysed qualitatively using thematic analysis.
Results Three themes emerged from the analysis: carers' perceptions of participants' health; barriers and facilitators to weight loss; and carers' perceptions of the weight loss intervention. Data analysis showed similarities between the experiences reported by the carers who supported participants who lost weight and participants who did not. Lack of sufficient support from people from the internal and external environment of individuals with ID and poor communication among carers, were identified as being barriers to change. The need for accessible resources tailored to aid weight loss among adults with ID was also highlighted.
Conclusion This study identified specific facilitators and barriers experienced by carers during the process of supporting obese adults with ID to lose weight. Future research could utilise these findings to inform appropriate and effective weight management interventions for individuals with ID.

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Keywords carers, intellectual disabilities, obesity, weight loss

Introduction

International epidemiological data on the prevalence and incidence of intellectual disabilities (ID) range from three to five per 1000 of the general population in developed nations, and are estimated to be higher in developing countries (Fujiura *et al.* 2005). Individuals with ID have more complex health needs than the general population (Cooper 1997) and experience significant health inequalities, including barriers to accessing health services and exclusion from health promotion strategies (Alborz *et al.* 2005; Emerson & Baines 2010).

Obesity and intellectual disabilities

There is global concern about the epidemic of obesity and its impact on health (Haslam & James 2005). The prevalence of obesity is higher in adults with ID than in the general population (Melville *et al.* 2008), with increased rates of secondary health risks and increased mortality rates (Haveman *et al.* 2010).

Sustainable weight loss of 5% of initial body weight has been associated with clinically important health benefits in obese individuals (Avenell *et al.* 2004; Ryan 2005). Evidence suggests that this weight loss is best achieved with a multi-component weight loss intervention, incorporating dietary changes that produce a 600 kilocalorie (kcal)/2510 kilojoule (kJ) per day energy deficit, increased levels of physical activity and the use of behavioural approaches to promote and sustain changes in physical activity and dietary patterns [National Institute for Health and Clinical Excellence (NICE) 2006; Scottish Intercollegiate Guideline Network (SIGN) 2010]. There is a lack of evidence on the effectiveness of weight loss interventions for adults with ID (Melville *et al.* 2011).

Some studies report that support from family or paid carers can have a positive impact on weight loss for adults with ID and obesity (Hamilton *et al.* 2007). Four weight loss studies have employed a behavioural approach within their intervention, with family or paid carer involvement. In the intervention, carer involvement in the studies varied from offering support to the participants during sessions, to encouragement and reinforcement of healthy lifestyle messages (Harris & Bloom 1984; Fox *et al.* 1985; McCarran & Andrasik 1990; Bazzano *et al.* 2009). No study explored the role of carers in the weight loss process.

Involvement of carers

Carers have a pivotal relationship with the person they support, often reporting the barriers or difficulties their clients' experience. This makes it essential to involve carers in research for examining the health and well-being of adults with ID (Kiernan 1999).

The role of carers in supporting individuals with ID has been recognised as an important factor in meeting the needs of individuals with ID (NHS Health Scotland 2004). Carers can have a strong influence on the dietary patterns of people with ID by making food choices on their behalf based on their own knowledge or preferences (Rodgers 1998). However, carers may have poor knowledge in relation to appropriate healthy eating and physical activity patterns (Melville *et al.* 2009). Therefore, carers may impact on the health risks of individuals they support by promoting unhealthy food choices (Smyth & Bell 2006).

To date, there is limited evidence on the views and experiences of carers supporting individuals with ID participating in a weight loss intervention (Jinks *et al.* 2010).

The present study aimed to:

1 explore the experiences of carers supporting adults with ID participating in a multi-component weight loss intervention;

2 identify strategies that carers and participants adopt to overcome barriers to change in lifestyle habits; and

3 record carers' perceptions of the acceptability and utility of the multi-component weight loss intervention.

Methods

The present study used a qualitative design to explore carers' experiences and behaviour, with emphasis on their attitudes, interactions and views (Mays & Pope 1996; Silverman 2005). Ethical approval was gained from the Scotland A Research Ethics Committee, and the relevant local research ethics committee.

Participants

The study sample was recruited from carers supporting adults (≥18 years) with ID and obesity (body mass index ≥30 kg^2) participating in a study of a weight loss intervention (TAKE 5). TAKE 5 is a multi-component weight loss intervention that fully incorporates the recommendations of current clinical guidelines (Melville *et al.* 2011). The weight loss intervention included a personalised dietary prescription (PDP) producing a 600 kcal/2510 kJ per day energy deficit, methods to support increased physical activity levels and the use of behavioural approaches to promote change in physical activity and dietary patterns. TAKE 5 comprised nine individual sessions, involving carers to support the participants where appropriate. The intervention included booklets and a DVD that provided information in a form appropriate to the cognitive needs of the participants. The TAKE 5 intervention aimed for a 5% weight loss from the initial body weight, of participants over a period of 6 months. A full description of the TAKE 5 intervention and the results of the feasibility study examining weight loss have been reported previously (Melville *et al.* 2011).

A purposive sample of 24 carers took part: 16 paid and eight family carers who supported participants who had achieved a 5% weight loss ($n = 12$) or did not ($n = 12$). The carers provided full or part-time support (1–24 h) to the participants at home. The participants lived independently, in cluster care, in supported settings such as shared tenancies, or in family homes in the catchment area of NHS Greater Glasgow and Clyde, UK. Each carer, representing one participant each, was invited to participate in a research interview at the end of the weight loss study. Data from two interviews were of insufficient quality to be analysed qualitatively. Therefore, 22 interviews were included in the analysis.

