

**The tailoring and implementation of evidence-based multi-component weight management interventions for adults with intellectual disabilities who are obese: a whole systems approach.**

**by**

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A thesis submitted in partial fulfilment for the requirements of the degree of  
Doctor of Philosophy at the University of Central Lancashire

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## **ABSTRACT**

Adults with intellectual disabilities in the UK are more likely to be obese than their non-disabled peers and are at risk of experiencing serious medical conditions such as heart disease, stroke and Type 2 diabetes. UK weight management guidance recommends multi-component weight management interventions, tailored for different population groups. The aim of this thesis was to explore how evidence-based multi-component weight management interventions can be tailored for adults with intellectual disabilities who are obese. The thesis comprised three phases.

Phase One included an integrative review of evidence-based multi-component weight management interventions for adults with intellectual disabilities; an exploration of theories used to underpin weight management interventions for this population; and a mapping exercise to investigate the extent of weight management service provision for adults with, and without, intellectual disabilities. The review found emerging evidence to suggest that multi-component weight management interventions can be tailored and are effective for adults with intellectual disabilities. However, the review identified few studies (n=5) and none of the identified studies explored this population's views and experiences of such interventions. Phase One also found gaps in underpinning theories and insufficient service provision for this population.

Phase Two comprised three studies to explore participants' views and experiences of the barriers and facilitators to weight management for adults with intellectual disabilities. These studies included a qualitative study involving interviews with 14 health care practitioners; a co-produced focus group qualitative study involving 19 adults with intellectual disabilities and 8 of their carers; and a survey involving 19 carers and support workers. Thematic analysis of participants' responses highlighted their frustrations with several barriers including a lack of accessible healthy lifestyle information, a lack of resources, a lack of reasonable adjustments, inconsistencies in caring support, unmet training needs for carers and support workers, and socio-economic and environmental barriers. Facilitators included the provision of clear and accessible healthy lifestyle information, provision of

resources, consistent caring support, reasonable adjustments, and training for carers, support workers and health care practitioners.

Phase Three involved a synthesis of findings from Phases One and Two. The overall findings imply that it is inequitable support and barriers associated with complex systems-related issues, rather than poor lifestyle choices or a lack of motivation, which inhibits this population from managing their weight if they want to. A whole systems approach is needed to address the systems-related issues and barriers experienced by this population, rather than a sole reliance on non-evidence-based weight management interventions (such as diet-only or exercise-only interventions) focused primarily on individual behaviour change to achieve short-term weight loss.

This thesis has made an original contribution to research knowledge by providing an in-depth comprehensive picture of the challenges involved in weight management for adults with intellectual disabilities from their own perspectives, and from the perspectives of others involved. The thesis included the first published integrative review of evidence-based multi-component weight management interventions for adults with intellectual disabilities. A unique co-produced qualitative focus group study involving this population was also undertaken. The thesis has implications for research, policy and practice. It presents a whole systems approach and a logic model outlining the types of systems-related activities needed at several levels to overcome identified barriers and to contribute to reductions in the inequities and inequalities experienced by adults with intellectual disabilities who want to manage their weight.

## **Accessible summary**

- People with weight problems may have serious health conditions like heart disease, stroke and diabetes.
- People who want to manage their weight should be able to access services to help them.
- This research involved people with intellectual disabilities, carers, support workers, health care practitioners and service providers.
- People spoke about barriers to weight management for those who have intellectual disabilities.
- Findings may inform service improvements for people with intellectual disabilities who want to manage their weight.

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## LIST OF ABBREVIATIONS

BCW	Behaviour Change Wheel
BME	Black and other minority ethnic groups
BMI	Body Mass Index
CCGs	Clinical Commissioning Groups
CHD	Coronary Heart Disease
CVD	Cardiovascular Disease
EBCD	Experience-based co-design
FOI	Freedom of Information Requests
GP	General Practitioner
HIAT	Health Inequality Assessment Toolkit
HCP	Health Care Practitioner
IHAL	Improving Health and Lives
ID	Intellectual Disabilities
MeSH	Medical Subjects Headings
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
NIHR CLAHRC NWC	National Institute of Health Research's Collaboration for Leadership in Applied Health Research & Care North West Coast
PHE	Public Health England
QOF	Quality Outcomes Framework
RCT	Randomised Control Trial
SCT	Social Cognitive Theory
SMR	Standard Mortality Ratio
SPOC	Single Point of Contact
UCLan	University of Central Lancashire
UK	United Kingdom
WHO	World Health Organisation

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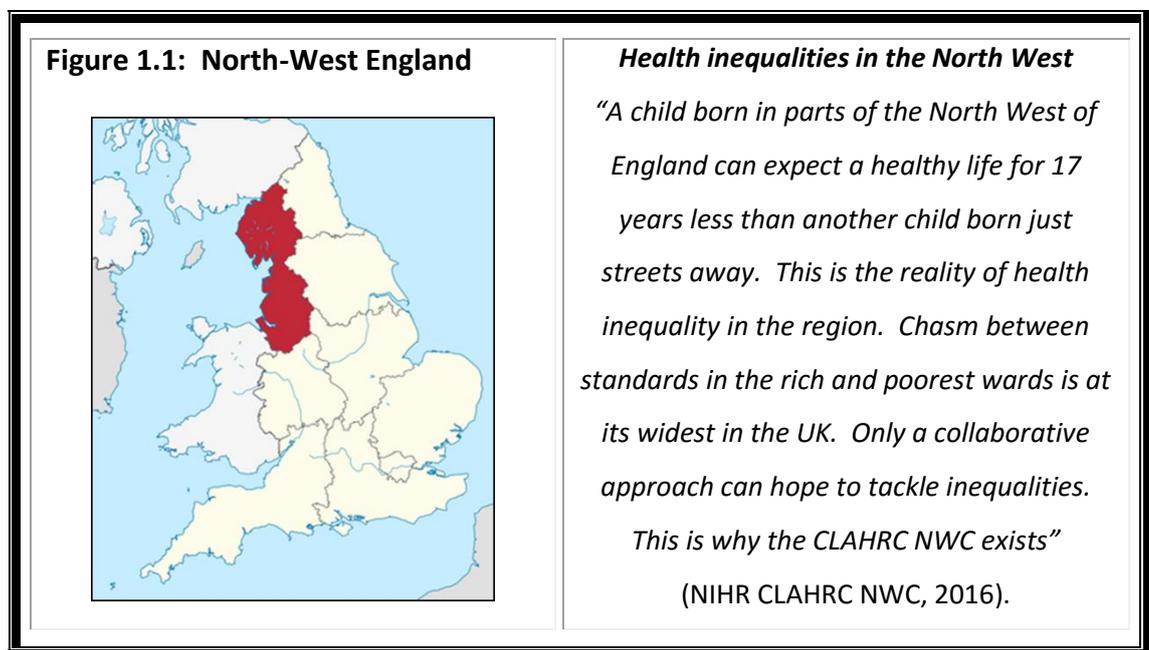
Over the past three years, I am honoured to have met many talented and inspirational women and men who are working tirelessly to address health inequalities, including: Lynn James-Jenkinson, Dr. Henrietta Trip, Dr. Liz Croot, Dr. Melanie Rimmer, Dr. Craig Melville, Dr. Cath Hankey, Dr. Melanie Chapman, Professor Mark Gabbay, and Dr. Jane Cloke (to name but a few). Thanks also go to my postgraduate colleagues for their collective support and understanding including: Dawn, Sam, Lydia, Flo, Jane, Naoimh, and thanks to the Research Support Office.

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## Foreword

This thesis was undertaken from October 2014 to September 2017 at the University of Central Lancashire. The postgraduate studentship was funded by the National Institute of Health Research's Collaboration for Leadership in Applied Health Research & Care North West Coast (NIHR CLAHRC NWC). The NIHR CLAHRC NWC works collaboratively with partners from universities, local authorities, the NHS and the public in Cheshire, Cumbria, Lancashire and Merseyside to address health inequalities in the North West through applied health care research (NIHR CLAHRC NWC, 2016). Figure 1.1 highlights the region and rationale.



The NIHR CLAHRC NWC serves a population of 7 million people in the North West and is based around key themes: evidence synthesis; knowledge exchange, engagement and effective implementation; improving public health; improving mental health; managing complex needs; delivering personalised health and care; and capacity building. Patient and public involvement is an essential component of the NIHR CLAHRC NW's funded research. The NIHR CLAHRC NWC has also developed a Health Inequalities Assessment Toolkit (HIAT) to ensure that the collaboration's activities have the potential to contribute to reducing health inequalities (NIHR CLAHRC NWC, 2016). The HIAT has been utilised for this thesis.

# CHAPTER ONE

## INTRODUCTION

This chapter presents the background and rationale for this thesis within the context of health inequalities for people with intellectual disabilities. The overall aim and objectives of the thesis are presented in this chapter. An outline of the thesis is also provided in this chapter. The chapter begins by providing a definition of intellectual disabilities and health inequalities.

### BACKGROUND

#### *Defining intellectual disabilities*

'Intellectual disability or intellectual disabilities' is a term used globally for this population group, although other terms exist such as 'learning disability or learning disabilities'. The term 'intellectual disability' used in this thesis refers to individuals with a significantly reduced ability to understand new or complex information, to learn and apply new skills (impaired intelligence) which results in a reduced ability to cope independently (impaired social functioning), with a manifestation of these problems before the age of 18 years (World Health Organisation, 2015). The levels of intellectual disabilities vary from mild-to-moderate to severe and profound intellectual disabilities. People with mild-to-moderate intellectual disabilities often live independently and are usually able to communicate most of their needs, but they may need some support to understand complex issues. People with severe intellectual disabilities often use basic words and gestures to communicate their needs, but they may need a high level of support with some daily activities such as cooking and shopping. People with profound intellectual disabilities have an intelligence quotient estimated to be under 20 and therefore severely limited understanding, more than one disability, great difficulty communicating and they require a high degree of support with most aspects of daily life (Mansell, 2010).

The exact numbers of people with intellectual disabilities is unknown. It is estimated that 225,000 children and 901,000 adults in England have intellectual

disabilities (Improving Health and Lives, [IHAL] 2016). Approximately 200,000 adults in England use specialist services for people with intellectual disabilities or are known to health or social care services as having intellectual disabilities (IHAL, 2016). However, many more may not be known, as they do not use these specialist services.

### *Defining health inequalities*

The term 'health inequalities' refers to differences in health status between social groups which are unnecessary and avoidable but, in addition, are also considered unfair and unjust (Whitehead, 1992). Research into health inequalities has highlighted a range of determinants involved. For example, social and environmental determinants (Marmot and Wilkinson, 2006), cumulative exposure to multiple adversities across a life course (Graham, 2007), exposure to complex psychological and biological pathways (Conger and Donnallan, 2007; Matthews, Gallo and Taylor, 2010; Shonkoff, 2010), and differential vulnerability or resilience of people when exposed to adversity (Davydov et al., 2010). Health inequalities may also be associated with inequities in the way that health services respond to needs of different population groups (Holly and Sharp, 2014; Emerson and Hatton, 2014). Inequities may lead to inequalities.

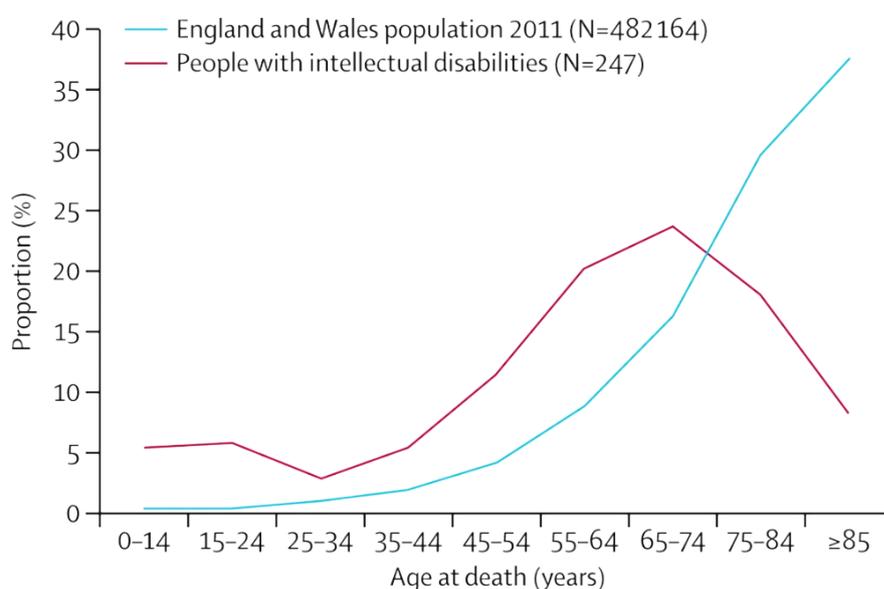
The health inequalities experienced by people with intellectual disabilities are recognised nationally and internationally (Emerson and Hatton, 2013). Reducing health inequalities experienced by people with intellectual disabilities is emerging as an explicit area of focus in public health and primary health care (Department of Health, 2014). Examples of national initiatives designed and introduced to address these health inequalities in primary care and public health include the introduction of annual health checks for people with intellectual disabilities in 2009, and the adoption of intellectual disabilities as a priority by the Royal College of General Practitioners in 2010. Under the Equality Act 2010, there is also a statutory requirement for all health care services to make reasonable adjustments to meet the needs of people with disabilities (including people with intellectual disabilities).

The next section outlines more contextual detail as to why reducing health inequalities experienced by people with intellectual disabilities has emerged as a priority in public health and primary health care.

### *Health inequalities and people with intellectual disabilities*

People with intellectual disabilities have a shorter life expectancy compared to their non-disabled peers (DeSalvo et al., 2006; Glover and Ayub, 2010; Emerson and Hatton, 2014; NHS Digital, 2017). A confidential inquiry in 2013 reviewed the deaths of 247 people with intellectual disabilities in England & Wales and found that 22% of people with intellectual disabilities were younger than 50 years when they died compared to 9% of the general population (Heslop et al., 2014). Figure 2 highlights the earlier age of death for people with intellectual disabilities compared with that for people in the general population of England & Wales in 2011. The Inquiry highlighted that 48% of the deaths in people with intellectual disabilities were avoidable or preventable, either by public health interventions (12%), quality healthcare (28%) or both (9%) (Heslop et al 2014). Data for 2014/15 revealed that the Standardised Mortality Ratio (SMR) for people with intellectual disabilities in England was 298.1 (i.e. almost three times the expected number of deaths occurred) (NHS England, 2016).

**Figure 1.2: Age at death of people with intellectual disabilities compared with that for people who died in England and Wales in 2011. Reproduced from the full report of the Confidential Inquiry (Heslop et al., 2014)**



People with intellectual disabilities are also more likely to experience a range of long-term health conditions. A long-term condition is defined as a condition that cannot, at present, be cured; but can be controlled by interventions (Department of Health, 2012). Examples of long-term conditions experienced by people with intellectual disabilities include epilepsy, mental health issues and diabetes, many of which can be managed (Taggart and Cousins, 2014). A study in 2015 used large-scale primary care data to investigate the prevalence of a range of medical conditions in patients with intellectual disabilities compared to patients without intellectual disabilities in England (Carey et al., 2016). The study found that people with intellectual disabilities had a higher prevalence of recorded long-term conditions including epilepsy (18.5%), mental illness (8.6%) and dementia (1.1%) (Carey et al., 2016). Increased rates of conditions such as diabetes amongst adults with intellectual disabilities have been reported in population studies undertaken in England (Glover, Emerson and Eccles, 2012) as well as in Europe and USA (Havercamp, Scandlin and Roth, 2004; Straetmans et al., 2007; Reichard and Stolze, 2011; Morin et al., 2012). It is estimated that 270,000 people with intellectual disabilities in the UK have Type 2 diabetes, and that the prevalence of Type 2 diabetes is two to three times higher in people with intellectual disabilities than among the non-disabled population (Diabetes UK, 2009). Systematic reviews exploring the prevalence of diabetes in this population group suggest a heightened need for greater access to diabetes self-management education interventions specific to the needs of people with intellectual disabilities (McVilly et al., 2014; MacRae et al., 2015). However, little is known about the management of conditions such as diabetes in this population and this represents a significant challenge for health care practitioners (Taggart et al., 2014; Brown et al., 2017).

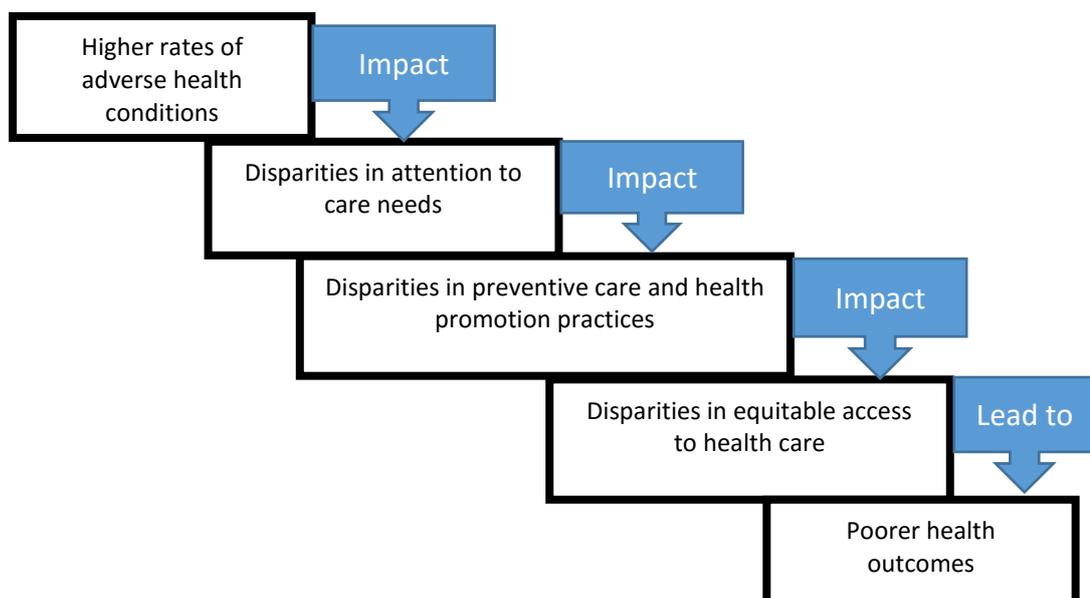
The fact that people with intellectual disabilities are dying prematurely and are experiencing higher levels of long-term conditions than the general population is a health inequality issue. The main contributors to the health inequalities experienced by people with intellectual disabilities may include:

- A greater risk of exposure to social determinants of poorer health such as poverty and unemployment.

- An increased risk of health problems directly related to intellectual disabilities (such as congenital abnormalities related to people with moderate to profound intellectual disabilities).
  - Communication difficulties and limited health literacy skills, which may reduce their capacity to understand and convey health needs effectively to others.
  - Personal health risks and behaviours related to diet and lack of exercise.
  - Barriers relating to access to mainstream health care.
- (Emerson, 2011).

Some authors suggest that there is a 'cascade of disparities' leading to poorer health outcomes for people with intellectual disabilities as illustrated in Figure 1.3 (Krahn and Fox, 2014). At the top of the cascade people with intellectual disabilities may have higher rates of adverse health conditions such as epilepsy and gastrointestinal disorders which put them at higher health risk, and some medical conditions such as congenital heart problems associated with Down Syndrome may not be preventable (RCN, 2013; Krahn and Fox, 2014). However, all the remaining disparities that follow in the cascade are either preventable or amendable to intervention (Krahn and Fox, 2014).

**Figure 1.3: 'Cascade of Disparities' leading to poorer health outcomes in people with intellectual disabilities (Krahn and Fox, 2014)**



Furthermore, 'one-size-fits-all' interventions that are designed to improve the general population's health may contribute to a widening of health inequalities within certain population groups (White, Adams and Heywood, 2009). This is because the interventions may be more effective within some population groups than others, or because there may be a preferential take-up of the interventions by the most advantaged in society before a subsequent take-up effect by less advantaged groups who may be more in need of the interventions i.e. an 'inverse care law' or an 'inverse equity hypothesis' (Tudor Hart, 1971; Victora et al., 2000). Health guidelines are designed and developed to address the health needs of the general population. However, current UK health guidelines may fail to address the needs of people with intellectual disabilities at risk of serious medical conditions (Mizen et al., 2012). Health care practitioners may have limited knowledge and experience of the needs of people with intellectual disability (Department of Health, 2008). This may contribute to a lack of confidence in providing care and support and may lead to further disadvantage and poor health outcomes (Bradbury-Jones et al., 2013).

There have been few systematic reviews of physical health issues, which are important to people with intellectual disabilities. Systematic reviews that have been conducted are heavily weighted towards mental health with little coverage of many areas important to the health and mortality of people with intellectual disabilities such as diseases of the circulatory system (Robertson et al., 2015). Further research to explore physical health conditions, which influence the health and wellbeing of people with intellectual disabilities, is needed. Such research is needed to inform the types of interventions that may be effective and appropriate in addressing health inequalities experienced by this population group and to inform associated health guidelines.

### *Potentially preventable causes of death in people with intellectual disabilities*

Potentially preventable causes of death that are relatively common and affect many people with intellectual disabilities include cardiovascular disease (CVD) (Glover and

Ayub, 2010). CVD includes all diseases of the heart and circulation including coronary heart disease (CHD), congenital heart disease and stroke (British Heart Foundation, 2016). In 2014, CVD was the second biggest cause of death in the United Kingdom, causing 27 per cent of all deaths in the general population (British Heart Foundation, 2016). CVD is also a leading cause of death in people with intellectual disabilities (Glover and Ayub, 2010).

Certain sub-groups of people with intellectual disabilities are at higher risk of CVD including women, older people, people with mild intellectual disabilities who live more independently, and people with intellectual disabilities who are obese (de Winter et al., 2012). The rates of CVD in people with intellectual disabilities are increasing due to factors such as increased longevity (Elliott, Hatton and Emerson, 2003), low socio-economic status (Wallace and Schulter, 2008), a sedentary lifestyle (Haveman et al., 2011; Hilgenkamp, van Wijck and Evenhuis, 2011; Temple, Frey and Stanish, 2006), changes in living arrangements as people with mild-to-moderate intellectual disabilities are living more independently in the community and away from institutional residences (Elliott, Hatton and Emerson, 2003; NHS Health Scotland, 2004; Young, Naji and Kroll, 2012), and a high prevalence of obesity in this population group (Public Health England, 2015b).

Prevention strategies need to focus on areas where deaths from conditions such as CVD are potentially preventable (Tyrer and McGrother, 2009). Obesity is a major risk factor for CVD. Prevention strategies should therefore include and target people with intellectual disabilities who are obese and most at risk of CVD (Tyrer and McGrother, 2009).

The next section of this chapter explores and compares the prevalence of obesity in adults with and without intellectual disabilities. The recommended UK guidance on obesity and weight management interventions for all adults (with and without intellectual disabilities) is also explored.

## *Obesity and the general population*

Obesity, defined as a body mass index (BMI) of 30 or greater, is an increasingly prevalent problem in England. In England, the prevalence of obesity rose from 13% (men) and 16% (women) in 1993 to 26% (men) and 24% (women) by 2013 (Health Survey for England, 2013). Obesity increases an individual's chances of developing a range of medical conditions including CVD, as well as Type 2 diabetes, and certain types of cancer such as breast and colon cancer (Wilson et al., 2002; World Health Organisation, 2004). Obesity related conditions might lead to premature mortality (death). Life expectancy is reduced by an average of 3 years for people with Class 1 obesity (BMI of 30 – 35) or eight to ten years in the case of Class 3 obesity (BMI of >40) (National Obesity Observatory, 2010). Obesity can also increase the risk of co-morbidities (the presence of one or more additional diseases or disorders co-occurring with a primary disease or disorder). Table 1.1 outlines adult BMI classification and the related risk of co-morbidities.

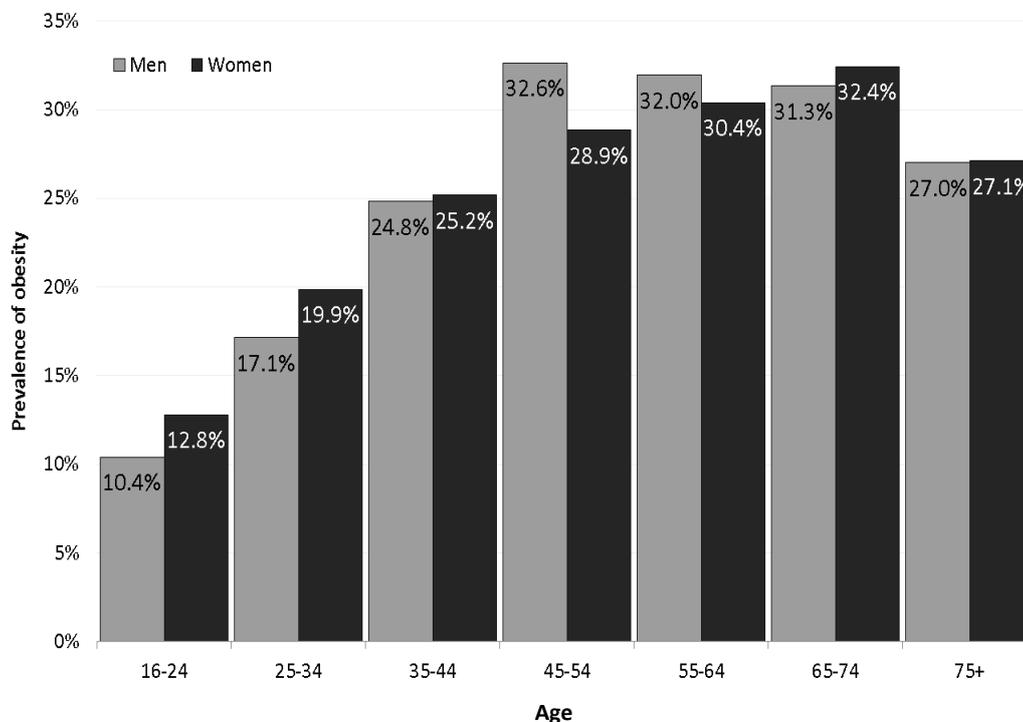
**Table 1.1: Classification of Body Mass Index (BMI) and the related risk of co-morbidities (NHS, 2006)**

<b>Classification</b>	<b>BMI</b>	<b>Risk of co-morbidities</b>
Underweight	<18.5	Low (but increased risk of other clinical problems)
Desirable weight	18.5 – 24.9	Average
Overweight	25.0 – 29.9	Mildly increased
Obese	>30	
- Class 1	30.0 – 34.9	Moderate
- Class 2	35.0 – 39.9	High
- Class 3	>40	Very high

*(Note: The Body Mass Index (BMI) is often used as a calculation for determining a person's percentage of fat based on their height and weight for people aged 18 to 65. The BMI Calculator does not apply to infants, children, teens, pregnant or breast-feeding women, extreme athletes or adults over the age of 65).*

Figure 1.4 highlights how obesity is related to age, steadily rising through middle age and then decreasing in older age (75 years and over) in the general population of England (Public Health England, 2015a).

**Figure 1.4: All Adults - obesity prevalence by age and sex using Health Survey Data for England 2011-2013 (Public Health England, 2015a)**



Obesity also has a significant economic impact as well as a human impact. Obesity is estimated to cost the UK economy £15.8bn per annum, including £4.2bn per annum in costs to the NHS (Public Health England, 2015a). These costs are predicted to rise to £50bn by 2050 if the problem of obesity is left unchecked (Butland et al., 2007).

### *Obesity in people with intellectual disabilities*

Obesity is more common in adults with intellectual disabilities. Obesity affects 46% of female and 32% of male adult patients with intellectual disabilities who are registered with primary health care in England and who have had a BMI recorded, compared to 30% of female and male adult patients without intellectual disabilities (NHS Digital, 2017).

The reasons for the high prevalence of obesity found amongst people with intellectual disabilities are complex. Contributing factors may include genetic factors, prescribed medication, poor dietary habits, and very high levels of physical inactivity (Rimmer and Yamaki, 2006; McGuire et al., 2007; Rimmer et al., 2010; Singh et al., 2010; Matthews et al., 2011). People with intellectual disabilities may be unable to access services and activities due to issues such as restrictions on support, transport, time, personal income, location, accessibility to available sports and leisure facilities and open spaces, poor weather, and staff or carers' concerns that physical activity may exacerbate health problems or cause injury (Messent and Cooke, 1998; Horvat and Franklin, 2001; Cartwright et al., 2017). Some individuals with intellectual disabilities may be physically disabled as well as intellectually disabled and unable to leave their accommodation, and thus sedentary activities and a culture of 'staying-in' may predominate (Messent and Cooke, 1998). Other contributing factors may be implicated including socio-economic deprivation (Emerson, 2003), or overfeeding of individuals with intellectual disabilities by carers or support workers to prevent boredom or conflict (Melville et al., 2007). Some people with intellectual disabilities may be unknown to primary health care services and some may not receive preventative services such as Annual Health Checks, screening services, or accessible health promotion information (Taggart et al., 2014; Brown et al., 2017). People with intellectual disabilities can also face barriers to accessing health care services. For example, problems with communication, a lack of support to help them access appropriate health care services, discriminatory attitudes amongst healthcare staff, and failure by health service providers to make reasonable adjustments to health care services so that they can be used by people with intellectual disabilities (Hatton, Roberts and Baines, 2011).

Certain sub-groups of people with intellectual disabilities are at even greater risk of obesity. Individuals with mild-to-moderate intellectual disabilities living in less restrictive residential settings, able to do their own food shopping and prepare their own meals, and people with certain genetic conditions such as Down Syndrome are more likely to be obese (Rimmer et al., 1993; Prasher, 1995; Rubin et al., 1998; Robertson et al., 2000; de Winter et al., 2012). Primary care data in England suggests a greater prevalence of obesity in females with intellectual disabilities (0 to

75 years+): 45% of female GP patients with intellectual disabilities were obese compared to 32% of male GP patients with intellectual disabilities and 29% of female and male patients without intellectual disabilities (NHS Digital, 2017). The explanation for the high prevalence of obesity in females with intellectual disabilities (at all ages) is unclear. There is some suggestion that it may be related to lower rates of participation in physical activities for girls than for boys (Cairney et al., 2005), or with the presence of smoking related asthma in females with intellectual disabilities (Gale et al., 2009).

Children (aged 0 – 17 years) and younger people with intellectual disabilities (aged 18 – 35 years) are at greater risk of obesity than those at the same age without intellectual disabilities. Primary care data in England for 2014/15 highlights that patients with intellectual disabilities aged under 35 years are more likely to be obese than those without intellectual disabilities (NHS Digital, 2017). It is unclear why greater numbers of children and young people with intellectual disabilities develop obesity than their non-disabled peers. There may be lifespan phases and or transitional issues involved (Johnson et al., 2006; Melville et al., 2007). However, what is clear from the evidence available is that individuals with intellectual disabilities tend to become obese at a much earlier age than the general population (Bhaumik et al., 2008; Melville et al., 2008; Public Health England, 2015a). Consequently, people with intellectual disabilities are more likely to experience obesity-related medical conditions and associated health problems at a much younger age than the general population (Melville et al., 2008; Rimmer et al., 2010). This finding is supported by recent analysis of primary health-care data on 1,424,370 adults registered with 314 Scottish practices which found that multi-morbidities (defined as two or more conditions additional to the intellectual disability) are more common in adults with intellectual disabilities and that these occur at an earlier age (Cooper et al., 2015).

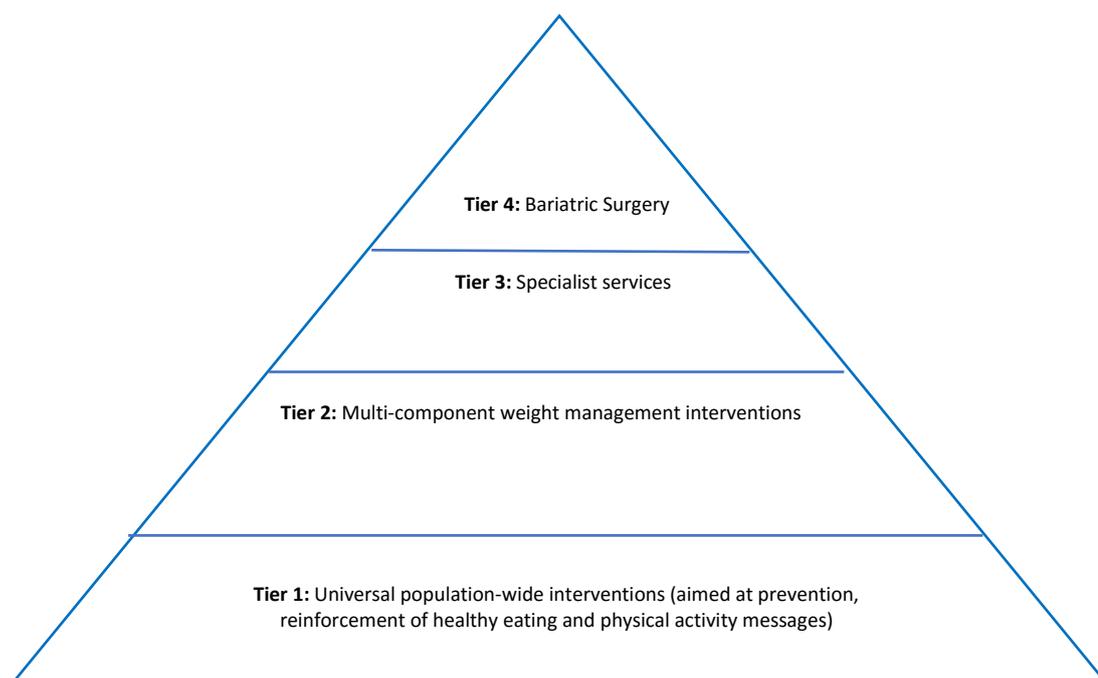
The prevalence of obesity and associated obesity health risks for people with intellectual disabilities highlights the need for further research and for the development of tailored interventions and services for this population group. Being obese reduces both the quality of life and the life expectancy of people with

intellectual disabilities and there is a need for collective work involving this population in weight management and in maintaining healthy lifestyles (Rimmer et al, 1994; Janicki et al., 2002; Prasher and Janicki 2002; Doody and Doody, 2012; Gronhuis and Aman, 2014; Brown et al., 2017).

### *UK obesity and weight management guidance*

UK public health and clinical guidance on obesity and weight management recognises the requirement for a multi-faceted approach to help reduce the prevalence of obesity in the general population (McPherson, Marsh and Brown, 2007). Different weight management services are offered at different levels, or 'tiers', of obesity and related health risks (Figure 1.5).

**Figure 1.5: The tiers of weight management care in England (Department of Health, 2013)**



### *Tiers of weight management*

The UK guidance for managing people who are obese or overweight (Scottish Intercollegiate Guidelines Network [SIGN], 2010; National Institute of Health and Care Excellence [NICE], 2014a) recommends universal services such as primary health care advice and information for Tier 1 target groups (BMI $\geq$ 25-30 +/- co-

morbidities or BMI $\geq$ 30-35 with no co-morbidities). The UK guidance recommends multi-component lifestyle weight management interventions for Tier 2 target groups (people who have failed to lose and maintain >5kg or >5% of their body weight at Tier 1 and either a BMI $\geq$ 30 with co-morbidity, or women with BMI>30 in pregnancy) (SIGN, 2010; NICE, 2014a). Table 1.2 provides a summary of the Tier 2 recommended weight management interventions. Tier 2 weight management interventions may include programmes, clubs or courses that are provided by private, public or voluntary sectors and which may be based in community facilities, workplaces, in primary care facilities or on-line (SIGN, 2010; NICE, 2014a). Individuals may self-refer themselves or they may be referred to services by a health or social care provider (SIGN, 2010; NICE, 2014a).

**Table 1.2: UK Recommended Tier 2 weight management interventions (SIGN, 2010; NICE 2014a)**

Multi-component: including 600kcal/day energy deficit diets i.e. containing 600kcal less than the person needs to stay the same weight, physical activities that fit easily into people's lives e.g. walking, cycling; and behaviour change methods such as problem-solving and goal setting.
Multi-disciplinary: including input from registered dietitians, psychologists and physical activity instructors.
At least 3 months in duration, with sessions that are offered at least weekly or fortnightly, which monitor weight and include a 'weigh-in' at each session.
Inclusive of achievable weight loss goals and targets for the individuals.
Focused on lifestyle change and the prevention of future weight gain.
Inclusive of discussions on how to reduce sedentary behaviour and the types of physical activities that can be incorporated into daily life.
Tailored to the individual and provide on-going support.

UK guidance is based on a substantial body of evidence (including 29 randomised controlled trials of tier 2 weight management interventions lasting 12 months). The evidence concluded that multi-component weight management interventions (that address dietary habits, physical exercise and behaviour change techniques) were the most effective interventions at helping adults lose weight and maintain that weight loss for at least 12 to 18 months (NICE, 2014a).

In 2013, the NHS Commissioning Board, NHS England and Public Health England Working Group recommended the introduction of tier 3 weight management

services for patients who are very obese, and or morbidly obese patients (BMI $\geq$ 35) (or patients that have not responded to previous tiers of treatment) requiring more specialised management. One example is the Rotherham Institute:

[www.rotherhaminstituteforobesity.co.uk](http://www.rotherhaminstituteforobesity.co.uk). However, these types of services are yet to be commissioned in many UK areas (Hughes, 2015). Tier 4 weight management services include bariatric weight loss surgery for those with a BMI $\geq$ 40, or a BMI between 35 and 40 and an obesity-related condition such as high blood pressure or Type 2 diabetes that might improve if the patient lost weight (NHS Choices, 2017).

UK guidelines recommend that GPs in primary health care services screen for and opportunistically encourage patients to lose weight (SIGN, 2010; NICE, 2014a). GPs in the UK receive payments for recording patients with a BMI $\geq$ 30 (British Medical Association, 2012) via the Quality and Outcomes Framework (QOF) scheme which rewards GP practices for the provision of quality care and improvements in the delivery of clinical care. In theory, GP practices should therefore target patients who could benefit from weight management interventions. However, this is not a requirement of the QOF and it may not be done in practice in the UK (Michie, 2007; Shiffman et al., 2009; Noordman, Verhaak and van Dulmen, 2010). The QOF therefore incentivises GPs to record BMI, but there is no target in relation to actual weight management interventions or outcomes. GPs have reported several barriers to action, including insufficient time and knowledge, a belief that the intervention would be ineffective, a lack of awareness of available weight management interventions, and fear of causing offence (Hiddink et al., 1995; Foster et al., 2003; Leverence et al., 2007; Michie, 2007; Henderson, 2015). Other studies have found variations in health care practitioners' confidence levels for specifically supporting individuals with intellectual disabilities to gain and maintain a healthy weight (Stein 2000; West Midlands NHS Trust, 2011).

The UK guidelines acknowledge that there is minimal evidence from controlled studies as to which weight management interventions are effective for people with intellectual disabilities who are obese (SIGN, 2010; NICE, 2014a). The NICE guidelines suggest that this lack of evidence may contribute to inequalities and access to services as experienced by this population group (NICE, 2014b p35). The

NICE guidance also recommends that interventions should be tailored to meet the needs of different population groups (Recommendation 9, NICE, 2014a). In 2016, Public Health England published guidance for health care commissioners, providers, practitioners, carers and intellectual disabilities professionals on making reasonable adjustments to weight management services for people with intellectual disabilities (Public Health England, 2016a). The guidance provided examples of reasonable adjustments at the patient level including 'easy-read' leaflets or booklets that may help to inform patients' decision making. The guidance also provided eleven case studies from across England, of which, three received some form of evaluation. However, the examples and case studies provided in the guidance focused on the processes of managing weight through diet-only or exercise-only interventions. Such interventions also tended to be primarily concerned with promoting behaviour change. However, wider socio-economic and environmental interventions (e.g. promotion of walking routes, the taxing of less healthy foodstuffs, and anti-poverty strategies) may need considering for adults with intellectual disabilities (Emerson and Hatton, 2014).

### *Previous weight management reviews*

Previous reviews have explored weight management interventions for adults with intellectual disabilities (Hamilton et al., 2007; Jinks et al., 2011; Sales and Walker, 2011; and Spanos et al., 2013). These reviews were concerned with identifying which types of weight management interventions are delivered to adults with intellectual disabilities. The interventions that were identified by these reviews included stand-alone dietary interventions, stand-alone physical activity interventions, behavioural and / or educational interventions, health promotion interventions, or a combination of these different components. To date, there have been no specific reviews of evidence-based multi-component weight management interventions for adults with intellectual disabilities. Further research exploring evidence-based multi-component weight management interventions for adults with intellectual disabilities is vital given that the problem of obesity is greater for adults with intellectual disabilities than it is for the general adult population, and given the health risks associated with obesity.