Interviews

The interview schedule comprised a series of semi-structured questions. An initial set of open-ended questions defined the areas to be explored, allowing the interviewee and interviewer to deviate and explore comments in detail (Mays & Pope 1996). The interview schedule was developed based on the recommendations of Patton (1987), using questions based on behaviour or experience, opinion or value, feeling and knowledge. The schedule was divided into three general topics: (1) carers' perceptions of weight loss; (2) challenges faced while supporting participants to change his/her dietary and physical activity patterns; and (3) carers' perceptions of the weight loss intervention.

After reviewing three early interviews, the schedule was revised to include extra prompts to assist the researcher to explore the experiences of carers with the intervention, fully. All the interviews were conducted on a one-to-one basis, in participants' own homes, by one of the researchers (DS). They lasted between 30–40 min. Interviews were audio-recorded digitally, using the Olympus DSS player 2300, to allow review of interviewing quality and transcription of the data. Carers were assured that their views would remain anonymous and confidential.

Data analysis

The main objective of the analysis was to explore the positive and negative experiences of carers supporting participants with ID, during the process of a weight loss intervention. All data were anonymised and transcribed verbatim. The transcribed interviews were not shared with the carers. Although respondent validation is considered as the ultimate check (Lincoln & Guba 1985), the researchers believe that this method may rely on the false assumption that interviewees share the same critical ability as the researcher (textual reference) or can act as unbiased assessors (Murphy *et al.* 1998).

The qualitative data software analysis package, ATLAS.ti 5.2 software (Scientific Software Development GmbH, Berlin, Berlin-Brandenburg, Germany) was used to organise the transcripts and analyse the data. The qualitative analytic method used was thematic analysis, which is a flexible method that can be used to explore experiences of participants and describe patterns within the qualitative data, without being influenced by other pre-existing theoretical frameworks. The analysis was an inductive process, as the categories and the themes, unlike the topics of interest, were not predetermined prior to the coding of the data (Ezzy 2002). It was performed in the following six steps as outlined by Braun & Clarke (2006): (1) the researcher listened to the audio recordings and read the transcripts several times to familiarise himself with the data. A list of ideas were produced and discussed with a second researcher (CM) before (2) identification of potential data-driven codes. Extracts were matched with the listed codes: (3) codes were collated to more general codes followed by the creation of potential sub-themes and broader concepts the themes (4) revision of the themes, collapsing the ones sharing relevant data and designing a thematic map (5) acceptance of the final themes and addition of descriptions (6) the researcher chose extracts that were associated with the themes and the research questions for the report.

The process of coding and production of themes was an ongoing process susceptible to changes following review and discussion with an additional researcher. As a measure of validity, the additional researcher (CM) reviewed the process of data analysis and analysed three randomly selected transcripts and cooperated with the primary researcher in the linking of codes and the development of themes. As the same researcher gathered all data, continuity and consistency of approach and interpretation were preserved.

For purposes of confidentiality, all names from the extracts have been changed. When providing extracts from the interviews the following transcripts conventions are used:

. . . – Short pause;
(. . .) – Words omitted to shorten quote;
[Text] – explanatory information included by author;
C – Comment provided by the carer; and
I – Comment made by interviewer.

Results

The following three master themes were identified:

- Carers' perceptions of participants' health;
- Barriers and facilitators to weight loss; and
- Carers' perceptions of the multi-component weight loss intervention.

Each theme was discussed, subdivided into smaller sub-themes and represented by verbatim extracts from the interviews. Extracts were chosen from paid and family carers of:

1 participants who lost weight (at least 5% weight loss form initial body weight); and
2 participants who did not lose weight (<5% weight loss from initial body weight).

Theme 1: Carers' perceptions of participants' health

Reasons to lose weight

The carers from both groups identified three main reasons they felt a participant should try to lose weight: health, mobility and psychosocial reasons. According to most of the carers, participants should lose weight to improve their health in general. When asked to be more specific they reported that weight loss can prevent heart problems, prevent diabetes and increase life expectancy. Psychosocial reasons such as increased independence, opportunities for employment and emotional benefits were also identified to a lesser extent.

> C: Long-term health benefits . . . and obviously health risks and things like that have been reduced. I: When you say health risks, what do you mean? C: Diabetes and heart disease, any other illnesses caused by obesity and things.

Impact of weight loss on participants

Carers from both groups mainly described the noticeable impact of weight loss on participants' appearance. Other impacts of weight loss described were improvement of mobility, e.g. walking, improvement in sleeping patterns and breathing. Changes in confidence and emotional benefits were also reported:

> There has obviously been a good weight loss and that in turn has probably made her a bit more confident because when we were buying clothes she didn't always like to go in and try them on, now she can't wait to try them on. (Paid carer of a participant who lost weight)

Theme 2: Barriers and facilitators to weight loss

Barriers in the care plan

The carers of participants who did not lose weight explained that they had difficulties supporting the participants when other care staff did not follow the support plan for weight loss, or did not comply with the recommendations of the PDP, e.g. offering too many foods high in fat and in larger than recommended portions. In addition, limited cooking skills, less healthy cooking methods or frequent dining out were reported as barriers in several interviews. Carers from both groups spoke about the need for motivated staff who can work in a 'consistent' way to facilitate the support of a participant during the weight loss process:

> We tried to follow the guidelines (. . .) but again it's the consistency, it has to be everybody. (Paid carer of a participant who did not lose weight)

Carers from both groups reported that big teams and 'new staff' replacing permanent staff for short periods could not provide appropriate support for the participants. It is more difficult to sustain effective communication in big teams and new staff may provide less efficient weight loss support than carers that have worked with a participant for longer periods:

> If there are too many people there it gets lost, the communication gets lost, it breaks down. (Family carer of a participant who lost weight)

> You get somebody in who is just new and ach [oh well] I'll just do that for quickness and doesn't know what they've been through. (Paid carer of a participant who lost weight)

Carers from both groups expressed the need for more time to support participants during the weight loss intervention. In particular, family carers had difficulties offering support to participants and dealings with their own 'busy' life at the same time:

> I've got a very busy life as well, my mum passed away as well and my dad wasn't well either so it's quite a busy household, my husband, my kids, myself – I've got a daughter in care so I find it quite hard. (Family carer of a participant who lost weight)

Paid carers reported that instability with the support shifts acted as a barrier to their efforts to support participants during the weight loss intervention. They suggested that more time with the specific participant was needed in order to be able to offer appropriate support with menu planning and to ensure that the rest of the staff and the participant followed the intervention.

In addition, poor staffing levels and supporting more than one person in the same accommodation acted as a barrier to the carers' efforts to provide better support to a participant in a weight loss intervention. In some cases, carers had to support and to prepare meals for two people who had different dietary requirements (high calorie diet for an undernourished client and low calorie diet for an obese TAKE 5 participant) but lived in the same accommodation.

Facilitators in the care plan

Carers from both groups suggested that small teams, with established staff, can provide better support to a participant in a weight loss intervention. The benefits of a small stable team include better communication, ensuring that the weight loss plan is followed more closely and a consistent environment, which is essential for many adults with ID:

> We are a stable team, we're able to talk to each other; we can see each other on a regular basis (. . .) so we can pass any information on as far as dietary requirements are. (Paid carer of a participant who lost weight)

> They [small team] would build up a routine with Anne, so therefore Anne would get used to going out on x day with so and so (. . .). (Family carer that provides support with paid carers to a participant who lost weight)

Two carers spoke about the importance of involving participants with activities that could facilitate the weight loss process and can have a positive impact on their confidence such as healthy cooking and healthy shopping:

> There's no point just saying 'Look there's your dinner, that's all you are getting', I think you've got to involve them. They are looking to lose weight and if you can involve them as much as possible and includes prepare it [meal]. (Paid carer of a participant who lost weight)

> She'll not know the difference, say it was like she picked up a jelly for instance and it's sugar in it and picking up another one and saying 'Oh that one not got any sugar (. . .)' and just basically prompting and reminding her and giving her a healthier alternative. (Paid carer of a participant who lost weight)

The carers of participants who lost weight described praising and giving positive encouragement to a participant as a successful strategy to support participants to reach their targets during the weight loss process:

> At the beginning it was hard for him, like everybody else it's hard when you go on a diet, but we'd always praised him and gave him that support. (Paid carer of a participant who lost weight)

Barriers within belief systems

It was acknowledged, mainly by the carers of participants who lost weight, that not all the carers or family members shared the same view of the benefits of weight loss for obese adults with ID. Some carers felt that there was lack of understanding from other carers or family members who frequently perceived their efforts as acts of 'deprivation'. They also reported that their colleagues would not consider weight loss as a priority for an adult with ID, or they would regard someone having ID as a justification for not restricting food choice:

> It's obviously a social thing and it's very difficult to overcome it, especially when the person has a handicap (. . .) they think 'Oh goodness let him have it'. (Family carer of a participant who lost weight)

Both groups of carers stated that 'freedom of choice' was consistently debated between carers and other support staff at participants home, and resource centres. For some support staff, adults with ID are responsible for their own choices. However, a carer explained that there is a need to support people with ID to make an informed choice in relation to healthy lifestyles:

> Some carers saying 'Well she's an adult she's got a choice' (. . .) we've got to help her make – still give her choices but help her to make healthier choices. (Paid carer of a participant who lost weight)

Participants' efforts to adopt healthy lifestyles

Barriers to change. Carers of participants who did not lose weight reported having difficulties supporting participants who were unwilling to increase their physical activity levels or make healthy food choices when unsupported. A mother of a participant expressed her strong concerns about her son's ability and motivation, to make healthy food choices when he is not at home:

> We obviously are a big influence with him staying at home, but we would eventually hope that he does go somewhere and the thought terrifies me from the point of view of if he can then eat whenever and whatever. (Family carer of a participant who lost weight)

The participants' level of ID was perceived as a barrier during the process of weight loss, by both groups of carers. Some participants were not able to understand the principles of weight loss, including following a healthy diet and increasing physical activity patterns:

> She doesn't understand the contents of food and portioning (. . .), she doesn't understand a small loaf shouldn't just last a day. (Paid carer of a participant who did not lose weight)

Intellectual disabilities or cognitive difficulties were seen as having an impact on participant's motivation to lose weight. Carers did try to explain the health benefits of weight loss to participants but it was described as a challenging process. Discussion or experience of the health risks associated with obesity did not appear to have an impact on participants:

> Her health doesn't motivate her, because she doesn't have that understanding or concept. (Family carer of a participant who lost weight)

Facilitators of change. According to the views of both groups of carers, weight loss can be successful when a participant is motivated to lose weight and willing to make changes in his/her diet and physical activity patterns:

> You've always got to have a client that is willing to lose weight; if the clients aren't willing to lose weight it isn't going happen. (Paid carer of a participant who lost weight)

Carers highlighted the ability and the efforts of some participants to make changes with their diet and physical activity independently. This helped the carers to build a relationship of 'trust' with the participants.