## *Conclusions*

Obesity is common in adults with intellectual disabilities. Adults with intellectual disabilities who are obese are at risk of experiencing serious obesity-related medical conditions which affect both their quality of life and their life expectancy. There seems to be a recognition by UK policy-makers of the need to address obesity in adults with intellectual disabilities and UK guidance recommends evidence-based multi-component weight management interventions, which are tailored for different population groups, including adults with intellectual disabilities. However, research, policy and guidance to inform the practice and provision of tailored evidence-based multi-component weight management interventions for this population is lacking.

## **Aim**

The overall aim of this thesis is to explore how evidence-based multi-component weight management interventions can be tailored for adults with intellectual disabilities who are obese and at risk of obesity related health conditions.

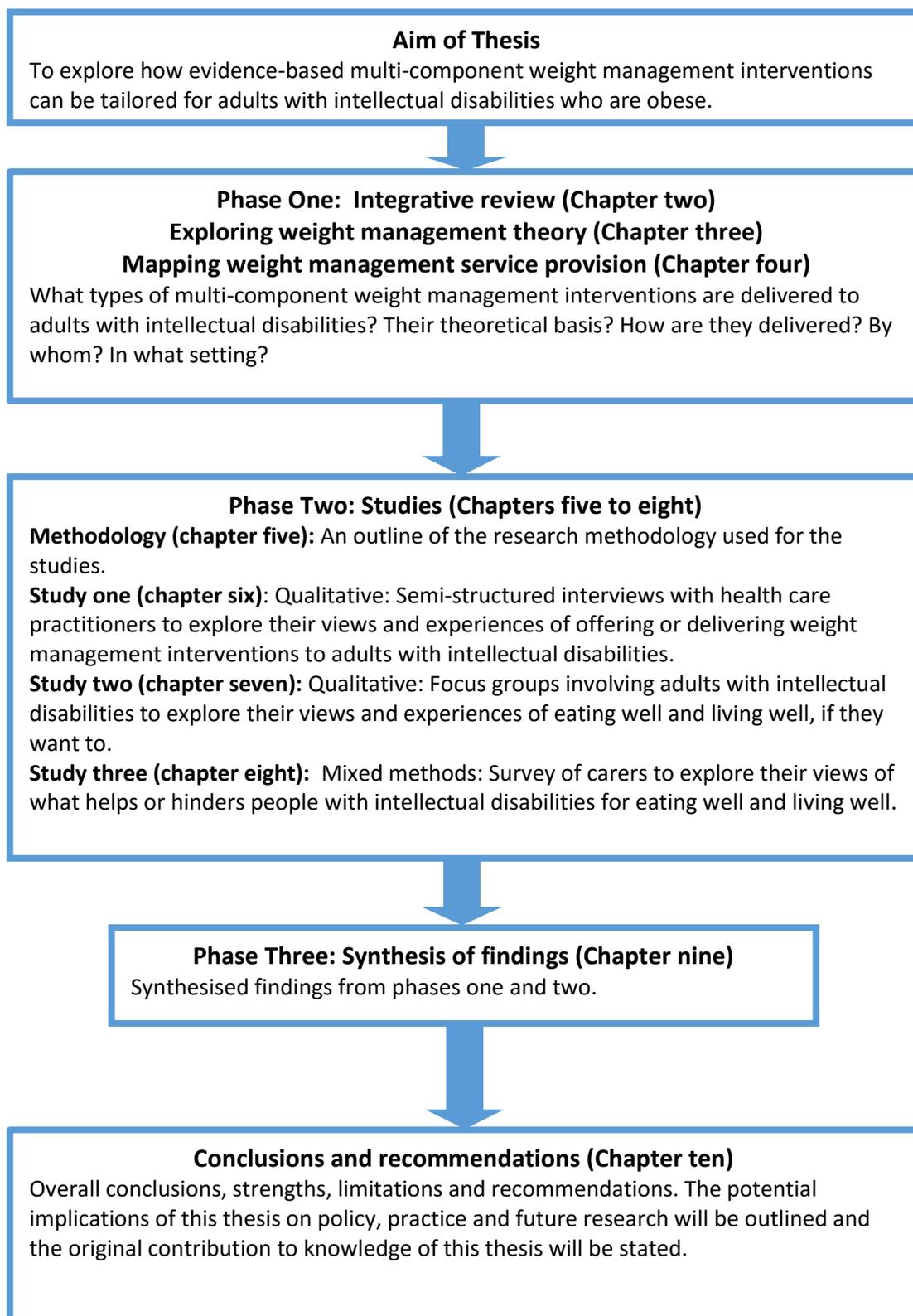
## **Objectives**

- To explore what types of evidence-based multi-component weight management interventions are delivered to adults with intellectual disabilities, their theoretical basis, how they are delivered, by whom and in what setting.
- To explore the barriers and facilitators to weight management interventions for adults with intellectual disabilities, from the differing perceptions of service commissioners, service providers, health care practitioners, adults with intellectual disabilities, their carers and support workers.
- To recommend how to encourage the tailoring and implementation of evidence-based multi-component weight management interventions for adults with intellectual disabilities within a complex system, such as health care.

## **Outline of thesis**

The thesis includes three main phases. These are phases summarised in Figure 1.6 and outlined narratively below.

**Figure 1.6: Flowchart highlighting the phases of research for this thesis**



The first phase involved an integrative review, an exploration of theories underpinning weight management interventions for adults with intellectual disabilities, and a mapping exercise to explore the extent of weight management service provision for adults (with, and without, intellectual disabilities). The review is described in chapter two. The exploration of theory is described in chapter three, and the mapping exercise is described in chapter four. The review summarises the existing literature describing the types of multi-component weight management interventions delivered to adults with intellectual disabilities and how they are delivered - including if and how these interventions are tailored for this population group. Chapter three assesses whether interventions delivered in practice have been informed by theoretical underpinnings. The mapping exercise described in chapter four explores the extent of weight management service provision for adults (with and without intellectual disabilities) nationally and locally in Lancashire, a county in North West England. 67% of the total adult population in Lancashire are overweight or obese ( $BMI \geq 25$ ), which is above the England prevalence of 64.8% (Lancashire County Council, 2017).

Findings from the first phase were used to inform research in phase two of the research. The second phase involved three separate studies. One of these studies was a co-produced focus group study engaging adults with intellectual disabilities in the research design and co-production of innovative focus group materials. The methodology for the research in phase two is described in chapter five. The methodology chapter sets out the aims, objectives, methods, subjects, and sampling for each of the three studies. The chapter also discusses the procedure for the identification, recruitment and consenting of participants, ethical considerations, as well as the data collection and data analysis techniques used.

The first study in Phase Two was a qualitative study that involved face-to-face semi-structured interviews with a sample of health care practitioners based in the North West of England. This study aimed to explore how health care practitioners (principally – but not limited to - General Practitioners and General Practice Nurses) recognise obesity in adults with intellectual disabilities and how they manage interventions for adults with intellectual disabilities who are obese. The study's

findings are presented in chapter six. Chapter six also includes a discussion of the study's findings, a discussion of the study's strengths and limitations, and a comparison with what is already known in the existing literature about health care practitioners' views and experiences of obesity and weight management interventions for adults with intellectual disabilities who are obese.

The second study in Phase Two was a co-produced qualitative study that comprised focus groups and a wider group discussion involving adults with intellectual disabilities and their carers or supporters. The focus groups and wider group discussion aimed to explore participants' perceptions of what may help or make it difficult for them to eat well, live well and manage their weight, if they want to. The study utilised innovative focus group materials to elicit responses from participants. The study's findings are described and discussed in chapter seven. Findings are compared with other previous related research. Study strengths and limitations are also explored.

Phase Two's third study involved a survey of carers and supporters of people with intellectual disabilities. The aim of the survey was to explore carers' or supporters' perceptions of what helps or makes it difficult for people with intellectual disabilities to eat well, live well and manage their weight, if they want to. The findings are described and discussed in chapter eight. Strengths and limitations of the study are also discussed.

In Phase Three, the studies' findings from Phase Two were synthesised with Phase One findings. The overall findings are discussed in chapter nine.

Finally, in chapter ten, the main conclusions, strengths and limitations of the overall programme of research are summarised. The potential impact of this thesis on policy, practice and future research are outlined and recommendations arising from the programme of research are presented. The original contribution to knowledge of this thesis is also stated in this chapter.

# CHAPTER TWO

## PHASE ONE: INTEGRATIVE REVIEW

Chapter one provided the background and rationale for further research into multi-component weight management interventions for adults with intellectual disabilities who are obese and at risk of obesity-related medical conditions including cardiovascular disease. The first chapter also presented an outline of the phases of research undertaken for this thesis. This chapter reports an integrative review of multi-component weight management interventions delivered to adults with intellectual disabilities conducted during the first phase of this thesis. The chapter presents the review's aim, methods, findings, discussion of findings and conclusions, together with the identified studies' limitations and limitations of the review.

### BACKGROUND

Previous reviews of weight management interventions for adults with intellectual disabilities have been conducted (Hamilton et al., 2007; Jinks et al., 2011; Sales and Walker, 2011; Spanos et al., 2013b). A range of weight management interventions were identified by these reviews including stand-alone dietary interventions, stand-alone physical activity interventions, behavioural and / or educational interventions, health promotion interventions and various combinations of these different components. To date, however, there have been no comprehensive integrative reviews of evidence-based multi-component weight management interventions for adults with, or without, intellectual disabilities.

### 2.1 Aim

The aim of the integrative review undertaken in the first phase of this thesis was to identify the type of multi-component weight management interventions delivered to adults with intellectual disabilities – including if and how these interventions are

tailored for this population group. This review aimed to address the following research questions:

1. What types of multi-component weight management interventions are delivered to adults with intellectual disabilities?
2. How are multi-component weight management interventions delivered to adults with intellectual disabilities, by whom and in what setting?
3. Are multi-component weight management interventions effective in terms of achieving clinically significant weight loss in adults with intellectual disabilities who are obese?
4. What are the views and experiences of participants, their carers and the health care practitioners involved in the delivery of multi-component weight management interventions?

## **2.2 Methods**

The first phase of this thesis incorporated an integrative review, which utilised systematic review methodology to combine the findings of a range of different research studies including quantitative and qualitative studies (Evans, 2007). Reviews conducted in this way have the potential to develop a comprehensive understanding of problems relevant to health and social care because their inclusion of a diverse range of data sources can enhance a holistic understanding of the phenomenon of concern (Whittemore and Knafl, 2005; Evans, 2007).

### *Inclusion and exclusion criteria*

The inclusion and exclusion criteria used for the review are outlined in Table 2.1.

**Table 2.1: Integrative Review - Inclusion and exclusion criteria**

<p><b>Inclusion criteria</b></p> <p>Primary research studies of individuals with intellectual disabilities (and other terms used to describe this population group) aged 18 years and over participating in multi-component weight management interventions (involving all three recommended components of diet, physical exercise and behaviour change) and or their carers and or support workers and or the health care practitioners involved in the delivery of such interventions to adults with intellectual disabilities.</p> <p>Studies of mixed samples (with and without intellectual disabilities) could be included if some data is reported just for people with intellectual disabilities.</p> <p>Peer reviewed full text journal articles.</p> <p>All studies published since the start of the databases (no time limit).</p> <p>All types of primary research study designs including: randomised controlled trials (RCTs), cluster RCTs, quasi-experimental pre-test and post-test intervention studies, cohort studies, retrospective studies, experimental or trial studies and qualitative studies.</p> <p><b>Exclusion criteria</b></p> <p>Studies including children or young people with intellectual disabilities (and other terms used to describe this population group) aged under 18 years because they may require different interventions to adults.</p> <p>Studies that investigated weight management in adults when obesity is specifically attributed to specific genetic syndromes such as Prader-Willi syndrome or Bardet-Biedl syndrome because this review is concerned with non-genetic modifiable lifestyle risk factors.</p> <p>Studies involving pharmacology or surgery because the review is concerned with non-pharmacological lifestyle weight management interventions.</p> <p>Studies involving 'Special Olympics' athletes were excluded as these individuals may not be representative of all adults with intellectual disabilities. <i>Special Olympics is the world's largest sports organization for children and adults with intellectual disabilities, providing year-round training and competitions to 5.7 million athletes and Unified Sports partners in 172 countries (<a href="http://www.specialolympics.org/">http://www.specialolympics.org/</a>)</i></p> <p>Abstracts only, editorials, position statements, commentaries, discussions and conference papers.</p> <p>Non-English language studies were excluded due to limited resources available for translation purposes.</p>
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### *Search Strategy*

A search strategy was developed to search electronic databases including Ovid Medline (1946 to 14/07/2015), Embase (1974 to 15/07/2015), CINAHL Complete (Cumulative Index to Nursing & Allied Health Literature) (1975 to 14/07/15) and Cochrane (1993 to 16/07/2015) using MeSH headings, key terms and syntax specific to each database. These are major bibliographical databases of medicine, life sciences, pharmacology and biomedical information that contain articles from academic journals covering medicine, nursing, pharmacy, dentistry and health care. The key terms searched were adapted from a previous systematic review of weight

management interventions in this population group (Spanos et al., 2013a). The key terms and MeSH headings used were combined using the Boolean operators “AND” and “OR”. The search strategy is shown in Table 2.2.

**Table 2.2: Search Strategy**

1	exp Learning Disorders/ or exp Intellectual Disability/
2	learning disabilities.mp.
3	intellectual disabilities.mp.
4	mental retardation.mp.
5	mental retardation/
6	mentally disabled persons.mp. or exp Mentally Disabled Persons/
7	developmental disabilities/
8	obesity.mp. or exp Obesity/
9	overweight.mp. or exp Overweight/
10	underweight.mp. or exp Thinness/
11	weight loss.mp. or exp Weight Loss/
12	weight gain.mp. or exp Weight Gain/
13	diet/
14	Nutrition Therapy/ or nutrition.mp.
15	physical activity.mp.
16	lifestyle.mp. or exp Life Style/
17	exp Exercise/
18	exp Body Mass Index/ or exp Body Weight/ or weight management.mp. or exp Food Habits/ or exp Hypertension/
19	exp Behavior Therapy/ or exp Health Knowledge, Attitudes, Practice/ or behaviour change.mp. or exp Health Promotion/
20	health education.mp. or exp Health Education/
21	primary prevention.mp. or exp Primary Prevention/
22	1 or 2 or 3 or 4 or 5 or 6 or 7
23	8 or 9 or 10 or 11 or 12
24	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
25	22 and 23 and 24
26	limit 25 to (English language and humans and all adult)
KEY	
/ = Mesh – Medical subject heading	
exp = explore subject heading	
mp = multi-purpose (searches several fields at once)	
Also searched the following word variations:	
ti = title word search	
ab = abstract word search	
kw = key word search	

A sensitivity search was also carried out, which included forward and backward citation tracking of studies retrieved, checking frequently cited authors, conducting searches by hand of relevant journals (Journal of Applied Research in Intellectual Disabilities, Journal of Intellectual Disability Research, Journal of Intellectual and Developmental Disability, Obesity Reviews) and searching Google Scholar. Papers were initially screened on title and those retained were screened on abstract. Any articles that appeared to meet the inclusion criteria were read in full. Any queries over articles that the postgraduate student had were discussed with members of

the supervision team to reach a consensus over whether to exclude or include such articles.

### *Selection*

The process for selecting studies for inclusion in the review is illustrated in the flowchart outlined in Figure 2.1. A table of excluded abstracts and full-text articles (and reasons for exclusion) is included in Appendix 1.

### *Data extraction*

Data for the following characteristics were extracted:

- Study metadata (author, title, year of publication, country of origin, setting and study type).
- Staff delivering the intervention (professions).
- Type of intervention (description, duration and any follow-up).
- Participants' characteristics (age, sex, sample size, record of weight status, record of the type of intellectual disability e.g. mild, moderate, profound or severe).
- Outcome measures (e.g. weight and BMI change).
- Findings.

### *Critical appraisal*

The quality assessment of a study considers the appropriateness of the study's design to the study's research objective, the risk of bias (including selection bias, allocation bias, detection bias, reporting bias), and other issues related to the study's quality including, for example, data collection methods, attrition, choice of outcome measure, appropriate use of statistical tests, integrity of the intervention, generalisability and replicability (based on the intervention's description) (Centre for Reviews and Dissemination, 2009). A checklist was developed to assess the quality of identified studies. The checklist was based on the criteria of the Critical Appraisal Skills Programme (CASP) tool ([www.casp-uk.net](http://www.casp-uk.net)), a critical appraisal framework developed by Walsh and Downe (2006) for use with qualitative studies,

and the CONSORT checklist for assessing the quality of controlled trials ([www.consort-statement.org](http://www.consort-statement.org)). Studies that were critically appraised were rated as either strong, moderate or weak. The criteria for the appraisal included, for example, whether:

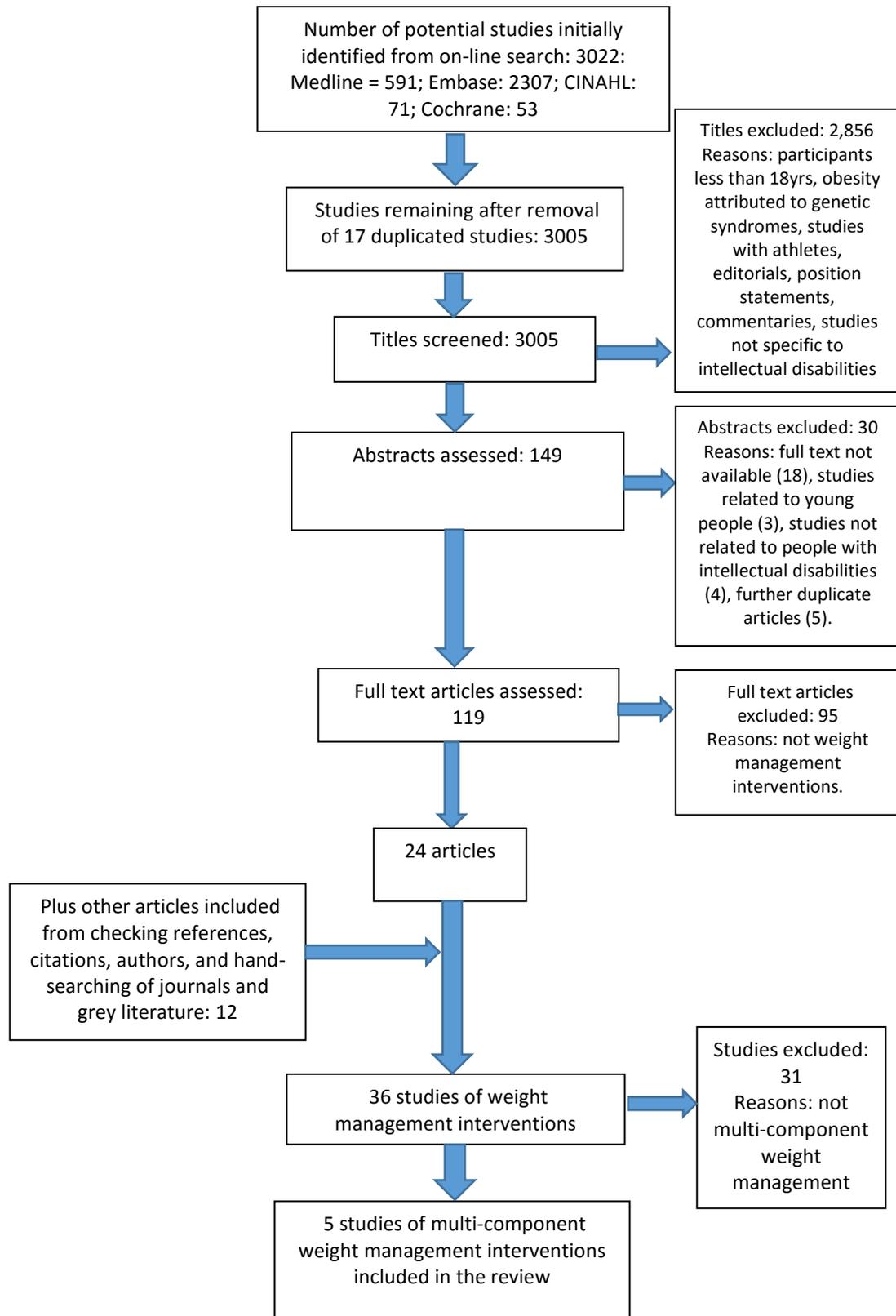
- The research question(s)/objectives/hypotheses were clear and appropriate.
- The sample size was given (for quantitative studies).
- The number of participants was given (for qualitative studies).
- A randomization method was used (for quantitative studies).
- Recruitment of participants was adequately described (in qualitative studies).
- The attrition rate was adequately described (in both qualitative and quantitative studies).
- The method / design was apparent and consistent with the research intent (in both qualitative and quantitative studies).
- The outcomes of the intervention were clearly described (in both qualitative and quantitative studies).
- The data analysis was adequately described and rigorous (in both qualitative and quantitative studies).

Critical analysis commenced with an initial reading of each study. A summary of each study was then made during the second reading. The summary outlined how each stage of the critical analysis framework had been demonstrated within the study. An example of a completed appraisal for one of the studies included in the critical analysis is included as Appendix 2.

### *Data analysis*

Narrative data synthesis was carried out to describe the types of interventions delivered to adults with intellectual disabilities who are obese and how these interventions can be appropriately implemented for this population group. Meta-analysis could not be performed as there was heterogeneity among the studies in terms of study types, sampling techniques, sample sizes, types of interventions, different outcome measures and variations in how outcome measures were assessed.

**Figure 2.1: Flowchart illustrating the literature search process**



## 2.3 Findings

On initial screening of titles and abstracts, 120 articles appeared to meet the inclusion criteria. Full text papers were obtained for 119 of the 120 articles. The full text paper for one of these 120 articles was not available (Beeken et al., 2015) and it transpired from follow up contact made with the practitioners involved in this study's ('Shape-Up') intervention that this was a general healthy eating advice and training programme, rather than a multi-component weight management intervention (comprising diet, exercise and behaviour change components). 95 of the 119 full text papers' studies were excluded because they were not multi-component weight management interventions either. A further 12 full text papers were identified by checking references of identified articles, citation searches, searches of key authors and hand-searching journals and grey literature. 36 full text papers were assessed. 31 out of the 36 full text articles assessed were excluded because the interventions were either health promotion interventions (10 articles), behaviour and or educational interventions (8 articles), physical only interventions (8 articles), or diet-only or diet and physical activity only interventions (3 articles). There was insufficient information provided regarding the actual components of the studies' interventions in 2 of the 31 studies and it was therefore not clear whether they were studies involving multi-component weight management interventions.

5 studies met the eligibility criteria for inclusion in the review and these all included diet, exercise and behaviour change components (Melville et al., 2011; Bergstrom et al., 2013; Spanos et al., 2013b; Spanos et al., 2014; and Sundblom et al., 2015). The study protocol for the cluster randomised controlled trial (RCT) (Bergstrom et al., 2013) identified by the review was also obtained and reviewed for further information about the study (Elinder et al., 2010).

Table 2.3 provides a summary of the 31 excluded articles. Table 2.4 provides a summary of the five multi-component weight management intervention studies included in this review.

**Table 2.3: Excluded weight management intervention studies**

Type of intervention	References
Health Promotion	Aronow and Hahn, (2005) Bazzano et al., (2009) Bradley, (2005) Chapman et al., (2005) Chapman et al., (2008) Ewing et al., (2004) Marshall et al., (2003) McDermott et al., (2012) Poyner, (2008) Rimmer et al., (2004)
Behaviour	Fisher, (1986) Fox et al., (1984) Fox et al., (1985) McCarran and Andrasik, (1990)
Behaviour and education	Geller and Crowley, (2009) Harris and Bloom, (1984) Mann et al., (2006) Sailer et al., (2006)
Diet-only	Jolly and Jamieson, (1999)
Physical activity-only	Calders et al., (2011) King and Mace, (1990) Mendonca et al., (2011) Moss, (2009) Oviedo et al., (2014) Stanish et al., (2001) Wu et al., (2010) Yen et al., (2012)
Diet and physical activity	Draheim et al., (2002) Saunders et al., (2011)
Unclear	Steele and Capehorn, (2015) Thomas and Kerr, (2011)

The five identified studies included a cluster randomised controlled trial (RCT) (Bergstrom et al., 2013), two quasi-experimental studies involving the pre-testing and post-testing of an intervention (Melville et al., 2011; Spanos et al., 2014) and two qualitative studies (Spanos et al., 2013b; Sundblom et al., 2015). The mean sample size of the intervention groups in the studies was 54 and sample sizes ranged from 17 to 130. Mixed gender groups were used in two studies (Melville et al., 2011; Spanos et al., 2014) and the gender was not specified in other studies. Three studies included adult participants with mild to moderate intellectual disabilities (Melville et al., 2011; Bergstrom et al., 2013; Spanos et al., 2014). Two of these studies also included adults with severe to profound intellectual disabilities (Melville et al., 2011; Spanos et al., 2014). Two studies included only adults with

intellectual disabilities with obesity (Melville et al., 2011; Spanos et al., 2014). One study also included 57% of adults with intellectual disabilities who were overweight or normal weight as well as 43% of adults with intellectual disabilities who were obese (Bergstrom et al., 2013). The other studies involved only carers of people with intellectual disabilities (Spanos et al., 2013b) or only health care practitioners (Sundblom et al., 2015).

One study involved participants with intellectual disabilities who were taking part in a tailored version of an existing multi-component weight management intervention and matched this with participants without intellectual disabilities taking part in the existing (non-tailored) weight management intervention (Spanos et al., 2014). No identified studies involved both participants with and without intellectual disabilities taking part in the same multi-component weight management intervention.

Two studies (Melville et al., 2011 and Spanos et al., 2014) included outcome measures for height, weight, Body Mass Index (BMI), waist circumference, physical activity (accelerometers), dietary and physical activity (questionnaire). Information was also collected on blood pressure, hypertension, heart disease, diabetes, arthritis, asthma, sleep apnoea. One study utilised semi-structured interviews with carers involving questions related to carers' perceptions of weight loss, challenges faced whilst supporting participants to change diet and physical activity, and carers' perceptions of the intervention (Spanos et al., 2013b). Two studies included outcome measures for physical activity (pedometry), BMI, waist circumference, dietary quality (photographs), satisfaction with life (quality of life scale) and work routine changes (Bergstrom et al., 2013; Sundblom et al., 2015).

**Table 2.4: Studies included in the integrative review**

Country	Setting	Type of study	Participants	Intervention components, theoretical basis and staff involved	Duration	Follow up	Outcomes assessed	Findings
<b>Bergstrom et al., (2013)</b>								
Sweden	Residential based setting  33 sites	Cluster RCT	N=130 with mild or moderate intellectual disabilities (57% women and 43% men aged 20–66 years) 43% obese.	Complex multi-component intervention based on Social Cognitive Theory (Bandura, 1986). Aimed to improve health behaviour (diet and physical exercise) of residents through personal factors, such as knowledge, skills, preferences, and self-efficacy among the residents as well as through improvements in their social and physical environment, which was dependent on the knowledge, skills, and work routines of the caregivers. The intervention included health ambassadors, a health course for residents and a study circle for carers.	12 – 16 months	No follow up after 16 months	Physical activity Weight loss using BMI Waist circumference Dietary quality Life satisfaction	Positive intervention effect was found on physical activity, with an average increase of 1608 steps per day among participants in the intervention group. No significant effects were found on BMI.

<b>Melville et al., (2011)</b>								
UK	Residential -based setting	Quasi- experi- mental (pre- and post- testing of an interve- ntion)	N=47 with mild, moderate, severe and profound intellectual disabilities. 59% females, 41% males. Mean age 48.3 years. 100% obese.	Intervention (Take 5) based on recommendations for multi-component weight management interventions (NICE, 2014a). The intervention included a personalised dietary prescription 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. The intervention was delivered by a dietician and a sports medicine graduate to individual participants in their own homes using accessible resources. Carers were involved in supporting participants.	9 sessions each lasting up to 60 minutes, held every 2 to 3 weeks	24 weeks	Weight loss using BMI Waist circumference Levels of physical activity	Of the 47 participants who completed the TAKE 5 multi-component intervention, 17 (36%) lost 5% or more of their initial body weight.
<b>Spanos et al., (2013b)</b>								
UK.	Residential - based setting	Qualita tive	N=24 carers (carers of people with intellectual	Qualitative study which explored the experiences of carers supporting adults with intellectual disabilities	6 months	None	Carers' views of an intervention	This study identified barriers and facilitators experienced by carers during the process of supporting an individual with an intellectual disability to lose

			disabilities participating in a multi-component weight management intervention).	participating in a multi-component weight management intervention (Take 5) delivered by a dietician and a sports graduate. Take 5 components included energy deficit diet, methods to increase physical activity levels and behavioural change approaches. The intervention was based on UK recommended guidance for multi-component weight management interventions (NICE, 2014a).				weight. These included the need for motivation, improved support and for adapted information and materials to improve communication.
<b>Spanos et al., (2014)</b>								
UK.	Residential - based setting.	Quasi-experimental (pre- and post-testing of an intervention)	N=52 with mild, moderate and profound intellectual disabilities (61% females and 39% males). Median age 51 years and age range 26-73. 100%	TAKE 5 intervention (described in Melville et al., 2011 above) for obese adults with intellectual disabilities. Delivered by researchers and dieticians.	9 sessions held over a 16-week period	None	Weight loss using BMI	Compared the Glasgow and Clyde Weight Management Service's (GCWMS) multi-component weight management intervention with TAKE 5 (a tailored version of GCWMS intervention for adults with intellectual disabilities). No significant differences found between the 2 groups in the amount of weight loss, change in BMI, success of achieving 5% clinically significant weight loss, and rate of weight loss across the 16-week intervention.

			obese (BMI ≥30).					
<b>Sundblom et al., (2015)</b>								
Sweden	Residential based setting.	Qualitative	N=17 staff and managers.	This qualitative study described the implementation process for a multi-component intervention designed to improve the diet and physical activity of adults with intellectual disability, viewed from the perspectives of staff involved in the delivery of the intervention (health ambassadors, support staff and managers). The intervention was based on Social Cognitive Theory (Bandura 1986) and consisted of three components: (i) a health course for residents, (ii) a health ambassador in each residence and (iii) a study circle for the staff in each residence.	12 – 16 months	None	The views of staff involved in the delivery of the intervention	Findings highlighted the importance of motivation for change among managers, carers and participants.

### *Quality of included studies*

All the included studies provided clear rationales for the research, contextualised by existing literature. The research designs in these studies were apparent, appropriate and consistent with the research intent and or research objectives. Sample sizes were given in all the studies, although it was unclear whether steps were taken to try to reduce sampling bias in two studies (Melville et al., 2011; Sundblom et al., 2015). All the studies provided detailed descriptions of the multi-component intervention. This would enable replicability of the intervention. One identified cluster RCT (Bergstrom et al., 2013) followed the CONSORT checklist for the transparent reporting of trials ([www.consort-statement.org/?o=1001](http://www.consort-statement.org/?o=1001)). This included, for example, the use of a power calculation and measurement of intervention fidelity. The results of this study are therefore generalizable to similar contexts regarding participants and type of residences (Bergstrom et al., 2013). Two intervention studies were based on Social Cognitive Theory (Bergstrom et al., 2013; Sundblom et al., 2015) whilst the other studies followed recommended UK guidance relating to multi-component weight management interventions (Melville et al., 2011; Spanos et al., 2013b; Spanos et al., 2014).

### *What types of multi-component weight management interventions are delivered to adults with intellectual disabilities?*

Three UK studies examined a multi-component weight management intervention (TAKE 5) tailored for delivery to adults with intellectual disabilities with obesity (Melville et al., 2011; Spanos et al., 2013b; and Spanos et al., 2014). Two Swedish studies evaluated a complex multi-component intervention tailored for adults with intellectual disabilities who were underweight, normal weight, overweight or obese (Bergstrom et al., 2013; Sundblom et al., 2015). Table 2.5 provides a description of TAKE 5 and the complex multi-component intervention.

**Table 2.5: Description of the identified studies' multi-component weight management interventions**

**'TAKE 5' multi-component weight management intervention for adults with intellectual disabilities who are obese. References: Melville et al., (2011); Spanos et al., (2013b); Spanos et al., (2014)**

TAKE 5 is an adaptation of the Glasgow and Clyde Weight Management Service's multi-component weight management intervention (GCWMS) designed for delivery to the general population of adults with obesity. TAKE 5 has been adapted for delivery to adults with intellectual disabilities who are obese. The intervention includes:

- 9 themed sessions that incorporate UK weight management guidance and recommendations for the management of obesity.
- A personalised diet calculated to achieve an energy deficit of 2510kJ day (600 kcal per day).
- Advice to improve physical activity (5 days of moderate physical activity, 45-60 mins).
- Behavioural change techniques.

Themes discussed in weight loss sessions include:

- The benefits of losing weight, motivation towards a healthy lifestyle, energy deficit diets, the importance of physical activity, principles of healthy eating, healthy ways to cook, emotions and overeating, disadvantages of eating out and takeaways, using behaviour change to alter 'unhealthy habits', coping with cravings, diet myths, an introduction to new ways of motivating participation in physical activity, relapse prevention and evaluating success.

Key themes discussed in the weight management sessions include:

- Individualised maintenance dietary planning, the importance of being active and adopting regular eating patterns, regular self-monitoring of weight and food intakes, barriers to healthy eating and physical activity, snacking, lapses, eating out/social activities, healthy menu planning and an overview of the principles of weight maintenance.

**Complex intervention based on Social Cognitive Theory. Refs: Bergstrom et al., (2013) and Sundblom et al., (2015)**

The complex intervention (incorporating diet, physical activities and behaviour change) reported in studies by Bergstrom et al., (2013) and Sundblom et al., (2015) comprises: (1) appointment of a health ambassador in each community residence who attend network meetings with other health ambassadors from other residences, (2) a study circle for carers, and (3) a health course for the residents. The intervention lasts 12–16 months. The complex intervention is aimed at strengthening knowledge and skills among participants and staff in a supportive environment. The intervention is based on Social Cognitive Theory (28) according to which behaviour, personal factors and environmental influences all interact in a dynamic process.

*How are multi-component interventions delivered to adults with intellectual disabilities, by whom and in what setting?*

Different practitioners were involved in the delivery of the identified multi-component weight management interventions to adults with intellectual disabilities. These included dieticians and sports graduates (n=2), health ambassadors, support staff and managers (n=2), researchers and dieticians (n=1). The studies' interventions took place in residential based settings. The mean duration of the multi-component interventions was 9 months (range = 2 to 16 months). None of the identified studies evaluated the long-term effectiveness of the multi-component weight management interventions beyond the end of the intervention. All the multi-component weight management interventions described in the studies were tailored for adults with intellectual disabilities. Table 2.6 summarises how the identified multi-component weight management interventions were tailored for adults with intellectual disabilities.

**Table 2.6: Summary of how multi-component weight management interventions were tailored for adults with intellectual disabilities**

Use of appropriate communication tools such as Talking Mats, photos, symbols, pictorial illustrations and food models / tools to simplify information, simple spoken and written communication, DVDs and the use of hand-outs appropriate for people with intellectual disabilities ( <i>Melville et al., 2011; Spanos et al., 2014</i> ).
Sessions delivered by health care professionals and clinical researchers (with experience of working with people with intellectual disabilities) ( <i>Melville et al., 2011; Bergstrom et al., 2013; Spanos et al., 2014</i> ).
Sessions delivered on a personalised focused, one-to-one basis to participants in their own homes ( <i>Melville et al., 2011; Spanos et al., 2014</i> ).
The presence and support of carers where appropriate ( <i>Melville et al., 2011; Spanos et al., 2014</i> ).
The incorporation of behavioural methods for problem solving, self-control, goal setting, emotional coping responses and maintaining motivation ( <i>Melville et al., 2011; Bergstrom et al., 2013; Spanos et al., 2014</i> ).
The inclusion of physical activities that participants could undertake in their own home or in other familiar environments ( <i>Melville et al., 2011; Bergstrom et al., 2013; Spanos et al., 2014</i> ).
Physical activities in keeping with the individual participant's own level of abilities ( <i>Melville et al., 2011; Bergstrom et al., 2013; Spanos et al., 2014</i> ).
Training, peer-education, knowledge, health literacy and motivation techniques for participants, carers and staff ( <i>Melville et al., 2011; Bergstrom et al., 2013; Spanos et al., 2014</i> ).

### *Are multi-component interventions effective for adults with intellectual disabilities who are obese?*

UK clinical guidelines for multi-component weight loss interventions for all adults advocate a weight loss period of 3–6 months, followed by a weight maintenance intervention (Scottish Intercollegiate Guideline Network 2010; NICE 2014a; NICE 2014b). Currently, however, there is no published audit assessing the clinical effectiveness of UK multi-component weight management interventions for adults with intellectual disabilities that follow national clinical guidelines for the general population and are delivered by health care practitioners (Spanos, 2013a). Two studies included in the integrative review reported 5% weight loss outcomes in participants who were obese (Melville et al., 2011; Spanos et al., 2014). Both evaluated the TAKE 5 intervention tailored for delivery to adults with intellectual disabilities who are obese. Melville et al., (2011) reported that 36% of participants with an intellectual disability who were obese achieved a 5% weight loss with the TAKE 5 intervention. Spanos et al., (2014) reported that 41% of participants with intellectual disabilities who were obese achieved a 5% weight loss with TAKE 5 compared to 37% in a comparison group of adults without intellectual disabilities who were obese. However, whilst 5% weight loss provides a useful benchmark for evaluating whether a patient's response to treatment is 'effective', where individual patients are concerned, greater weight loss may achieve better health outcomes, and even less weight loss may bring patient benefits (Jensen et al., 2013; Williamson, Bray and Ryan, 2015).

### *What are the views and experiences of participants, their carers and the health care practitioners?*

The review did not identify any studies exploring adults with intellectual disabilities' views and experiences of multi-component weight management interventions. One study explored the views and experiences of 24 carers of participants with intellectual disabilities (Spanos et al., 2013b) and another explored the views and experiences of 17 staff involved in the delivery of a multi-component intervention to adults with intellectual disabilities (Sundblom et al., 2015). These studies identified a lack of support for individuals with intellectual disabilities and poor

communication as barriers in the implementation of multi-component weight management interventions. The role of supportive carers was emphasised along with the need for motivation amongst participants, carers and health care practitioners. The studies also emphasised the need for accessible resources to aid communication with individuals with intellectual disabilities.

## **2.4 Discussion**

This review found a lack of multi-component weight management intervention studies involving adults with intellectual disabilities. The review identified only five studies (from 2011 to date) describing just two different tailored multi-component weight management interventions for adults with intellectual disabilities. Three studies were from the UK and the other two were Swedish. Only two of the studies from the UK reported weight loss outcomes in participants with obesity (Melville et al., 2011; Spanos et al., 2014). Of the excluded studies (highlighted in Table 2.3), there were 31 other studies (8 of which were from 2011 to date) exploring other types of weight management interventions including: health promotion interventions, behaviour and or educational interventions, physical only interventions, diet only or diet and physical activity interventions. This finding suggests that researchers have only recently started conducting trials of multi-component weight management interventions for adults with intellectual disabilities nationally and internationally and that some researchers are still conducting trials of non-evidence-based weight management interventions.

Significantly, none of the identified studies explored the views and experiences of adults with intellectual disabilities. The voices of this population were missing from the research. Furthermore, only two studies explored the views and experiences of carers or health care practitioners involved in the delivery of multi-component weight management interventions (Spanos et al., 2014; and Sundblom et al., 2015). Measuring weight loss or physical activity outcomes alone is not sufficient to measure the effectiveness or acceptability of a multi-component weight management intervention. Further qualitative research may provide an insight into the perceived effectiveness and acceptability of multi-component weight

management interventions and how such interventions could be tailored from the perspectives of adults with intellectual disabilities, their carers and health care practitioners.