Communication

Barriers to communication. Communication between carers in a team was mainly through the use of written reports, known as the 'communication book'. Matters of concern were discussed during staff meetings. One of the barriers highlighted by both groups of carers was a lack of communication between staff in a team supporting a participant. Transfer of information through the use of a 'communication book' was often unsuccessful particularly for the carers of participants who did not lose weight:

> Mary [carer] was good at writing everything up, but does everybody read it? (Paid carer of a participant who did not lose weight)

Carers from both groups reported difficulties with establishing communication with the external environment of a participant, such as the staff at resource centres they attended. The carers at home explained that the main communication route with the key workers at resource centres was annual reviews and they felt that there was lack of information provided by the support staff at centres.

Facilitators of communication. Carers of participants who lost weight facilitated communication with the participants by encouraging them to make lifestyle changes and discussing the benefits of weight loss. A carer reported that a client's ability to communicate and express his feelings to them was also important to allow better individual support:

> He was able to talk to us and we were able to understand it to help him. And that's all it is, is for us to understand it so we can help the client. (Paid carer of a participant who lost weight)

Only two carers of participants who lost weight used direct communication with other staff or family members of the supported individuals to ensure consistency with the weight loss intervention.

Support from the external environment: resource centres and respite units

Barriers to support from the external environment. A majority of carers from both groups reported that they felt there was insufficient support from resource centres to facilitate changes in a participant's diet or physical activity. They reported that resource centres would take participants for meals in fast food outlets, were less likely to support participants to make healthy food choices and they would not follow the advice given by the participant's main carers:

> She was getting McDonald's every week definitely, every time she went bowling with the Centre she was getting McDonald's. (Paid carer of a participant who did not lose weight)

Two carers of participants who lost weight were disappointed with respite units or resource centres not offering a healthy diet. They tried to take control by providing the healthy foods needed for the specific participant at respite or preparing packed lunches for the participant to take to the centre.

Facilitators of support from the external environment. External support from resource centres was provided by promoting healthy lifestyles through specific projects or clubs that participants attended in. These included walking clubs or sessions on achieving healthy eating habits. Only two carers from both groups were satisfied with the meals and foods provided at resource centres.

External barriers. Carers from both groups reported two main external factors that acted as barriers to their efforts to support participants with weight loss. One was the weather, which during the winter prevented participants from doing one of their main physical activities, walking. The second reported factor was safety. Some carers did not feel that participants were safe to do activities outdoors without support:

> I wouldn't let him go a walk on his own which is a key thing you know, so therefore you have to have somebody with him at all time. (Family carer of a participant who lost weight)

Theme 3: Carers' perceptions of the weight loss intervention

Influence of the intervention

The TAKE 5 intervention was recognised as improving the knowledge of the participants and the carers. The aspects of each consultation cited as the most beneficial were checking the participant's weight and reviewing progress with the participant and the carers.

The targets set at the end of each consultation were regarded by both groups of carers as suitable and achievable for both participants and carers. Participants appeared to enjoy setting targets at the end of the consultation and reported liking the process of aiming for something. Carers reported supporting their client to achieve their targets but also described the importance of being flexible regarding the time needed to reach a target because the result would still be of benefit:

> I think the targets were really attainable; they were fine they weren't overstretching anybody, worker or the person. (Paid carer of a participant who lost weight)

Influence of the intervention resources

Carers described the PDP as a good illustration of a healthy balanced diet, helping the carers to identify the food groups and the appropriate daily amounts that needed to be offered to a participant:

> It [PDP] gave staff an idea of a balanced diet which I didn't think Louise had (. . .) if we were completing that and see where it was falling short in certain areas, try and encourage a change of diet to reflect the amount of carbohydrates, fruit and vegetables. (Paid carer of a participant who lost weight)

However, some carers of participants who did not lose weight thought the PDP was too complicated for them and for their colleagues and unsuitable to the cognitive needs of participants.

Several carers from both groups described the booklets as a good source of information and felt they were suitable to meet needs of adults with ID. Carers praised the inclusion of pictures in the booklets that allowed participants who could not read text to use them:

> Mary can't read, Mary can see pictures and work out – that means that and that means this (. . .) and she could see the pictures and went 'oh that's right, that's what I should be eating and that's what I shouldn't be eating'. (Paid carer of a participant who lost weight)

Carers of participants who lost weight explained that using a food diary was another useful tool as long as there was consistency in completion. The food diary was used to record a participant's daily intake, allowing the carers to understand how close the participant's intake was to the principles of a balanced diet.

Suggestions for the intervention

Most carers from both groups were satisfied with the intervention but two carers suggested the intervention should be simplified and adapted more to the needs of the participants. Recommendations included the use of simpler language, to make the intervention 'less complicated', developing strategies to motivate participants and providing set menus.

Several carers of participants who did not lose weight suggested the use of training for staff that would focus on the principles of a healthy balanced diet and cooking:

> I think definitely will be good to give them [Carers] some kind of training (. . .). I mean quite a lot of people cook at home but you know that maybe be 10 out of 30. (Paid carer of a participant who did not lose weight)

The carers reported that there is a need for ongoing support for the participants and the carers regarding their lifestyle. This support could be provided by a health professional that may have an impact on their knowledge and on the participant's motivation to lose weight.

Discussion

It is clear from these findings that the support of adults with ID during a weight loss intervention is a complex and multifaceted process. The results indicated that carers involved in the multi-component weight loss intervention had a general knowledge on the heath risks associated with obesity. The carers correctly identified the major health benefits of weight loss, but less often described the improvements in terms of quality of life, such as a participant becoming more independent or confident. Similar findings have been reported, where carers recognised the health benefits of healthier lifestyles for adults with ID more readily than self-image or quality of life benefits (Melville *et al.* 2009).

The role of the carers in a weight loss intervention

It is well known that carers can have a positive impact upon the health and well-being of people with ID but their role in assisting weight loss in obese individuals is unclear. In this study, the carers highlighted that they facilitated weight loss when they supported and involved participants with ID in practical issues such as healthy cooking and shopping. This means that individuals with ID should not just be passive recipients of healthy living messages but should be encouraged to take an active role in implementing a healthier lifestyle (Pownall 2010).

Successful weight loss interventions have frequently incorporated behavioural techniques to promote changes in diet and physical activity (Norris *et al.* 2005). The carers in this study used behaviour change techniques such as social encouragement and praise, which is similar to the finding of previous weight loss studies (Hamilton *et al.* 2007), but they were also involved in setting dietary targets based on the participants' preferences. In addition, carers promoted realistic physical activity targets based on the ability of both the participant and carer, with walking reported as one of the most common activities. Temple *et al.* (2000) described walking as a low cost opportunity for moderate physical activity and advocated the promotion of the health benefits of intensive walking in adults with ID.

Barriers and solutions

This study identified similarities in the barriers the two groups of carers reported experiencing while supporting participants to lose weight. For all carers, the level of organisation of a service provided to an adult with ID was an important factor during weight loss. The carers expressed the need for a care plan that incorporated small established staff teams that can follow the weight loss plan consistently, and establishing better communication and cooperation between the staff within the same support team. In addition, the findings suggest that carers who support an adult with ID during the weight loss process would benefit from having consistent shift patterns and more one-to-one time allocated with the person they support.

Barriers in communication and cooperation were also identified between the carers from the internal and external service. Annual reviews were not seen as sufficient or effective as a communication method to support the weight loss of the participants. A future qualitative research study assessing the perspectives of the carers working in the external environment could potentially reveal more information about the principles of the services provided at resource centres but also could reveal mechanisms to establish better communication with the carers at the home of the individuals with ID.

The majority of the carers at home described how the unhealthy dietary patterns of the participants at resources centres inhibited their efforts to lose weight and less carers described the positive influence of resource centres on weight loss through health promotion projects. The determinants of obesity in adults with ID are multi-factorial and can be associated with genetic predispositions or metabolic abnormalities but more often are associated with environmental factors (Melville *et al.* 2008). The environment can affect health by asserting a multi-institutional (family, resource centres, local communities) influence on the behaviour (Baranowski *et al.* 2003). Therefore, solutions may require an ecological approach to address the complex behavioural influences. This means that future research could explore the interrelationships among internal and external environmental influences and provide information essential to the management of obesity in adults with ID.

The poor staffing levels described by the paid carers as a barrier to their efforts to support weight loss have been reported in other studies where staff could not support participants to improve their physical activity levels (Messent *et al.* 1998; Temple & Walkey 2007). In contrast, and similar to other studies, family carers described difficulties while supporting participants and also meeting their own needs (Kerston *et al.* 2001; Burton 2008). Thus, a weight loss intervention, as for any other health service, should be flexible and aim to accommodate the needs of the adults with ID, along with the needs of the carers who support them.

According to current policies, carers should assist people with ID to increase control of their own lives by supporting and respecting their choices (Department of Health 2009). The findings of this study suggest that this aspect of policies has caused uncertainty among carers supporting people with ID to lose weight. Adults with ID may lack the cognitive ability to assess the consequences of long-term unhealthy food choices (Smyth & Bell 2006). Therefore, some carers believe that individuals should be supported to make informed choices. Other carers may decide to act passively, following the recommendations of public policies and expressing respect to the rights of people with ID.

However, it has to be noted that 'health' is a multi-dimensional and relative term which can be perceived by people in different ways (Blaxter 1990). This means that even if carers are trained to help people with ID to make their own choices based on their abilities, 'as long as these choices are not detrimental to their health' (as recommended by Bannerman *et al.* 1990), they may still act based on what their own beliefs are about a 'healthy lifestyle' or 'quality of life'.

Cognitive impairments were recognised by the carers as having an impact on the participants' understanding and motivation to lose weight. 'Lack of understanding' of the health benefits of physical activity is rated as one the most significant barriers in adults with ID (Hawkins & Look 2006). Reinforcement of healthy living messages in this study was seen as a partial solution to this difficulty, and discussion of the health benefits of weight loss was used as a mechanism to motivate participants. However, the latter was generally described as unsuccessful. It is, therefore, important that motivational goals are pertinent to each individual participant and may be related more to day-to-day priorities rather than the overriding health benefits of weight loss.