This is the first known integrative review to identify the types of multi-component weight management interventions delivered to adults with intellectual disabilities – including if, and how, interventions are tailored for this population group (Doherty et al., 2017). Emerging evidence was found to suggest that evidence-based multi-component weight management interventions can be tailored for adults with intellectual disabilities. The personalised focused and themed sessions delivered by a health care practitioner on a one-to-one basis in an individual's home - together with the involvement of motivated carers, participants and health care practitioners may be key factors in the reported effectiveness of tailored multi-component intervention. However, the multi-component weight management interventions identified may not reflect current routine practice. It is not clear whether the implementation of such highly intensive, personalised one-to-one interventions is sustainable in routine practice following completion for trials of such interventions. In routine practice, health care practitioners may not have long-term access to the types of funding and other resources made available to researchers for clinical research trials of such interventions. Adults with intellectual disabilities who are obese might be referred to other types of weight management interventions e.g. diet-only or physical activity-only interventions delivered in group settings by health care practitioners without experience of working with individuals who have intellectual disabilities. Carers might not be as involved or as motivated as they appeared to be with the studies' interventions.

One of the studies comparing a tailored version of a multi-component weight management intervention for adults with intellectual disabilities with a non-tailored version for their non-disabled peers (TAKE 5) reported finding no clinically significant differences in weight loss outcomes between adults with or without intellectual disabilities who are obese (Spanos et al., 2014). This suggests that a tailored multi-component weight management intervention may be equally effective in adults with and adults without intellectual disabilities who are obese.

However, further controlled studies are required to confirm this one study's findings.

Another study, evaluating a different tailored intervention, included participants who were underweight (2%), normal weight (28%), overweight (27%) or obese (43%) (Bergstrom et al., 2013). This intervention was targeted towards increasing the physical activity levels of participants rather than just weight change outcomes alone and a positive intervention effect was found on physical activity, with an average increase of 1608 steps per day among participants. However, further research is needed to evaluate this intervention when it is run routinely in practice by service providers rather than by clinical researchers under research conditions.

Current UK guidelines recommend a longer-term weight maintenance phase to prevent future weight gain or health risks (NICE 2014a; NICE 2014b; SIGN 2010), yet only two of the review's identified studies evaluated the weight management effectiveness of a multi-component weight management intervention after 16 months (Bergstrom et al., 2013; Sundblom et al., 2015). However, the other three studies are recent and future follow-up studies may be planned. Follow-up studies are required to assess the weight maintenance of participants in the longer-term and the sustainability of the intervention. Future multi-component weight management intervention studies also need to provide clear descriptions of what an intervention comprises, its theoretical basis, its expected outcomes, how it is implemented, how it is monitored and how it is evaluated in line with Medical Research Council (MRC) guidelines for complex interventions (Craig et al., 2008; Spanos et al., 2013a; Moore et al., 2015). However, it is acknowledged that there are methodological and practical challenges involved in undertaking research in this field. For example, a researcher's choice of intervention may be constrained by issues such as sample recruitment, settings and resources available, and evaluation may take place whilst the intervention is being implemented, rather than starting beforehand (Craig et al., 2008; Moore et al., 2015).

### *Studies' limitations*

The samples used in the studies were heterogeneous. Two studies limited their inclusion criteria to only include participants who were obese (Melville et al., 2011; Spanos et al., 2014). One study included 43% of obese participants and the other 57% were either underweight, normal weight, overweight or underweight (Bergstrom et al., 2013). Three studies included participants with mild to moderate intellectual disabilities (Bergstrom et al., 2013; Melville et al., 2011; Spanos et al., 2014) and two of these studies also included people with severe and profound intellectual disabilities (Melville et al., 2011; Spanos et al., 2014). The other two studies explored the views and experiences of carers and health care practitioners involved in the delivery of an intervention (Spanos et al., 2013b; Sundblom et al., 2015). All the studies related to people living in residential settings rather than with family members or in other supported housing. These limitations raise queries as to whether the studies' intervention findings are generalizable to all adults with intellectual disabilities.

### *Strengths and limitations of this review*

This was the first known published integrative review of multi-component weight management interventions delivered to adults with intellectual disabilities. However, the review was limited to English language studies. The review identified only five studies. These were from the UK and Sweden. There may be other relevant studies published in different languages from other countries. The review was also limited to studies involving adults with intellectual disabilities. There may be transferable evidence from studies involving children and young people from this population.

## **2.5 Conclusions**

This review found a lack of evidence-based multi-component weight management intervention studies involving adults with intellectual disabilities. The review identified emerging evidence that suggests that multi-component weight management interventions can be tailored for adults with intellectual disabilities who are obese and that such tailored interventions may lead to weight loss

outcomes in this population. However, there were relatively few studies identified, the studies were methodologically different and used different samples. In addition, a wider range of outcome measures (e.g. BMI, waist circumference, dietary quality, changes in physical activity levels, and satisfaction with life) may be needed in future intervention studies. Therefore, it is not possible to make any conclusive recommendations about such interventions and how they may be tailored for adults with intellectual disabilities. Further controlled studies (with a qualitative element) based on MRC guidelines for complex interventions are justified in this field. However, given the high prevalence of obesity and the associated health related risks and the need for interventions in this population group, and given that the risks associated with these interventions are low, then health care providers and practitioners may wish to consider findings from the emerging studies to help tailor existing weight interventions for this population group.

### *Recommendations for future research in this field*

The review's findings highlight gaps in research knowledge concerning evidence-based multi-component weight management interventions and how they can be tailored for adults with intellectual disabilities. The perceptions of adults with intellectual disabilities are missing from the existing studies of these interventions. The review's findings imply that further (controlled and qualitative) research of these evidence-based interventions is required to inform UK obesity and weight management policy, guidance and practice. The review has identified some recommendations for future research in this field. These are summarised in the concluding chapter, chapter ten (conclusions and recommendations).

### *Implications for policy and practice*

Policy makers, service commissioners, providers and health care practitioners should consider obesity and associated health risks in adults with intellectual disabilities as an important health inequality issue. This review suggests that UK obesity and weight management research, policy and guidelines fails to fully investigate and address the needs of this population. This may contribute to

inequities experienced by this population. Further research involving adults with intellectual disabilities may inform policy and practice into obesity and weight management for this population group.

### *Summary of chapter*

This chapter described an integrative review that aimed to identify the types of multi-component weight management interventions delivered to adults with intellectual disabilities – including if and how interventions are tailored for this population. The chapter discussed the review’s findings, strengths, limitations and implications for policy and practice. The next phase of research (described in chapter three) explores the theoretical underpinnings used to inform weight management interventions for adults with intellectual disabilities.

## CHAPTER THREE

### EXPLORATION OF WEIGHT MANAGEMENT THEORY

#### INTRODUCTION

The previous chapter outlined an integrative review to identify the types of multi-component weight management interventions delivered to adults with intellectual disabilities – including if and how these interventions are tailored for this population. The review found emerging evidence to suggest that multi-component weight management interventions can be tailored for adults with intellectual disabilities and that such tailored interventions might lead to short-term weight loss outcomes in adults with intellectual disabilities who are obese. However, the review identified few studies and it was therefore not possible to make conclusive recommendations about these interventions and exactly how they can be tailored for adults with intellectual disabilities who are obese. This chapter explores the underpinning theories used to inform weight management interventions for adults with intellectual disabilities.

#### 3.1 Weight management theories and discussion of theories

The purpose of a theory is to provide practitioners with a guide for action in their routine day-to-day practice (Cochrane, 2014). The theory therefore needs to be applicable in day-to-day practical settings (Fox, 2003). However, the extent to which theoretical approaches have informed interventions generally in health care is unclear (Davies et al., 2010). There is scant research evidence available on how to design theory-based health related interventions (Michie, 2008a), and existing health care interventions and intervention studies are poor at describing the theoretical basis for their intervention (Dixon-Woods et al., 2011). Studies are also poor at describing the components of an intervention, its expected outcomes, or how it should be implemented (Dixon-Woods et al., 2011). Evaluations and improvement programmes for health interventions seem to determine only whether an improvement has taken place and, if so, whether it is attributed to the intervention under study and whether it can be replicated (Portela et al., 2015).

Such studies do not investigate questions of *why* or *how* any change occurred in the participant(s), or the surrounding context, or explain the theoretical basis for the intervention (Portela et al., 2015). There appears to be an assumption that practitioners will automatically take up research-informed guidance (Fox, 2003). However, researchers may develop the underpinning theories for interventions in isolation and the theories may be irrelevant and impractical in routine practice (Tsui, 2013). Thus, there may be a gap in evidence-based recommendations underpinned by theory, and a gap in what recommendations are implemented in practice (Flodgren et al., 2010; Roth, 2006). Weight management practitioners may be reluctant to adopt interventions developed by academics in clinical settings because they may consider interventions impractical, non-transferable, non-generalizable or non-replicable in routine practice in everyday settings (Cochrane, 2014). Some studies suggest that obesity and weight management guidelines may not be useful in practice and, as a result, the guidelines may not be utilised by practitioners (Kirk et al., 2012). Some other authors point out that research and practice to date has so far been unable to tackle the increasing prevalence of obesity in society and that a different approach is needed (Greener et al., 2010; Michie and West, 2013; Ong et al., 2014; Taubes, 2014).

A meta-analysis conducted for the development of UK obesity and weight management guidance examined studies including behaviour change components in weight management interventions (SIGN, 2010; NICE, 2014a). The studies were sourced from four key reviews (McTigue et al., 2003; Avenell et al., 2004; Shaw et al., 2005; Smith et al., 2005). Based on these reviews' findings, the UK guidance recommended the inclusion of behaviour strategies in weight management interventions including: self-monitoring of behaviour and progress, stimulus control (*where patient is taught how to recognise and avoid triggers that prompt unplanned eating*), cognitive restructuring (*modifying unhelpful thoughts or thinking patterns*), goal-setting, problem-solving, assertiveness training, slowing down the rate of eating, reinforcement of changes, relapse prevention and strategies for dealing with weight gain (SIGN, 2010; NICE, 2014a). However, the studies informing the guidance do not appear to have included samples of different population groups. This is problematic as an intervention may be unacceptable for different population

groups' recipients thus indicating that the components and theoretical basis of the intervention may need re-examining (Campbell et al., 2000). Furthermore, the UK guidance indicated that the effectiveness of behaviour strategies based on a Transtheoretical 'Stages of Change' model (Bridle et al., 2005) had been examined but found that there was only limited evidence for the effectiveness of this model (SIGN, 2010; NICE, 2014a). The limited evidence cited within the guidance suggested that the Transtheoretical model was as equally effective as using other materials - such as booklet-based interventions - in increasing levels of physical activity at six months compared to no intervention at all (Marshall et al., 2003).

### *Weight management interventions for adults with intellectual disabilities: Theoretical basis*

A previous systematic review to explore the types of weight management interventions delivered to adults with intellectual disabilities found that some interventions included behaviour control strategies such as self-monitoring, goal setting and reward strategies (Spanos et al., 2013a). However, no information was available on the theories used as the basis for such behaviour change strategies (Spanos et al., 2013a).

The integrative review conducted for this thesis (in chapter two) found 36 studies involving several types of weight management interventions delivered to adults with intellectual disabilities including diet-only or physical activity-only interventions, diet and physical activity interventions, behaviour-only interventions, behaviour and education interventions, health promotion interventions and multi-component interventions. However, 28 of the 36 studies did not provide any information on the theoretical underpinnings of their studies' interventions. Four studies cited Social Cognitive Theory (SCT) as the theoretical basis for the studies' intervention (Bazzano et al., 2009; McDermott et al., 2012; Bergstrom et al., 2013; and Sundblom et al., 2015). Four other studies stated that a 'behaviour treatment package' underpinned the studies' interventions (Harris and Bloom, 1984; Fox et al., 1985; McCarran and Andrasik, 1990; and Melville et al., 2011). Two of these did not state the theoretical basis for their behaviour treatment package (Fox et al., 1985;

Melville et al., 2011). The other two (Harris and Bloom, 1984; McCarran and Andrasik, 1990) stated that they had based their weight management behaviour treatment packages for this population group on behaviour theories developed in the 1970s. The behaviour theories from the 1970's emphasised gradual weight loss based on self-monitoring of daily food intake, increased awareness of nutrition, external cues and influences for eating, moderate exercise, group meetings with peers, weekly weigh-ins, and positive reinforcement including peer support, monetary reward, praise and encouragement (Staugaitis, 1978). Whilst these 1970s studies presented evidence to suggest that short-term weight loss could be achieved in this population group using these theories, the studies had methodological weaknesses including small and heterogeneous sample sizes, poor control and a lack of follow-up to examine longer-term weight management. Weight loss may have been controlled in the short-term using these behaviour theories, but there was no evidence to demonstrate whether weight control could be maintained in the longer-term for this population.

Only two of the five evidence-based multi-component weight management intervention studies identified by the review provided information on the theoretical basis for their studies' intervention (Bergstrom et al., 2013; Sundblom et al., 2015). These two studies indicated that Social Cognitive Theory (SCT) was the theoretical basis for the intervention described in their studies.

### *Social Cognitive Theory*

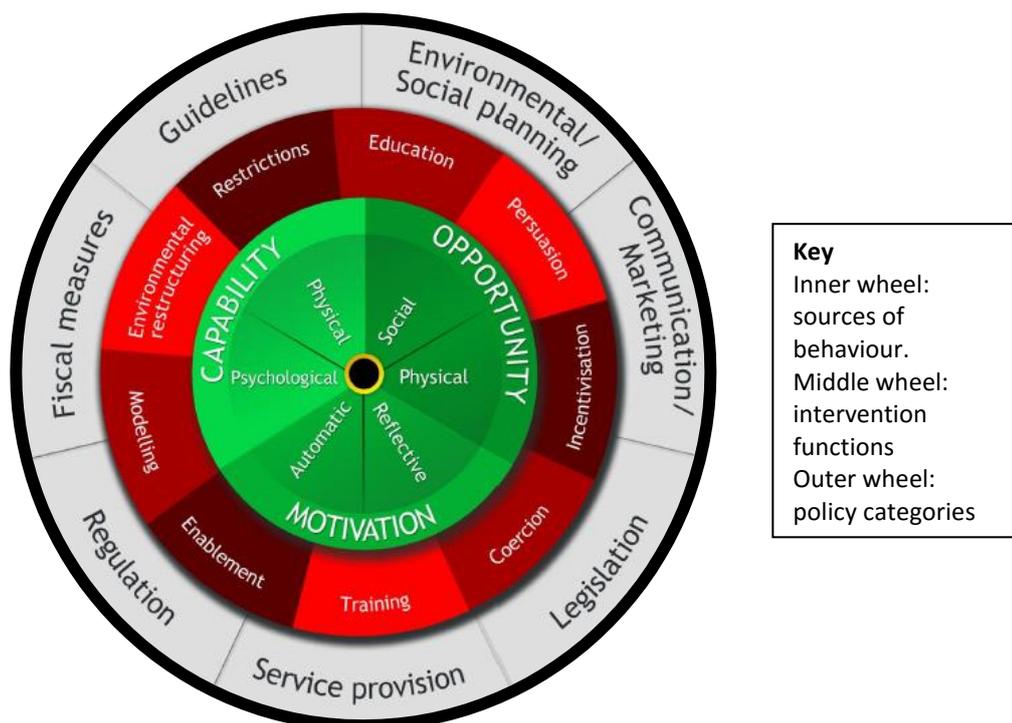
SCT was developed in 1960s (Bandura and Walters, 1963; Bandura, 1986). SCT was originally developed as a psychological theory but the theory was believed to have wider implications and was therefore adopted in other fields such as physical activity and health promotion (e.g. Bazzano et al., 2009). SCT specifies how to change the main internal determinants of behaviour, namely self-efficacy, using techniques such as mastery of experiences, modelling, persuasion and giving physiologically compatible experiences (Michie, 2008a). The theory seeks to understand influences on behaviours and purports that a person's behaviour both influences - and is influenced by – other external factors (including other people's

behaviour), personal factors and attributes of the behaviour itself (Kerr et al., 2016). However, this theory does not appear to consider other biological, hormonal, genetic, emotional, and motivational dispositions that may influence an individual's behaviour. It is not clear how an individual with an intellectual disability (or indeed, any individual without an intellectual disability) can autonomously change or self-monitor their own behaviour, particularly if their surrounding socio-economic and environmental circumstances are dire and their supportive networks are poor. Other theoretical approaches from other related fields of study may offer possible ways forward for the development of tailored obesity and weight management interventions for adults with intellectual disabilities. Some of these are explored below.

### *Behaviour change wheel (BCW)*

The Behaviour Change Wheel (BCW) is a theoretical model (Figure 3.1), which places the individual at the centre of the wheel, encircled by intervention functions, and then by policy categories that contain several social and contextual issues (Michie and West, 2015). In this theoretical model, an individual's type of behaviour may be influenced by environmental constraints, while social and psychological issues may impact on the individual's intention to change their behaviour e.g. through social pressures and social norms (Ong et al., 2014). However, whilst this model acknowledges wider environmental and social issues, the solutions still appear to be focused on the individual and their responsibility for their own behaviour control (Ong et al., 2014). Such an approach may not provide a sufficiently 'fine-grained view' of people's everyday lives and agendas and it may exclude the views of people from marginalised groups - such as people with intellectual disabilities (Ong et al., 2014).

Figure 3.1: Behaviour Change Wheel (Michie, Atkins and West, 2015)



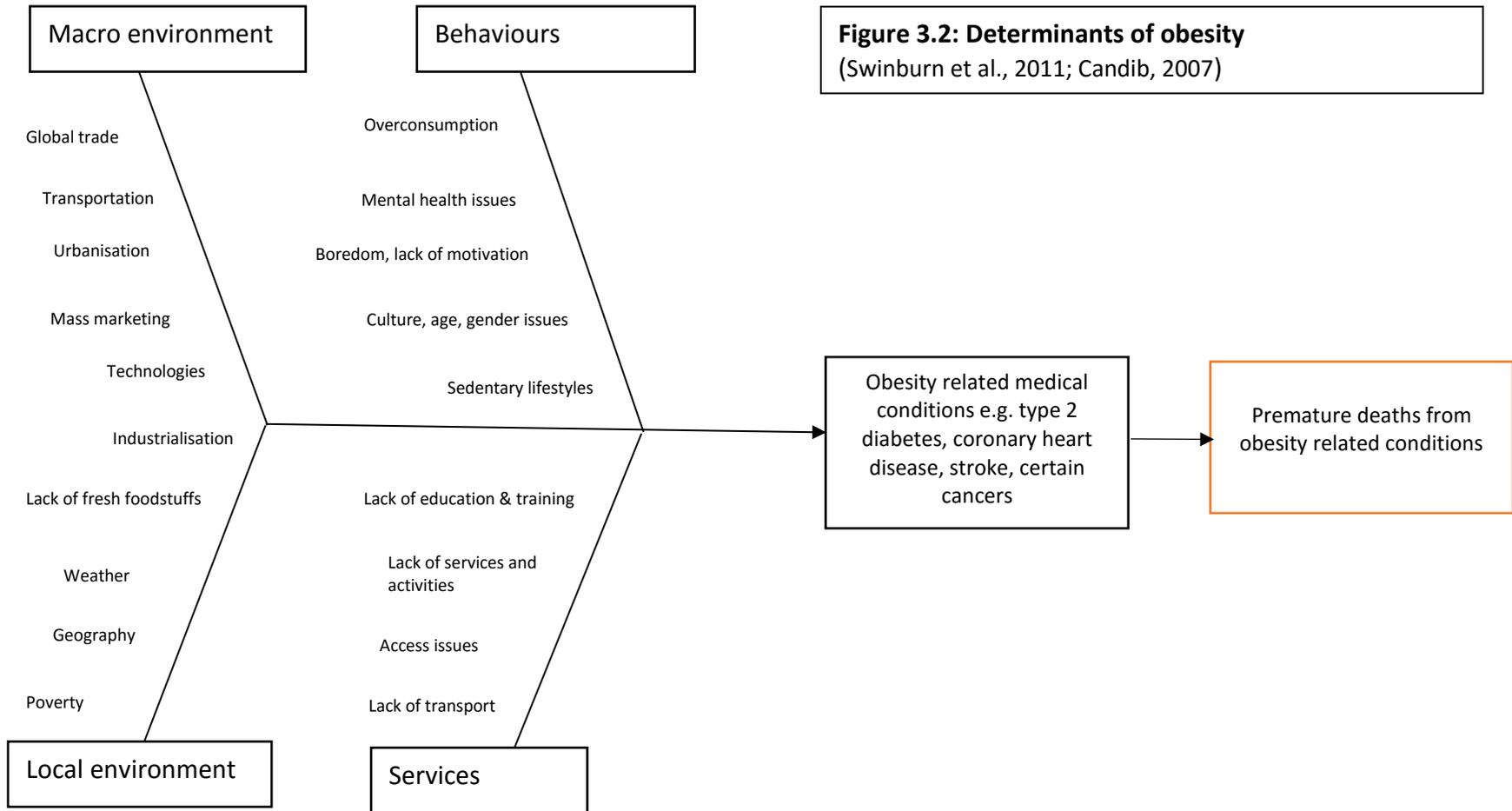
### Complex interventions

Attempts to tackle complex problems such as obesity increasingly use complex interventions. The Medical Research Council (MRC) has produced guidance for complex interventions (Craig et al., 2008; Moore et al., 2015). The guidance recommends that complex interventions be developed systematically, using the best evidence available and based on the most appropriate theory. The MRC states that interventions should be tested using a phased approach beginning with trials and then moving on to exploratory and full evaluations, with wide dissemination of results and further research to monitor implementation (Craig et al., 2008; Moore et al., 2015). However, the MRC's approach appears to be primarily concerned with evaluating the implementation of trials of complex interventions rather than on the theoretical underpinning for the intervention.

Solutions for complex problems like obesity and weight management may be not be found from current research because obesity is highly resistant to change (Stubbs et al., 2011) and because of a need for a wider 'systems thinking' perspective (Hamid, 2009; Rutter, 2011). The obesogenic environment, defined as 'the sum of influences

*that the surroundings, opportunities, or conditions of life have on promoting obesity in individuals or populations'* (Swinburn, Egger and Raza, 1999 p564), has been identified as part of the cause for obesity in the general population (Swinburn et al., 2011). However, changing the obesogenic environment may be problematic because the issues are so complex, challenging and wide ranging. For example, readily accessible cheap food (Bleich et al., 2008), marketing and advertising strategies promoting less healthy foodstuffs (Swinburn et al., 2011), the growth of fast food outlets (Stanton, 2006), and increasing dependence on fast-food takeaways and convenience foods because of the fast pace of modern life which may promote over-consumption (Ulijaszek, 2007). Interventions to change environmental context have not been fully considered for adults with intellectual disabilities (Emerson and Hatton, 2014).

Figure 3.2 summarises some of the issues which may conspire to lead to obesity, obesity-related medical conditions and, potentially, to premature deaths. Figure 3.2 highlights the complexity of the determinants involved in obesity for all individuals' behaviour (both individuals with and without intellectual disabilities alike) requiring complex interventions. Table 3.1 provides some examples of the types of interventions that may be needed at different levels of interaction to tackle some of these determinants of obesity.



**Table 3.1 Tackling the determinants of obesity: examples of the types of interventions that may be needed at different levels of interaction (World Health Organisation, 2014)**

Levels of interaction	Examples of the types of interventions that may be needed
Macro Environment	Political and public support for obesity interventions. Governmental finances to support obesity interventions. High-level policy interventions e.g. regulating the growth of fast-food outlets, anti-poverty strategies, improvements in income distribution, welfare payments, investment in early childhood to ensure children get the best start in life, addressing fiscal policies to lower the price of fruit and vegetables and to increase prices of foods high in fat, sugar, salt and sugar-sweetened beverages. Restrictions on the marketing of foods high in sugar, salt and unhealthy fat. Clearer food labelling and advice on portion sizes. A shift towards the creation of more 'salutogenic' environments (Antonovsky, 1979) i.e. focusing on factors that support health and wellbeing, rather than on factors that cause obesity.
Local environment	Designing and creating healthier neighbourhoods e.g. introduction of accessible and safe walking and cycling routes, safer travel routes, accessible local leisure / fitness / social facilities, Healthy Schools, safe and accessible parks and open spaces, and making healthier foods more accessible locally.
Behaviours	Primary population prevention activities e.g. targeted measures to remove barriers to physical activity for females from certain BME groups, and for those requiring childcare support. Consistent messages through effective social marketing. Tailored health education and health promotion programmes. Tailored (tiers 1-4) weight management interventions.
Services	Providing evidence-informed advice about maintaining a healthy bodyweight. Continuous support (or referral to support) for those wanting to undertake a weight management intervention. Improving nutrition adequacy and physical activity opportunities. Improving the uptake and accessibility of screening, monitoring and health checks in primary health care. Anti-discrimination and equal opportunities policies and practice.

### *Obesity and 'whole systems thinking' theory*

The complexity of obesity was confirmed by the Foresight Report (Butland et al., 2007) which referred to obesity as a complex web of factors that have exposed our inherent vulnerability to weight gain (Butland et al., 2007 p3). A Foresight Map was constructed to conceptualise a system-wide view of the main determinants of obesity and the relationships between these determinants. The Foresight Report and the Foresight Map highlighted the futility of single initiatives undertaken in isolation and that a 'one-size-fits-all' approach is unlikely to work (Butland et al.,

2007). The Report therefore advocated a 'whole systems thinking' theory for obesity.

In 2015, Leeds Beckett University was commissioned and funded by Public Health England with support from the Local Government Association and the Association of Directors of Public Health to translate the Foresight Map into a 'Whole Systems Programme' (Leeds Beckett University, 2015). 'Systems Thinking Theory' was to be used to inform this 'Whole Systems Programme'. The Programme was being developed at the time of writing. The systems thinking theorists believe that there are several factors potentially responsible for most problems (Bar-Yam, 2004). The advocates for this theory warn against dissecting complex systems into isolated theoretical components of cause and effect because this may obscure the view of the system (Hamid, 2009). It is believed that only when components are seen in association with other parts of the system is understanding clarified (Hamid, 2009). Some authors believe that systems thinking provides a framework for problem-solving that considers issues in their entirety and thereby enhances our understanding of, and responsiveness to, the issues involved (Mehrjerdi, 2013). However, the prospect of developing assessments to capture the systems to inform complex interventions such as weight management interventions using systems thinking theory and then putting this into practice is daunting (Finegood et al., 2010). Furthermore, the theoretical work is currently being undertaken over several years by a team of researchers with dedicated resources. It is not clear how this theoretical approach will be rolled out and practically applied by practitioners and it is not yet clear how this theoretical approach will be applied, and be of practical benefit, to adults with intellectual disabilities who are obese or overweight (Finegood et al., 2010).

### *Qualitative research*

Qualitative research explores the wider context of people's lives - including the everyday lives and strategies of people living with a long-term condition (Taylor and Bury, 2007; Ong et al., 2014). Qualitative research may play a useful role in identifying and assessing barriers and facilitators that may, in turn, prove helpful in informing the theoretical design and the practical implementation of an

intervention (Portela et al., 2015). Re-emphasising the wider environmental context and the experiences of the individuals concerned through qualitative research may provide an improved understanding of why and how interventions might work, for whom, in what circumstances, and may thus lead to, more meaningful support for individuals and health care practitioners (Campbell et al., 2000; Ong et al., 2014). An approach that harnesses qualitative methods may lead to improvements in the theory, design and implementation of complex interventions such as multi-component weight management interventions for adults with intellectual disabilities (Campbell et al., 2000).

### *Co-produced research*

Research approaches such as 'Co-Produced Research', 'Appreciative Inquiry' (AI), and 'Experience-Based Co-Design' (EBCD), may shed light on barriers and facilitators involved in weight management for this population and may help develop potential theories and solutions to identified barriers. Co-production in research aims to instil principles of empowerment in practice by actively working with individuals and communities (such as people with intellectual disabilities) and facilitating their greater control over the research process (Collins and Evans, 2002). Co-production has emerged as a potential solution to criticisms that research is often conducted which fails to engage people in issues of concern to them (Collins and Evans, 2002). Advocates of co-produced research argue that research is enhanced through individuals or communities' 'experiential expertise' as their involvement may highlight relevant questions which may be otherwise neglected by so-called research 'experts' (Collins and Evans, 2002). AI engages people in positive conversations and raises their participation in building on what already works, imagining how much better it can be, and in making positive changes to bring about improvements (AI Commons, 2017). EBCD is a type of participatory action research in which service users and service providers work together in partnership to co-design services or pathways together (Donetto et al., 2015).

### *Research involving people with intellectual disabilities*

The development of tailored multi-component weight management interventions for dealing with the problem of obesity in people with intellectual disabilities is hindered by a lack of qualitative research directly involving this population group. Historically, researchers have tended to draw theories from psychology to devise interventions to modify the individual behaviour of individuals with intellectual disabilities. The person with an intellectual disability has tended to be treated as a passive recipient of an intervention rather than an active participant involved in research to promote their own health or wellbeing (Walmsley and Johnson, 2003; Simons and Watson, 2015). People with intellectual disabilities need to be active participants in research concerning the development of interventions that affect their health and well-being i.e. 'Nothing about us, without us' (Stack and McDonald, 2014).

### **3.2 Conclusions**

There is a paucity of information on the theoretical underpinnings of weight management interventions for adults with intellectual disabilities. The few studies that have published any information about their theoretical basis have tended to base their interventions on behaviour control strategies and associated theories such as SCT that were first developed in the 1960s and 1970s. Such theories may have limitations because they are based on limited studies with methodological weaknesses including small and unrepresentative sample sizes, poor control and a lack of follow-up to examine longer-term weight management. Furthermore, people with intellectual disabilities have not been active research participants in these studies. They were passive recipients of interventions. These studies also failed to address other external factors such as wider environmental and socio-economic issues surrounding the individuals with intellectual disabilities. It may be challenging for an individual with an intellectual disability to change, manage or control their own individual behaviour if they are not supported and if their surrounding circumstances are not conducive to making changes. There is also a corresponding lack of practical guidance for practitioners to inform their day-to-day practice in delivering obesity and weight management interventions for this

population. These findings suggest that new thinking and ways of working are needed to bridge the identified gaps in theory, gaps in theory-based practice, and gaps in studies of evidence-based multi-component weight management interventions involving this population. Efforts in future may need to be practically driven rather than theoretically driven. In other words, practical solutions co-produced by adults with intellectual disabilities, researchers and practitioners in everyday settings may inform the development of new theoretical models or frameworks – rather than the other way around. Therefore, greater co-production and collaboration between researchers, practitioners, service commissioners, adults with intellectual disabilities and their carers may inform the design and delivery of evidence-based multi-component weight management interventions for this population group. In turn, this practice-based approach may inform new theoretical approaches.

### *Summary of chapter*

This chapter discussed the theoretical underpinnings of weight management interventions for adults with intellectual disabilities and found that few studies have published information on the theoretical underpinnings of their studies' interventions. Some of the few studies identified stated that their interventions were based on behaviour control strategies. However, such strategies may be unrealistic for some adults with intellectual disabilities who may not be able to autonomously change their behaviour without support, and who may lack the wider socio-economic, environmental and supportive means necessary to make such changes. Furthermore, whilst such interventions may have achieved weight loss goals in the short-term, there was a lack of evidence to support longer-term weight management. The next chapter explores the extent of weight management service provision for adults with, and without intellectual disabilities, in Lancashire – a county based within the North West of England.

## **CHAPTER FOUR**

# **MAPPING WEIGHT MANAGEMENT SERVICE PROVISION FOR ADULTS**

### **INTRODUCTION**

The previous chapter explored the theoretical underpinnings of weight management interventions for adults and found gaps in the theoretical underpinning of weight management interventions for this population. Gaps were also identified in the practical application of evidence-based interventions underpinned by theory. This chapter explores the extent of weight management service provision for adults with, and without intellectual disabilities nationally in England and locally in Lancashire – a county based within the North West of England.

### **BACKGROUND**

Little was known about the extent of weight management service provision for adults in the general population of England until a mapping exercise was conducted by Public Health England (PHE) in 2014 to explore the provision of tiers 2 and 3 weight management interventions in England. (Figure 1.5 and Table 1.2 outlined earlier in chapter one provide an explanation of these tiers). The PHE exercise found that 61% of local authorities who participated in the research (111 out of 152 local authorities) provided at least one, tier 2 weight management service for obese adults in their local area (Public Health England, 2015b). However, the response rate was poor for tier 3 weight management services for morbidly obese adults: 12% response rate (n=26/209) from Clinical Commissioning Groups (CCGs) who are the main commissioners of more specialist tier 3 weight management services. PHE was therefore unable to establish the true extent of tier 3 weight management service provision.

The PHE exercise identified barriers to the commissioning of weight management services generally in England including:

- A lack of evidence on the long-term effectiveness of weight management services.
- A lack of guidance for the commissioning of weight management services.
- A lack of dedicated funding for weight management services.
- A lack of priority for weight management services.
- A lack of joint commissioning of weight management services between local authorities and CCGs.
- Provider difficulties.
- Disjointed obesity pathways.
- Contracts not necessarily meeting patients' needs.
- Problems recruiting patients to services.

The UK obesity and weight management guidance recommends the tailoring of weight management services to meet the needs of different population groups (SIGN, 2010; NICE, 2014a; NICE 2014b). Under equality legislation, it is also a legal requirement for public services in England to ensure that their services are 'reasonably adjusted' to make them accessible for people with disabilities (HMSO, 2010). The PHE mapping exercise did not explore the extent of tailored or reasonably adjusted weight management services for different population groups. In August 2016, PHE published separate guidance on making reasonable adjustments to weight management services for people with intellectual disabilities (Public Health England, 2016a). However, only one of the examples provided was a tailored evidence-based multi-component weight management service for adults with intellectual disabilities (comprising healthy eating, exercise and behaviour change components), and this example was not routinely available. The other examples were of single component weight management services comprising either diet-only or physical activity-only tailored weight management services for this population group but none of these were routinely available in practice. Therefore, there is a lack of information and knowledge on evidence-based tailored multi-

component weight management services for adults with intellectual disabilities including the extent of service provision nationally.

#### 4.1 Aim

The aim of this mapping exercise was to explore the extent of evidence-based multi-component weight management services routinely provided for adults (adults with, and without, intellectual disabilities) in Lancashire, North West England (figure 4.1).

#### Figure 4.1: Districts of Lancashire

Map reproduced from Lancashire Care NHS (<https://www.lancashirecare.nhs.uk/Volunteering-Opportunities>)



Lancashire comprises a total population of 1.5 million(m) (1.1m adults aged 18 – 90 years) resident in 14 districts (Lancashire County Council, 2017a). The latest available figures (mid-Jan 2013 to mid-Jan 2016) suggest that 67% of the total adult population in Lancashire are overweight or obese (BMI $\geq$ 25) which is above the national average of 64.8% (Lancashire County Council, 2017a).

### *Obesity in adults with intellectual disabilities in Lancashire*

In Lancashire, an estimated 27,433 adults (aged 18+ years) have an intellectual disability (Lancashire County Council, 2017b). These estimated figures are predicted to rise to 28,575 by 2035 (Lancashire County Council, 2017b). Recent GP primary care data (2014/15) highlighted that, of those adult patients (aged between 18 and 75 years) in Lancashire that had had their BMI tested, 44% of females and 31% of males with intellectual disabilities were obese (BMI $\geq$ 30), compared to 31% of females and males without intellectual disabilities (NHS Digital, 2017). The data revealed that the prevalence of obesity was greatest in females with intellectual disabilities at all ages in Lancashire (NHS Digital, 2017). The data also highlighted that obesity prevalence is higher in younger female and male adults with intellectual disabilities (aged 18 – 44 years) than in their non-disabled peers in Lancashire. Table 4.1 provides a summary of the percentage of male and female adult patients with and without intellectual disability in Lancashire, recorded as obese (by age range). Although Table 4.1 shows that the overall percentage of obesity is the same for men with and without intellectual disabilities, the percentages for the age ranges are different. This may be due to higher earlier mortality in men with intellectual disabilities which may be partially related to obesity i.e. men with intellectual disabilities may be dying of CVD in their 40-50s.

**Table 4.1: Percentage of female and male GP adult patients with and without intellectual disabilities (ID) with obesity (BMI $\geq$ 30) in Lancashire CCGs (2014/15) (Ref: NHS Digital, 2017).**

Age	Females non-ID	Females ID	Males non-ID	Males ID
18-24	17.51%	36.27%	12.34%	26.91%
25-34	25.46%	40.68%	22.56%	34.02%
35-44	32.29%	48.41%	31.36%	32.05%
45-54	37.91%	45.07%	37.62%	33.26%
55-64	39.04%	47.39%	38.34%	29.43%
65-74	35.82%	52.10%	34.17%	21.68%
75+	24.54%	38.30%	21.91%	18.18%
<b>Total</b>	<b>30.95%</b>	<b>44.48%</b>	<b>31.25%</b>	<b>30.95%</b>

## **4.2 Objectives**

The objectives of the mapping exercise were to:

1. Explore the extent of weight management service provision for all adults with obesity in Lancashire (adults with and without intellectual disabilities).
2. Gather detailed information on any weight management services provided.
3. Explore any barriers to the commissioning of weight management services for adults in Lancashire.

## **4.3 Methods**

A mapping exercise was undertaken between July and November 2016 which involved email enquiries to local authorities (to meet objectives 1 and 2) and follow up interviews with service commissioners and providers (to meet objectives 1, 2 and 3).

## **4.4 Sample and setting**

The exercise involved selective sampling of local authorities, service commissioners and providers of weight management services from the 14 districts of Lancashire.

### *Procedure*

#### *a) Email enquiries*

Email enquiries were sent to the single point of contact (SPOC) email addresses for Lancashire County Council and for all the 14 district local authorities included in Lancashire (including one city council). These email enquiries were re-directed by the SPOC within the respective local authorities to the relevant departments within these local authorities. The local authorities treated the email enquiries as Freedom of Information (FOI) requests. The email enquiries were followed-up by face-to-face interviews held with a sample of service commissioners and service providers with responsibilities for commissioning or providing weight management services for adults in Lancashire.

#### *b) Interviews*

Favourable ethical opinion for the interviews was obtained from the University of Central Lancashire and approval obtained from NHS Research & Development

(appendix 3). Lancashire County Council identified 11 potential participants (health care practitioners involved in the delivery of weight management services) for the follow up face-to-face interviews. Information about the mapping exercise, including a Participant Information Sheet, (appendix 4) was emailed to the 11 potential participants. 6 participants replied and agreed to take part in face-to-face interviews. Written consent was obtained from all participants (appendix 5). Arrangements for interviews were made and interviews were held in the participants' places of work e.g. council offices, leisure or sports centres.

#### **4.5 Data collection**

The emails sent to the local authorities, and the interviews held with interviewees, requested information on: eligibility criteria; referral routes; what the service comprised (e.g. diet, physical activity, behaviour change components); who commissioned the service; who delivered the service; how long the service lasted; whether the service was free to users or not; whether the services were tailored for different population groups such as people with intellectual disabilities; and whether services had been evaluated.

Email responses were gathered from local authorities. Interviews held were digitally recorded (apart from one interview that could not be digitally recorded due to background noise).

#### **4.6 Data analysis**

Data gathered from local authorities' email responses were collated in a table for data analysis purposes. Digital recordings of interviews were transcribed. Data from the transcripts were analysed using a thematic analysis approach to identify emergent patterns and themes (Ritchie and Spencer 1994). This thematic analysis approach is described in the next chapter (Chapter Five: Methodology). The process involved familiarisation with the data, open coding, the generation of a thematic analysis coding framework (appendix 6), indexing and mapping data extracts to the framework, followed by a process of interpretation. The process

also involved referring to the email responses and transcripts for evidence to back up arising themes.

## **4.7 Findings**

### *Email enquiries findings*

14 local authorities in Lancashire responded to the email request for information. None reported routinely providing tailored weight management services for adults with intellectual disabilities. 12 of the 14 respondents reported that tier 2 evidence-based multi-component weight management services for all adults in Lancashire (aged  $\geq 16$  years) had recently been commissioned by Lancashire County Council (since April 2016). The two other local authorities (Blackburn-with-Darwen and Blackpool) stated that they had commissioned their own tier 2 multi-component weight management services for adults. Blackburn-with-Darwen's local authority commissioned their own local authority's sports and leisure services to deliver their weight management service for adults, while Blackpool's local authority commissioned external providers. Table 4.2 provides a summary of weight management service provision for all adults in Lancashire. The information presented was gathered from responses to the email enquiries. The latest adult population estimates (aged 16 – 90) for each of these districts is also presented in Table 4.2 as part of the context.