Similar difficulties with a perceived lack of motivation of people with ID in adopting a healthy lifestyle patterns, and especially in engaging in physical activities, have been also reported in other studies (Messent *et al.* 1998). However, motivation to make lifestyle changes can be influenced by different factors (Georgiadis *et al.* 2006) and may be only partially relevant to cognitive impairments. A study has shown that improved self-image is a greater motivator in women than in men and personal health has a bigger influence on the motivation of older people, and men (Satia *et al.* 2001). This type of study to investigate which factors motivate involving adults with ID during a weight loss process has not been reported in the literature.

The weight loss intervention was described by carers as successful when participants were able to make lifestyle changes independently. This suggests that, where possible, a weight loss intervention should aim to empower a participant's ability in decision-making, goal setting and attainment, and self regulation. The successful impact of interventions on the self-determination of adults with ID and subsequently on their quality of life has been explored (Algozzine *et al.* 2001) but it has not been examined in weight loss interventions.

Overall, the carers were satisfied with the TAKE 5 multi-component weight loss intervention, including the behavioural techniques used, and they praised the adapted resources used to promote a healthy lifestyle. Marshall *et al.* (2003) also used adapted health promotion materials in a health promotion intervention, leading to weight loss in adults with ID. However, in the study reported here, the carers of participants who did not lose weight described barriers associated with the complexity of some aspects of the intervention. Therefore, the prescription of the energy deficit diet, necessary for successful weight loss according to clinical guidelines, may require further simplification and adaption to meet the needs of people with ID and their carers.

All carers stressed the need for ongoing support, and opportunities for carer training from health professionals, to facilitate appropriate healthy lifestyles for individuals with ID. Previous studies have shown that carer training on health promotion and on models of active support can influence healthy eating practices and improve activity levels of people with ID (Kneringer & Page 1999; Jones *et al.* 2001). Therefore, health promotion and training initiatives should target not only individuals with ID but also carers involved in supporting healthy lifestyle choices (McGuire *et al.* 2007; Melville *et al.* 2009).

Limitations and strengths

Reflexivity can be defined as the potential influence of the researcher's background or knowledge to the collection of the data and to the shaping of the data analysis (Murphy *et al.* 1998). In this study, the interviewer (DS) was the weight management coordinator who delivered the sessions with each participant during the weight loss study. This could have been a potential source of bias and the researcher was aware that this could have an impact on the data collection process and its quality. Therefore, prior to each interview carers were informed that reporting their experiences and personal beliefs would provide important information relevant to the development of any future weight loss services for adults with ID. In addition, to eliminate the impact of the researcher on the quality of the data, for initial interviews 'peer debriefing' sessions were used. These sessions allowed the researcher to discuss the circumstances of the data collection with a second researcher with experience in qualitative research (CM) but not closely involved with the data collection process (Guba & Lincoln 1989). One of the strengths of the study is the inclusion of a variety of carers (e.g. paid carers, family carers) minimising influences from one specific type of carer to the analysis.

Conclusion

Qualitative research can provide important information on the implementation and effectiveness of weight loss interventions for both health professionals and service users. The present study showed that carers can play an important role in supporting adults with ID in multi-component weight loss interventions. The support provided to adults with ID needs to be part of a holistic and well-coordinated service to help to ensure that carers from the external and internal environment have the same aims. Weight management services would maximise their effectiveness by using information and materials adapted to the needs of adults with ID, and employ strategies to improve self-determination and motivation, while considering the barriers that could challenge the carers who support individuals.

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References

Alborz A., McNally R. & Glendinning C. (2005) Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *Journal of Health Services Research & Policy* **10**, 173–82.

Algozzine R., Browder D. & Karvonen M. (2001) Effects of interventions to promote self-determination for individuals with disabilities. *Review of Educational Research* **71**, 219–77.

Avenell A., Broom J., Brown T. J., Poobalan A., Aucott L., Stearns S. C. *et al.* (2004) Systematic review of the long-term effects and economic consequences of treatments for obesity and implications for health improvement. *Health Technology Assessment* **8**, 1–182.

Bannerman D. J., Sheldon J. B., Sherman J. A. & Harchik A. E. (1990) Balancing the right to habilitation with the right to personal liberties: the rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis* **23**, 70–89.

Baranowski T., Cullen K. W., Nicklas T., Thompson D. & Baranowski J. (2003) Are current health behavioral change models helpful in guiding prevention of weight gain efforts? *Obesity Research* **11**, 23S–43S.

Bazzano A. T., Zeldin A. S., Diab I. R., Garro N. M., Allevato N. A. & Lehrer D. (2009) The Healthy Lifestyle Change Program: a pilot of a community-based health promotion intervention for adults with developmental disabilities. *American Journal of Preventative Medicine* **37**, 201–8.

Blaxter N. (1990) *Health and Lifestyles*. Tavistock, Routledge, London.

Braun V. & Clarke V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**, 77–10.

Burton M. (2008) Grounding constructions of carers: exploring the experiences of carers through a grounded Approach. *British Journal of Social Work* **38**, 493–506.

Cooper S. A. (1997) Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *British Journal of Psychiatry* **170**, 375–80.

Department of Health (2009) *Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities*. HMSO, London.

Emerson E. & Baines S. (2010) *Health Inequalities and People with Learning Disabilities in the UK: 2010*. Improving Health & Lives: Learning Disabilities Observatory, Durham.

Ezzy D. (2002) *Qualitative Analysis: Practice and Innovation*. Allen and Unwin, Sydney, NSW.

Fox R. A., Rosenberg R. & Rotatori A. F. (1985) Parent involvement in a treatment program for obese retarded adults. *Journal of Behavior Therapy and Experimental Psychiatry* **16**, 45–8.

Fujiura G. T., Park H. J. & Rutkowski-Kmitta V. (2005) Disability statistics in the developing world: a reflection on the meanings in our numbers. *Journal of Applied Research in Intellectual Disabilities* **18**, 295–304.

Georgiadis M. M., Biddle S. J. H. & Stavrou N. A. (2006) Motivation for weight-loss diets: a clustering, longitudinal field study using self-esteem and self-determination theory perspectives. *Health Education Journal* **65**, 53–72.

Guba E. & Lincoln Y. (1989) *Fourth Generation Evaluation*. Sage, Beverly Hills, CA.

Hamilton S., Hankey C. A., Miller S., Boyle S. & Melville C. A. (2007) A review of weight loss interventions for adults with intellectual disabilities. *Obesity Reviews* **8**, 339–45.

Harris M. B. & Bloom S. R. (1984) A pilot investigation of a behavioral weight control program with mentally retarded adolescents and adults: effects on weight, fitness, and knowledge of nutritional and behavioral principles. *Rehabilitation Psychology* **29**, 177–82.

Haslam D. W. & James W. P. (2005) Obesity. *Lancet* **366**, 1197–209.

Haveman M., Heller T., Lee L., Maaskant M., Shooshtari S. & Strydom A. (2010) Major health risks in aging persons with intellectual disabilities: an overview of recent studies. *Journal of Policy and Practice in Intellectual Disabilities* **7**, 59–69.

Hawkins A. & Look R. (2006) Levels of engagement and barriers to physical activity in a population of adults with learning disabilities. *British Journal of Learning Disabilities* **34**, 220–6.

Jinks A., Cotton A. & Rylance R. (2010) Obesity interventions for people with a learning disability: an integrative literature review. *Journal of Advanced Nursing* **67**, 460–71.

Jones E., Felce D., Lowe K., Bowley C., Pagler J., Gallagher B. *et al.* (2001) Evaluation of the dissemination of active support training in staffed community residences. *American Journal of Mental Retardation* **106**, 344–58.

Kerston P., McLellan L., George S., Mullee M. A. & Smith J. A. (2001) Needs of carers of severely disabled people: are they identified and met adequately? *Health Social Care in the Community* **9**, 235–43.

Kiernan C. (1999) Participation in research by people with learning disability: origins and issues. *British Journal of Learning Disabilities* **27**, 43–7.

Kneringer M. & Page T. J. (1999) Improving staff nutritional practices in community-based group homes: evaluation, training, and management. *Journal of Applied Behavior Analysis* **32**, 221–4.

Lincoln Y. S. & Guba E. G. (1985) *Naturalistic Inquiry*. Sage Publications, Inc. Beverly Hills, CA.

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**, 147–53.

Mays N. & Pope C. (1996) *Qualitative Research in Health Care*. BMJ Books, London.

McCarran M. S. & Andrasik F. (1990) Behavioral weight-loss for multiply handicapped adults: assessing caretaker involvement and measures of behavior change. *Addictive Behaviors* **15**, 13–20.

McGuire B. E., Daly P. & Smyth F. (2007) Lifestyle and health behaviours of adults with an intellectual disability. *Journal of Intellectual Disability Research* **51**, 497–510.

Melville C. A., Cooper S. A., Morrison 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**, 425–37.

Melville C. A., Hamilton S., Miller S., Boyle S., Robinson N., Pert C. *et al.* (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. *et al.* (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* **10**, 1553–62.

Messent P. R., Cooke C. B. & Long J. (1998) Daily physical activity in adults with mild and moderate learning disabilities: is there enough? *Disability and Rehabilitation* **11**, 424–7.

Murphy E., Dingwall R., Greatbach D., Parker S. & Watson P. (1998) Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment* **2**, 1–274.

National Institute for Health and Clinical Excellence (NICE) (2006) *Obesity: The Prevention, Identification, Assessment and Management of Overweight and Obesity in Adults and Children*. NICE, London.

NHS Health Scotland (2004) *Health Needs Assessment Report. People with Learning Disabilities in Scotland*. NHS Health Scotland, Edinburgh.

Norris S. L., Zhang X., Avenell A., Gregg E., Bowman B., Schmid C. H. *et al.* (2005) Long-term effectiveness of weight-loss interventions in adults with pre-diabetes: a review. *American Journal of Preventative Medicine* **28**, 126–39.

Patton M. Q. (1987) *How to Use Qualitative Methods in Evaluation*. Sage, London.

Pownall J. D. (2010) *Health knowledge and expected outcomes of risky behaviour: a comparative study of non-disabled adolescents and young people with intellectual and physical disabilities*. Unpublished PhD Thesis, University of Glasgow, Glasgow.