**Table 4.2: Weight management services for all adults in Lancashire**

Location / (Population, 000s, aged 16-90)	Weight Management Services for Adults
<p><b>Burnley (69.77)</b>  <b>Hyndburn (63.76), Ribble Valley (48.24), Pendle (64.84), Rossendale (55.84).</b></p>	<p>‘Up and Active’ was commissioned by Lancashire County Council to provide a local version of the ‘<b>Active Lives and Healthy Weight Service</b>’ - a Tier 2 weight management service for adults: <a href="http://www.upandactive.co.uk/weight-management/">http://www.upandactive.co.uk/weight-management/</a> The service was commissioned by Lancashire County Council for 12 districts in Lancashire and was available for all adults aged 16 years and over with BMI≥25. Adults could self-refer or be referred by a GP. The service was free to users. A variety of weight management services were provided - from weekly drop-ins to full weight management courses. Drop-ins comprised a weigh-in, 45 minutes of information and advice, and 45 minutes of physical activity tailored to individual needs. Drop-ins were designed to help people achieve and maintain their weight loss goals, and provide ongoing support and advice. The service ran for 12 weeks. Each weekly session lasted for up to 2 hours. The service provided:</p> <ul style="list-style-type: none"> <li>• Structured weight loss programme based on calorie control (1400 women/ 1900 men)</li> <li>• Calculation of BMI (which will also calculate personal calorie intake)</li> <li>• Structured weekly health topics</li> <li>• Evidence based guidelines</li> <li>• Links to Healthy Recipes (recipe finder)</li> <li>• Weekly Action plans</li> <li>• Tips/ Did you know?</li> <li>• Links to 5-10 minutes exercise/ stretch/tone video clips</li> <li>• Online forum chat (followers 30,499/ 13,388 posts)</li> <li>• Calorie counter (access to 150,000 foods)</li> <li>• Topics included: Fad diets/barriers/motivation, portion size/food labels, Eatwell guide/meal planning, activity tasters, benefits of exercise and maintenance.</li> </ul>
<p><b>Preston (113.65), Chorley (92.31), South Ribble (89.76)</b></p>	<p>ABL Health was commissioned by Lancashire County Council on behalf of Preston, Chorley and South Ribble local authorities to provide a local version of ‘<b>Active Lives and Healthy Weight Service</b>’ (components described above): <a href="http://www.ablhealth.co.uk/">http://www.ablhealth.co.uk/</a> ABL Health had experience of providing tailored weight management services for adults with intellectual disabilities.</p>
<p><b>West Lancashire (93.22)</b></p>	<p>Lancashire County Council commissioned West Lancashire local authority, in partnership with West Lancs Community Voluntary Council, Skelmersdale Community Food Growing Initiative and West Lancashire School Sports Partnership provided a local version of the ‘<b>Active Lives and Healthy Weight Service</b>’.</p>
<p><b>Lancaster (118.63)</b></p>	<p>Lancashire County Council commissioned Lancaster City Council to provide a local version of ‘<b>Active Lives and Healthy Weight Service</b>’.</p>
<p><b>Wyre (92.33), Fylde (65.14)</b></p>	<p>The YMCA was commissioned by Lancashire County Council to provide version of the ‘<b>Active Lives and Healthy Weight Service</b>’: ‘Y:Weight programme’ <a href="http://ymcayactive.org/health-wellbeing/adult-weight-management/">http://ymcayactive.org/health-wellbeing/adult-weight-management/</a> The providers reported that the programme provided adaptations based on an individual basis where necessary.</p>
<p><b>Blackburn-with-Darwen (112.7)</b></p>	<p>A service entitled ‘Healthwise’, commissioned by Blackburn-with-Darwen Council, was available to adults aged 16 and over in Blackburn-with-Darwen. <a href="http://www.refreshbwd.com/service/healthwise/">http://www.refreshbwd.com/service/healthwise/</a> The service was a free referral only service. Referral routes included: GP / Practice Nurse or other health care professional. The referral criteria included: BMI ≥35, or BMI ≥30 with a least one co-morbidity, or a newly diagnosed diabetic, or pregnancy / post-natal (following 8-week check), cardiac related events, stroke, or inactive for at least 6 months and presenting with at least one co-morbidity. The 12-week intervention involved diet, exercise, motivational interviewing and behaviour change techniques. Providers had, in the past, delivered tailored (diet focused) weight management services for groups of adults with intellectual disabilities.</p>
<p><b>Blackpool (114.21)</b></p>	<p>Blackpool Council commissioned ‘Health Works’: 12-week weight management programme for adults aged 16 years+ with BMI ≥25. 9 months follow up available. No maximum age or weight criteria. GP or GP Nurse referral only: <a href="http://blackpoolccg.nhs.uk/local-services/weight-management/new-lifestyle-managements-service-health-works/">http://blackpoolccg.nhs.uk/local-services/weight-management/new-lifestyle-managements-service-health-works/</a></p>

### *Interview findings*

6 participants took part in face-to-face interviews. The interviewees provided some information by way of background context to the setting up of local services. This information is outlined in the next section.

### *Background context to setting up of services*

The interviewees stated that there had been a fragmented approach to the application of recommended weight management service specification guidance and to the provision of tier 2 evidence-based weight management services for all adults (both with and without intellectual disabilities) across Lancashire. One interviewee outlined that, until March 2016, there had been “*approximately 30 different contracts.*” A consultation briefing paper on obesity and weight management in Lancashire provided by one interviewee showed that these different contracts related to a plethora of schemes which ranged from food growing initiatives to exercise referral, cycling, walking and other types of physical activity-only based schemes. These schemes had different entry and exit criteria, different service components, different performance measurement tools (making it difficult to compare the effectiveness of different services), different providers, different contract values and different coverage for the people of Lancashire.

The interviewees explained that 12 local authorities in Lancashire had worked together in 2015 with Lancashire County Council to de-commission these previous schemes and that Lancashire County Council had re-commissioned a new evidence-based tier 2 multi-component weight management service for all adults in Lancashire. They stated that this new service was based on weight management service specification guidance issued by the Department of Health (Department of Health, 2013). Consequently, an ‘*Active Lives and Healthy Weight Management Service*’ was launched in April 2016 for a period of three years. This was a multi-component weight management service, which comprised diet, physical activity and behaviour components in line with UK obesity and weight management guidance recommendations on evidence-based practice. The twelve-week service was free for those adults aged 16 and over with a BMI $\geq$ 25 and adults could self-refer or be

referred by their GP or other health care practitioner. A twelve-month follow-up service was available. The interviewees pointed out that the service specification included a requirement for service providers to make reasonable adjustments for individuals such as people with intellectual disabilities and people from BME communities.

A separate tier 2, multi-component weight management service entitled 'Healthwise' was available to adults aged 16 and over in Blackburn-with-Darwen. Blackburn-with-Darwen's sports and leisure department ran this service. It was a GP referral only service. The referral criteria included a BMI $\geq$ 35 or a BMI $\geq$ 30 with at least one co-morbidity, or a newly diagnosed diabetic, or pregnancy / post-natal (following an eight-week check), cardiac related events, stroke, or inactive for at least six months and presenting with at least one co-morbidity. The twelve-week service was free to service users and included diet, exercise, motivational interviewing and behaviour change components. Blackpool's local authority had commissioned a twelve-week service entitled 'Health Works' for adults aged 16 years and over with a BMI $\geq$ 25. This was a GP or GP Nurse referral-only service, which was free to recipients. A nine-month follow up service was also available.

Table 4.3 provides a summary of tier 2 weight management service providers in Lancashire. This information was gathered from the interviews held with service commissioners and providers. The table highlights the range of different weight management service providers (including partnerships of public, private, voluntary and community sector providers) commissioned across the county of Lancashire.

**Table 4.3: Weight management service providers in Lancashire**

<b>Lancashire district</b>	<b>Provider(s)</b>
East Lancashire – Burnley, Pendle, Rossendale, Hyndburn and Ribble Valley	Partnership of providers involving trusts and a local authority: Pendle Leisure Trust (lead provider) in partnership with Burnley Leisure Trust, Hyndburn Leisure Trust, and Ribble Valley Borough Council.
West Lancashire	Partnership of providers involving a local authority and voluntary and community organisations: West Lancashire Borough Council (lead provider) in partnership with West Lancashire CVS, Skelmersdale Community Food Growing Initiative, and West Lancashire School Sports Partnership
Fylde and Wyre	Single private sector provider: Fylde Coast YMCA
Lancaster	Single public-sector provider: Lancaster City Council
Greater Preston, Chorley, and South Ribble	Single private sector provider: ABL Health (lead provider)
Blackburn-with-Darwen	Single public-sector provider: Blackburn-with-Darwen’s sports and leisure services.
Blackpool	Single private sector provider: Health Works

### ***Themes***

Four main themes emerged from the data analysis of the interviews held with service commissioners and providers. These themes are presented and discussed in the following sections.

#### ***Theme 1: Barriers to funding and joint commissioning***

A theme of barriers to funding and joint commissioning emerged from the interviews. Lancashire County Council had experienced challenges with the identification and provision of ongoing funding for tier 2 weight management services for all adults (both with and without intellectual disabilities). The County Council has also experienced challenges involved in working with twelve different local authorities to jointly de-commission previous projects and to jointly commission a new tier 2 weight management service for Lancashire. The County Council highlighted that it was the responsibility of the Clinical Commissioning Groups in Lancashire to commission tier 3 weight management services for morbidly obese adults.

Whilst all the 14 local authorities in Lancashire and one county council provided tier 2 weight management services for all adults, interviewees explained that these were not priority statutory services. Interviewees were concerned that funding for weight management services for all adults may be withdrawn in the future due to a backdrop of diminishing year-on-year financial and staffing resources and ongoing budget savings requirements for local authorities and other partners:

*“There’s just gonna be less and less. I mean we’ve lost staff this year, we don’t know that we’ll lose any next year but I’d be surprised if we didn’t.”*  
(HCP3)

### ***Theme 2: Gaps in weight management service provision***

A theme of gaps in weight management service provision emerged from the interviews held with service commissioners and providers. Interviewees highlighted gaps in the provision of services for all morbidly obese adults in Lancashire with a BMI $\geq$ 35:

*“There’s a gap around the top end of tier 2 and tier 3 services...clients are going round in circles with nowhere to go”. (HCP2)*

Efforts had been made by service commissioners and providers to develop and deliver tailored weight management services for adults with intellectual disabilities in Lancashire but their efforts had been met with ongoing challenges including the implications for resource allocation:

*“They’re [people with intellectual disabilities] probably one of the hardest groups to work with to be fair, from experience yeah. And it’s really time intense as well, this is where that funding needs to come in where everything’s being pulled away from doing things that are time intense....our funders want us to see the masses.” (HCP2)*

### ***Theme 3: Gaps in service monitoring and evaluation***

It was not possible to obtain information from the interviews on whether reasonable adjustments to the newly commissioned tier 2 weight management services were routinely made for adults with intellectual disabilities. The explanation given by interviewees for this lack of information was because the services were newly commissioned. (The new service had commenced in April 2016 and the case study interviews were held between July and November 2016). There also appeared to be an expectation amongst the service commissioners interviewed

that services would be automatically reasonably adjusted by service providers to meet the needs of different population groups and one interviewee referred to the following section of the service specification:

*“The Provider must provide appropriate assistance and make reasonable adjustments for Service Users, who do not speak, read or write English or who have communication difficulties (including without limitation hearing, oral or learning impairments)” (HCP1).*

However, it was unclear from reading the service specification provided by the interviewee how such reasonable adjustments to services would be monitored in the future. There appeared to be no obvious in-built systems for monitoring the numbers of people with intellectual disabilities being referred to and or accessing these services, or for gathering evidence of reasonable adjustments undertaken by service providers, or for obtaining feedback from service users with intellectual disabilities on their views and experiences of the reasonable adjustments made to services.

#### ***Theme 4: Tailored weight management services***

The mapping exercise explored whether weight management services were tailored for different population groups such as people with intellectual disabilities. The exercise found five examples of tailored weight management services for adults with intellectual disabilities in Lancashire. These examples included a tailored diet-only weight management service for adults with intellectual disabilities, a tailored physical activity-only service for adults with intellectual disabilities, a healthy eating advice service for adults with intellectual disabilities, and two tailored multi-component weight management services for adults with intellectual disabilities. However, only one of these tailored services (a physical activity only service) was routinely provided to adults with intellectual disabilities in one district of Lancashire and the focus of this service related to increasing physical activity amongst people with intellectual disabilities rather than weight management. Only two identified examples were of evidence-based multi-component weight management services tailored for people with intellectual disabilities (ABL-Health, and Health Trainers) but neither of these services were routinely provided across Lancashire.

`ABL-Health' was an organisation which had experience in delivering tailored evidence-based multi-component weight management services to people with intellectual disabilities. The ABL-Health tailored multi-component weight management service comprised diet, physical exercise and behaviour change components. However, ABL-Health was commissioned to provide weight management services for all adults in the Preston, Chorley and South Ribble districts of Lancashire, and the targeted service was not routinely provided to adults with intellectual disabilities across the whole of Lancashire.

Blackburn-with-Darwen had provided Health Trainers delivering eight-week `Eatwell' groups – providing basic nutrition advice supported by the `Eatwell' guide and one-to-one brief advice around physical activity, healthy eating, motivational interviewing and behaviour change. In the past, these Health Trainers had delivered targeted programmes to groups of people with intellectual disabilities but these programmes were no longer provided because of ongoing funding difficulties. Blackburn-with-Darwen also reported that another weight management service focusing on diet had previously been delivered to adults with intellectual disabilities. The sessions were delivered in group sessions and had incorporated food education and cooking skills. However, problems incurred with ongoing funding resulted in the demise of these programmes.

Other identified tailored services provided for adults with intellectual disabilities in Lancashire included `Shape-Up' (with a healthy eating advice focus) and `Motivate' (a physical activity-only focused service). `Shape-Up' was described by interviewees as a twelve-week sessional programme, which provided general healthy eating advice for people with intellectual disabilities in Preston, Lancashire. Interviewees stated, however, that `Shape-Up' was not primarily focused on weight management. `Shape-Up' was run by volunteers who were trained by nutritional experts from the University of Central Lancashire (UCLan). However, interviewees explained that `Shape-Up' had incurred ongoing funding difficulties and was not routinely available for all adults with intellectual disabilities across the whole of Lancashire. Blackburn-with-Darwen's social services department (through their Learning Disability Partnership Board) had commissioned a physical activity-only

programme for people with intellectual disabilities called 'Motivate'. The 'Motivate' programme was delivered by Blackburn-with-Darwen's Healthy Lifestyles Team. The sessions primarily aimed to help people with intellectual disabilities to lead an active lifestyle and to improve their health and well-being, and so were not primarily focused on weight management. The physical activity-only sessions for people with intellectual disabilities provided by Motivate included, for example: archery, cycling, dancing, football, gym, gardening, swimming, team games and walking. The service had been running for approximately ten years. Interviewees stated that Motivate was very popular:

*"Over 400 people with learning disabilities accessed at least one Motivate session per week" (HCP3)*

#### **4.8 Discussion**

This mapping exercise found barriers involved in the provision of weight management services for all adults in Lancashire (adults with and without intellectual disabilities). This included a lack of ongoing dedicated funding for services and concerns over a lack of more specialist weight management services. The barriers identified were similar to those previously identified by PHE in their national mapping exercise (Public Health England, 2015b).

The mapping exercise found that evidence-based multi-component weight management services for all adults with obesity (with and without intellectual disabilities) were not widely provided across Lancashire despite the high prevalence of obesity in the adult population. Until April 2016, there had not been an adherence to UK guidance on the commissioning of weight management services. There had been a plethora of different schemes with a range of different service criteria and service providers across Lancashire. It had not been possible for commissioners to measure the effectiveness of these services or to make comparisons between different services because they were so different. 12 local authorities had therefore worked with Lancashire County Council to develop a single service specification based on weight management service specification guidance issued by the Department of Health. However, the new service was still being delivered by a range of different providers in 12 different districts with

potentially different methods of service delivery and potentially different outcomes for service users. Also, in the other two districts of Lancashire, Blackburn-with-Darwen and Blackpool local authorities were delivering different commissioned weight management services.

Participants involved in this mapping exercise spoke about a gap in specialist tier 3 service provision for all morbidly obese adults (with and without intellectual disabilities) with a BMI $\geq$ 35 in Lancashire. The service provision options available for those adults with severe obesity appeared to be very limited in Lancashire. The obesity pathways and service options available for all adults with severe obesity in Lancashire therefore need clarifying.

This mapping exercise also found that no performance monitoring information relating to adults with intellectual disabilities was available and there did not appear to be any in-built systems or mechanisms for monitoring service delivery to adult females and males with intellectual disabilities (or by different age ranges). Such performance monitoring information is needed to ascertain whether existing services are being reasonably adjusted or tailored for adults with intellectual disabilities, whether they are effective in terms of achieving clinically significant weight loss in this population (and sub-groups), and whether any weight loss goals that are achieved are sustainable in the longer-term (after twelve months). Performance monitoring and service evaluation information may inform ongoing service developments and improvements.

Local authorities are the main commissioners of tier 2 weight management services but these organisations are not legally obliged to provide such services. This lack of statutory status and funding challenges for weight management services for all adults appears to be at odds with the human and economic costs of obesity to the NHS and to wider society. There is an invest-to-save argument for weight management services (NICE, 2014a). Health care resources, which are currently used in the treatment of obesity related conditions, could be reduced in the longer-term if greater priority was given to weight management services including priority

investment in the provision of tier 2 and tier 3 weight management services for all adults (including the tailoring of such services for different population groups).

There is evidence of local expertise available within Lancashire that may help develop and deliver tailored or 'reasonably adjusted' multi-component weight management services for people with intellectual disabilities who are obese or overweight. The mapping exercise found evidence that service commissioners and providers in Lancashire had previously developed and delivered tailored weight management services for people with intellectual disabilities. However, their efforts had been stifled largely due to ongoing funding challenges and they were unable to provide ongoing tailored weight management services for this population.

This mapping exercise found that weight management service provision appears to be insufficient to meet the needs of all obese adults both with, and without, intellectual disabilities in Lancashire. This is despite evidence to highlight a high prevalence of obesity in the adult population of Lancashire (in both adults with and without intellectual disabilities).

### *Comparison with other studies*

The mapping exercise conducted as part of Phase 1 of this programme of research for this thesis found barriers involved in the provision of weight management services for all adults in Lancashire (adults with and adults without intellectual disabilities). The barriers identified by this regional mapping exercise mirrored those previously identified by PHE in their national mapping exercise of weight management services for obese adults (Public Health England, 2015b). The barriers identified included a lack of ongoing dedicated funding for tier 2 evidence-based multi-component weight management services and concerns over the lack of more specialist weight management services.

In 2010/11, a similar regional mapping exercise was conducted to map the extent of weight management services available for adults with intellectual disabilities living in Surrey, UK (Smallman, Engel and Nelson, 2011). The findings from the 2010/11

study similarly highlighted that the obesity prevalence amongst adults with intellectual disabilities in Surrey was high (42% of adults with intellectual disabilities in Surrey were classified as obese). However, the study found that obesity services were not well communicated or well organised for this population and that having an intellectual disability was significantly associated with reduced GP referrals to weight management services (Smallman, Engel and Nelson, 2011). GPs who did not refer their obese patients to relevant services stated that they were unaware of services or they commented on the lack of service availability. Most the GP respondents stated that service provision in terms of weight management was inadequate for this population group. The Surrey-based study involved a small sample size and the study's findings were therefore limited. However, the findings from the Surrey study, and from this Lancashire mapping exercise, imply that evidence-based weight management service provision for adults with intellectual disabilities is insufficient despite the high prevalence of obesity in this population group (Smallman, Engel and Nelson, 2011; Lancashire County Council, 2017a). The findings from this mapping exercise also suggest that insufficient service provision is an issue for *all* obese adults in Lancashire and the issue is more acute for adults who are morbidly obese.

It may be challenging for some weight management service commissioners, providers and health care practitioners to understand that the obesity and weight management challenges experienced by people with intellectual disabilities are not an inevitable consequence of their intellectual disability, but rather that they are associated with a need to promote greater equity (Northway, 2016). This includes greater equity of access to weight management services, to associated healthy lifestyle information and activities, and changes to their surrounding environments and support networks. All of this requires even more support and resources (Northway, 2016).

### *Study's limitations*

This mapping exercise involved only a sample of service commissioners and service providers in one county of North West England. The study may only reflect views

and experiences from one local English context. The exercise would have benefited from interviews with Clinical Commissioning Groups in Lancashire to explore identified gaps in more specialist service provision including tier 3 weight management service provision for morbidly obese adults in Lancashire. The exercise would have benefited from further email enquiries, questionnaires, interviews or focus groups with other service commissioners and providers from other English counties. However, this was not possible due to time constraints and resource limitations. Therefore, the findings and conclusions of this mapping exercise are limited. Findings are not generalizable but the findings do provide a local context.

#### **4.9 Conclusions**

This mapping exercise found that adherence to UK guidance on obesity and weight management has been ad-hoc and that evidence-based multi-component weight management services for all adults (both with and without intellectual disabilities) have not been routinely provided in Lancashire until more recently. This is worrying given the high prevalence of obesity in all adults (with and without intellectual disabilities) in Lancashire.

The mapping exercise identified barriers involved in the provision of tier 2 evidence-based multi-component weight management interventions including problems identifying ongoing funding for services and joint commissioning challenges involved in the provision of more specialist weight management services.

No evidence was available to demonstrate that tier 2 evidence-based weight management services are routinely tailored for adults with intellectual disabilities in Lancashire who are obese or overweight. There did not appear to be any in-built performance monitoring or evaluation systems in place for gathering information relating to the numbers of adults with intellectual disabilities referred to services and or the effectiveness of services for this population. Such information is needed to ensure that services are not disadvantaging this population and to demonstrate that services are complying with equality duties and requirements. However,

weight management services had only been recently commissioned in Lancashire at the time of writing and these issues may be addressed in future.

## **Recommendations**

Recommendations for future research and practice arising from the findings of this mapping exercise are summarised in the concluding chapter (chapter ten: conclusions and recommendations).

### *Summary of chapter*

This chapter described findings from a mapping exercise conducted to explore the extent of evidence-based weight management service provision for all adults (adults with and without intellectual disabilities) in Lancashire, North West England. The exercise found that adherence to UK guidance on obesity and weight management had been ad-hoc and that evidence-based weight management service provision for all adults may be insufficient given the high prevalence of obesity in all adults (both with and without intellectual disabilities) in Lancashire. Future research needs to explore barriers and facilitators to obesity and weight management for adults with intellectual disabilities from the perspectives of health care practitioners, adults with intellectual disabilities and their carers and support workers. This forms the focus of the next phase of this research. The next chapter outlines the methodology used for the research conducted in Phase Two of the programme of research for this thesis.

## **CHAPTER FIVE**

### **PHASE TWO: METHODOLOGY**

#### **INTRODUCTION**

The previous chapters outlined Phase One of the programme of research for this thesis. Phase One reviewed the available research (chapter two), explored theories used to underpin weight management interventions for adults with intellectual disabilities (chapter three), and mapped the extent of evidence-based weight management service provision for adults with, and without, intellectual disabilities in Lancashire (chapter four). This chapter presents an overview and a rationale for studies conducted in Phase Two of the research for this thesis. The chapter explains the choice of methods used in the studies and the data collection and analysis processes used. The ethical implications of the studies are also examined.

#### **BACKGROUND**

None of the studies identified for inclusion in the integrative review in Phase One (chapter two) explored the views and experiences of adults with intellectual disabilities participating in multi-component weight management interventions, and only two included studies explored the views of carers or health care practitioners involved in the delivery of these interventions. The review also explored the theoretical underpinnings of weight management interventions for adults with intellectual disabilities (chapter three). The review found that few weight management studies had provided information on the theoretical underpinning of their studies' interventions (8 out of all 36 weight management studies identified). Those that did provide information indicated that behaviour control strategies underpinned their studies' interventions. However, the studies used to develop these behaviour control strategies had methodological weaknesses including small sample sizes, a lack of robust controlled trials and a failure to provide any evidence on the longer-term effectiveness of the interventions. The

studies also lacked cognisance of the wider external factors affecting an individual's ability to make behaviour changes. This may be particularly challenging for people with intellectual disabilities who may not have the support they need to make individual behaviour changes (Ong et al., 2014). The mapping exercise conducted in Phase One (described in chapter four) found a lack of tailored evidence-based multi-component weight management services routinely provided for adults with intellectual disabilities. Phase One's findings indicated a need for further qualitative research involving adults with intellectual disabilities, their carers and health care practitioners to explore their views and experiences of barriers and facilitators to weight management for adults with intellectual disabilities.

### *Qualitative Research and Grounded Theory*

Qualitative research facilitates the detailed investigation of people's views and experiences and allows researchers to explore the perspectives of participants and the influences involved in their experiences (Hennink, Hutter and Bailey, 2010). Grounded Theory was one of the first attempts to develop a systematic method for analysing qualitative data and Glaser and Strauss are considered to be the founders of Grounded Theory in the 1960s (Hennink, Hutter and Bailey, 2010). Glaser recommended that researchers should await the emergence of objective theory through the Grounded Theory process (Glaser, 1992). In other words, the researchers should remain objective and separate themselves from what is occurring in the research process (Trip, 2016). This approach is to ensure that Grounded Theory is arrived at through the ongoing collection and analysis of data, without having any preconceived ideas of any existing theory, and of then trying to fit the data to those preconceived ideas (Glaser, 1992, p. 15). Grounded Theory, as espoused by Glaser, therefore requires an avoidance of reviewing literature in the first instance because this might affect the researcher's ability to remain neutral and to allow categories to emerge from the data (Trip, 2016). However, in the 1960s, researchers did not routinely submit ethics applications and research proposals prior to commencing their research. Ethics applications in contemporary research are now mandatory and some knowledge of the literature is required to

produce research proposals for ethical approval (Pidgeon and Henwood, 1997; Allan, 2003).

Over time, there have been other authors who have sought to compare, contrast and develop the traditional Glaserian approach and there are several different (and competing) recommendations concerning how to perform Grounded Theory. For example, Strauss teamed with Corbin to explore new directions in Grounded Theory, which allowed some flexibility to elaborate or develop an area of interest from that which is already known (Strauss & Corbin, 1998). Charmaz (2006) argued that the researcher is not able to consider themselves separate from the interactions within which data is sourced as they come with personal and professional experiences and knowledge which inform their inquiry. Therefore, this latter approach acknowledges that the researcher can bring his or her own standpoint to the process. Indeed, there can be no claim by the research to indicate that they can completely know the viewpoint of participants (Hastrup, 1995). Researchers, in the end, are telling their version of participants' understandings (Geertz, 1973).

Grounded Theory includes a range of procedures (including theoretical sampling) and stages (including open coding, axial coding and selective coding) with the aim of producing a theory grounded in the data. However, some authors believe that Grounded Theories are rarely used, even if a Grounded Theory method is claimed (Pidgeon and Henwood, 1997). This may be due to the difficulties encountered when applying Grounded Theory. For example, the need for some form of agenda and proposal (including ethical approval); time and resource constraints prohibiting unfocused investigation; no clear instructions in the theoretical approach for coding (particularly if there are no pre-conceived ideas); not knowing when to end coding or when to finish analysis; or how many concepts can contribute to the emerging theory (Allan, 2003).

### *Thematic analysis*

Thematic analysis is a popular approach used in qualitative research that is not tied to any one theoretical or epistemological position (Braun and Clarke, 2006).

Thematic analysis differs from Grounded Theory in that it aims to summarise data into themes that are described and explained, rather than necessarily developing any new theory to describe the findings (Ryan and Bernard, 2000). Thematic analysis identifies codes, themes and patterns from participants' accounts. The task of the researcher in thematic analysis is to try to present and explain a 'story' from all the perspectives. Thematic analysis was used in Phase One's mapping exercise (chapter four) and it is also used in Phase Two of this programme of research (chapters six – nine) to present and explain a 'story' of weight management for adults with intellectual disabilities from the perspectives of adults with intellectual disabilities, carers, support workers, health care practitioners, service providers and service commissioners.

### **5.1 Phase Two: Aim**

To identify barriers and facilitators to weight management for adults with intellectual disabilities from the perspectives of: (1) health care practitioners involved in the delivery of weight management interventions; (2) adults with intellectual disabilities; and (3) carers and support workers of people with intellectual disabilities.

### **5.2 Objectives**

1. To explore how health care practitioners (principally – but not limited to - GPs and General Practice Nurses) recognise obesity in adults with intellectual disabilities and how they manage interventions for adults with intellectual disabilities.
2. To explore adults with intellectual disabilities' perceptions of what may help or make it difficult for people to eat well and live well.
3. To explore adults with intellectual disabilities' perceptions of weight management interventions.

4. To explore carers' and support workers' perceptions of what helps or makes it difficult for a person with intellectual disabilities to eat well, live well and manage their weight, if they want to.

### **5.3 Methods**

Phase Two involved three separate studies:

#### **Study One**

To meet Phase Two, Objective 1: Qualitative research. Face-to-face, semi-structured interviews with 14 health care practitioners involved in the identification of obesity in adults and or the delivery of weight management interventions for adults (with and without intellectual disabilities).

#### **Study Two**

To meet Phase Two, Objectives 2 and 3: Qualitative research. Co-produced focus groups involving 19 people with intellectual disabilities and 8 of their carers and support workers.

#### **Study Three**

To meet Phase Two, Objective 4: Mixed methods. A survey involving 19 carers and support workers of people with intellectual disabilities.

Table 5.1 provides an overview of each of the three studies involved in Phase Two.

**Table 5.1: Phase Two studies' overview**

<p style="text-align: center;"><b>Phase Two, Objective 1: Study One</b></p> <p><b>Method: Qualitative.</b> Face-to-face, semi-structured interviews with health care practitioners.</p> <p><b>Sample:</b> 14 health care practitioners involved in weight management services. Interviews were held between April and November 2016.</p> <p><b>Data collection:</b> Study topic guide, informed by Phase 1, to explore:</p> <ol style="list-style-type: none"><li>1. How health care practitioners recognise obesity in adult patients with intellectual disabilities, and in adult patients without intellectual disabilities.</li><li>2. What types of interventions are offered and / or delivered to obese adult patients with intellectual disabilities, and to obese adult patients without intellectual disabilities.</li><li>3. How interventions are delivered to obese adult patients with intellectual disabilities and without intellectual disabilities.</li><li>4. Health care practitioners' experiences of offering and / or delivering interventions to obese adults with intellectual disabilities and without intellectual disabilities.</li><li>5. Aspects considered to be important to the implementation of interventions for obese adults with intellectual disabilities, as perceived by health care practitioners.</li><li>6. Health care practitioners' views on what, if any, training, guidance or resources they would like to enable them to better engage with obese adults with intellectual disabilities on interventions to manage their obesity.</li></ol> <p><b>Analysis:</b> Thematic analysis.</p>
<p style="text-align: center;"><b>Phase Two, Objectives 2 and 3: Study Two</b></p> <p><b>Method: Inclusive qualitative.</b> Co-produced focus group study involving adults with intellectual disabilities (carers or support workers) and a wider group discussion.</p> <p><b>Sample:</b> 4 focus groups involving 19 adults with intellectual disabilities aged over 18 years, and 8 of their carers or support workers. Focus groups were held in September 2016.</p> <p><b>Data collection:</b> Easy-read worksheets and questionnaires for the focus groups co-designed by people with intellectual disabilities for people with intellectual disabilities, informed by Phase 1, to explore:</p> <ol style="list-style-type: none"><li>1. What factors help or hinder people with intellectual disabilities from eating well and living well.</li><li>2. Whether people with intellectual disabilities have any concerns about their health.</li><li>3. Whether people with intellectual disabilities have any concerns about their weight.</li><li>4. Participants' views and experiences of weight management interventions.</li></ol> <p><b>Analysis:</b> Thematic analysis.</p>
<p style="text-align: center;"><b>Phase Two, Objective 4: Study Three</b></p> <p><b>Method: Mixed methods.</b> Survey of carers and support workers.</p> <p><b>Sample:</b> 19 carers and support workers who are known to a self-advocacy group for people with intellectual disabilities. The survey was held between December 2016 and the end of February 2017.</p> <p><b>Data collection:</b> Survey questionnaire (on-line, email and postal versions made available) to explore carers' or support workers' perceptions of what factors help or hinder people with intellectual disabilities from eating well and living well.</p> <p><b>Analysis:</b> Thematic analysis.</p>

## 5.4 Design

### Study One: Interviews

Study One fulfilled Phase Two, Objective 1 and involved face-to-face, semi-structured interviews with health care practitioners. This method was selected for several reasons. Interviews are widely used as a data collection tool in qualitative research to gather in-depth information and meanings about participants' views and experiences about a phenomenon of interest (Labuschagne, 2003; Lambert and Loiselle, 2007). Semi-structured interviews are underpinned by the assumption that little knowledge exists about the topic and therefore, there are no predetermined questions to pose to interviewees (Ryan, Coughlan and Cronin, 2009). Semi-structured interviews offer a flexible approach to the interview process (Tod, 2006) and they are a commonly used data collection method in health and social care research (Sandelowski, 2002; Ryan, Coughlin and Cronin, 2009). Semi-structured interviews may use a study topic guide but there is sufficient flexibility within these types of interviews to allow for unanticipated responses and issues to emerge (Tod, 2006). A semi-structured face-to-face interview allows the interviewer to pursue less structured questioning and enables an exploration of spontaneous issues that may be raised by the interviewee (Ryan, Coughlin and Cronin, 2009). This flexible approach also enables clarifications that may be needed by the interviewer (Berg, 2009). The semi-structured face-to-face interview therefore enables more of a conversation about a specific topic rather than more formal rigid questioning (Ryan, Coughlin and Cronin, 2009).

One of the strengths of semi-structured interviews that are conducted face-to-face is that they provide the researcher with an opportunity to interpret non-verbal cues through observation of body language, facial expression and eye contact which may enhance the interviewer's understandings of what is being said (Ryan, Coughlin and Cronin, 2009). However, telephone and email interviews are increasingly used in qualitative research, as these may be more cost effective than face-to-face interviews because they require less travel (Ryan, Coughlin and Cronin, 2009). Email interviewing may be less threatening than face-to-face or telephone interviews and some potential problems associated with face-to-face interviews

such as interviewee self-consciousness may also be minimised (Meho, 2006). However, there is less flexibility in email interviewing to pursue unanticipated issues or to seek clarification of responses from interviewees than there is with face-to-face semi-structured interviewing (Ryan, Coughlin and Cronin, 2009).

### **Study Two: Focus groups**

Focus groups are an important qualitative data collection technique (Madriz, 2000). Focus groups became popular in the 1940s as a way of bringing together a group of people with shared interests for the purposes of discussing or examining a topic (Fontana and Frey, 1994; Gates and Waight, 2007). They are one of the main data collection techniques used in a collaborative group or participatory research approach (Gates and Waight, 2007). The size of a focus group can range from between three to 14 people who are interested in the research topic (Gates and Waight, 2007). The groups may be newly formed or they may be pre-existing groups and research participants may be unpaid or paid for their time (Gates and Waight, 2007). Focus groups are usually run by a facilitator whose role it is to keep the conversation flowing and focused (Gates and Waight, 2007). The focus group approach can facilitate the flow of dialogue and enable new ideas to emerge (Richie and Spencer, 1994). Focus groups can be effective in eliciting responses from a wide range of people on a wide range of different topics (Kaehne and O'Connell, 2010). Focus groups may allow participants to feel relaxed, build confidence, be empowered, encourage ownership of discussions and to explore a topic from different angles in safe, non-threatening environments (Cambridge and McCarthy, 2001; Kaehne and O'Connell, 2010). They may enable participants to interact, build rapport and enable practical contributions to research discussions alongside their peers, although there may be an element of unpredictability, which requires the researcher to think on their feet and respond accordingly, especially in people with intellectual disabilities (Kaehne and O'Connell, 2010). For example, the mix of communication issues, behaviours, sensory impairments and backgrounds of individuals with intellectual disabilities in a focus group may not make for a productive dynamic (Nind, 2008).

Focus groups require participants to be willing to disclose their views and opinions to the wider group, to be ready to engage, to listen to the views and opinions of their peers, to reflect on others' opinions and to be mindful about confidentiality issues (Richie and Spencer, 1994; Kaehne and O'Connell, 2010). Participants also need to have some investment in the topic for group discussion (Kaehne and O'Connell, 2010). The advantages of using a focus group approach include the accessibility of the focus group, the breadth of views and experience within the group and the opportunity for group interaction, which can provide valuable insights into a research topic (Gates and Waight, 2007). Focus groups may be more practical and economical to use than other methods and they may be easier to organise than individual interviews (Drayton et al., 1989). Participants may also find the experience more stimulating than other research methods such as interviews (Bristol and Fern, 1996).

Evidence suggests that people with intellectual disabilities are better supported in small focus groups with the addition of a skilled facilitator who is familiar with the participants' communication (Fraser and Fraser, 2001). However, there may be challenges to using a focus group approach with people with intellectual disabilities.

These include:

- (1) Communication and the capacity to engage effectively: the effect of the intellectual disability and the ability of participants to engage in debate, to respond to and to reflect upon other people's points of view (Kaehne and O'Connell, 2010). Furthermore, some people with intellectual disabilities may be even quieter than usual in focus groups (Booth and Booth, 1996).
- (2) The role of carers or supporters in focus groups, who may not truly represent the views of people with intellectual disabilities or who may provide well-rehearsed responses to questions (Kaehne and O'Connell, 2010). In addition, research participants may provide a positive response bias i.e. a reluctance to say something critical about a topic (Ottmann and Crosbie, 2013).
- (3) Research saturation: The issue of using pre-existing groups that may be established for different purposes and the problem of over consulting pre-existing groups for the purposes of focus group research. These pre-existing groups may not be interested in the research topic or they may tire of being

involved in focus groups for different pieces of research (Kaehne and O'Connell, 2010).

- (4) Ethical implications and the capacity of the research subject to change lives i.e. will the research lead to any meaningful action and positive changes for the participants? This is an important consideration. There may be the potential for the research to reveal upsetting life experiences and vulnerable individuals may need to be protected from re-living such trauma or oppression – especially if no action is taken to improve people's lives and conditions because of their engagement in the research (Kaehne and O'Connell, 2010).

Despite these challenges, available evidence suggests that people with intellectual disabilities can, and do want to, contribute to research and they want to have their voices heard (Heller et al., 1996; Ham et al., 2004). Including people with intellectual disabilities in research into issues in which they are the experts and have experiences of, can promote inclusion of their voices and can help make society more accountable to their needs (O'Neill, 1989). The focus needs to be on overcoming the researcher's limitations rather than highlighting the challenges and limitations of participants (Booth and Booth, 1996).

Focus groups were selected for interviewing adults with intellectual disabilities in Study Two, Phase Two of this thesis. This was because the self-advocacy group for people with intellectual disabilities felt that focus groups would provide a stimulating, non-threatening and inclusive environment in which people with intellectual disabilities could explore issues alongside their peers and their carers or supporters. It was also felt that the focus groups may be a more practical way of generating new data from people with intellectual disabilities i.e. new insights that may not necessarily emerge from other research techniques such as individual interviews or narratives (Fraser and Fraser, 2001). Due to resource and time constraints, focus groups were also considered an easier and more practical approach than separate interviews with individuals.

### **Study Three: Surveys**

Study Three fulfilled Phase Two, Objective 4 and involved a survey. A survey was selected for interviewing carers and support workers of people with intellectual disabilities. It was not possible to hold separate focus groups with carers or support workers of people with intellectual disabilities because their priority is to support the people with intellectual disabilities. Therefore, it would not have been appropriate to ask them to use their valuable time and resources to travel to and attend focus groups solely for carers and support workers. Whilst carers and support workers were involved in the focus groups involving adults with intellectual disabilities, it was not possible to elicit their views and experiences because they were ensuring that the views of the people they supported had been gathered and captured. The self-advocacy group for people with intellectual disabilities who advised on the research therefore suggested that a survey questionnaire sent to all 100 carers and support workers involved in their network would reduce the amount of time and resource commitment required of these carers and support workers. This approach would also facilitate the gathering of responses from a larger number of carers and support workers that may make the findings more generalizable.

Surveys are an important method of collecting health care data (McPeake, Bateson and O'Neill, 2014). Surveys can be delivered to potential participants in several ways, including post, telephone, face-to-face, and electronically (McPeake, Bateson and O'Neill, 2014). Electronic surveys may be web-based, where prospective participants can access the survey questionnaire and complete it on-line, or they may be email surveys that are either embedded in the text of an email, or the questionnaire is sent as an attachment to an email that introduces it. Electronic surveys can be cheaper than postal and telephone surveys (Robson, 2011). However, selection bias of participants is an issue for surveys as it may not be possible to obtain a representative sample of the population (Ahern, 2005; Jones et al., 2008). Response rates to email or web surveys can be lower than those of postal surveys (Scott et al., 2011) due to issues such as unfamiliarity with the web, inconsistent reliability of internet access or lack of trust in sending information over the internet (Scott et al., 2011). Personalised email reminders stating the average time it would take to complete the survey may improve the rate of responses from

electronic surveys (McPeake, Bateson and O'Neill, 2014). Questionnaire-based surveys do not offer definitive answers, but rather act as a valuable tool in helping to understand a situation (Rowley, 2014).

## **5.5 Participants, sampling and recruitment**

Non-probability sampling (selective, snowball and convenience sampling) was selected as the most practical sampling approach for the purposes of this phase of the research programme because it was not possible to obtain representative samples of participants due to time and resource constraints of the research and due to difficulties identifying and accessing representatives of all the study populations. Non-probability sampling provided an opportunity to gain access to difficult-to-identify populations of adults with intellectual disabilities and difficult-to-access populations of health care practitioners, carers and support workers. However, such techniques are prone to bias meaning that findings may not be truly representative or generalizable.

### **Study One: Health care practitioners**

Selective sampling was used to identify and interview GPs or General Practice Nurses in primary health care who were involved in the identification of obesity in patients and or weight management interventions for obese adults in the North West of England. Snowball sampling was used to identify and interview other health care practitioners (such as health facilitators or dieticians) who were involved in the delivery of weight management services for obese adults in the North West of England.

### **Study Two: Adults with intellectual disabilities**

Convenience sampling was used to identify adults with intellectual disabilities and their carers or supporters from the North West of England to take part in focus groups. The participants who agreed to take part in the study were self-selected as adults with mild-to-moderate intellectual disabilities.

### **Study Three: Carers or supporters of people with intellectual disabilities**

Selective sampling was used to identify and survey carers or support workers of people with intellectual disabilities from the North West of England. The definition

of carers in this thesis is someone who cares, unpaid, for a friend or family member with an intellectual disability. The definition of a support worker is someone who is formally paid to support a person(s) with an intellectual disability. A carers' and support workers' network was used as the sampling framework. The participants who agreed to take part in the study were self-selected as carers or support workers of people with intellectual disabilities.

## **5.6 Recruitment procedure**

### **Study One: Health care practitioners**

The Clinical Commissioning Groups (CCGs) in the Lancashire region were approached and informed about the research. The CCGs were advised that the research was for a postgraduate research degree. CCGs were asked to send information via email to General Practitioners' (GP) practices on behalf of the postgraduate student. The email contained attachments: a participant information sheet and covering letter (appendix 4 and 7). The covering email letter advised potential participants that the research was for a student's postgraduate research degree. The letter asked GPs and or General Practice Nurses (GP Nurses) to contact the postgraduate student either by email or by telephone if they wished to take part in the research. There was an opportunity for the GPs and GP Nurses to ask questions and seek clarification. The postgraduate student attended GP locality meetings and training events to verbally introduce the research to potential participants. Introductions to the postgraduate student were also made to other potential participants (GPs) from the wider North West region by other health care participants (snowballing technique).

GPs or GP Nurses who were interested in the research contacted the postgraduate student by email and a mutually convenient date, time and venue was arranged to discuss the research further, to answer any queries that they might have had and to seek potential participants' consent for involvement in the research. Face-to-face interviews were then held with 7 GPs and 1 GP nurse who had provided their written consent (see appendix 5 for copy of the consent form used).

Other health care practitioners (such as health facilitators or dieticians) were identified and recruited using a snowballing technique. Information on other health care practitioners who were involved in the delivery of weight management interventions and who might be willing and able to participate in the research study was sought and obtained from the weight management service commissioners. Introductions to the health care practitioners were made by the service commissioners to the postgraduate student. The postgraduate student then sent a covering letter by email to the 11 prospective participants and attached the participant information sheet (appendix 4 and 7). These prospective participants were asked in the email to contact the postgraduate student if they wished to take part in the research. An email address and mobile number were provided to potential participants for this purpose. There was an opportunity for these other health care practitioners to ask questions and seek clarification. The postgraduate student then arranged a mutually convenient date and time with those health care practitioners who expressed an interest in participating in the research study to obtain their consent to participate in the research, and to conduct face-to-face semi-structured interviews in their places of work. Face-to-face interviews were held with 6 other health care practitioners. Interviews held with all participants (GPs, GP nurses and other health care practitioners) lasted an average of 28 minutes per interview (range 13 - 52 minutes).

### **Study Two: Adults with intellectual disabilities**

The aim of this study was to use co-production methods to explore the views and experiences of adults with intellectual disabilities in relation to barriers and facilitators to eating well, living well and managing their weight, if they wanted to. A self-advocacy group for people with intellectual disabilities was approached by the postgraduate student in the first instance to ascertain if the proposal for the research study was relevant and of interest to people with intellectual disabilities. The response was that this was of interest and was of relevance to people with intellectual disabilities. The self-advocacy group advised that focus groups would be the most appropriate method of involving and engaging people with intellectual disabilities in the research. People with intellectual disabilities from the self-advocacy group assisted the postgraduate student with recruitment of participants

through a North West Regional Forum for people with intellectual disabilities. This recruitment process involved the use of unique co-produced easy-read research materials (appendices 8 - 10). 19 self-selected adults with intellectual disabilities were recruited to the study. They were supported by 8 of their carers or support workers.

Focus groups and a wider group discussion involving all the focus groups were arranged to take place in a familiar location and venue for the participants with intellectual disabilities and their carers or support workers. All the participants were from the North West of England. Facilitators from a self-advocacy group for people with intellectual disabilities with experience of communicating with this population – and who were familiar with participants - assisted with the facilitation of the focus groups.

### **Study Three: Carers and support workers**

A self-advocacy group for people with intellectual disabilities assisted with the recruitment of carers and support workers of people with intellectual disabilities to the survey in study three. The sampling framework was a Regional Carers' and Support Workers' Network membership list containing 100 carers or support workers of people with intellectual disabilities from across the North West of England. 19 responses to the survey were received.

## **5.7 Data collection**

### **Study One: Health care practitioners**

A study topic guide (appendix 11) was produced for the semi-structured face-to-face interviews. The study topic guide focused on an exploration of the views and experiences of health care practitioners involved in obesity and weight management of adults (with and without intellectual disabilities). The study topic guide included questions about the challenges and barriers involved in weight management for adults generally and specifically for adults with intellectual disabilities.

### **Study Two: Adults with intellectual disabilities**

Advisors from the self-advocacy group worked with the postgraduate student to co-produce easy-read focus group materials, including a study topic guide comprising a questionnaire and worksheet (appendix 12) to elicit responses from focus group participants. The postgraduate student supplied the advisors with draft outline information for the recruitment materials and focus group materials. The advisors then adapted this outline information to create easy-read accessible formats using simple words and pictures. A full draft was then produced and materials were finalised with some minor amendments by the advisors. The easy-read questionnaires provided space for individual participants to provide detailed information on some, or all, of the research questions, if they wanted to. The easy-read worksheets were a single sheet of A4 designed so that individual participants could write familiar words or draw pictures to represent their responses. The worksheet and questionnaire included questions about what helped or hindered them from eating well and living well, whether they had any concerns about their health, whether they had any concerns about their weight, and whether they had been referred to and or used weight management services and, if so, what were their experiences of these services. Advisors were paid for their services.

### **Study Three: Carers and support workers**

A survey questionnaire (appendix 13) was designed for the carers or supporters of people with intellectual disabilities. The survey questionnaire included questions about carers' or supporters' perceptions of what helps or hinders people with intellectual disabilities from eating well or living well. The survey was made available in electronic and paper based formats: on-line web based survey format, in an electronic format for emailing purposes and in hard-copy format for the postal responses. The on-line survey link was emailed electronically to carers or supporters of people with intellectual disabilities by the self-advocacy group together with a participant information sheet (appendix 14). The email request was for survey responses to be completed either on-line using the web link provided, or electronically with completed responses being emailed back to the postgraduate student or for surveys to be completed by hand using a hard copy version of the survey (available on request) and posted back to the postgraduate student using

the freepost envelope provided for this purpose. The carers' social media page also posted information on the survey. Potential participants also received an email and social media page reminder about the survey.

## **5.8 Data analysis**

Each of the three studies in Phase Two were analysed using thematic analysis in accordance with Braun and Clarke's (2006) framework. Table 5.2 summarises the approach taken for the three studies conducted during Phase Two of this programme of research. The key themes identified in each of the studies and the collective themes that emerged from the data were verified by the doctoral supervision team. These were written up and checked by members of the doctoral supervision team. Any discrepancies were discussed and reviewed to reach a consensus agreement.

The three studies were analysed separately. Chapters six, seven and eight outline the findings from each of these studies.

**Table 5.2: Thematic analysis approach used in Phase Two (Braun and Clarke, 2006)**

<p><b>Stage 1</b>  <b>Study One:</b> Transcriptions were made from digital recordings taken of each interview.  <b>Study Two:</b> Hand written responses from each of the focus group participants' questionnaires, worksheets and group discussion notes were typed up and transferred into two excel spreadsheets: one spread-sheet for questionnaire responses and one for worksheet responses.  <b>Study Three:</b> Survey responses from individual survey participants were transferred onto an excel spread-sheet.</p>
<p><b>Stage 2</b>  Familiarisation with the data: For each study: the postgraduate student familiarised herself with the data from each of the studies. This involved reading and re-reading the transcripts (study one), excel spreadsheets (studies two and three) and the notes from each interview or focus group in studies one and two. For each study: Patterns of meaning and issues of potential interest in the data were explored. Potential codes and ideas were jotted down. The analysis was not a linear process. It was more iterative – a constant moving back and forth through the data set – without rushing. The process developed over time. This stage involved immersion in the data and active reading and re-reading – searching for meanings and patterns - taking notes, marking ideas for coding. Coding continued to be developed throughout the entire process of analysis. Transcripts and excel spread-sheets were checked back against original recording for accuracy during this process.</p>
<p><b>Stage 3</b>  Open-coding. For each study: words and phrases were written down in the margins of hard copy transcripts or hard copy excel spread-sheets which summarised or categorised what was being said by respondents.</p>
<p><b>Stage 4</b>  Initial coding for each study began when a list of ideas about what was in the data and what was interesting about them was generated. Coding was done first manually and then using NVivo v11 computer software tool for each of the three studies. As many patterns or themes as possible were jotted down. Some of the surrounding context was noted. As these were generated, the postgraduate student looked for overlapping categories or themes from the collated data.</p>
<p><b>Stage 5</b>  Sorting codes into themes: themes in each of the separate studies were searched for when all the data was coded and collated. Thematic frameworks and thematic network maps were used to do this. The postgraduate student began to think about relationships between codes, between themes in each of the separate studies.</p>
<p><b>Stage 6</b>  Review themes: the postgraduate student considered the validity of the themes in relation to the data set, but also to see whether the thematic 'map' accurately reflected meanings in the data.</p>
<p><b>Stage 7</b>  Defining and naming themes: the postgraduate student explored the 'essence' of a theme – what is interesting about them and why. A detailed analysis of each theme was written to tell a 'story' of what each theme said and how it relates to the broader picture in each of the studies. Sub-themes were considered too.</p>
<p><b>Stage 8</b>  The 'story' of the data was described to validate the analysis for each of the separate studies. Data extracts provided from respondents were described under each of emerging themes to validate the analyses and to put forward an argument for the research claims.</p>

## **5.9 Ethical issues**

### **Study One: Health care practitioners**

Ethical opinion for the interviews with health care practitioners was sought from the University of Central Lancashire's Science, Technology, Engineering, Medicine and Health (STEMH) Ethics Committee, and permission from the NHS. Favourable ethical opinion was obtained from the University of Central Lancashire (STEM 393 dated 20.10.15) and approval obtained from NHS R&D (197599 dated 03.03.15) (appendix 3). The participant information sheet for this study was produced so that all individuals participating in the studies knew exactly what was involved for them as well as what they should do if they wished to withdraw from the research together with the complaints procedure to follow if they had a complaint to make about the research (appendix 4). Written consent was obtained from participants using a consent sheet (appendix 5).

### **Study Two: Adults with intellectual disabilities**

Ethical opinion for the co-produced focus group study was sought from the University of Central Lancashire's Science, Technology, Engineering, Medicine and Health (STEMH) Ethics Committee. Favourable ethical opinion was obtained from the University of Central Lancashire (STEMH 502 dated 18.07.16) (appendix 15). NHS approval was not required for this study because it did not involve recruitment via the NHS. Due to the nature of focus groups complete anonymity could not be guaranteed. Ground rules were set at the beginning of the focus groups. These included the importance of not disclosing what was said within the discussion outside of the research and of respecting the opinions of the other group members. Although the importance of anonymity was emphasised, it was reiterated that anonymity could not be completely ensured but confidentiality would be maintained.

Informed consent from the participants in study two was sought using an easy-to-read participant information sheet (appendix 9) and by an opportunity for potential participants to ask questions about the research. All participants were asked to sign an easy-read consent form to indicate their agreement to participate in the

research (appendix 10). Information from the focus groups was anonymised so that individual participants and their individual views were not identifiable from the findings or any subsequent publications. No potential harm to participants was expected from this research.

It was possible that, during the focus groups, participants may have talked about abuse or malpractice by service providers. Participants were therefore advised in the Participant Information Sheet and verbally by the postgraduate student that she and / or the facilitator(s) would report any talk of abuse or very “bad practice” by service providers to the service’s commissioners and / or to the relevant regulatory bodies e.g. the Care Quality Commission (independent regulator of health and social care in England).

The postgraduate student completed safeguarding vulnerable adults training for the purposes of working with individuals with intellectual disabilities who are classed by the Disclosure & Barring Service (DBS) as vulnerable adults.

Participants involved in studies one and two agreed that they understood that their participation was voluntary and that they could withdraw without giving a reason and without their being any repercussions. The participant information sheets also outlined how all the information and data collected would be stored securely and that they would not be identified as individual participants in the study. The participants also agreed to give permission for the researcher to hold relevant personal data on the proviso that it would be held securely and in accordance with data protection legislation and that it would be destroyed after five years in accordance with the University of Central Lancashire’s policies and procedures. Participants involved in studies one and two also agreed to be digitally recorded.

As part of the ethical approval processes for the studies, the postgraduate student undertook a risk assessment and action plan to mitigate against any potential risks or issues involving either the studies’ participants (for example, disclosure of abuse) or involving the postgraduate student herself (for example, lone working risks).

### **Study Three: Carers and support workers**

Ethical opinion was sought and favourable ethical opinion was obtained from the University of Central Lancashire's Science, Technology, Engineering, Medicine and Health (STEMH) Ethics Committee as an extension to study two: STEMH 502 dated 11.11.17 (appendix 16). NHS approval was not required for this study as the participants were not NHS patients.

All participants involved in each of the three studies were informed that their details would be kept private and confidential and that their responses would be anonymised.

### *Strengths and limitations*

The strengths and limitations of the three individual studies are described respectively in the following chapters: Study One (chapter six); Study Two (chapter seven); and Study Three (chapter eight).

Phase Two involved different research designs: interviews, focus groups and a survey. Combining different methods in this way facilitates triangulation of methods which can lead to richer data and allow researchers to be more confident of their results (Jicks, 1979).

### *Summary of chapter*

This chapter presented the rationale for the choice of studies' designs in Phase Two of this research. The chapter outlined the methodology and processes involved in research design, sampling, recruitment, data collection and analysis. The chapter provided information on ethical considerations – including ethical considerations for working with people with intellectual disabilities. The following three chapters detail the findings from each of the three studies respectively.

## **CHAPTER SIX**

### **STUDY ONE: INTERVIEWS INVOLVING HEALTH CARE PRACTITIONERS**

#### **INTRODUCTION**

Phase One of the research programme for this thesis (described in chapters two, three and four) justified the need for further qualitative research involving adults with intellectual disabilities, their carers or support workers, and health care practitioners, to explore their views and experiences of barriers and facilitators to weight management for adults with intellectual disabilities. The previous chapter (chapter five) outlined the rationale for the three studies undertaken in Phase Two of this programme of research. The methodology chapter described the approach, sampling and recruitment of participants, and the data collection and analysis used in each of the three studies. The chapter also outlined the ethical considerations. This chapter (chapter six) describes the main findings gathered from the first of the three studies conducted during Phase Two. The first study was a qualitative study involving face-to-face semi-structured interviews with health care practitioners. This chapter discusses themes and findings arising from the study and compares the study's findings with other studies' findings. The chapter also discusses the study's limitations.

#### **6.1 Study One: Aim**

The aim of this qualitative study was to explore how health care practitioners in primary health care (principally – but not limited to - General Practitioners (GPs) and General Practice Nurses) recognise and manage obesity in adults with intellectual disabilities.

## **6.2 Objectives**

The objectives of the study were to explore:

- How health care practitioners recognise (and record) obesity in adult patients with intellectual disabilities, and in adult patients without intellectual disabilities.
- What types of interventions are offered, and or delivered, to obese adult patients with intellectual disabilities, and to obese adult patients without intellectual disabilities.
- How interventions are delivered to obese adults with intellectual disabilities and without intellectual disabilities.
- Health care practitioners' experiences of offering and or delivering interventions to obese adults with intellectual disabilities and without intellectual disabilities.
- Aspects considered important to the specific implementation of interventions for obese adults with intellectual disabilities, as perceived by health care practitioners.
- Health care practitioners' views on what, if any, training, guidance or resources they would like to enable them to better engage with obese adults with intellectual disabilities on interventions to manage their obesity.

## **6.3 Method**

A qualitative study involving face-to-face semi-structured interviews with participants was undertaken.

## **6.4 Sample and setting**

Chapter five (methodology) described the sample selection and recruitment process for the study. The sample included primary health care practitioners (HCPs) – primarily General Practitioners (GPs) - and other health care practitioners involved in the identification of obesity in adults and or the delivery of weight management services for all adults (with and without intellectual disabilities). The setting used for

the interviews was GP practices and other venues used in the delivery of weight management interventions (e.g. leisure centres) in Lancashire, North West England.

## **6.5 Data collection**

A study topic guide (appendix 9) was used in semi-structured interviews involving health care practitioners. The study topic guide contained research questions designed to elicit responses from participants, although other lines of enquiry were followed if the participants raised other points of interest.

## **6.6 Data analysis**

Digital recordings were made of the semi-structured face-to-face interviews with health care practitioners. These digital recordings of interviews were transcribed verbatim. The content of transcriptions and notes were analysed by the postgraduate student using thematic analysis as described by Braun and Clarke (2006) to identify codes and themes, and by use of a thematic network analysis tool (Attride-Stirling, 2001).

The individual transcripts were firstly read and re-read by the postgraduate student to explore any emerging issues and patterns of meaning. NVivo v11 software was used to assist with the thematic analysis. Open coding of each individual transcript was used to explore the data. The data within and between the individual transcriptions were compared through constant comparison techniques. Potential codes and themes (including sub-themes, organising themes and global themes) were identified first by hand and then using NVivo software. A thematic coding framework (appendix 17) and thematic network analysis tool were produced by the postgraduate student to aid the analysis and for the purposes of presentation of the emerging codes and themes and supporting evidence. Assessment of the validity of the analyses was undertaken through regular sharing of the data analyses and discussion with the supervisory team.

## **6.7 Findings**

14 health care practitioners from Lancashire participated in the interviews for study one. These included 7 GPs, 1 General Practice Nurse, and 6 other health professionals involved in the delivery of weight management interventions.

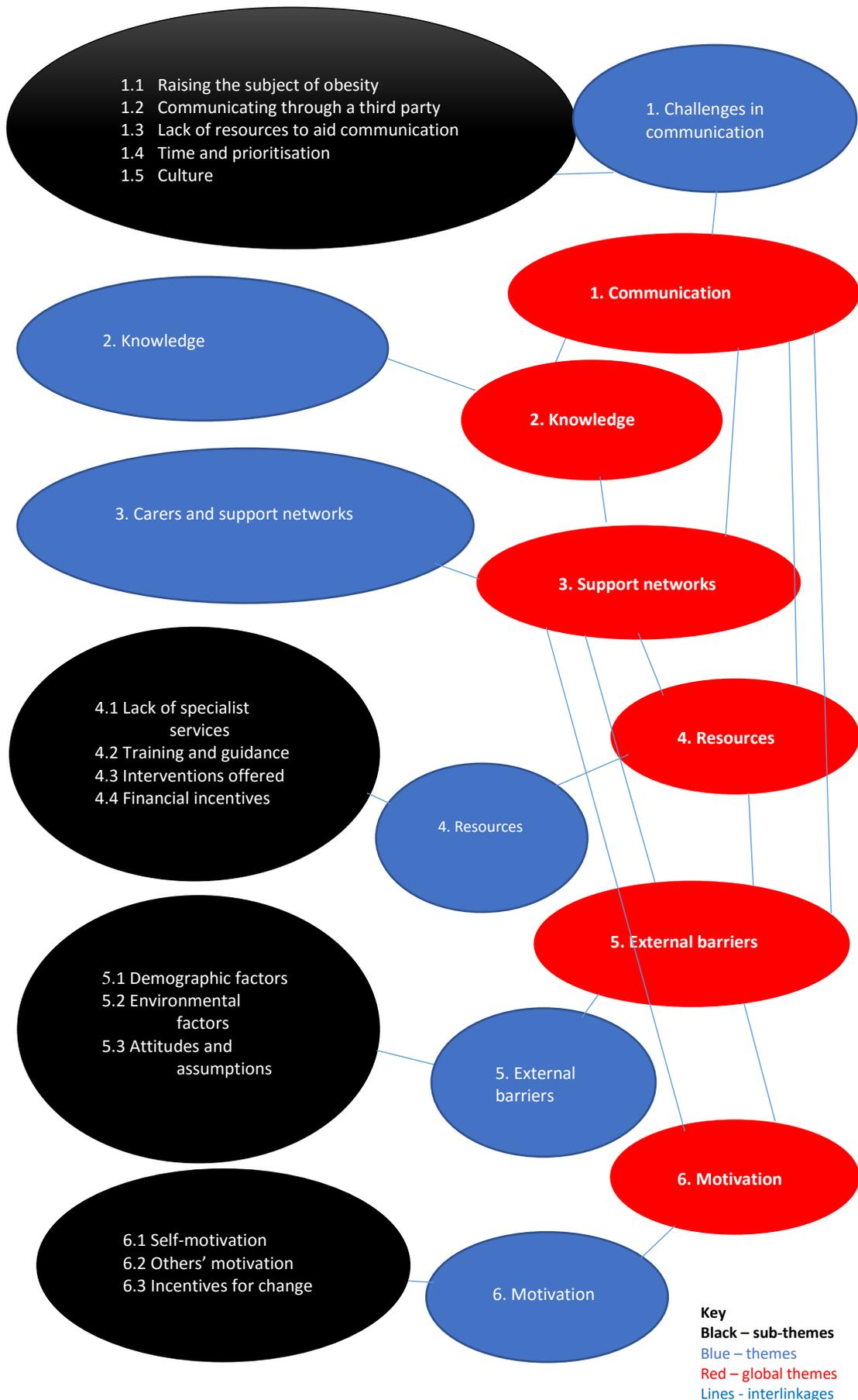
### ***Themes***

The thematic analysis of findings highlighted 6 themes, 15 sub-themes within these themes and 6 overarching global themes. Table 6.1 summarises the themes, sub-themes and global themes that emerged from the data analysis. Figure 6.1 is a thematic network illustrating these themes and their interconnectivities. There was no application of ranking or hierarchy of importance for the themes as all appear equally important and all appear interconnected. The analysis highlights the complexity of the issues involved in obesity and weight management for adults with intellectual disabilities from the perspectives of health care practitioners.

**Table 6.1: Study One - Summary of themes and global themes**

<b>Themes</b>	<b>Global themes</b>
<p><b>1. Challenges in communication</b></p> <p>Sub-themes:</p> <p>1.1 Raising the subject of obesity.            1.2 Communicating through a third party.            1.3 Lack of resources to aid communication.            1.4 Time and prioritisation.            1.5 Culture.</p>	<b>Communication.</b>
<p><b>2. Knowledge.</b></p>	<b>Knowledge.</b>
<p><b>3. Carers and support networks.</b></p>	<b>Support networks.</b>
<p><b>4. Resources</b></p> <p>Sub-themes:</p> <p>4.1 Lack of specialist services.            4.2 Training and guidance.            4.3 Interventions offered.            4.4 Financial incentives.</p>	<b>Resources.</b>
<p><b>5. External barriers</b></p> <p>Sub-themes:</p> <p>5.1 Demographic factors.            5.2 Environmental factors.            5.3 Attitudes and assumptions.</p>	<b>External barriers.</b>
<p><b>6. Motivation</b></p> <p>Sub-themes:</p> <p>6.1 Self-motivation.            6.2 Others' motivation.            6.3 Incentives for change.</p>	<b>Motivation.</b>

**Figure 6.1: Thematic network of health care practitioners' responses**



## **Theme 1: Communication**

### *Sub-theme 1.1 - Raising the subject of obesity with patients*

All participants indicated that it was the role of the GP to raise the issue of obesity with any patients who appeared to be obese. Participants suggested that patients were more likely to trust, and act upon, a GP's advice. However, one GP stated that whilst s/he did not have a problem raising the issue of obesity with patients, s/he suggested that it was perhaps more of a role for other practice staff to be conducting the tests for obesity and managing obesity in patients because s/he was very short of appointments:

*"I'm pretty good at it [raising the subject of obesity with patients] but I don't know that it's my role to continuously do it because you know, I'm very short of appointments and I don't necessarily think it's the GPs role...to be weighing people and geeing them up. Sort of that role has been sort of moved sideways onto the nursing team and they do an excellent job of it, but I don't have any issues myself in raising the matter and trying to support people with it." (GP7)*

Most GP participants commented that obesity was a sensitive issue to raise with a patient and one GP also stated that s/he felt hypocritical telling patients that they were overweight:

*"So, I think it's something that needs to be dealt with sensitively. Obviously, you know I don't want them to be feeling down and then just start eating more...But then there's also from the doctor's side... my BMI is in the overweight category, so I also feel a bit hypocritical when I'm telling patients that they're overweight." (GP1)*

One participant involved in the delivery of weight management interventions was quite scathing about overweight or obese health care practitioners providing weight management advice to patients:

*"I mean to me, I think it's insane that health professionals are absolutely morbidly obese themselves and having to speak to patients who are then expected to take a health intervention message off someone who is probably bigger than them and with more medical conditions and you just think it's all wrong, it's completely wrong". (HCP2)*

### *Sub-theme 1.2 - Communicating through a third party*

All GPs interviewed stated that it was a challenge to raise the subject of obesity with patients who had intellectual disabilities because of issues to do with

communication. One GP talked about having to have a three-way conversation with a carer (or support worker) as well as the patient and that this diluted motivation for change:

*“You’re trying to motivate a carer to motivate the patient. So, it’s second hand motivation” (GP4)*

Participants stated that this was sometimes even more challenging for patients with intellectual disabilities as their accompanying carers or support workers may be overweight:

*“If somebody’s got you know, special needs where their IQ is affected so they can’t take in what you’re saying then you’re just dealing with the carers. And most carers seem to be overweight....But you’re trying to get somebody to do something with somebody that they themselves may not be doing in the first place.” (GP4)*

Participants commented on problems associated with caring support. They had come across a lack of continuity of care for some individuals with an intellectual disability. This led to difficulties having to communicate with different carers at different consultations or weight management sessions as not every person with intellectual disabilities had consistent support by the same carer or support worker. They found that some of the support workers they spoke to were unaware of the health needs of the person they were supporting. Health care practitioners believed that this lack of continuity of caring support for people with intellectual disabilities undermined the impact of a weight management intervention:

*“Different carers come along, like they’d come along on a weekly basis and they’d have different carers coming with them to the sessions and there’s no support then.” (HCP4)*

*“A challenge that I came across before as well, especially with people who are not supported by the same carer all the time, who are in facilities maybe where there are several different carers and different shifts, is that each time you see somebody you have different carers, different knowledge, maybe different views themselves on weight loss. And you don’t always get all the information and it’s a continuous form and that can be hard to judge whether what you have recommended is actually making an impact or whether it’s sort of in one ear and hasn’t actually had an impact, and coming out the other as it were. So, that’s definitely a challenge.” (GP6)*

### *Sub-theme 1.3 Lack of resources to aid communication*

Most participants spoke about a lack of resources to aid communication on obesity and weight management with patients who have intellectual disabilities. For example:

*“I’m aware that there’s a lot of easy-to-read information out there but we don’t really have that [in general practice].” (GP1)*

*“Some people have mild learning disability and so if we have more information like leaflets or pictures or pamphlets... written information sometimes they can take home and read if they can, or pictures or things or more information to offer to patients.” (GP2)*

*“Those patients that cannot understand or comprehend literature easily, to actually show them pictures, perhaps some kind of picture grams, and this is what can happen to them.” (GP3)*

Some participants spoke about how some patients (particularly patients with intellectual disabilities) were ‘eager to please’, and that these patients may not communicate the right information to health care practitioners about their lifestyle behaviours:

*“What our staff have experienced is again, depending on the level of learning disabilities, they are always quite eager to please. So, the approach that our staff take needs to be significantly different because if we were to say right, ok well have you reached your five a day today, they will say yes to us; and that doesn’t actually represent what has happened.” (HCP6)*

*“Like I’ve eaten loads of fruit and vegetables, not eaten any chocolate, not eaten any crisps, but they would have done, cos the carer would come along with them and say no, actually they have done, they have eaten all of that, they’ll be sneaking that out of the kitchen or whatever. Or they’ll have had like a full loaf of bread.” (HCP4)*

### *Sub-theme 1.4 Time and prioritisation*

All the GPs commented on how difficult it was to discuss obesity and weight management with a patient (either with or without intellectual disabilities) during an average (10 minutes) consultation. Participants stated that they had to prioritise the patient’s presenting medical condition within the available time slot and, consequently, there was often little time left to discuss obesity and weight management with their patient:

*“Overweight can be a problem, a third or a fourth problem in the normal consultation. So, by the time they’ve finished their first or second medical consultation you see that you’ve kind of run out of time then if they do raise the subject of wanting to lose weight...” (GP3)*

Participants commented that there is an onus on health promotion in primary care and that GPs’ practices should offer more time and attention to people with intellectual disabilities, but they also acknowledged associated time constraints:

*“There is more of an onus in general practice to be looking out for the health, health promotion. Things like annual checks. So, we should be more hands on in a way with patients with learning disability you know, take our time, double appointments, all these kind of things...so that we can give these patients more time and effort.” (GP1)*

*“I think we could perhaps improve things if we offered more than an annual check, perhaps if we offered six monthly checks...More frequent offering of appointments would be better but everybody’s very busy you know.” (GP5)*

### **Sub-theme 1.5 Culture**

Some participants mentioned cultural issues that may form a barrier to talking about obesity and weight management with people from Black and Minority Ethnic (BME) groups (including people with intellectual disabilities from BME groups):

*“A lot of them feel they are quite healthy, especially in our culture [South Asian ethnic groups], they don’t like anyone who is slimly built, especially with kids; so that kind of, that kind of mentality kind of goes with them into to adulthood.” (GP3)*

*“Day centres would have been key and a really useful way to get messages across but again, we’ve got the makeup of the town which is for the sake of argument...is about twenty-five percent BME now and like culturally, I don’t wanna sound like a big stereotype but people generally would stay at home. If you got children with a learning disability they’re not gonna come out, they won’t go to day centres, and they won’t come out and access our services. So, you’ve kind of got an element of people there who aren’t getting out anywhere so you’ve kind of got no chance because you’re not even gonna come across.” (HCP3)*

### **Theme 2: Knowledge**

The GPs interviewed suggested that local weight management services were always changing and they commented on how they found it difficult to keep up with what services were available for referral purposes:

*“We’re writing to file it, we’ve populated our obesity list with yet another patient, and what services are available?” (GP3)*

*“In terms of all these different kind of weight management, exercise services and all these other things, I personally feel that it’s just touch and go. It depends you know, that I get the letter in the pigeon hole recently and that kind of thing...and they complain that we don’t refer enough patients to them, which is absolutely right because I think some of these are brilliant but there’s just not that communication and awareness.” (GP1)*

Most participants perceived GPs’ knowledge of weight management services to be poor:

*“I think knowledge of the services is still quite poor....we were having a lot of difficulty with GPs not knowing what services either existed or how to refer to it.” (HCP2)*

*“Weight management services? I don’t think we’ve got any weight management services I am afraid.” (GP7)*

### **Theme 3: Support networks**

Participants spoke about the importance of caring support for people with intellectual disabilities from regular carers who were familiar with the person and who helped support them with their weight management. They indicated that it was not helpful when there were inconsistencies with carers’ support and if the carers themselves were overweight or obese. For example:

*“We try to encourage the parents or the support workers and carers to actually be part of the groups when we are delivering any session cos it’s the only way you can get that message across...I mean we still see it at times in some of the groups we work with, the carers are in MacDonal’d’s and things, Costa with big creamed drinks.” (HCP2)*

*“Depending on the level of learning disability, common things that we find across the board is you’ll have someone who will come with a carer who is brilliant and gets really on board, and then the staff turnover is so high that you are almost starting again and there is a new carer coming in place.” (HCP6)*

*“So, if they’ve got a supportive carer who understands them and understands their needs and their likes and dislikes, and what will work within their lifestyle, then I think there’s a good chance. Equally, if it’s the other end of the spectrum, if their carers are always changing all of the time or we are getting a disjointed picture, the person’s not very interested in*

*losing weight and does become quite skilled at gaining weight, can be much more challenging.” (GP6)*

*“You could have someone who is really skilled but if they don’t enjoy it they are probably not gonna put as much effort into it...I’m sure they have got the appropriate qualifications to be in that role, but that doesn’t make them good at their job... There can be a gulf between carers and quality.” (HCP7)*

They also spoke about the need for support and training for carers in weight management. For example:

*“They [carers or support workers] get blamed for things and they are probably not supported as much as they need to be. And the same for families as well, so whether this is paid carers or family carers, there is probably very little support in terms of dealing with supporting adults with some of their weight...A lot of carers have had little training in weight management.” (HCP6)*

#### **Theme 4: Resources**

##### **Sub-theme 4.1 - Lack of specialist services**

Some participants commented that more specialised, tailored services for people with obesity and intellectual disabilities were required:

*“You’ve got to improve their access to a lot of services available, specialised interventions for their needs.” (GP3)*

*“I think there’s need to have your more specialist intervention where it isn’t integrated and then you know, everything else is sort of open to everybody... I think it’s hard with any sort of service we deliver its hard just integrating everybody all into one thing.” (HCP3)*

Participants also perceived a lack of opportunities for different health care staff (from a range of specialities), carers and service users to come together to pool their knowledge, skills and resources and to develop and share weight management resources with and for people with intellectual disabilities:

*“The people at the council who’ve had twenty years’ experience working in learning disability probably have zero experience in health, and it’s probably linking those together that’s going to be key.” (HCP3)*

The issue of having services which represented ‘Value for Money’ for commissioners and or funders was raised during the interviews with participants.

Participants spoke about how services that are time intensive for small population groups (such as people with intellectual disabilities) were not prioritised by funders:

*“They’re probably one of the hardest groups [people with intellectual disabilities] to work with to be fair, from experience, and it’s really time intense... If you spend a lot of staff hours working with just a really small group of people...when really our funders want us to see the masses.” (HCP2)*

#### *Sub-theme 4.2 - Training and guidance*

Most participants spoke about their own training needs. For example:

*“I haven’t had any training in terms of dealing with patients with intellectual disability and weight....You know, we hear about the obesity epidemic but we’re not given any specific training for example, brief intervention regarding weight management.” (GP1)*

*“I’ve got a thirteen percent chance of having a heart attack, does that mean I am going to have a heart attack?...How on earth do I put that in context or visualise this as an abstract concept? I don’t think we have a lot of training on... statistics and risk, I think we are not always good at explaining that as GPs – I think particularly with people who have learning disabilities.” (GP3)*

*“GP’s training...they spend like about seven hours in total where they’re looking at exercise and physical activity, and there needs to be more importance around healthy lifestyles at that point rather than always going down the clinical and like a medicalised model where you know, you treat a condition with whatever tablets.” (HCP2)*

*“I’ve not had any external training...Sounds quite bad that doesn’t it?” (HCP4)*

*“Potentially, awareness training around adults with learning disabilities because I don’t think all staff have got a very broad awareness of the different types of learning disabilities.” (HCP5)*

*“Well I go to a lot of sort of meetings you know, educational meetings and I don’t think I’ve ever [gone to a meeting] on obesity.” (GP7)*

However, some participants suggested that health care practitioners need to be motivated to undertake any training and some stated that they did not need any training in weight management because there were other health care practitioners to whom GPs could refer patients. Some indicated that the subject of weight management for people with intellectual disabilities, whilst valuable, was not a high enough priority for training:

*“You’ve got to be really motivated...you know people really don’t take on the message and therefore if some course comes up about obesity, that’s the last thing I’m gonna go to. Whereas if there’s a course on new treatments in hypertension or new treatments in epilepsy or... that’s what I’m gonna go to.” (GP4)*

*“I suppose I could do with a bit better training on more specific dietary problems but I suppose that’s why we have dieticians isn’t it? We can refer.” (GP5)*

*“It’s never gonna be high enough on the priority list that anyone will sort of think that this is the training we need... I mean we’ve done every course under the sun you know, for weight management and all the exercise related things but even working with children there’s still no sort of training you can do for working with children and families is there? So I’d expect with learning disabilities its... I wouldn’t even have a clue where you’d look at any sort of training.” (HCP2)*

### *Sub-theme 4.3 - Interventions*

The participants interviewed all offered a range of weight management interventions. For example, the GPs stated they had a role, as part of their primary health care team, in raising patients’ awareness of the links between obesity and certain medical conditions, of offering brief advice and interventions, of investigating causes of obesity, as well as signposting and referral to other services. The GPs interviewed all offered Annual Health Checks for people with intellectual disabilities. These included checks of a patient’s weight. The health care practitioners involved in the delivery of weight management interventions offered a range of services including dietary interventions, exercise interventions, and behaviour change interventions. They provided gender and culturally specific weight management programmes. The weight management interventions were provided by a range of health care practitioners, including dieticians, physiotherapists, and psychologists. These practitioners adapted and developed some bespoke programmes to meet the needs of individuals and they provided examples of reasonable adjustments to services that they had developed for people with intellectual disabilities. The examples provided included the provision of clearer, simplified information, smaller group or one-to-one sessions, the involvement of carers (if appropriate) in weekly sessions, confidence building activities, rapport building and matching the personalities of staff with patients who

have intellectual disabilities. However, most participants acknowledged a lack of local and routinely available tailored weight management services for people with intellectual disabilities who are obese or overweight. They stated that this was because of funding constraints and because of a drive by commissioners and service providers to provide universal services for all obese patients as opposed to targeted services for different targeted groups including people with intellectual disabilities:

*“I mean we’ve lost staff this year, we don’t know that we’ll lose any next year but I’d be surprised if we didn’t... you’ll see as many people as possible at a very kind of like low level and it’s all about getting people into physical activities, but targeting individuals with specific conditions or whatever has been pulled back.” (HCP3)*

#### ***Sub-theme 4.4 - Financial incentives***

Participants involved in the delivery of weight management services spoke about the value of financial incentives for GPs. They commented that GPs are incentivised to measure obesity prevalence but not to intervene. For example, they spoke about how GPs receive financial incentives for conducting Annual Health Checks for people with intellectual disabilities, and for identifying patients with obesity and placing them on an Obesity Register. However, the participants were not aware of any financial incentive for GPs to deliver weight management interventions and or to refer obese patients to weight management services:

*“They’re getting QOF points aren’t they for sort of putting people on diabetes medication and things like that and I don’t think they get the money for people losing weight do they? (HCP2)*

### ***Theme 5: External barriers***

#### ***Sub-theme 5.1 - Demographic factors***

Participants spoke about the impact of wider environmental, demographic and socio-economic factors on the delivery of weight management interventions:

*“I think because of the area we working in you know, the demographics of the people with the BME populations, it’s quite a tough area to deliver. Especially when all the stuff coming from the Government is around like the big wider interventions that are cheap and more cost effective that it’s all well and good if you are working with an apparently healthy population but when you are working with people who’ve got multiple co-morbidities... your general advice doesn’t work. You can’t just tell them to go out for a thirty*

*minute walk every day to get your physical activity in cos they're never gonna do it. And we've got rubbish weather... So you know you can provide that service to people but there needs to be wider support really doesn't there? (HCP2)*

*"You know like low income families of which there are you know, lots, it's probably far easier and cheaper to go to Farm Foods, fill a trolley to brimming, and it will feed your family for a week full of absolute beige nonsense (processed food), but people will be full for a week." (HCP3)*

Participants also spoke about how a patient's priorities may change if their circumstances change. For example, if a relative passes away, or if their mental health declines, it is still important to address their weight in these situations but that there may be other priorities that may need dealing with first.