Rodgers J. (1998) 'Whatever's on her plate': food in the lives of people with learning disabilities. *British Journal of Learning Disabilities* **26**, 13–16.

Ryan D. (2005) Risks and benefits of weight loss: challenges to obesity research. *European Heart Journal* **7**, 27–31.

Satia J. A., Kristal A. R., Curry S. & Trudeau E. (2001) Motivations for healthful dietary change. *Public Health Nutrition* **4**, 953–9.

Scottish Intercollegiate Guideline Network (SIGN) (2010) *Management of Obesity: A National Clinical Guideline*. SIGN, Edinburgh.

Silverman D. (2005) *Doing Qualitative Research: A Practical Handbook*, 2nd edn. Sage, London.

Smyth C. M. & Bell D. (2006) From biscuits to boyfriends: the ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities* **34**, 227–36.

Temple V. A. & Walkey 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**, 28–38.

Temple V. A., Anderson C. & Walkley J. W. (2000) Physical activity levels of individuals living in a group home. *Journal of Intellectual and Developmental Disability* **25**, 327–41.

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Carers' perspectives on a weight loss intervention for obese adults with intellectual disabilities: a qualitative study

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Introduction: Multicomponent interventions and the involvement of carers could have an impact in the process of weight loss for adults with Intellectual Disabilities (ID). However, currently no studies have explored the role of carers in supporting adults with ID and obesity, during weight loss. This study evaluated the impact of a multicomponent weight loss intervention on carers' experiences and perceptions at 6-months post weight loss.

Methods: Using purposive sampling, 24 paid carers or family members who supported adults with ID in a multicomponent weight loss intervention, were recruited. Semi-structured interviews were conducted and later transcribed verbatim at week 24. The transcripts were analyzed using ATLAS ti 5.2 software, alongside a 'thematic analysis' as a qualitative analytical method.

Results: The following themes were identified: (i) carers' perceptions on their client's health, (ii) weight loss barriers and facilitators, (iii) carers' perceptions on the programme. Carers identified the health and psychosocial benefits of weight loss, and reported making positive efforts to encourage participants to improve their diet and physical activity. They identified (i) lack of support from other people and (ii) lack of communication among their colleagues, as key elements inhibiting their participant's efforts. There was mixed feedback from the carers regarding the programme.

Conclusion: This study identifies specific facilitators and barriers experienced by carers during the process of supporting adults with ID to lose weight. Future research should utilize these findings to develop appropriate and effective weight management interventions for this group.

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Carers' perspectives on a weight loss intervention for obese adults with intellectual disabilities: a qualitative study

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The prevalence of obesity rates has been reported to be higher in adults with Intellectual Disabilities (ID) than in the general population(1). It is likely that multi-component weight management interventions that involve carers could have considerable impact on process and potentially on actual weight loss for adults with ID(2). To date no studies have explored the role of carers in supporting adults with ID and obesity during a weight loss programme. The aims of the present study were (i) to explore perceptions of carers supporting adults with ID as they participated in a 6-month multi-component weight loss intervention (TAKE 5), (ii) to identify strategies that carers and participants adopt to overcome barriers to changes in lifestyle, and (iii) to record carers' perceptions of the acceptability and utility of the multi-component weight loss intervention.

TAKE 5 is a multi-component weight loss intervention that is consistent with recommendations included in current clinical guidelines(3). TAKE 5 comprised nine individual sessions delivered to fifty-four adults (≥ 18 years) with ID and obesity (BMI $\geq 30\,kg/m^2$), involving carers (paid carers or family carers) to support the participants where appropriate. The TAKE 5 intervention aimed for a 5% weight loss from initial body weight after 6 months. A purposive sampling method was used to incorporate the experiences of twenty-four carers who were paid (*n* 16) or family carers (*n* 8) and who supported participants who successfully achieved a 5% weight loss (*n* 12) or did not (*n* 12). One to one semi-structured interviews were conducted and later transcribed verbatim at week 24. The transcripts were analysed using ATLAS ti 5.2 software, alongside a 'thematic analysis'(4) as a qualitative analytical method.

The main themes that emerged on analysis were carers' perceptions on participants' health; barriers and facilitators in weight loss and carers' perceptions of the multi-component weight loss intervention. Carers described the weight loss as being beneficial to participants' health. Furthermore, they discussed their efforts to encourage and aid participants to improve their diet and physical activity. However, lack of sufficient support and poor communication among carer colleagues were identified as being inhibitory. The need for resources tailored to aid weight loss among adults with ID was also highlighted.

This study identified specific facilitators and barriers experienced by carers during the process of supporting obese adults with ID to lose weight. Future research should utilise these findings to develop appropriate and effective weight management interventions for this group.

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1. Melville CA, Cooper S-A, Morrison J *et al*. (2008) The prevalence and determinants of obesity in adults with intellectual disabilities. *J Appl Res Intell Disabil* **21**, 425–437.
2. Hamilton S, Hankey CA, Miller S *et al*. (2007) A review of weight loss interventions for adults with intellectual disabilities. *Obes Rev* **8**, 339–345.
3. Melville CA, Boyle S, Miller S *et al*. (2011) An open study of the effectiveness of a multi-component weight loss intervention for adults with intellectual disabilities and obesity. *B J Nutr* **105**, 1553–1562.
4. Braun V & Clarke V (2006) Using thematic analysis in psychology. *Qual Res Psych* **3**, 77–110.

Appendix 9

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