### *Sub-theme 5.2 - Environmental factors*

Participants commented that obesity is more a product of the environment rather than any individual 'failing'. They spoke about the impact of wider environmental factors on the delivery of weight management interventions, particularly for people with intellectual disabilities:

*"I think its environmental more than anything, I mean if you started having you know like your healthy work place, your healthy catering within day centres and things like that, it would be looking at wider things...It's got to be that environment that they're constantly in. If they're just getting dragged off to MacDonald's and things, there has to be some sort of more influence over you know..." (HCP3)*

*"It's that obesogenic environment, everything is set up for getting whatever food you want when...Planning and your environments and things like that, I think that's only where anything's going to change. It's too easy to keep eating loads of junk and then not you know, doing any physical activity. I think environment needs change doesn't it?" (HCP2)*

### *Sub-theme 5.3 - Attitudes and assumptions*

Participants raised the issue of negative attitudes towards and assumptions about people with intellectual disabilities that can make it difficult to deliver weight management interventions to this population group:

*"They just feed him junk food cos that's what he eats and he won't eat anything else. And they're not gonna have a conflict with him...I can see an attitude of well, this person's not got much in their life and if they like eating*

*burgers well let them eat burgers, cos what else have they got?... one of the few pleasures they have in life might be eating and they'll be given what they like..” (GP4)*

*“A girl on my team she’s got a son with learning disabilities, he’s quite severe really, she said he’s put loads of weight on, he’s quite big and she said I’m trying to get him on a diet...but then in school, the dinner ladies are giving him extra portions she said, so his teachers engage and then she said I have to keep going in saying look, they say oh well he’s hungry, she said so that’s what you’re up against but just from personal experience” (HCP2)*

*“...they have a good life... They get taken out, they get taken out to the seaside, they get taken out for meals, they go swimming, they are always out and they go to the café and the carers take them out for a walk. When they go in the café, they might want a bun or an ice-cream, cos that’s what’s been implemented from childhood probably and ice cream and buns are nice aren’t they? So that’s what they’ll want. And if you go in and say oh here’s a light Waldorf salad, he’ll go out the door under a bus.” (HCP1)*

Participants also perceived that the media had a role to play in perpetuating negative attitudes and discrimination against all people who are obese:

*“I think also the media has got an awful lot to answer for...there’s still this real prejudice around weight and people who are overweight are lazy, they are greedy, they’ve got no self-control, and if you speak to health care practitioners, I’m pretty confident that you’ll find that and them kind of opinions amongst them.” (HCP7)*

Participants indicated that prevailing negative attitudes towards all obese people negatively affects all people with obesity (and not just those individuals with intellectual disabilities who are obese): leading to defeatism or negativity in individuals:

*“People would much rather say watch television than do something that is potentially embarrassing. So, if they perceive other people are seeing them and if they are walking round the park or jogging, or something like that or in the gym who are a lot healthier around them – yeah, that’s not unique to people with learning difficulties but it’s definitely present there as well.” (GP6)*

## **Theme 6: Motivation**

### *Sub-theme 6.1 Self-motivation*

Participants commented that patients were often in denial or they made excuses about their weight when discussing the subject of weight and that this made it difficult as they were not ready to make the necessary changes needed to lose weight:

*“Whether the patients want to accept it or not is another thing, patients are many times in denial.” (GP2)*

*“I think there’s always issues, its raising the issue of weight because as soon as you do raise that, unless that person’s acknowledged they’ve got this problem, their defences are as soon as you start mentioning it.” (HCP2)*

*“If they’ve been referred to you by maybe a GP or anything like that, they might be in denial of... in denial that they are overweight and that there is an issue kind of thing. So that’s kind of difficult really and getting them, if they’re not ready to change as well, if they’re not in that frame of mind where they want to make the changes and they want to lose weight then it’s really, really difficult to encourage them to do it.” (HCP4)*

Participants commented that people needed to be self-motivated to lose weight but that this might be a particular challenge for people with intellectual disabilities:

*“I think they find it very difficult to change. But those that do, it’s from their personal motivation so therefore with special needs patients, you’re trying to motivate a carer to motivate the patient. So its second hand motivation.” (GP4)*

*“I had another guy who did have learning difficulties and came to an appointment and he was twenty-five stone, something like that and I said why do you want to lose weight? What’s brought you here? [he said] me family, they are on my back, they want me to lose weight. I said well what about you, what do you want? He said I’m fine, I like what I do, I like my life, its fine. So, he didn’t have the motivation to change.” (HCP7)*

### *Sub-theme 6.2 - Others’ motivation*

Participants spoke about the importance of other people’s motivation, particularly motivated carers or support workers involved in the interventions, and the importance of having confidence to make changes:

*“I’ve got a guy who has got Downs Syndrome who is phenomenal...He’s got a fantastic relationship with his parents, a fantastic relationship with his carers and he comes to see us at one of the community venues and he is doing so, so well. And he knows he’s overweight, he is actively engaged with us but he’s phenomenal, I think he’s lost about two stone...but I think confidence is a big thing as well.” (HCP7)*

### *Sub-theme 6.3 - Incentives for change*

Participants talked about incentives for change and that weight management was not simply about ‘calorie counting’. They stated that it was also about helping someone to feel better about themselves, their mental health, their physical health, their image and their appearance. Participants stated that image, appearance and health were more motivating factors than weight loss goals for some obese or overweight individuals with, or without intellectual disabilities. Participants suggested that there was too much irrelevant emphasis on weight loss outcomes in the UK obesity guidance:

*“So I think particularly as you know, as time has progressed, people are a lot more concerned with their image and it’s becoming more challenging in dealing with it, particularly in younger patients as well as older patients. So I think it’s something that needs to be dealt with sensitively.” (GP1)*

*“It’s different for different people. I found for women, oh and for men as well, it was more appearance; a lot of it was appearance and fitting into clothes and things like that. I found that was one of the main ones for them.” (HCP4)*

*“We had another guy who had a learning disability and he was working really, really hard with the dieticians...If you set a goal with him, he would achieve that goal. Now his goal, was to be able to reduce his size enough so he could buy a jacket off the high street, a particular brand of jacket he wanted to be able to buy.” (HCP4)*

*“I think there needs to be less emphasis on BMI and weight loss cos I mean you’ve probably read all the research. You know, your five to ten percent weight loss, what relevance is that to anybody?” (HCP2)*

None of the participants interviewed found the existing UK guidelines for obesity and weight management helpful in their routine practice. For example:

*“Off the top of my head, all the government guidelines I’ve read, there’s never anything really that’s targeted towards that group [people with intellectual disabilities].” (HCP2)*

*"They are a guide...The programmes are not based on guidance, we are aware...and try and follow...but I wouldn't say we build programmes on NICE guidance." (HCP5)*

*"Very often the guidelines will often say what needs to be done, but actually on a day to day level, that might not kind of be practical or achievable." (HCP6)*

*"I've got to be honest, sometimes I don't find it that particularly useful the guidance to be honest with you." (GP5)*

*"I am aware of them but I am not up to date with them (laughter)." (GP6)*

*"But it is a long time since I read those guidelines, a very long time since I read the guidelines." (HCP7)*

A draft findings report was shared with participants via email for validation purposes (appendix 18). Feedback received included the following quote from one of the GPs who participated in the study:

*"Thank you for this draft which has served as a reminder to me...and perhaps that's what GPs really need, constant reminders? We all set off with good intentions but due to all the other pressures and constraints on us we lose focus along the way? This certainly applies to me anyway. It is very interesting work, good luck." (GP7).*

## **6.8 Discussion**

This study's findings suggest that there are complex challenges involved in weight management for health care practitioners. The perceived challenges identified by this study were associated with the interconnecting themes of communication, knowledge, caring support, resources, external barriers, and motivation.

The study's findings indicate that it may be a challenge initially for GPs to raise the subject of obesity with patients (both adult patients with and without intellectual disabilities). GPs may feel hypocritical raising the subject with patients if they are obese or overweight themselves. GPs may not have sufficient time within a standard consultation to discuss the subject of obesity because of the need to prioritise the patient's presenting medical conditions. Then, if the subject of weight is raised with their patients, some GPs suggested that some patients would be in denial, or they would make excuses, or they would not be motivated to change.

Other published studies have cited similar challenges associated with raising the subject of obesity with patients. Patient surveys and recordings of consultations suggest that guidelines on primary care screening and GP brief interventions to motivate weight loss (Moyer and Force, 2012; NICE, 2014), and to refer patients to weight management programmes, are not routinely implemented (Shiffman et al., 2009; Noordman, Verhaak and van Dulmen, 2010; Dewhurst et al., 2017). Other studies have also found that it is the patient rather than the GP, who instigates half of the discussions about weight loss (Noordman, Verhaak and van Dulmen, 2010). Reported barriers in other studies have included insufficient time and knowledge, a belief that the interventions will be ineffective, and fear of causing offence (Henderson, 2015; Michie, 2007; Hiddink et al., 1995; Foster et al., 2003; Dewhurst et al., 2017). There may also be some nihilism about weight loss in primary care (Swinburn and Arroll, 2016). Only one UK study in primary care has investigated a GP brief intervention for obesity (Aveyard et al., 2016). However, this one previously published study of a brief intervention for obesity involving 2758 obese patients, found a net weight loss benefit of 2.45kg at 12 months in the group receiving a 30-second active intervention by primary care physicians (Aveyard et al., 2016). This study suggested that the GPs were concerned about raising the issue of obesity with their patients – primarily for fear of causing offence, although, patients were likely to welcome the weight loss intervention and to lose weight. The study's intervention also involved GP training on how to discuss weight with patients within the consultation, on weight measurements, on giving brief advice, and follow-up (Aveyard et al., 2016). Therefore, a brief 30-second intervention on weight management by a trained GP could potentially reduce mean weight in obese populations (Aveyard et al., 2016). However, there is a need for further research so that the evidence base for such GP brief interventions for weight management matches that which exists for other similar interventions (Stead et al., 2013). There is also a need for further research to explore whether such GP brief interventions are effective for adults with intellectual disabilities.

This study found that GPs experience communication difficulties when raising the subject of obesity with adult patients who have intellectual disabilities. Participants spoke about having to go through carers to communicate with this population and a

need for more resources such as 'easy-read' resources to enable better communication. They also stated that it was difficult to raise the subject through carers or support workers of adults with intellectual disabilities especially if the carers or support workers (or the GP) were overweight or obese themselves. Participants also perceived that some adults with intellectual disabilities may not receive continuity of caring support and so the impact of any intervention may be undermined.

Other studies in this field have reported similarly on the significance of communication and the need for accessible resources to aid weight management with people who have intellectual disabilities and who are obese (Spanos et al., 2013b; Sundblom et al., 2015). People with intellectual disabilities face a range of communication barriers: between 50% and 90% of people with intellectual disabilities have significant communication difficulties (Baker et al., 2010). They may struggle to understand new and complex information due to problems with memory, attention and information processing (Chinn, 2017). Other research has identified a range of poor communicative practices displayed by health care practitioners in their interactions with this population group including not using age-appropriate language, speaking only to the carer present, failing to acknowledge or address the worries of the patient with intellectual disabilities, and lacking knowledge of communication disability (Ziviani et al., 2004; Murphy, 2006; Chinn, 2017). Studies suggest that factors such as time constraints and lack of continuity in health service provision may exacerbate these communication problems (Law et al., 2005; Mastebroek et al., 2014). These findings imply a need for communication training and resources for health care practitioners so that they are better able to engage with people who have intellectual disabilities.

This study found that time is an important consideration for GPs and other health care practitioners. The average time spent by UK GPs with each of their patients is 10 minutes (Royal College of General Practitioners [RCGP], 2017). This is considerably lower than other developed countries. Over 90% of GP consultations in the UK are completed in under 15 minutes compared with 27% in other countries, including Germany, France, Australia and the United States (RCGP, 2017).

The RCGP stated that UK GPs want to spend more time with patients. However, demands for GP services have risen by 15% since 2010, but the number of GPs and time available within consultations has not risen in line with demands (RCGP, 2017). Therefore, more GPs, more practice staff and more resources for primary care are needed (RCGP, 2017).

The GPs interviewed in the study spoke about the value of Annual Health Checks for people with intellectual disabilities (including height, weight and BMI checks) believing that patients with intellectual disabilities might be getting more time and a better health screening than adults without intellectual disabilities. Annual Health Checks for adults with intellectual disabilities may identify weight management issues in this population group. The Annual Health Checks, introduced under GP contract changes in 2009, are not mandatory but there is a financial incentive attached (GPs receive £140.00 for each check in 2017/18). To meet the requirement for the financial incentive, practices must provide a comprehensive review of physical and mental health, including a full physical examination, a syndrome-specific check and weight assessment. However, latest available data from GP registers found that nationally, only 52% of those individuals with intellectual disabilities who were eligible received a health check in 2015/16 (Public Health England, 2016b). The reasons why there has not been a greater provision and uptake of the annual health checks are unknown. Reasons might include, for example, patients (and or their carers) not receiving an invitation from their GP to attend health checks, or patients actively choosing not to attend the health checks, or an unwillingness by GPs to receive training and or organise the necessary appointments for the checks (Slowie and Martin, 2014). Alternatively, GPs may not be persuaded about the benefits of the annual health checks compared with the amount of time involved in setting up and providing the health checks (Slowie and Martin, 2014). Furthermore, the returns to the practice may be too small if they have comparatively few adult patients with intellectual disabilities (Slowie and Martin, 2014). Where there is a low uptake, there is a comparative inequality issue and action is needed to address the situation (Slowie and Martin, 2014).

Other challenges uncovered by the study included negative attitudes and assumptions about people with intellectual disabilities that may make it difficult for messages about weight management to be actioned. For example, some health care practitioners perceived that some carers or support workers were feeding people with intellectual disabilities the wrong kinds of food to avoid any kind of conflict with the person they supported. Health care practitioners suggested that any health advice given by them in such scenarios would not make any difference and implied that it may be a waste of their time and resources. Participants in this study perceived that people with intellectual disabilities experience several discriminatory attitudes and assumptions. Other studies have confirmed these findings e.g. Mencap, (2007). In addition, there may be negative assumptions amongst health care practitioners. For example, a recent systematic review of mainstream health practitioners' attitudes towards this population found stigmatising attitudes appeared to be present (Pelleboer-Gunnink et al., 2017).

This study identified cultural issues. For example, issues for health care practitioners in trying to understand what services are culturally acceptable and available for patients with intellectual disabilities from different BME groups. Other studies have found that in many cultures a person's heavier weight is associated with health and higher social standing (Sobal and Stunkard, 1989). This image may linger in the collective imagination and losing weight may be contraindicated (Candib, 2007). In other words, culture may shape how some people consider weight (Gremillion, 2005). These positive perceptions of excess weight may persist despite the known connection between obesity and serious health conditions (Candib, 2007). Furthermore, one study found that the likelihood of people self-classifying themselves as overweight or obese declined between 1988-1994 and 1999-2008 among US adults, despite increases in the prevalence of obesity (Langellier et al., 2015). The US study also found disparities in weight self-perceptions with BME males and females less likely to perceive themselves as overweight than White males and females of the same BMI (Langellier et al., 2015). Both groups experienced a downward shift in overweight self-perceptions between survey periods, but there was a pronounced shift in BME males and females over a wider range of BMI values (Langellier et al., 2015). These declines in the likelihood of

people classifying themselves as overweight may affect weight loss efforts (Langellier et al., 2015). A search of electronic databases (CINAHL, Ovid Medline and Cochrane 23.02.17) did not identify any studies that have specifically examined weight self-perceptions in overweight or obese people with intellectual disabilities from different BME groups. It may be useful for future research to explore how issues of intersectionality affect weight management. For example, future research might explore weight management issues involved for individuals with intellectual disability by different BME groups, age groups, sex, socio-economic groups, types and severity of intellectual (and physical) disability, residential settings, and by different geographical locations. People with intellectual disability are not a homogeneous group. Future research should acknowledge this and explore issues of intersectionality.

This study's findings suggest that GPs may not be aware of what weight management services are available locally and more marketing of services to GPs may be required to raise their awareness of services' availability. However, other studies suggest that GPs may resist any pressure to refer their patients to services that they lack faith in, and or they may fail to accept obesity as part of their workload (Ogden et al., 2001; Epstein and Ogden, 2005; Leverence et al., 2007; Dewhurst et al., 2017). The Quality Outcomes Framework (QOF), which pays GPs to register obese patients, may need reviewing to provide incentives to GPs to proactively offer advice to obese and overweight patients and to refer them to weight management services where appropriate (Lacobucci, 2014).

In terms of support networks, the study found that health care practitioners valued the continuity of caring support. However, they suggested that carers and support workers needed more support and training. They spoke about challenges they had encountered in having to communicate with patients through different carers or support workers. Other studies have reported that support from carers can have a positive impact on weight loss for adults with intellectual disabilities who are obese (Hamilton et al., 2007; Spanos et al., 2013b). This is because carers can influence the diet and food choices of people with intellectual disabilities (Rodgers, 1998). However, carers may have poor knowledge about healthy eating and physical

exercise (Melville et al., 2009; Cartwright et al., 2017), and they may promote unhealthier food choices and activities in this population group (Smyth and Bell, 2006). A systematic review of carer-led interventions to monitor, promote and improve health in this population group found a paucity of research in this area (Hithersay et al., 2014). This suggests that the most appropriate means of engaging carers in a way that will reliably improve health outcomes for this population group is currently unknown. Future research is required in this field (Hithersay et al., 2014).

In terms of resources, the study found a lack of specialist services, a lack of accessible resources, a lack of financial incentives, and a lack of opportunities for different service providers and service users to come together to discuss and develop appropriate resources for patients with intellectual disabilities who are obese. The study's findings also imply that there is a need for training for health care practitioners on how better to engage with patients who have intellectual disabilities as well as training on obesity and weight management generally. However, the study's findings also imply that health care practitioners need to be motivated to attend such training and some may not be motivated.

Other studies have identified the need for 'user-friendly' resources to aid communication about weight management with this population group (Hamilton et al., 2007; Jinks et al., 2011; Spanos et al., 2013a; Sundblom et al., 2015). Other studies have found that the provision of general health care for adults with intellectual disabilities has largely depended on doctors who appear to receive little training in disability, and or disability support staff who, conversely, appear to receive little training in health (Tracy and McDonald, 2015). The training and education of professionals from a range of disciplines is therefore vital in addressing health inequalities and poor health outcomes experienced by people with intellectual disabilities (Tracy and McDonald, 2015). People with intellectual disabilities should be involved in such training (Tracy and McDonald, 2015 p29).

Some resources for health care practitioners were available at the time of writing but there may be a lack of awareness of these, and over, available resources. For example:

- The Royal College of General Practitioners' (RCGP) health checks for people with learning disabilities toolkit ([www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx](http://www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx) [accessed 31.07.17])
- The Royal College of Nursing guidance on better health care for this population group (Royal College of Nursing, 2013).
- A national programme of 'Transforming Care' – to improve services for people with intellectual disabilities in the UK - was being rolled out which included a programme of action on workforce development and training for health care practitioners (NHS England, 2015).
- Also, in 2014, a 'Learning Disability Made Clear' toolkit was introduced for health care practitioners (West Midlands NHS Trust, 2014).
- The Royal College of Speech and Language Therapists have produced guidance on communication standards (reasonable adjustments to communication that people with intellectual disabilities should expect in health care settings) (Royal College of Speech and Language Therapists, 2013).

The study identified external barriers. Health care practitioners commented on an 'obesogenic' environment and socio-economic, demographic and geographical factors that worked against patients' attempts to manage their weight. Mention was also made of the role of the media which participants suggested influenced negative attitudes towards all people with obesity. Other research has shown that economic and technological advances in modern society have led to an obesogenic environment (Kumanyika et al., 2002; Bleich et al., 2008; Cutler et al., 2003; Kitchen, Kim and Schultz, 2008; Harris et al., 2009; Butland et al., 2007; Swinburn, Sacks, and Ravussin, 2009). Other studies have highlighted the importance of developing interventions for obesity and weight management at several levels (Lakerveld et al., 2012). The risk of exposure to environmental adversities is also unevenly distributed (Emerson and Hatton, 2014). People with intellectual disabilities are more likely to be in a lower socio-economic group and exposed to a range of social and

environmental adversities than their non-disabled peers (Emerson and Hatton, 2014). However, further research is required to investigate the significance of socio-economic and environmental determinants experienced by people with intellectual disabilities, including how this may vary with factors such as age, gender, ethnicity and severity of intellectual disability (Emerson and Hatton, 2014).

The study found that participants perceived that motivation and confidence are influential factors in weight management but that self-motivation might be a challenge for some people with intellectual disabilities who need additional support. The participants believed that incentives help motivate behaviour change in individuals with intellectual disabilities but these incentives needed to be wider than just 'calorie counting' and weight loss goals. The participants suggested a need for personalised incentives such as helping someone to feel better about themselves, their image and their mental health, rather than seeking statistical weight loss outcomes. Participants stated that statistical concepts may be meaningless to patients and may be difficult for GPs to explain to all their patients.

Other studies have found that motivation is an important consideration in obesity and weight management and that a perceived lack of motivation may be an important barrier to successful weight management (Sonntag et al., 2012). Other studies have found that appearance may be a greater motivator for weight loss in adults with obesity and intellectual disabilities, rather than simply seeking weight loss outcomes (Jones et al., 2015). It may be useful to use image and appearance as topics to raise the subject of obesity and weight management in patients with intellectual disabilities. Broaching the perceived sensitive subject of obesity and weight management in this way may help initiate or bolster their motivation to make lifestyle changes to lose weight (Jones et al., 2015). This may be a useful approach in other individuals with obesity also (individuals who are without intellectual disabilities) as other studies have suggested that appearance is a good motivator for weight loss in young people and in women (La Rose et al., 2013). However, other research suggests that when people (without intellectual disabilities) reach the age of thirty-five or forty, they are motivated to lose weight mainly for health reasons (La Rose et al., 2013; Hankey, Leslie and Lean, 2002).

Whilst this 'appearance' approach may be useful in the short term in certain population groups using such triggers may be harder to maintain in the longer-term, particularly if the motivating appearance factor was linked to a forthcoming social event (Lawrence et al., 2001).

Finally, none of the participants in this study commented that the UK obesity and weight management guidance was particularly helpful in guiding their practice. This study's findings imply that the UK official guidance for practitioners needs reviewing and improving so that the guidance contains clearer and more practical guidance for health care practitioners on managing interventions for adults with intellectual disabilities who are obese or overweight. Other studies similarly suggest a need for clearer weight management guidelines for all population groups (Dewhurst et al., 2017).

## **6.9 Study's strengths and limitations**

The strength of this study is that it is one of the few studies conducted to explore the views and experiences of health care practitioners involved in the identification of obesity and the delivery of weight management interventions for adults with intellectual disabilities. Conducting face-to-face semi-structured interviews in this study involved travelling to different geographical locations, which proved time-consuming and it may have been better to conduct structured telephone interviews or surveys. However, there is less flexibility in structured telephone interviews and surveys to seek clarification of responses or to pursue unexpected responses from interviewees than there is with face-to-face semi-structured interviewing (Ryan, Coughlin and Cronin, 2009). The flexibility of face-to-face semi-structured interviews in this study enabled further clarification of responses and further exploration of participants' responses with them.

The study was limited as it involved a small sample of health care practitioners from one region of the North West of England. There were challenges involved in the recruitment of participants to the study. This was due to GPs' and other health care practitioners' time constraints. There may have been a participant bias as the GPs

and health care practitioners who volunteered to participate in the study may have been more interested in the subject of obesity and weight management in people with intellectual disabilities than those who did not volunteer to take part in the study. Finally, transcripts form a prominent part of the data analysis process in qualitative research. Transcripts were used in this study. However, it is acknowledged that there is a risk of transcripts restricting the rich qualitative process into the confines of simple black and white text (Roller and Lavrakas, 2015). In this way, the mood of a conversation can be lost in a transcript. The tone of a voice can be lost. Mannerisms and body language can be lost. Life is not lived in black or white. Transcripts are therefore merely a device for data analysis and they have their limitations (Roller and Lavrakas, 2015).

## **6.10 Conclusions**

The study described in this chapter aimed to explore how health care practitioners recognise, and manage obesity in adults with intellectual disabilities. The study found that GPs' time constraints may restrict discussion of obesity and weight management with patients (regardless of whether patients have intellectual disabilities or not), and that some GPs were reluctant to raise the subject of obesity with patients if they were overweight or obese themselves. The findings also suggest that the QOF may need reviewing to provide incentives to GPs to offer brief interventions for obese and overweight patients and to refer them to weight management services (Aveyard et al., 2016).

This study found that better and more accessible resources in primary care may be needed to facilitate improved communication of weight management issues with patients who have intellectual disabilities. Participants in this study indicated that they often need to rely on carers or support workers (who may also be overweight or obese) to help with communication. The study's findings suggest that improved training for GPs on communicating messages about obesity and weight management to patients generally, and on how to communicate better with individuals who have intellectual disabilities may be needed. However, the study

also found that health care practitioners must be motivated and they need time to undertake such training – which may be challenging for these busy professionals.

The study found that not all the GPs in the study were fully aware of what weight management services were available locally for referral purposes. The findings suggest that improved information and marketing of local weight management services for GPs may be required. In addition, weight management referral processes between GPs and service providers may need reviewing and improving. However, GPs need persuading that these services will be able to meet the needs of their patients – particularly those with intellectual disabilities and those from BME communities. The QOF, which pays GPs to register obese patients may also need reviewing.

The study's findings highlighted the value and importance of caring support from a practitioner perspective. The findings suggest that some carers or support workers who are unfamiliar with the needs of the person they are supporting may undermine attempts at weight management and that training for carers is required. The findings suggest that consistent caring support from carers is vital to the success or otherwise of weight management in adults with intellectual disabilities.

Participants perceived how an 'obesogenic' environment, the negative media, and socio-economic and demographic factors worked against their patients' attempts to manage their weight. Further research should explore the impact of such factors on obesity and weight management for this population. High-level strategic policy and public health interventions may be needed to address such factors.

Motivation was perceived by participants to be another factor in weight management for adults with intellectual disabilities. However, self-motivation might be challenging for adults with intellectual disabilities who may also need motivated carers and motivated health care practitioners to support them. This may be doubly difficult for them if some of their carers, support workers and health care practitioners are overweight or obese and unmotivated themselves to change. These findings imply that some carers, support workers and health care

practitioners may need to participate in weight management interventions and to be motivated alongside the people with intellectual disabilities whom they support.

## **Recommendations**

The findings from this study have highlighted some areas for the attention of future research and practice. These are summarised in the concluding chapter (chapter 10).

### *Summary of chapter*

This chapter explored how health care practitioners recognise, and manage obesity in adults with intellectual disabilities. The chapter highlighted the main findings gathered from the first of the three studies conducted during Phase Two of the programme of research for this thesis: face-to-face semi-structured interviews involving health care practitioners. The next chapter describes findings from the second of the three studies conducted during Phase Two: a co-produced focus group study involving adults with intellectual disabilities (and their carers) to explore their views and perceptions of eating well, living well and managing their weight, if they want to.

## CHAPTER SEVEN

### STUDY TWO: CO-PRODUCED FOCUS GROUP STUDY INVOLVING ADULTS WITH INTELLECTUAL DISABILITIES

#### INTRODUCTION

The previous chapter (chapter six) outlined findings from a study which involved semi-structured interviews with health care practitioners. The study involving health care practitioners was the first study of three studies conducted for Phase Two of the programme of research for this thesis. This chapter describes findings from the second study conducted in Phase Two which involved a co-produced focus group study involving adults with intellectual disabilities (supported by either their carers or support workers).

#### 7.1 Study Two: Aim

The aim of this study was to use co-production methods to explore the views and experiences of adults with intellectual disabilities in relation to barriers and facilitators to eating well, living well and managing their weight, if they wanted to.

#### 7.2 Objectives

The objectives of the research were to explore:

- What may help or may make it difficult for people with intellectual disabilities to eat well and live well, if they want to\*, from the perspectives of adults with intellectual disabilities themselves.
- Weight management interventions from the perspectives of adults with intellectual disabilities.

*\* the premise here being that people with intellectual disabilities should be afforded the same choices in life as their non-disabled peers.*

## *Approach*

A self-advocacy group involving adults with intellectual disabilities and their carers in the North West of England was approached by the postgraduate student and asked whether they thought co-produced research on this topic was relevant, interesting and of concern to them and to others with intellectual disabilities. A unanimous positive response was received and two adults with intellectual disabilities from the self-advocacy group volunteered to advise on the research methods, questions, materials and recruitment of participants.

### **7.3 Method**

Small focus groups (up to 7 participants) were chosen for this study in line with the preferences of the self-advocacy group, who stated that people with intellectual disabilities are better supported in smaller facilitated focus groups rather than in individual interviews or larger focus groups. Available evidence also suggests that people with intellectual disabilities can be better supported in small sized focus groups that are facilitated by a skilled facilitator who is familiar with the participants' communication (Fraser and Fraser, 2001).

### **7.4 Sample and setting**

The self-advocacy group advised on the sampling and recruitment of participants. Convenience sampling was used to recruit a sample of self-selecting adults with intellectual disabilities aged 18 years and over (and their carers where appropriate) from the North West (NW) of England. Potential participants were all involved in a NW Regional Forum that was organised and facilitated by the self-advocacy group for people with intellectual disabilities who advised on the research. Potential participants were invited to participate in the study using easy-read covering letters, participant information sheets and consent forms co-produced by people with intellectual disabilities (appendices 7-9). Potential participants received a week's advance notification of the date of the Forum meeting and the focus groups. The focus groups were organised to take place during a routine meeting of the NW Regional Forum and held in a venue that was familiar to the people with intellectual disabilities.

### *Focus group procedures*

The Forum began with introductions and ground rules from the chair of the NW Regional Forum. 19 potential participants attended the Forum. Potential participants were then introduced to the study. All potential participants attending the Forum received a copy of the easy-read participant information sheet (appendix 8). The purpose of the participant information sheet was to aid their understanding of the research. Facilitators and carers or support workers read through the participant information sheets with the potential participants. All this was done to ensure they understood the nature of the study, what the study entailed, what being involved meant for them, what would happen to the information gathered, and whether they were happy to take part. Potential participants asked questions about what would happen to the information gathered from the focus groups and whether their carers could stay and support them with the study. It was explained that an easy-read report would be shared with people who had taken part in the study and that carers or support workers could stay to support participants. It was also explained that a report of findings would also be shared with health care staff and other staff involved in providing services so that staff could learn from participants. Participants were also advised that findings would be used to inform the postgraduate student's degree and that the findings may be used in journals or conferences so that a wider audience could learn from participants. Potential participants were advised that they could take part in the study or opt out if they wanted to and it was not compulsory to participate just because they had attended the Forum. All 19 of those who indicated that they wanted to take part then completed an easy-read consent form (appendix 9).

At the beginning, and again at the end of the focus groups, participants were advised that the research was ongoing and that an easy-read findings report would be shared with participants for further feedback purposes.

Participants, their carers, support workers, advisors and facilitators were all paid a one-off fee for their involvement in the co-produced study.

## **7.5 Data collection**

Advisors from the self-advocacy group worked with the postgraduate student to co-produce recruitment materials including easy-read letters to potential participants, participant information sheets, and consent forms. Original easy-read focus group materials, including a study topic guide comprising a questionnaire and worksheet (appendix 11) were co-produced by the advisors and the postgraduate student for use in eliciting responses from focus group participants. The postgraduate student supplied the advisors with draft outline information for the recruitment materials and focus group materials. The advisors then adapted this outline information to create easy-read accessible formats using simple words and pictures. The postgraduate student then produced a full draft, and materials were finalised with some minor amendments by the advisors. The easy-read questionnaires provided space for individual participants to provide detailed information on some, or all, of the research questions, if they wanted to. The easy-read worksheets were a single sheet of A4 designed so that individual participants could write familiar words or draw pictures to represent their responses. A wider group discussion, held at the end of the focus groups, involved all the focus groups coming together and verbally sharing and discussing their own individual and their own focus group's responses.

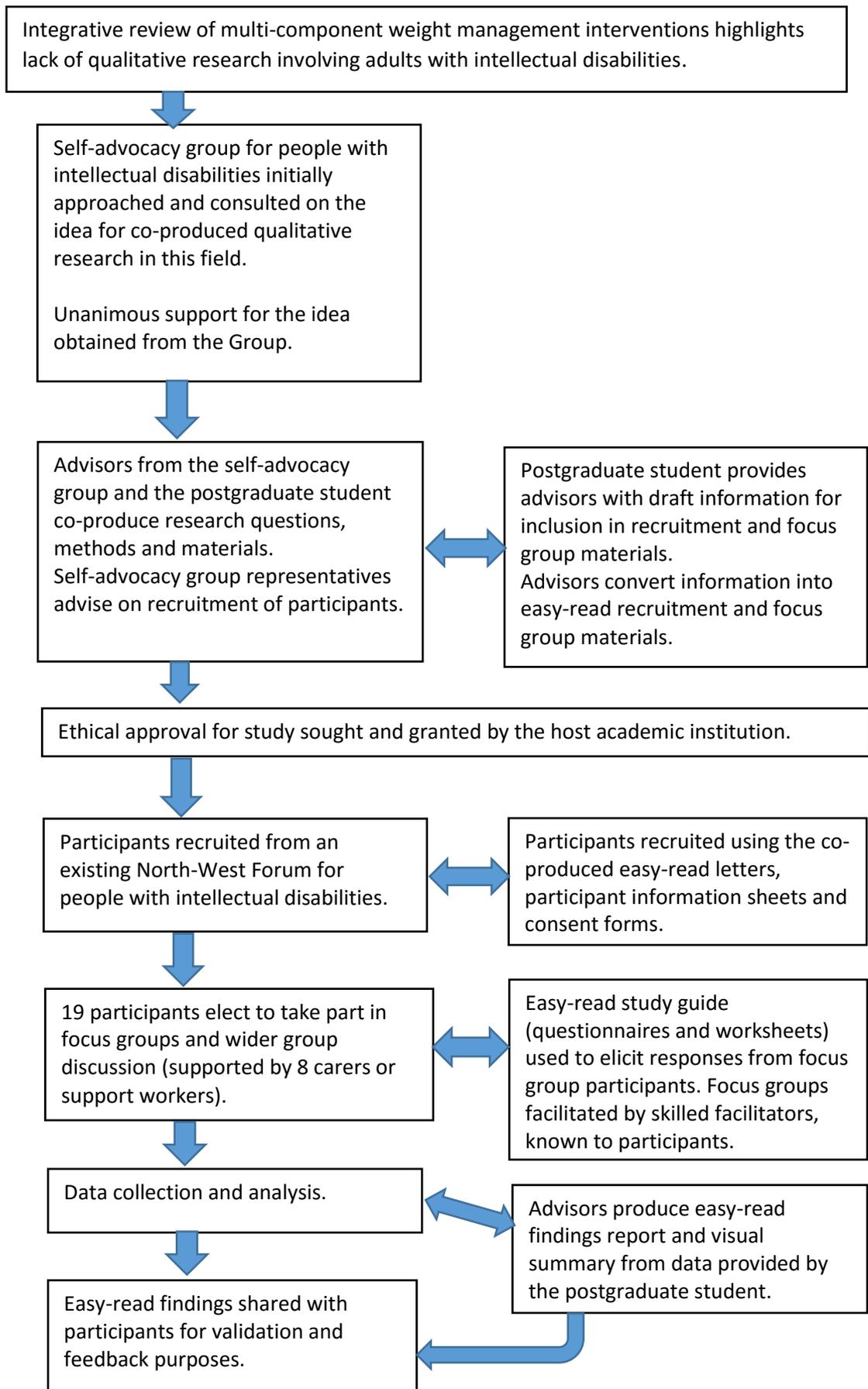
## **7.6 Data analysis**

Participants' responses from the worksheets, questionnaires and wider group discussion were transferred onto Excel spread-sheets for data analysis purposes. These were analysed using thematic analysis (Attride-Stirling, 2001; Braun and Clarke, 2006). The analysis involved the postgraduate student reading the text of each worksheet, questionnaire and the notes of the wider group discussion and assigning words and sentences with one or more open code and seeking out key issues raised. A coding framework (appendix 19) was devised as part of the thematic analysis process to reduce and dissect the collective text into coded text segments and themes. Basic themes, abstracted from the coded segments, were refined and further re-refined. NVivo v11 was used to assist the thematic analysis process. The process involved constantly referring to the data for evidence to support arising codes and themes and interconnections. These themes were then

assessed in turn to explore if there were any global themes arising from the data. Figure 7.1 provides a flow-chart highlighting stages of this study.

A thematic network (Figure 7.2) was developed as part of the analysis to illustrate these salient themes and the relationships between these themes. The validity and dependability of the analysis was assessed through regular discussion with members of the supervision team and through re-examining data documentation (e.g. original worksheets and questionnaires) to ensure findings were supported.

**Figure 7.1: Flow-chart summarising stages of the co-produced focus group study**



## **7.7 Findings**

All 19 adults with intellectual disabilities aged over 18 years (13 men and 6 women) involved in the Forum agreed to take part in focus groups and a wider group discussion involving all the focus groups. They provided informed consent using co-produced easy-read consent forms. The mean age of the participants who supplied age-related information (n=13) was 45 years (range 32 – 57). The participants were supported by 8 carers or support workers (4 men and 4 women).

Four focus groups and one wider group discussion (involving all the focus groups) were held during the Forum's routine meeting in September 2016 in a venue which was familiar to all participants. There was an average of 5 participants and 2 of their carers or support workers in each of the focus groups. The focus groups were facilitated by skilled facilitators from the self-advocacy group for people with intellectual disabilities who had experience of working with this population and who were known to participants. The four focus groups ran concurrently for 45 minutes, followed by a 15-minute group discussion involving all participants of all four focus groups, their carers or support workers, the facilitators, and the postgraduate student.

14 completed questionnaires and 17 completed worksheets were handed back to the postgraduate student at the end of the focus groups.

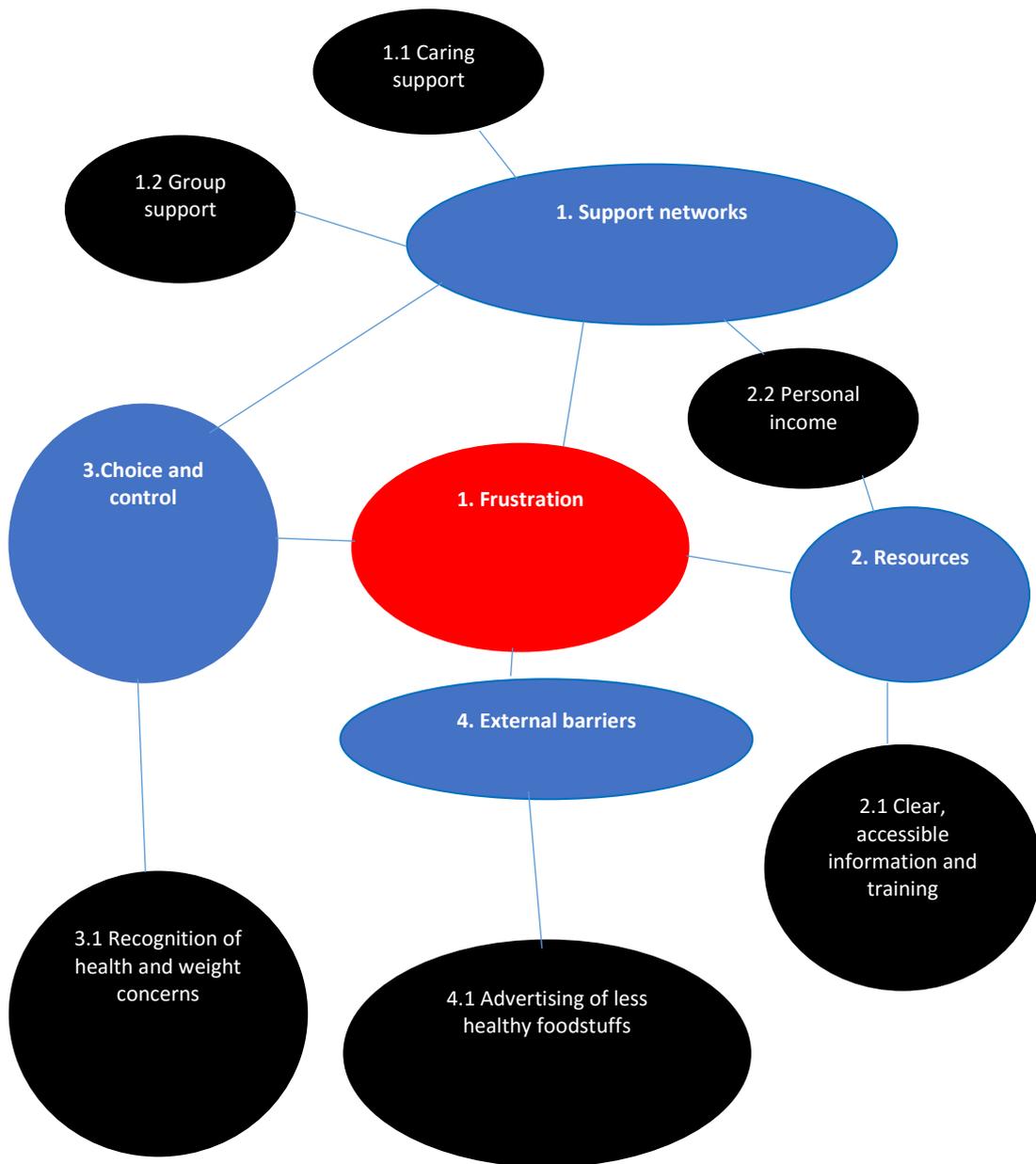
### ***Themes***

4 themes, 6 sub-themes, and one global theme arose out of the participants' responses to the questions in the worksheets, questionnaires and from the wider group discussion. These themes are highlighted in Table 7.1 and in Figure 7.2. The themes are discussed narratively below.

**Table 7.1: Study Two – Summary of themes and global themes**

Themes	Global themes
<p><b>1. Support Networks</b>            Sub-themes:            1.1 Caring support.            1.2 Group support.</p> <p><b>2. Resources</b>            Sub-themes:            2.1 Clearer, accessible information and training.            2.2 Personal income.</p> <p><b>3. Choice and control</b>            Sub-themes:            3.1 Recognition of health and weight concerns.</p> <p><b>4. External barriers</b>            Sub-themes:            4.1 Advertising of less healthy foodstuff</p>	<p>1. Frustration.</p>

**Figure 7.2: Study Two - Thematic network of adults with intellectual disabilities' responses**



**Key**

Black shapes = sub-themes  
 Blue shapes = themes  
 Red shape = global theme  
 Lines = interlinkages between themes

## **Theme 1: Support networks**

### **Sub-theme 1.1 - Caring support**

Participants indicated the importance of having support from carers and or support workers to help them with every-day tasks such as shopping and with accessing regular groups and activities to help them eat well, live well and manage their weight if they wanted to:

*“Support to buy shopping.”* (Participant 12)

*“Having support to take part in groups.”* (Participant 11)

However, some participants indicated that the support they needed to help them was not always available and some individuals with intellectual disabilities therefore did not have the opportunity to get out of their house:

*“Don't always have the support to get out.”* (Participant 8)

### **Sub-theme 1.2 - Group support**

Participants commented on the value of support from others such as those involved in weight management groups with similar weight loss goals:

*“I found [name of a commercial weight management service] helpful.”*  
(Participant 1)

*“Having people who wanted the same as me.”* (Participant 3)

*“Going to [name of a commercial weight management service]. Some of the staff are very supportive of me....Motivation and encouragement from the group.”* (Participant 10)

Participants expressed a desire to be matched with others with the same interests as them so they could be routinely taken to activities they enjoyed:

*“Buddies - other people who want to enjoy the same things as me like the rugby - so I can always get there.”* (Participant 13)

## **Theme 2: Resources**

### **Sub-theme 2.1 - Clearer, accessible information and training**

Participants cited the need for better, clearer and more accessible healthy lifestyle information. Some participants were unable to obtain accessible information and some had received conflicting information:

*“Information in easy read.”* (Participant 9)

*“[There is] No easy read.”* (Participant 12)

*“Not sure what to eat. What is healthy?”* (Participant 6)

*“Good information [needed] on how to be healthy.”* (Participant 7)

*“GP said I needed to lose weight but did not offer any help.”* (Participant 11)

Participants also stated that carers and support workers required training so they could better support people with intellectual disabilities:

*“Support workers - training to be able to support people correctly in cooking, eating, exercise.”* (Participant 12)

*“Support workers need to be trained up.”* (Participant 4)

### ***Sub-themes 2.2 - Personal income***

Participants expressed concerns about having sufficient personal income to manage and to pay for the routine support they needed, to buy the right kinds of foods, and to routinely attend activities:

*“I make sure I have enough money.”* (Participant 5)

*“Not having money to buy the right food.”* (Participant 14)

*“What happens if funding is lost?”* (Participant 12)

## ***Theme 3: Choice and Control***

### ***Sub-theme 3.1 - Recognition of health and weight concerns***

Most participants expressed health concerns and some reported several health conditions. Most participants also had concerns about their weight. However, some indicated in their questionnaire responses and in the wider group discussions that they were unable to access and receive appropriate support to deal with their weight concerns:

*“I'd like to join [name of a commercial weight management service] but no support to go and too expensive.”* (Participant 11)

*“Have seen a dietician. Not very helpful. Gave me wrong information.”*  
(Participant 2)

Those that expressed a desire to lose weight spoke about a lack of support and a lack of money which had prevented them accessing weight management services. However, some participants stated that they had been supported to attend a commercial weight loss service. One participant, who had been supported, had received a 'Slimmer of the Year' award for losing 30kgs in weight. None of the participants who wanted to lose weight (or who had lost weight) could recall being referred by their GP or any other health care practitioner to any weight management services. Those that had accessed weight management services said that they had either self-referred or they had been helped by their carer or support worker to access and attend them.

#### ***Theme 4: External barriers***

##### ***Sub-theme 4.1 – Advertising of less healthy foodstuff***

Participants in the wider group discussion verbalised their sense of frustration with external barriers. They stated that they found it difficult to access sports, leisure and recreational services as some of these were not adapted to meet their intellectual disabilities. Some participants also had physical disabilities as well as intellectual disabilities and stated that they had experienced further difficulties with accessing such services because of this. Participants in the wider group discussion also voiced their frustration over the advertising of less healthy foodstuffs on television during the recent Paralympics. They commented on the general widespread availability and marketing of less healthy fast-foods, takeaways and convenience foods over more healthy foodstuffs and they found it difficult to eat well due to issues such as confusing food labelling:

*“Understanding the tables and conflicting information”* (Participant 13)

Consequently, they indicated that it was often:

*“Easier to get a takeaway delivered.”* (Participant 12)

#### ***Overarching global theme of frustration***

An overarching theme of frustration emerged from the analysis of participants' responses. Participants expressed frustrations – in their focus group responses and in the wider group discussion - over identified barriers including restrictions to

personal incomes; difficulties obtaining appropriate support; inaccessible activities and services; and a lack of clear and accessible information on how to eat well and live well and why this was important.

14 participants provided suggestions for how the overall health and wellbeing of people who have intellectual disabilities could be improved (Figure 7.3). Their suggestions emphasise their need for greater awareness, understanding, support, and for better, clearer, accessible information and training on healthy lifestyles.

**Figure 7.3: Adults with intellectual disabilities' perceptions of what can be done to improve the health and wellbeing of people with intellectual disabilities**



## *Feedback*

An easy-read report of findings and a creative visual summary of findings (appendix 20) were co-produced by the advisors at the end of the study from data supplied by the postgraduate student. The report and a visual summary were shared with participants at the end of the analysis for validation and feedback purposes. No further comments or amendments were received from participants.

## **7.8 Discussion**

This study found that adults with intellectual disabilities experience several barriers to eating well, living well and managing their weight if they wanted to. The barriers included problems accessing caring support; a lack of clear and accessible healthy lifestyle and weight management information; unmet training needs for carers and support workers; personal income restrictions; and external barriers such as the widespread marketing and availability of less healthy foodstuffs. Most participants had health and weight concerns but they were frustrated because they were unable to access the necessary support and resources to help them deal with their concerns.

Other studies have found similar barriers to support this study's findings (Messent, Cooke and Long, 1998; Spanos et al., 2013a; Spanos et al., 2013b; Sundblom et al., 2015; Cartwright et al., 2017). However, none of these previous studies were co-produced by adults with intellectual disabilities and, whilst two had asked participants for their views of barriers to physical exercise (Messent, Cooke and Long, 1998; Cartwright et al., 2017) none had asked participants for their views and experiences of barriers and facilitators to eating well, living well and weight management.

None of this study's participants who had weight concerns could recall being referred to weight management services by their GP or any other health care practitioner. Those that had accessed services had self-referred or had been helped by their carer(s) or support worker(s) to access commercial services which they stated were expensive. Therefore, there may be a lack of awareness of free, non-

commercial weight management amongst health care practitioners, carers and support workers as well as people with intellectual disabilities, or there may be problems with referral processes or access. However, the providers of such services also need to ensure that their services are accessible and tailored to accommodate the needs of people with intellectual disabilities, some of whom may also have physical, as well as intellectual, disabilities.

Previous studies of evidence-based weight management interventions for adults with intellectual disabilities have identified the need for participants to be motivated to manage their weight, and that carers and staff involved in interventions also needed to be motivated to support them (Spanos et al., 2013a; Spanos et al., 2013b; Spanos et al, 2014; Sundblom et al., 2015). These previous studies explored issues for adults with intellectual disabilities who were participating in weight management services. However, adults with intellectual disabilities in this study who wanted to manage their weight experienced barriers to accessing weight management services in the first place and they expressed their frustration with these barriers. The participants in this study appeared to be exhausted with the barriers they faced. The participants commented on external environmental barriers including the widespread availability of fast-food outlets that they perceived to be unhealthy. Interestingly, a Public Health England briefing on fast-food outlets (e.g. burger bars, kebabs shops, fish and chip shops) calculated that the total number of fast-food outlets across England was 47,928, of which, 1,282 were based in 12 districts of Lancashire (a crude outlet concentration rate of 121.85, significantly above the England rate of 87.8) (Public Health England, 2014). Blackburn-with-Darwen (128.1) and Blackpool (192.9) also recorded rates significantly above the National average (Public Health England, 2014).

Overcoming barriers identified by participants may lead to reduced feelings of frustration, increased feelings of motivation and longer-term weight management and health improvements for this population. This study suggests that when individuals with intellectual disabilities received support they were more likely to access and utilise weight management services and some achieved their weight loss goals. Participants also valued being with others who had the same interests as

them - such as the support of others in weight management groups with similar weight loss goals. Participants wanted matching with support workers so that they could attend activities that they enjoyed. This finding suggests a wider 'buddying' support systems or schemes may be beneficial and this requires further exploration.

This study's overall findings support other studies' arguments for greater collaborative working involving health care practitioners, service commissioners, service providers, people with intellectual disabilities, their carers and support workers (Taggart, Brown and Karatzias, 2014). Collaborative working may lead to practical action that, in turn, may contribute to reductions in some of the inequities in service provision and health inequalities experienced by this population (Taggart, Brown and Karatzias, 2014). These findings also imply the need for broader public health interventions to change the surrounding environments of adults with intellectual disabilities such as greater regulation of the number of fast-food outlets.

### *Issues encountered when conducting focus groups*

Some of the challenges described by other researchers who have conducted research involving this population group – such as issues involved in obtaining ethical approval and consent (Nicholson, Colyer and Cooper, 2013); focus group problems (Nind, 2008; Kaehne and O'Connell, 2010); and unresponsiveness and inarticulateness of participants (Booth and Booth, 1996) - were not encountered in this study. This may have been because of the adoption of strategies to reduce or mitigate the risks of any such potential problems arising. Table 7.2 summarises the principles of inclusive research and the strategies used to reduce or mitigate challenges.

**Table 7.2: Applying the principles of inclusive research**

Inclusive research principles	Applying the principles of inclusive research: strategies used
<p>The research should be inclusive of people with intellectual disabilities (Walmsley and Johnson, 2003).</p> <p>Research needs to be viewed by all involved as worthwhile and researchers must live up to the trust placed in them by participants (McDonald, Kidney, and Patka, 2013).</p> <p>People with intellectual disabilities have a right to be involved in research that affects their lives (Bigby, Frawley, and Ramcharan, 2014).</p> <p>Research must further the interests of people with intellectual disabilities and avoid tokenism; and, participants with intellectual disabilities must be able to exercise some control over the research (Johnson, Minogue, and Hopkins, 2014).</p> <p>Nothing about people with disabilities without them (Stack and McDonald, 2014).</p> <p>Researchers should use methods that facilitate a voice for people with intellectual disabilities and aim to empower them (Duckett and Fryer, 1998).</p> <p><i>“The focus should be on overcoming the researchers’ own limitations rather than highlighting challenges and limitations of participants”</i> (Booth and Booth, 1996 p67).</p>	<p>Early involvement of self-advocates in research proposals to ensure the research was relevant, of interest and meaningful to participants.</p> <p>Involvement of people who have intellectual disabilities in decisions about the research design.</p> <p>Obtained help from self-advocates to identify and recruit potential focus group participants.</p> <p>Co-produced accessible information designed by and for people who have intellectual disabilities e.g. easy-to-read materials.</p> <p>Use of pre-existing meetings and familiar and accessible venues for focus groups.</p> <p>Used trained facilitators who have experience of communicating with people who have intellectual disabilities.</p> <p>Set ground rules to keep group discussions flowing.</p> <p>Adopted a flexible and collaborative approach to the research process.</p> <p>Consulted and learned from people with intellectual disabilities as ‘experts-by-experience’.</p> <p>Paid for people’s involvement in the research.</p>

## 7.9 Study's strengths and limitations

The main strength of this study is that it is the first known co-produced qualitative study involving adults with intellectual disabilities to explore their views and experiences of barriers and facilitators to eating well, living well and weight management. The study entailed collaboration between the postgraduate student and adults with intellectual disabilities to generate new knowledge that neither could produce alone (Bigby, Frawley and Ramcharan, 2014). A strength of such an approach is that it aims to maintain the integrity and authenticity of the contributions made by people with intellectual disabilities (Bigby, Frawley and Ramcharan, 2014).

The study was not restricted to adults with intellectual disabilities who were obese or overweight, or adults with intellectual disabilities accessing weight management services. The study therefore captured the views of some adults with intellectual disabilities who were not obese or overweight and highlighted the challenges they faced in remaining so, as well as the problems of some who identified themselves as overweight or obese. However, there are limitations with this study. The participants included a small sample of self-selected adults with mild-to-moderate intellectual disabilities who were all involved in the same regional network. Participants may have taken part in the study because they had an interest in the topic. There were twice as many men as women and there was a limited age range (32-57 years), with no younger or older adults with intellectual disabilities. Therefore, findings may not be generalizable to all adults with intellectual disabilities. The presence of peers, carers, support workers, facilitators or researchers may have led to a positive response bias (Ottmann and Crosbie, 2013), and the provision of a one-off fee may have influenced participation. However, people should be compensated for their valuable time and contributions and this co-produced study's findings do provide an insight into the complexity of challenges faced by some adults with intellectual disabilities. Findings may be seen in terms of theoretical generalisability (Sim, 1998).

## **7.10 Conclusions**

This study has importantly involved adults with intellectual disabilities in qualitative co-produced research to explore their views and experiences of barriers and facilitators to eating well, living well and weight management. The study found that solutions to participants' identified barriers and associated frustrations are required. Practical solutions identified by participants included: provision of clear and accessible healthy lifestyle information, reasonable adjustments to services and activities so they are more accessible to this population, training for carers and support workers, wider 'buddying' support systems or schemes, and more collaborative working involving this population, their carers, support workers, health care practitioners, service commissioners and service providers. Public health interventions to tackle the wider environmental barriers identified by people with intellectual disabilities are also required.

## **Recommendations**

The findings from this study have highlighted some areas for future research and action. These recommendations are summarised in the concluding chapter (chapter ten).

### *Summary of chapter*

This chapter has described the findings from a focus group study that involved adults with intellectual disabilities in its co-production. The chapter has suggested some areas for future research and action. The next chapter (chapter eight) describes the findings from the third study conducted in Phase Two of the programme of research for this thesis. The third study involved a survey of carers and supporters of adults with intellectual disabilities, which aimed to explore their perceptions of this subject.

## **CHAPTER EIGHT**

### **STUDY THREE: SURVEY OF CARERS AND SUPPORT WORKERS**

#### **INTRODUCTION**

Chapters six and seven presented findings from the first two studies conducted during Phase Two of the programme of research for this thesis. The previous studies involved health care practitioners and adults with intellectual disabilities respectively. This chapter describes findings from the third study conducted in Phase Two which involved carers (defined as someone who cares, unpaid, for a friend or family member with an intellectual disability) and support workers (defined as someone who is formally paid to support a person or persons with an intellectual disability).

#### **8.1 Study Three: Aim**

This third study aims to identify barriers and facilitators to weight management for adults with intellectual disabilities from the perspectives of carers and support workers for people with intellectual disabilities.

#### **8.2 Objectives**

The study's objectives were to explore carers' and support workers' perceptions of what helps or makes it difficult for a person with intellectual disabilities to eat well, live well and manage their weight, if they want to.

#### **8.3 Method**

This third study involved a survey of carers and support workers for people with intellectual disabilities from across the North West of England.

## **8.4 Sample and setting**

The sampling framework for the survey was a North West of England Regional Network of 100 carers and support workers for adults with intellectual disabilities. This Network was organised by a self-advocacy group for people with intellectual disabilities. Potential participants received an invitation from the self-advocacy group to participate in the research on behalf of the postgraduate student. The Group sent an email to members of the Network to invite them to participate in the survey and attached a copy of a Participant Information Sheet (appendix 13). Two months later, the Group emailed a survey reminder to the Network and posted an invitation to participate in the survey on the Network's social media page. The sample included self-selected carers and support workers.

## **8.5 Data collection**

A survey questionnaire produced by the postgraduate student was used to elicit responses from the sample of carers and support workers (appendix 11). The survey questionnaire, based on similar questions from the co-produced focus group study involving adults with intellectual disabilities, was made available in three different formats: (1) an on-line survey questionnaire accessible via a website link; (2) an electronic (Word) version of the survey questionnaire that could be completed by computer and returned electronically by email; and (3) a hard copy version of the survey questionnaire with a freepost return envelope (available on request) for completion by hand and return by freepost.

## **8.6 Data analysis**

The survey questionnaire responses were analysed by the postgraduate student using thematic analysis as described by Braun and Clarke (2006) and by use of a thematic network analysis tool (Attride-Stirling, 2001). The individual responses were read and re-read by the postgraduate student to explore emerging themes and patterns of meaning. Open coding of the individual responses was used to explore the data. Potential codes and themes were identified first by hand and then by using NVivo v11 computer software. A thematic coding framework (appendix 21) and thematic network analysis tool were produced by the

postgraduate student to aid the analysis. Assessment of the validity of responses was undertaken through regular sharing of the data analyses and discussion with the supervisory team to overcome any data queries and to confirm data analysis findings.

## **8.7 Findings**

19 survey questionnaire responses were received (19% response rate) from participants who stated that they were either carers (defined as someone who cares, unpaid, for a friend or family member with an intellectual disability) or support workers (defined as someone who is formally paid to support a person or persons with an intellectual disability). All respondents (carers) provided responses using the on-line format of the survey questionnaire, accessed via a web-link. No email or postal responses were received which suggests that respondents preferred to use the on-line format of the survey questionnaire.

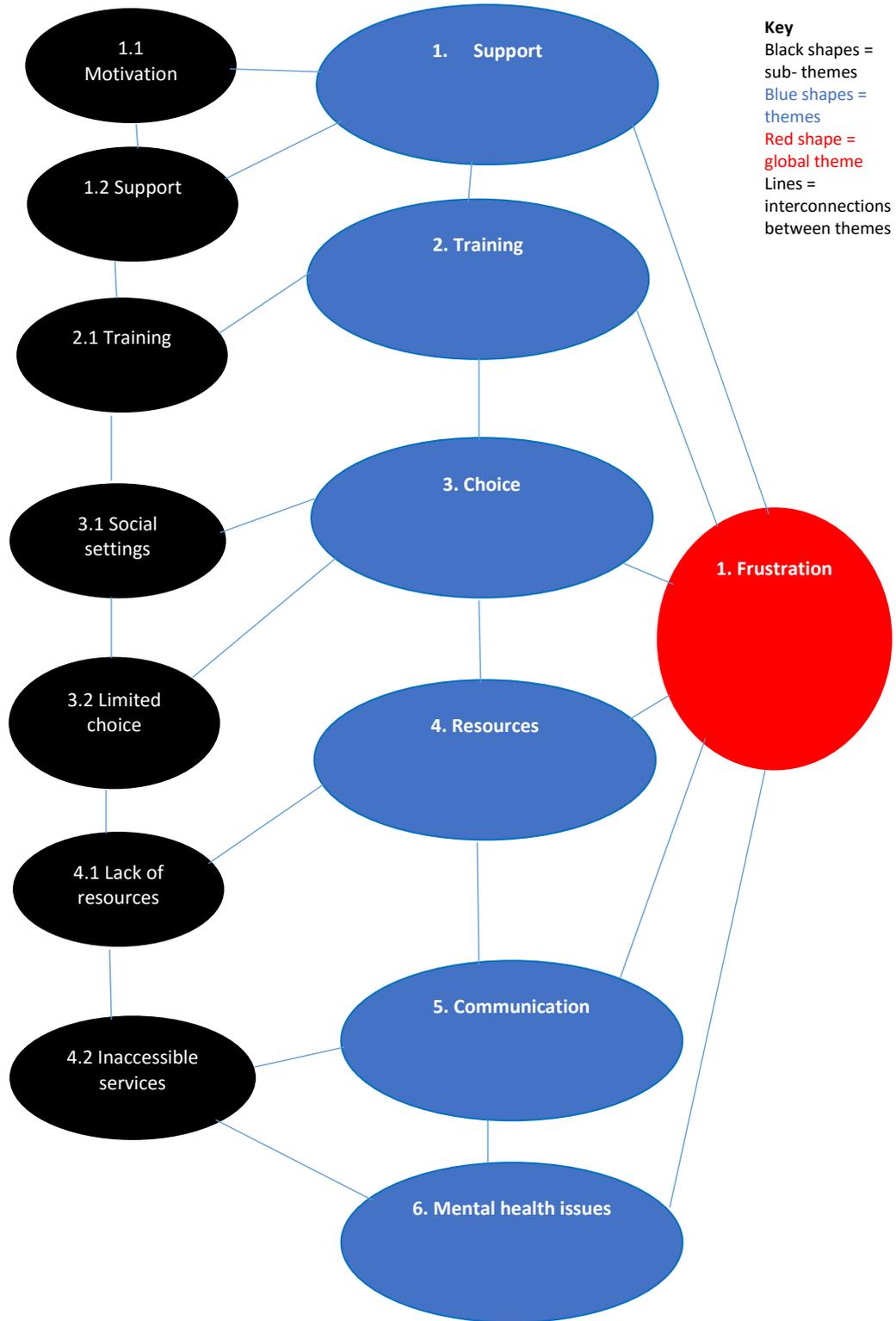
### ***Themes***

Thematic analysis of responses by the postgraduate student identified 6 themes, 10 sub-themes and 1 overarching global theme. Table 8.1 summarises these themes. Figure 8.1 illustrates these themes and their interconnectivities. There is no hierarchy or ranking of themes as all appeared equally important and inter-related. The themes highlight the carers and support workers' views and experiences of the complexity of challenges involved. A narrative discussion of themes follows below.

**Table 8.1: Study Three – Summary of themes and global themes**

Themes	Global theme
<p><b>1. Support</b>            Sub-themes:            1.1 Motivation            1.2 Support</p>	<p>1. Frustration (over lack of support, training, choice, resources, communication, help with mental health concerns, and action to tackle prejudice).</p>
<p><b>2. Training</b>            Sub-theme:            2.1 Training</p>	
<p><b>3. Choice</b>            Sub-themes:            3.1 Social settings            3.2 Limited choices</p>	
<p><b>4. Resources</b>            Sub-themes:            4.1 Lack of resources            4.2 Inaccessible services</p>	
<p><b>5. Communication</b></p>	
<p><b>6. Mental health issues</b></p>	

Figure 8.1: Thematic network of carers and support workers' responses



## **Theme 1: Support**

### *Sub-theme 1.1 - Motivation*

Respondents highlighted that self-motivation and the motivation of other people enables people with intellectual disabilities to eat well, live well and manage their weight, if they want to. However, respondents highlighted that self-motivation may be a challenge for people with intellectual disabilities:

*“Having people around them who encourage them to live well and demonstrate what living well is.” (Carer 3)*

*“Positive praise, encouragement.” (Carer 5)*

*“Lack of enthusiasm to look after just themselves. Motivation.” (Carer 13)*

### *Sub-theme 1.2 - Support*

Respondents highlighted that consistent caring support acted as a key facilitator for people with intellectual disabilities. However, they highlighted inconsistencies in caring support that acted as a barrier:

*“Having person centred care...sufficient support to take them out to socialise and exercise.” (Carer 7)*

*“Families may be trying very hard at home to assist the person to eat healthily, only for a provider of e.g. day services work totally contrary. This is often down to staff not being fully supported in how they assist a person to eat healthily, as often they don't themselves.” (Carer 9)*

## **Theme 2: Training**

### *Sub-theme 2.1 - Training*

Respondents suggested that there was a lack of knowledge and understanding about the needs of people with intellectual disabilities – particularly amongst some care providers' staff, support workers and health care practitioners. They stated that there was a need for training to bridge this gap and for more proactive working:

*“Staff not being trained to provide care to keep them healthy e.g. brushing teeth.” (Carer 7)*

*“Comes down to understanding the person's individual needs and them as a person and then to be proactive.” (Carer 8)*

*“Staff not educated.” (Carer 10)*

### **Theme 3: Choice**

#### **Sub-theme 3.1 - Social settings**

Respondents commented that social settings and routines such as sharing regular meals were conducive to enabling this population to eat well and live well, but that there was a lack of social activities and opportunities for this population to connect socially with others:

*“Good role models all sit together to eat”. (Carer 12)*

*“Having regular mealtimes and encouraging them to choose healthy foods.” (Carer 3)*

*“Lack of opportunity to connect with their communities and to make friendships and relationships.” (Carer 18)*

*“More social activities [needed] regarding diet and eating out” (Carer 5)*

#### **Sub-theme 3.2 - Limited choice**

Respondents commented that the choices of people with intellectual disabilities may be limited and this may act as a barrier to enabling them to eat well and live well:

*“Choices may be limited to staff skill level.” (Carer 16)*

*“Inability of person and carers to cook.....Having insufficient support to take them out to socialise and exercise.” (Carer 7)*

### **Theme 4: Resources**

#### **Sub-theme 4.1 - Lack of resources**

Respondents spoke about resource restrictions including restrictions to personal budgets. They also suggested that there was a lack of clear and accessible healthy lifestyle information and advice:

*“Cost of ‘healthy’ food and possibly the disadvantage of healthy often meaning cooking from scratch.” (Carer 6)*

*“Money. It's cheaper to follow a poor diet and buy convenience food.” (Carer 11)*

*“Low budget.” (Carer 7)*

*“Lack of the right support and information in a format they understand.”*  
(Carer 9)

*“Adverts on TV or the boxes that imply it's healthy...so (X name of a cereal) for example is not too bad but still has a lot of sugar...I'd like to see a sugar cube(s), easy read chart on all cereals.”* (Carer 17)

#### ***Sub-theme 4.2 - Inaccessible services***

Respondents commented on difficulties they had encountered in trying to access weight management services on behalf of this population. They also commented that people with intellectual disabilities find it difficult to access activities such as local sports and leisure services to help them exercise routinely and which help promote their health and wellbeing:

*“Lack of access to support services.”* (Carer 12)

*“Leisure activities may not be available locally.”* (Carer 19)

#### ***Theme 5: Communication***

Respondents commented on communication challenges. They stated that care providers' staff needed more involvement from family and carers to aid communication in certain circumstances:

*“Staff taking notice of their likes/interests and info from family if person cannot communicate their wishes very well.”* (Carer 7)

*“The major obstacle is not listening to the person, care providers' rules and regulations often get in the way.”* (Carer 19)

#### ***Theme 6: Mental health issues***

Respondents spoke about underlying mental health issues for this population:

*“I find mood can upset the situation and giving food they dislike.”* (Carer 2)

*“Anxiety and having to provide for themselves.”* (Carer 4)

Analysis found linkages between some of the six themes. These linkages are highlighted in Figure 8.1.

One overarching global theme emerged from analysis of these basic and organising themes: frustration. For example, respondents had expressed frustrations over

inconsistencies in caring support and income restrictions faced by people with intellectual disabilities. They articulated frustrations over a lack of training, choice, resources and access to services and activities. They were frustrated by communication challenges.

### *Other issues identified*

#### *a) Weight management concerns and issues*

The analysis found that half of the respondents stated that they were concerned about the weight of the person(s) with intellectual disabilities whom they supported. Some of these stated that the person they supported needed to lose weight but that they had not been helped or referred to services and that they were still seeking help:

*“When weight was creeping up but not obese - weight loss service implied should have waited until they were heavier but I wanted [the person] to be referred before it got that bad - to prevent it getting that bad.” (Carer 7)*

*“They only went because they had support to go. I don’t think they would without motivation and support”. (Carer 14)*

*“He is 23 stone and I am trying to find people to help me.” (Carer 17)*

Some respondents had attended weight management services to assist a person with intellectual disabilities to manage their weight. Those that had attended the services with the person they supported commented on the helpfulness of services, although not all the carers or support workers found these services helpful:

*“Yes [helpful]. They also did a home visit and seemed pleased with my support.” (Carer 2)*

*“Yes [helpful]. Gave advice and tips to me the carers on how to provide adequate calories.” (Carer 4)*

*“Yes [helpful]. Advice about portion sizes. Different carers / family had different ideas about a reasonable portion e.g. one thought 6 fish fingers reasonable, another 3. (Dietician thought 2!)” (Carer 7)*

*“Yes [helpful]. However, they were in some respects using inaccessible language.” (Carer 13)*

*“Yes [helpful]. Provided educational materials and ideas that can be referred to.” (Carer 16)*

*“No [not helpful]. I was already doing what they said.” (Carer 1)*

*b) Promoting the health and wellbeing of people with intellectual disabilities*

Most participants provided suggestions on how to improve the overall health and wellbeing of people with intellectual disabilities. However, a few stated that they did not know what to suggest. Table 8.2 provides a summary of the main themes arising from analysis of carers’ responses along with examples of their comments.

The main themes included:

- Better support for people with intellectual disabilities.
- Better support for their carers and families.
- Improved understanding by service providers.
- Improved training and education.
- Improved opportunities for this population to access social and leisure activities.

A summary of findings was produced by the postgraduate student and made available to the self-advocacy group who then shared the summary of findings via email and social media with the Network of carers and support workers inviting further feedback on findings (appendix 22). No further feedback was received.

**Table 8.2: Study Three – Participants’ perceptions of what can be done to improve the health and wellbeing of people with intellectual disabilities**

<b>Main themes</b>	<b>Carers’ comments (examples)</b>
Better support for people with intellectual disabilities	<p><i>“People should be given the information in a way which they understand. Accessible, easy read with pictures and symbols etc. Multi-media. Films really work to assist people to understand. Good support is equally important.” (Carer 18).</i></p> <p><i>“Make sure annual health check done and findings acted on.” (Carer 17).</i></p> <p><i>“Money - as it is cheaper to buy convenience food.” (Carer 11).</i></p> <p><i>“Empowering individuals to take control. Positive support for weight loss.” (Carer 10).</i></p> <p><i>“Experienced supportive staff / carers.” (Carer 12).</i></p> <p><i>“Care workers to help with everyday things like making and taking the person to regular check-ups e.g. dentist, dietician etc.” (Carer 4).</i></p> <p><i>“Stop limiting their lives to fit in with service requirements.” (Carer 19).</i></p>
Better support for families and carers	<p><i>“More physical and financial support for families and carers, and better access to people, services and equipment that can help.” (Carer 3).</i></p>
Improved understanding by service providers (of the needs of people with intellectual disabilities)	<p><i>“Have more mainstream services that understand their needs.” (Carer 9).</i></p> <p><i>“I felt the GPs have no correct training around this area, communication was poor and ignorance around my son's need relating to his fears of going to appointments and the unknown for him all of this related to him now being diagnosed with depression and now on antidepressant tablets.” (Carer 2).</i></p> <p><i>“Education to staff teams. GPs supporting more. Empowering individuals to take control. Positive support for weight loss” (Carer 10).</i></p> <p><i>“Get annual health checks going.... don’t exclude those who are just outside the 70 IQ or those with autism as they need help just as much.” (Carer 17).</i></p>
Improved training and education (involving health care staff, carers, support workers and people with intellectual disabilities)	<p><i>“Better education around healthy eating in schools / colleges with healthy choices being the first choice.” (Carer 6).</i></p> <p><i>“Better education, better understanding, more social activities regarding diet and eating out” (Carer 5).</i></p> <p><i>“Train carers. Make sure annual health check done and findings acted on” (Carer 7).</i></p> <p><i>“More educational material that is presented in ways that's fun to learn. Videos, games, visual etc. Cooking classes.” (Carer 16).</i></p>
Improved opportunities for people with intellectual disabilities	<p><i>“Good range of activities. Work, rest and play.” (Carer 12).</i></p> <p><i>“More social activities regarding diet and eating out.” (Carer 5).</i></p> <p><i>“Stop limiting their lives to fit in with service requirements.” (Carer 19).</i></p> <p><i>“Equal access to health care” (Carer 15).</i></p> <p><i>“We all have a part to play in helping our people with learning disabilities live a healthy life” (Carer 8).</i></p>

## **8.8 Discussion**

The aim and objectives of this third study were to explore carers' and support workers' perceptions of what helps or what makes it difficult for a person with intellectual disabilities to eat well, live well and manage their weight, if they want to.

The study found several themes arising from respondents' comments on this subject highlighting the challenges involved for carers and support workers. The underlying message arising from survey questionnaire responses is that facilitators include access to consistent quality caring support; training; accessible resources, activities, services; communication and an understanding of the needs of people with intellectual disabilities (by health care practitioners, care providers' staff, carers and support workers, and by wider society).

Over half of the respondents were concerned about the weight of the person(s) with intellectual disabilities whom they supported. However, despite these concerns, the survey found that few of the people with intellectual disabilities supported by carers or support workers had received referrals to weight loss services and that few had accessed such services if referred. Respondents spoke of their difficulties in attempting access to weight management services on behalf of the person whom they supported. Respondents stated that those individuals with intellectual disabilities who had attended services had only done so because of the support they had received. Some carers and support workers stated that they were still struggling trying to find weight management services for the people whom they supported and they found this frustrating. Of those study respondents who had attended weight management services to assist the person with intellectual disabilities who needed to lose weight, most commented on the helpfulness of these services, although a few did not find the services helpful.

This study's findings suggest a need for improvements in referrals and access to weight management services for people with intellectual disabilities who have weight management concerns. The findings also suggest a need for more

preventative (health promotion) services as well as weight management (treatment) services for this population as respondents had emphasised the need for improved opportunities to enable people with intellectual disabilities to access sports, leisure and social activities to promote their health and wellbeing. Such an approach would have benefits beyond obesity and its related physical problems e.g. mental health benefits, social engagement and confidence benefits.

Respondents valued accessible information, services and activities. They spoke about education and training requirements for care providers' staff, carers, support workers and health care practitioners to improve awareness and understanding of the needs of people with intellectual disabilities. The respondents commented that training should involve all of those with a professional interest in people with intellectual disabilities. The underlying message here is that improved collaborative training (involving health care practitioners, carers, staff and support workers) has a vital role to play in improving health and well-being outcomes for people with intellectual disabilities.

### *Comparison with other research in this field*

The findings from this survey echo findings from other similar research involving carers of people with intellectual disabilities. For example, in 2015, Wirral Mencap conducted a survey of 300 parents/carers via their membership list, existing service users, social media, and Wirral's Learning Disability Group (Wirral Mencap, 2016). (Wirral is a region of Merseyside, North West of England). The survey included questions relating to health (as well as questions relating to leisure, housing, personal development and support for carers). With regards to health, the survey established that weight was the greatest concern amongst the family carers that participated. Many carers indicated that this could be improved through increased opportunities for physical activities. They spoke about the need for "*less crafts and more physical activities*" such as swimming clubs for disabled people, more age-appropriate activities for people aged 25 years and over, more physical exercise sessions at day care centres, and more health education for this population. The respondents also similarly spoke about GPs' lack of understanding of the needs of

people with intellectual disabilities and a need for more targeted services staffed by people with specialist knowledge and experience of working with this population. They expressed training needs for carers and they wanted greater help in accessing activities and services for the people whom they supported. They valued continued health monitoring and screening services for people with intellectual disabilities such as Annual Health Checks. However, they were worried about budget cuts to the personal incomes of people with intellectual disabilities, and “*shrinking services*” due to budget cuts to local authority funded sports, leisure and day care services and spoke of how these cuts had negatively affected the health and wellbeing of people with intellectual disabilities (Wirral Mencap, 2016).

Other research studies into health care (not specifically weight management) have provided similar accounts of carers experiencing problems in:

- Negotiating health care systems (Ali et al., 2013).
- Communication (Ward, Nichols and Freedman, 2010).
- Accessing preventative services (Broughton and Thomson, 2000).
- Health care staff’s attitudes, knowledge and behaviour (Ali et al., 2013).
- Inadequate knowledge about the health needs of this population (Minnes and Steiner, 2009) which can result in diagnostic overshadowing (Webber, Bowers and Bigby, 2010). (*Diagnostic overshadowing refers to the process whereby symptoms of physical ill health are mistakenly attributed to either a mental health and or a behaviour problem or as being inherent in the person’s intellectual disabilities* [Emerson and Baines, 2010]).
- A lack of support for carers (Dinsmore, 2012).
- Unrealistic expectations placed upon carers (Iacono and Davis, 2003).
- A lack of continuity of care by paid carers (Willis, 2015).

Family carers elsewhere in other weight management studies have described how some dietary patterns in day care centres for people with intellectual disabilities have undermined the family carers’ attempts at weight loss for the people whom they support (Spanos et al., 2013b).

Continuity of care and 'knowing the client' is important in the identification of subtle changes in a client's health and behaviour (Singh, 1997). Therefore, carers may improve the health outcomes of people with intellectual disabilities by assessing, monitoring and promoting their health of the individuals they support (Hithersay et al., 2014). However, there is a paucity of research into carer-led health-related interventions for people with intellectual disabilities and the most appropriate means of engaging carers in interventions to improve health outcomes for this population group is currently unknown (Hithersay et al., 2014). Future research needs to establish how to involve carers and people with intellectual disabilities in the design and delivery of health-related interventions for people with intellectual disabilities (Hithersay et al., 2014). Including carers, and the people they support, in research and in the design of tailored multi-component weight management interventions may be an appropriate way forward. Involving carers and the people they support in research may lead to better adherence to, and engagement with interventions (Hithersay et al., 2014). Studies elsewhere have shown that the training of carers has influenced healthier eating practices and improved activity levels in people with intellectual disabilities (Kneringer and Page, 1999; Jones et al., 2001; Melville et al., 2009).

Some other studies have shown that supporting the person can become an ethical dilemma for some carers: balancing 'duty of care' for a person with intellectual disabilities over their right to choose – for example, when making choices about what to eat (Bergstrom and Wihlman, 2011; Gill and Fazil, 2013). Other studies have indicated that carers and people with intellectual disabilities must have the opportunity to obtain the necessary skills and to become empowered to make healthier choices (Sundblom et al., 2015). However, this study's findings suggest that carers and support workers experience challenges in accessing opportunities for such skills-based training.

This study's participants indicated a need for improved training for health care practitioners. Previous studies have similarly identified a lack of clear standards regarding the training of health care practitioners in the health needs of people with intellectual disabilities, as well as a lack of health-related training for staff providing

support for people with intellectual disabilities (Gillings-Taylor, 2004; Janicki et al., 2002; Wyatt and Talbot, 2013). These findings suggest that training should extend to include everyone with a shared interest in the needs of a person with intellectual disabilities: health care practitioners, service commissioners, service providers, staff from care providers, carers and people with intellectual disabilities themselves. In this collective and collaborative way, those involved in training may share learning and therefore may better understand the needs and issues involved in supporting people with intellectual disabilities in their everyday lives (Taggart, Brown, and Karatzias, 2014).

Other studies have shown that it may be difficult for individuals with intellectual disabilities and their carers to influence policy and practice in healthcare (Turner and Robinson, 2011). This may be because they are not visible in policy and practice, and that mechanisms for their involvement are not accessible to them (Turner and Robinson, 2011). Carers, and the people they support, therefore need to be more visible in research and in the design and delivery of health-related interventions – including weight management interventions. Previous reports have also highlighted that there is a lack of attention to the views and experiences of people with intellectual disabilities and their carers, and argue that this has prevented them from being active partners in their own care (Mencap, 2007). This implies that the equality duty to provide reasonable adjustments for people with disabilities as outlined in the Equality Act 2000 should be extended to include ways of engaging this population in research, policy and practice developments (Heslop, Hoghton and Marriott, 2014). The equality duty to provide reasonable adjustments includes the requirement for statutory services to provide accessible resources for people with disabilities. However, both this current study and other previous studies of weight management interventions for this population have described a lack of accessible resources for this population group (Spanos et al., 2013a). This may be because of a lack of awareness of the equality duty amongst health care staff and or there may be a need to raise greater awareness of this equality duty amongst health care practitioners and or provide resources to meet requirements.

One of the few previous studies of carers' views suggested that there is a need for consistent support for people with intellectual disabilities participating in weight management interventions (Spanos et al., 2013b). The carers involved in the previous study experienced similar difficulties when other less motivated staff or family members did not follow the support plan for the individual's weight loss (Spanos et al., 2013b). However, the previous study was concerned with exploring the views of carers supporting individuals who were participating in a weight management intervention. This present study has uncovered additional carers' concerns over difficulties in accessing weight management services for the people they support i.e. the stages before the actual participation of people with intellectual disabilities in weight management interventions and services. Future research may usefully explore the role of carers and support workers in promoting access to weight management services for people with intellectual disabilities.

Other research studies suggest there may be specific challenges for carers and support workers of people with intellectual disabilities from different sub-group populations. For example, a previous study involving interviews with 30 family carers of adults with intellectual disabilities from Black and minority ethnic (BME) communities in a district of London, found that: (a) carers did not receive sufficient accessible information about services; (b) there was poor communication between carers and service providers; and (c) carers and the people they supported were socially isolated from the community in which they lived and were unable to access services they needed (Hubert, 2006). It may be useful for future research to explore issues for sub-group populations and their carers i.e. intersectorality issues.

### **8.9 Study's strengths and limitations**

The strength of this study is that the on-line survey design facilitated responses from busy participants who did not have the time to participate in interviews or in focus group studies. However, the findings from this study are limited and do not represent the views of all carers of people with intellectual disabilities. The study included a small sample of self-selected carers and support workers involved in a carers' network from a North West region of England. There were challenges

involved in the recruitment of participants to complete this survey questionnaire and only 19/100 responses were received despite follow up email and social media reminders. Those that participated may have had more of an interest in the research topic than those that did not participate. The study did not differentiate responses received from carers and support workers. It may be useful for future research to compare differences in issues for unpaid and paid carers and support workers. People who did not define themselves as primary carers or support workers may not have participated in the survey. For example, they may have defined themselves as family members or they may not have perceived themselves to be the primary provider of caring support and they may have decided not to participate in the study. The study did not request information on the age, sex, ethnicity or type of intellectual disability (or other disability) of the person the carer supported. The study therefore did not explore specific issues for carers or support workers for adults with different intellectual disabilities. Also, an on-line survey precludes any in-depth exploration of themes with respondents (which may be done with interviewees in an interview).

## **8.10 Conclusions**

The respondents in this study cited several barriers that may make it difficult for people with intellectual disabilities to eat well, live well and manage their weight, if they want to. The barriers for people with intellectual disabilities identified by respondents included a lack of consistent support for people with intellectual disabilities, unmet training needs for health care practitioners and support workers, limited choices for people with intellectual disabilities, a lack of accessible resources for this population, communication challenges and mental health issues. The respondents expressed their frustrations with these barriers and commented on challenges that they had encountered in trying to access services on behalf of the people with intellectual disabilities whom they supported, some of whom wanted help with their weight management. The respondents expressed the need for accessible services, activities and resources to help people with intellectual disabilities. They stressed the importance of consistent, quality caring support for individuals with an intellectual disability. The respondents valued shared learning

and training involving carers, support workers, health care practitioners, service providers and people with intellectual disabilities. They commented that shared learning and training opportunities could help improve understanding of the needs of this population. The study's findings imply a need for greater collaborative working and support to assist this population with eating well, living well, and weight management, if they want to. The findings also suggest a need to enhance the capacity of people with intellectual disabilities, their carers or support workers to access weight management services, and other related activities such as social, sports and leisure activities. However, there is a corresponding need to ensure that such services and activities are reasonably adjusted and able to respond appropriate to the needs of this population in accordance with UK equality legislation. Promoting equity of access to such services and activities and provision of shared learning and training may help overcome some of the barriers and associated frustrations expressed by respondents in this study.

## **Recommendations**

Recommendations for future research arising from this study are summarised in the concluding chapter (chapter ten).

### *Summary of chapter*

This chapter highlighted the main findings from a survey of carers and support workers for adults with intellectual disabilities. The next chapter (chapter nine) describes a synthesis of overall findings from Phases One and Two.

## **CHAPTER NINE**

### **PHASE THREE: SYNTHESIS OF FINDINGS**

#### **INTRODUCTION**

This chapter describes a synthesis of overall findings from this phased programme of research. The chapter describes the main barriers and facilitators to weight management for adults with intellectual disabilities that have been identified from the synthesised findings. The chapter summarises the challenges involved in weight management for this population that have been identified from the different perspectives of those involved. The chapter also provides a summary of the strengths and limitations of the methods used in this phased programme of research.

#### **BACKGROUND**

The integrative review conducted in the first phase of this research programme found emerging evidence to suggest that evidence-based multi-component weight management interventions can be tailored for adults with intellectual disabilities who are obese and that such tailored interventions may be effective. However, none of the studies that were identified by the research had explored the views and experiences of adults with intellectual disabilities participating in multi-component weight management interventions. Phase One also found a lack of information on theories used to underpin weight management interventions for adults who have intellectual disabilities. Furthermore, the mapping exercise conducted in Phase One found insufficient tailored weight management service provision despite the high prevalence of obesity in this population.

Phase Two aimed to explore barriers and facilitators to weight management for adults with intellectual disabilities from the differing perspectives of: (1) health care practitioners involved in the identification of obesity and the delivery of weight management interventions for all adults (chapter six); (2) adults with intellectual

disabilities (chapter seven); and (3) carers and support workers (chapter eight). These studies identified several barriers to weight management for this population and some facilitators.

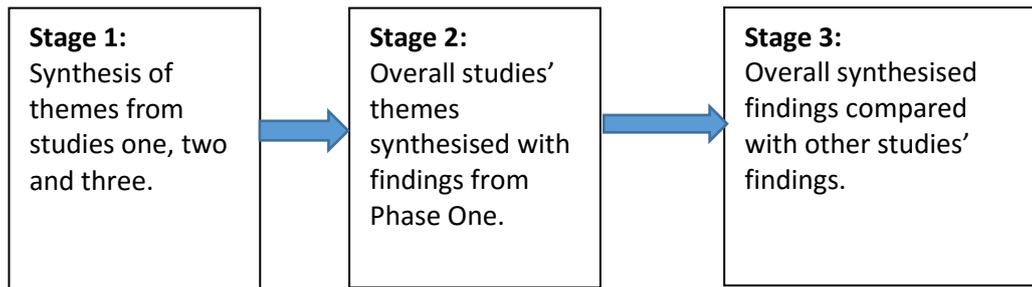
The aim of Phase Three was to provide a comprehensive picture of the issues involved in weight management for this population and to provide recommendations for future research, policy and practice.

## **9.1 Data synthesis**

Synthesis of studies allows a clearer conceptualisation of a phenomenon to emerge (Jensen and Allen, 1996). There is no single correct view of a phenomenon and the aim is therefore to seek consensus from a variety of sources on the nature of a phenomenon to facilitate new understanding(s) (Jensen and Allen, 1996). Findings are considered credible if they re-present faithful descriptions or interpretations of human experience that people having that experience would recognise from those descriptions in the findings (Jensen and Allen, 1996).

Data synthesis of overall findings from the phased programme of research for this thesis involved a three-stage process (outlined in Figure 9.1). Data synthesis began with a synthesis of the themes that had emerged from the three separate studies conducted in Phase Two. A thematic analysis coding framework (appendix 23) was produced to assist with the data synthesis and a thematic network diagram was also produced to illustrate the overall themes that emerged and their interconnectivities (Figure 9.2). These studies' synthesised findings were then synthesised with Phase One findings and the overall findings were compared with other studies' findings.

**Figure 9.1 Stages of data synthesis**



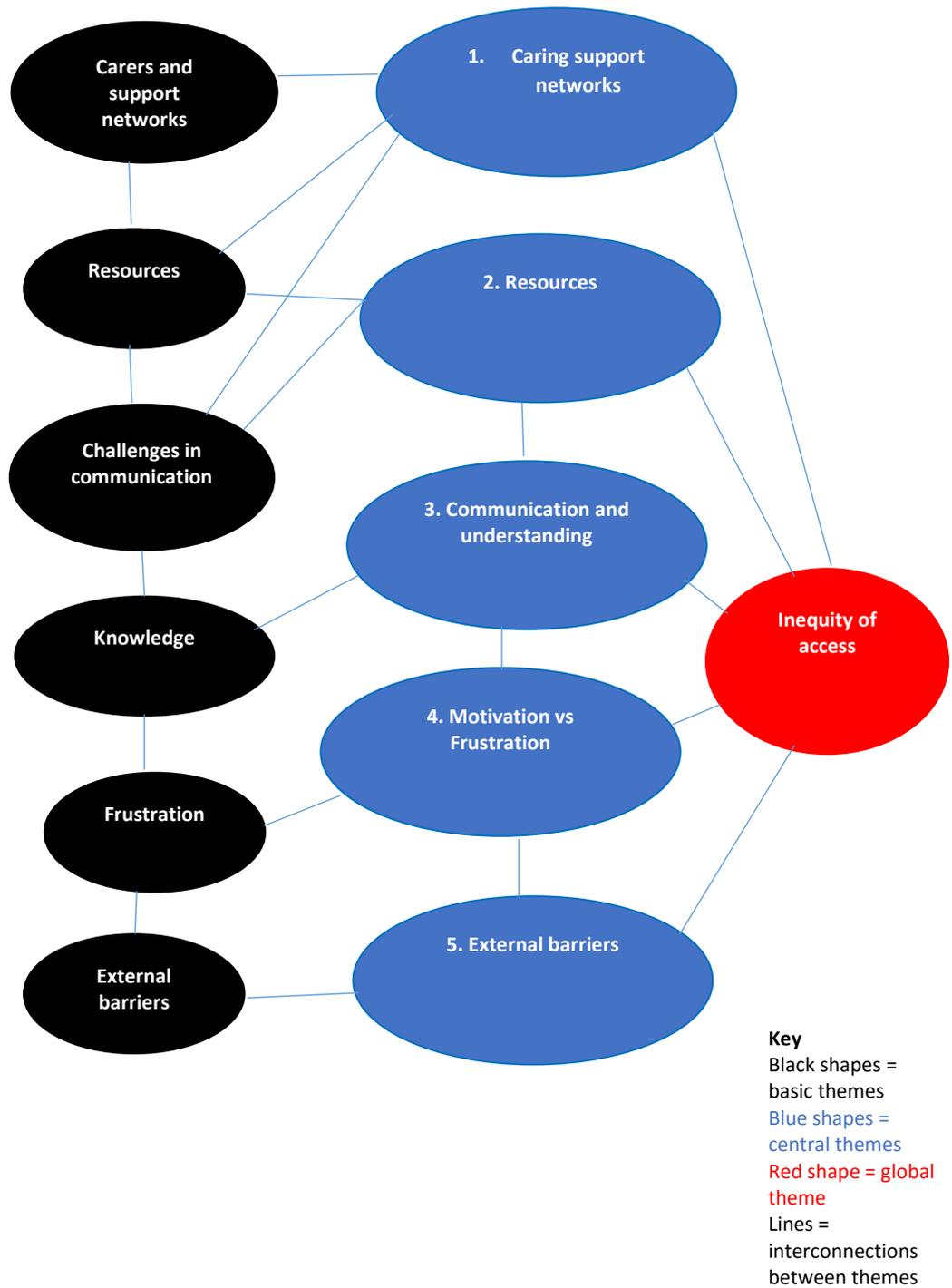
## **9.2 Stage 1: Synthesised studies' findings**

Five central themes emerged from the three separate studies undertaken in Phase Two of this research programme. Table 9.1 provides list of these central themes. Figure 9.2 illustrates these themes and their interconnectivities. A discussion of these central themes follows.

**Table 9.1: Phase Two - Central themes**

<p><b>Central Themes:</b></p> <ol style="list-style-type: none"><li>1. Caring support networks</li><li>2. Resources</li><li>3. Communication and understanding</li><li>4. Motivation vs frustration</li><li>5. External barriers</li></ol>
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Figure 9.2 Thematic network of synthesised Phase Two's themes



### **Central theme 1: Caring support networks**

All three studies' participants highlighted how caring support networks act as one of the main facilitators to eating well, living well and weight management for adults with intellectual disabilities. All three studies' participants stressed the need for continuity of caring support for adults with intellectual disabilities. Participants in studies one and two stressed that a lack of consistent caring support for adults with intellectual disabilities acted as a barrier to eating well, living well and weight management in this population group:

*"Families may be trying very hard at home to assist the person to eat healthily, only for a provider of e.g. day services work totally contrary. This is often down to staff not being fully supported in how they assist a person to eat healthily, as often they don't themselves." (Carer 9: Study 3).*

In addition, adults with intellectual disabilities in study two stated that they wanted matching with carers and or support workers who shared their interests and who could routinely take them to activities to help them to eat well, live well and manage their weight, if they wanted to. The participants with intellectual disabilities valued being with others - with their peers or with groups of people - who shared the same interests as them:

*"Buddies - other people who want to enjoy the same things as me like the rugby - so I can always get there." (Participant 13: Study 2).*

### **Central theme 2: Resources (information, education, training, time, money)**

All three studies' participants indicated that there was a lack of resources for this population including: a lack of accessible information, a lack of training for carers and support workers, personal income restrictions, and time and resource restrictions for GPs in primary health care. All the studies' participants commented that better, clearer and more accessible healthy lifestyle and weight management information was required to aid GPs and other health care practitioners' communication about healthy lifestyles with people with intellectual disabilities:

*"I'm aware that there's a lot of easy-to-read information out there but we don't really have that [in general practice]." (GP1: Study 1).*

*"Good information [needed] on how to be healthy." (Participant 7: Study 2).*

*“Lack of the right support and information in a format they understand.”*  
(Carer 9: Study 3).

Participants in studies two and three mentioned training needs for carers, providers’ staff and support workers on how to support a person with an intellectual disability:

*“Support workers - training to be able to support people correctly in cooking, eating, exercise.”* (Participant 12: Study 2).

*“Staff not being trained to provide care to keep them healthy e.g. brushing teeth.”* (Carer 7: Study 3).

There was also a recognition by some GPs in study one of their own training requirements on obesity and weight management generally for all their patients (with and without intellectual disabilities), and in terms of communicating with patients who have intellectual disabilities:

*“I haven’t had any training in terms of dealing with patients with intellectual disability and weight....You know, we hear about the obesity epidemic but we’re not given any specific training for example, brief intervention regarding weight management.”* (GP1: Study 1).

Participants in studies two and three stated that accessible adaptations, health advice, information, opportunities and activities acted as facilitators in helping people with intellectual disabilities:

*“Information in easy read.”* (Participant 9: Study 2).

*“People should be given the information in a way which they understand. Accessible, easy read with pictures and symbols etc. Multi-media.”* (Carer 18: Study 3).

Participants with intellectual disabilities in study two spoke with frustration of their socio-economic circumstances that, in turn, restricted their choice and control over access to support, activities and services. Carers and support workers in study three reiterated these frustrations:

*“Not having money to buy the right food.”* (Participant 14: Study 2).

*“Benefits being stopped when having a long stay in hospital. Causes huge anxieties.”* (Carer 4: Study 3).

GPs involved in the first study highlighted their own time constraints. They stated that GPs need to prioritise a patient’s medical condition within the appointment

time slot available, which often resulted in a lack of time to address underlying obesity and weight management issues:

*“Overweight can be a problem, a third or a fourth problem in the normal consultation. So, by the time they’ve finished their first or second medical consultation you see that you’ve kind of run out of time then if they do raise the subject of wanting to lose weight...”* (GP3: Study 1).

Health care practitioners in study one also emphasised the value of financially incentivised interventions for GPs such as Annual Health Checks for people with intellectual disabilities but stated that time was still an issue for them:

*“I think we could perhaps improve things if we offered more than an annual check, perhaps if we offered six monthly checks...More frequent offering of appointments would be better but everybody’s very busy you know.”* (GP5: Study 1).

These findings highlight GPs’ time and resource constraints and suggest the need for additional resources for GPs in primary health care to help them support individuals with intellectual disabilities who are obese or overweight. Health care practitioners in study one also suggested that there was a lack of opportunities for linking together different health, social care and intellectual disabilities specialisms:

*“The people at the council who’ve had twenty years’ experience working in learning disability probably have zero experience in health, and it’s probably linking those together that’s going to be key.”* (HCP3: Study 1).

These findings suggest that there is a need for greater collaboration between people with intellectual disabilities, their carers, support staff, health care practitioners and other health and social care staff involved with intellectual disabilities’ services to work together to promote the overall health and wellbeing of this population and to offer more practical ‘joined-up’ support, relative to their needs.

### ***Central theme 3: Communication and understanding***

Health care practitioners in study one commented on communication barriers, including the challenges they had experienced because of three-way conversations with carers or support workers – some of whom might be overweight or obese themselves:

*“If somebody’s got you know, special needs where their IQ is affected so they can’t take in what you’re saying then you’re just dealing with the carers. And most carers seem to be overweight....But you’re trying to get somebody to do something with somebody that they themselves may not be doing in the first place.” (GP4: Study 1).*

The health care practitioners in study one also acknowledged the sensitivities involved with obese or overweight health care practitioners in raising the issue of obesity and weight management with an obese patient.

Carers and support workers in study three spoke about their experiences of dealing with health care practitioners who had poor communication skills and who lacked empathy and understanding of the needs of people with intellectual disabilities:

*“I felt the GPs have no correct training around this area, communication was poor and ignorance around my son's need relating to his fears of going to appointments and the unknown for him all of this related to him now being diagnosed with depression and now on antidepressant tablets.” (Carer 2: Study 3).*

#### **Central theme 4: Motivation versus frustration**

The participants in studies one and three indicated that a lack of self-motivation amongst people with intellectual disabilities acted as a barrier to their weight management. Carers in study three spoke about how other people’s motivation helped people with intellectual disabilities:

*“Having people around them who encourage them to live well and demonstrate what living well is.” (Carer 3: Study 3).*

Participants with intellectual disabilities in study two reiterated the value of others’ motivation in supporting them with weight management:

*“Motivation and encouragement from the group.” (Participant 10: Study 2).*

However, participants with intellectual disabilities expressed their frustration with the barriers they had encountered when trying to manage their weight and consequently they stated that it was:

*“Easier to get a takeaway delivered.” (Participant 12: Study 2).*

These findings suggest that some adults with intellectual disabilities may want to manage their weight but that they may encounter barriers in trying to do so and

that these barriers may be so frustrating for them that they may not be able, or be motivated, to change.

### **Central theme 5: External barriers**

All three studies' participants mentioned external barriers including an obesogenic environment that inhibited people's weight management. For example:

*"It's that obesogenic environment, everything is set up for getting whatever you want when...Planning and your environments and things like that, I think that's only where anything's going to change. It's too easy to keep eating loads of junk and then not you know, doing any physical activity. I think environment needs change doesn't it?" (HCP2: Study 1).*

### **Global theme: Inequity of access**

A global theme of inequity of access emerged from the analysis of synthesised findings. The findings from the Phase Two studies imply a need for more equitable support relative to the needs of adults with intellectual disabilities. The findings highlight the complexity of the issues involved in obesity and weight management for adults with intellectual disabilities from the different perspectives of those involved. They also imply a need for broader public health interventions for adults with intellectual disabilities (i.e. interventions which address the wider environmental and socio-economic barriers experienced by this population), rather than a sole focus and reliance on clinical weight management interventions.

## **9.3 Stage 2: Synthesised findings from Phases One and Two**

The synthesised findings from Phase Two were then synthesised with findings from Phase One. This involved a process of reading and re-reading the Phase Two synthesised findings and comparing these with Phase One's findings. A thematic analysis framework was produced to assist with the process of synthesis (appendix 24).

The synthesis found that Phase One's findings support the central themes that emerged from the synthesised Phase Two studies' findings. The integrative review conducted in Phase One supports the Phase Two findings which indicate that carers have a pivotal role in supporting adults with intellectual disabilities and that carers'

input is vital in enabling the person they support to access weight management and associated healthy lifestyle interventions. However, a lack of research involving carers in weight management interventions for adults with intellectual disabilities makes it difficult to draw any clear conclusions on how carers can contribute to the weight management of the person they care for. Future weight management research could usefully explore contributions from carers. The integrative review's findings also support Phase Two's participants' expressed need for accessible resources to aid healthy lifestyles promotion and weight management amongst this population (Spanos et al., 2013a; Spanos et al., 2013b; Sundblom et al., 2015).

Participants in the Phase Two's studies expressed frustrations with the wider environment and commented on how this acted as a barrier to weight management. Phase One's exploration of weight management theories similarly found support for altering the environment to help address the problem of obesity in the adult population (Butland et al., 2007). Future research involving adults with intellectual disabilities may usefully explore how their surrounding environmental circumstances needs altering to support them with their weight management.

Phase One found gaps in tailored weight management service provision for adults with intellectual disabilities who are obese. These gaps were confirmed by Phase Two's findings. Some participants with intellectual disabilities who wanted to manage their weight struggled to access services and they were frustrated by this. None of the participants with intellectual disabilities who wanted to manage their weight could recall being referred by their GP, or any other health care practitioner, to weight management services. Individuals who had accessed services had either self-referred or they had been supported by their carers to access such services. These findings suggest a general lack of awareness of weight management services, and or problems with referral processes, and or access issues, and or a lack of faith by GPs in the effectiveness of such services for adults with intellectual disabilities.

Phase Two found that health care practitioners did not find current weight management guidance particularly helpful in their day-to-day practice. Phase One similarly found problems associated with weight management guidance. The

mapping exercise conducted in Phase One found that there had been an ad-hoc adherence to weight management guidance. These findings suggest a need to review weight management guidance so that it is more relevant to health care practitioners in their day-to-day practice and so that it includes more practical guidance on weight management interventions for adults with intellectual disabilities.

### ***Challenges in weight management for adults with intellectual disabilities***

The overall synthesised findings suggest that there are different challenges in weight management interventions for service commissioners, service providers, health care practitioners, as well as for adults with intellectual disabilities themselves, their carers and support workers. These different challenges are discussed below:

#### *1. Challenges for service commissioners*

As the main commissioners of weight management services, the synthesised findings suggest that local authorities face challenges identifying ongoing resources for the routine provision of evidence-based multi-component weight management services for all adults who are obese (and not just for those adults who have intellectual disabilities). Challenges also appear to exist in the joint commissioning (with Clinical Commissioning Groups) of more specialist weight management services for all adults who are morbidly obese - again, not just for those adults who have intellectual disabilities. This challenge appears to be compounded for adults with intellectual disabilities who are obese. The mapping exercise conducted in Phase One found that local authorities do not monitor their weight management services to ensure that they are accessible for adults with intellectual disabilities who are obese or overweight. These findings suggest that there may be a need for more dedicated ongoing resources for the commissioning and monitoring of weight management services for all obese adults generally, and for a greater pooling of local authority and clinical commissioning group resources (including staff, knowledge, skills, expertise, training as well as financial resources). The findings also suggest there is a need for additional dedicated resources to ensure that

weight management services are tailored for adults with intellectual disabilities who want to manage their weight. However, services also need monitoring and evaluating to ensure they are accessible, appropriate and effective for this population.

### *2. Challenges for health care practitioners*

The synthesised findings highlight that GPs and other health care practitioners involved in the identification of obesity and delivery of weight management interventions experience complex challenges including:

- A lack of resources to enable better engagement and communication with people who have intellectual disabilities on obesity and weight management.
- Problems communicating through carers or support workers who may also be obese, or who may not be fully aware of the needs of the individual with intellectual disabilities that they are supporting.
- GP time constraints.
- A lack of information on available weight management services (or GPs' lack of faith in services available) which may result in problems in GP referrals of patients with intellectual disabilities to weight management services.
- A lack of financial incentives for weight management interventions for all adult patients with obesity.

The health care practitioners involved in this research advocated Annual Health Checks for people with intellectual disabilities as one way of routinely monitoring the health (and weight) of people with intellectual disabilities. Annual Health Checks could potentially be an ideal opportunity for the development, and implementation, of an intervention through primary care. However, this needs exploring through future research.

### *3. Challenges for adults with intellectual disabilities*

The synthesised findings suggest that adults with intellectual disabilities (including those who also have physical disabilities) face challenges in trying to access physical exercise, sports, leisure facilities and weight management services to assist them with their weight management and with the promotion of healthier lifestyles. The findings suggest individuals with intellectual (and physical) disabilities require support relative to their needs to facilitate their equitable access to weight

management services and to healthy lifestyle activities on a routine basis. Participants involved in this programme of research lacked equitable access to accessible healthy lifestyle information, information on weight management and weight management services.

#### *4. Challenges associated with caring support*

The synthesised findings highlight challenges associated with access to consistent caring support for adults with intellectual disabilities. There is an underlying need for routine provision of consistent quality support for this population from motivated and trained carers and support workers who are preferably matched to meet the interests of the individuals whom they support. The research found that support workers and carers need training opportunities in *how* to better support this population group to eat well, live well and manage their weight and *why* this is important. Carers and support workers who are overweight or obese themselves may also need support to participate in weight management interventions alongside the people they support. Carers and support workers have a vital role to play in weight management of people with intellectual disabilities but their leading role needs supporting and their contributions need exploring through further research.

### **9.4 Stage 3: Comparison with other studies' findings**

Other related health care studies have similarly highlighted problems associated with caring inconsistencies, and the need for a more consistent approach to health care by carers and support workers supporting people with intellectual disabilities in the community (Hithersay et al., 2014; Willis, 2015). Previous studies have also identified barriers to accessing health care services for this population, including problems with communication and a lack of knowledge and understanding amongst mainstream health care practitioners in caring for people with intellectual disabilities (Sowney and Barr, 2004; Alborz, McNally and Glendinning, 2005; Clark and While, 2008; Perry et al., 2014). Access barriers (for example, physical, attitudinal and communication barriers) and inadequate professional education regarding disability issues may be overlooked in health care services according to other studies (Taggart and Cousins, 2014). These similar findings imply that there

are important gaps in access to weight management service provision and in healthy lifestyle information for this population which need to be addressed (Alborz, McNally and Glendinning, 2005; Perry et al., 2014).

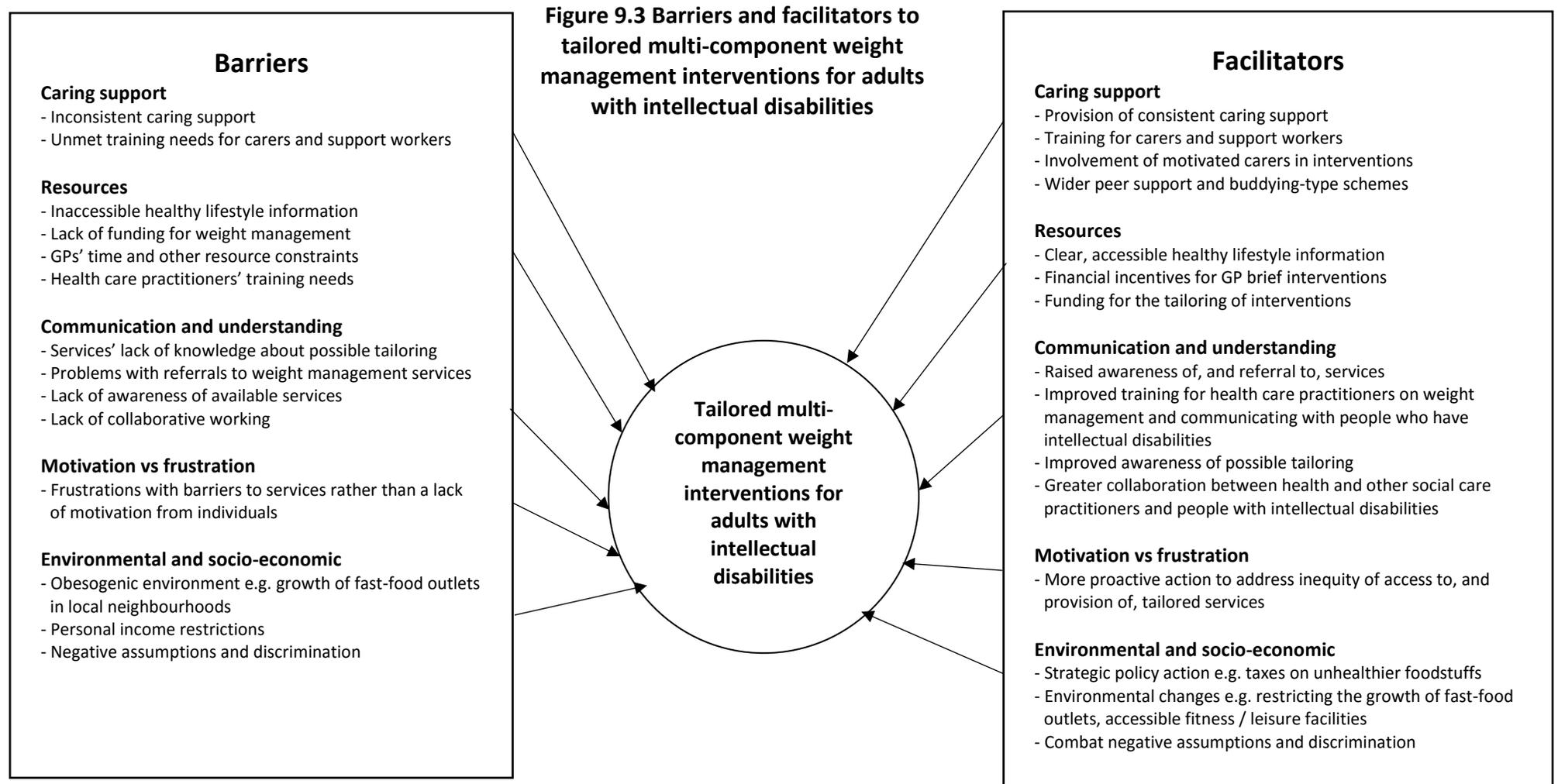
The importance of self-motivation for weight loss is discussed in other studies (Spanos et al., 2013a; Spanos et al., 2013b; Sundblom et al., 2015). In addition, there may be differences between the motivation of people with intellectual disabilities and the motivation of others. For example, individuals with intellectual disabilities may be more motivated to lose weight for appearance and image reasons, whereas carers may be more motivated by health reasons for weight loss in this population group (Jones et al., 2015). However, the significance of this programme of research is that it found that barriers to accessing weight management and healthy lifestyle interventions may negatively affect individuals' self-motivation and their ability to change. Socio-economic and environmental issues, and inequities of support and of access to services and facilities were the main identified barriers to weight management for adults with intellectual disabilities, rather than any poor lifestyle behaviour choices or a lack of self-motivation on the part of the individual with an intellectual disability.

Other identified studies acknowledge significant links between the obesogenic environment and weight management (Butland et al., 2007). However, there is a lack of information and guidance on how best to change the obesogenic environment for adults who have intellectual disabilities living in different community-based settings and who may, or may not, have choice and control over the amount of physical exercise that they can access, or the food that they select (Hsieh, Rimmer and Heller, 2014). Other studies similarly argue that people with intellectual disabilities may be at greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness (Emerson, 2011; Emerson and Hatton, 2014). The findings from other studies and from this research therefore suggest that future research needs to explore the relationship between obesity in this population and their surrounding environments and socio-economic circumstances to identify any potential and

practical changes that can promote their health and wellbeing (including weight management).

Researchers should, in future, seek to engage adults with intellectual disabilities in weight management research. Those involved in the design and delivery of weight management interventions should similarly seek the involvement of this population in future developments. Adults with intellectual disabilities should also be involved in the development of associated policies, guidance and training for health care practitioners and carers so that there is a greater awareness and a shared understanding of the needs of adults with intellectual disabilities and increased collective action to overcome identified barriers to weight management for them. Equality impact assessments of any new weight management policies, guidance, services and interventions should be conducted to ensure that these do not negatively affect this population and that appropriate action is taken to mitigate or reduce any potential risks identified. Improvements in weight management research, policy and practice (including the design and implementation of interventions) for this population may result if co-produced with, and for, this population group.

The synthesised findings that have emerged from this research have highlighted several systems-related issues, barriers and facilitators to weight management for adults with intellectual disabilities. These are summarised in Figure 9.3. These overall findings imply a need for more equitable support relative to the needs of adults with intellectual disabilities.



## **9.5 Strengths and limitations of synthesis**

The advantage of using and synthesising different approaches and sources of data in this programme of research is that it has enabled a rich and comprehensive picture to emerge of the barriers and facilitators to weight management for adults with intellectual disabilities. Triangulation refers to the use of multiple methods in research to develop a comprehensive understanding of a phenomena (Patton, 1999). Triangulation is sometimes viewed as a strategy to test research validity through the convergence of information (Carter et al., 2014). However, researchers generally use triangulation to bring about as much consensus as possible (Jensen and Allen, 1996), and to ensure that an account is rich, robust, comprehensive and well-developed (Robert Wood Johnson Foundation, 2008).

It is acknowledged that Phase One of this programme of research was limited. The integrative review's inclusion criteria were limited. There may be other relevant studies published in different languages from other countries and involving children and young people with intellectual disabilities. The review identified few relevant studies and it was not possible to compare findings as the studies used different methods and different samples of adults with intellectual disabilities. However, this was the first known published integrative review of evidence-based multi-component weight management interventions for adults with intellectual disabilities.

The mapping exercise conducted in Phase One was limited because it involved a small sample of service commissioners and service providers from one county of North West England. However, the local mapping exercise was only the second such local mapping exercise conducted that explored the extent of weight management service provision for adults with intellectual disabilities. The similar findings from these two mapping exercises suggest that these findings may be generalizable to adults with intellectual disabilities who are obese.

It is acknowledged that there were limitations with Phase Two's studies as these studies included non-representative samples of health care practitioners, of self-

selected adults with mild-to-moderate intellectual disabilities, and of self-selected carers and support workers from the North West of England. Those who participated in the studies may have had a particular interest in the research topic and they may not have been representative of all GPs, other health care practitioners, carers, support workers or adults with intellectual disabilities. However, the unique co-produced focus group study was not restricted to adults with intellectual disabilities who were obese or overweight, or to adults with intellectual disabilities accessing weight management services. The co-produced focus group study therefore uniquely gathered the views of some adults with intellectual disabilities who were not obese or not overweight (as well as the problems of some who identified themselves as overweight or obese) and highlighted challenges they faced managing their weight.

The phased programme of research utilised several methods and incorporated the different views and experiences of those involved in weight management for this population group. The findings have identified the main barriers and facilitators involved in the tailoring of such interventions.

## **9.6 Conclusions**

The phased programme of research for this thesis utilised several methods and incorporated the different views and experiences of those involved in weight management for this population group. This is the first known comprehensive phased programme of research to elicit information on evidence-based multi-component weight management interventions and the tailoring of such interventions for adults with intellectual disabilities from the different perspectives of those involved.

The synthesised findings highlight the complex systems-related challenges involved in weight management for adults with intellectual disabilities. The findings imply that adults with intellectual disabilities have limited support to access tailored evidence-based multi-component weight management interventions and services if they want to manage their weight. The findings suggest that this population

requires more equitable support from service commissioners, service providers, health care practitioners, carers and support workers. People who support people with intellectual disabilities should understand their needs, communicate effectively with them, be appropriately trained, resourced, care and be motivated to support them. The findings also imply that broader public health interventions (such as restrictions on the growth of fast-food outlets) are needed, rather than sole reliance on weight management interventions used in clinical settings which focus on self-motivation and behaviour change strategies in one or two areas (such as diet-only or physical exercise-only) to achieve short-term clinical weight loss outcomes.

### *Summary of chapter*

This chapter provided a synthesis of Phase One and Phase Two themes. This chapter has provided a comprehensive picture of the barriers and facilitators involved in weight management for adults with intellectual disabilities and the associated challenges for all those involved. The chapter described the strengths and limitations of the synthesised programme of research. The next chapter (chapter ten) provides the overall conclusions arising from the phased programme of research conducted for this thesis. The next chapter outlines recommendations for future research, policy and practice in this field. The strengths and limitations of the overall phased programme of research are summarised in the next chapter. The original contribution to knowledge is also stated.

# CHAPTER TEN

## CONCLUSIONS AND RECOMMENDATIONS

### INTRODUCTION

This thesis comprised a phased programme of research that aimed to explore how UK recommended evidence-based multi-component weight management interventions can be tailored for adults with intellectual disabilities who are obese. This chapter provides a discussion and summary of the main findings. The chapter provides recommendations for future research, policy and practice in this field, including how to encourage the tailoring and implementation of evidence-based multi-component weight management interventions for adults with intellectual disabilities using a whole systems approach. Strengths and limitations of the overall phased programme of research are summarised in this chapter. The original contribution to knowledge that this research programme has made is also stated.

### BACKGROUND

The introductory chapter of this thesis (chapter one) provided the rationale for this thesis. The first chapter provided the background context to indicate that obesity is a serious health inequality issue for adults with intellectual disabilities. The chapter highlighted that there is a higher prevalence of obesity in adults with intellectual disabilities in England than in their non-disabled peers, and that those who are obese are at risk of experiencing serious obesity-related medical conditions including coronary heart disease, stroke and Type 2 diabetes. UK obesity and weight management guidance recommends evidence-based multi-component weight management interventions, tailored for different population groups. Thus, the overarching aim of this thesis was to explore how evidence-based multi-component weight management interventions can be tailored for adults with intellectual disabilities who are obese. The overarching objectives were to: (a)

explore what types of evidence-based multi-component weight management interventions are delivered to adults with intellectual disabilities, their theoretical basis, how they are delivered, by whom and in what setting; (b) explore the barriers and facilitators to weight management interventions for adults with intellectual disabilities, from the differing perceptions of service commissioners, service providers, health care practitioners, adults with intellectual disabilities, their carers and support workers; and (c) to recommend how to encourage the tailoring and implementation of evidence-based multi-component weight management interventions for adults with intellectual disabilities within a complex system, such as health care. The first chapter outlined the three phases of research conducted to meet the overarching aims of objectives for this thesis.

Phase One involved the first known published integrative review of multi-component weight management interventions for adults with intellectual disabilities (described in chapter two). Phase One explored the theories underpinning weight management interventions for this population (described in chapter three). Phase One also included a mapping exercise to explore the extent of weight management service provision for all adults with, and without, intellectual disabilities (described in chapter four).

Phase Two comprised three studies to explore participants' views and experiences of barriers and facilitators to weight management interventions for adults with intellectual disabilities. These studies involved: (1) face-to-face semi-structured interviews with health care practitioners; (2) a unique co-produced focus group study involving adults with intellectual disabilities; and (3) a survey of carers and support workers for this population. The methodology for these studies was outlined in chapter five and the findings from each of these studies were outlined in chapters six, seven and eight respectively.

Phase Three (described in chapter nine) involved a synthesis of the main themes emerging from Phases One and Two. The synthesis highlighted the main barriers and facilitators to weight management for adults with intellectual disabilities and

summarised the challenges involved for service commissioners, service providers, health care practitioners, adults with intellectual disabilities and their carers and support workers.

The next section of this chapter provides a discussion and summary of the main findings from the phased programme of research.

## **10.1 Discussion of main findings**

The integrative review conducted in the first phase of this research found emerging evidence to suggest that multi-component weight management interventions can be tailored for adults with intellectual disabilities who are obese and that these can be effective. However, the review found that few national and international studies of evidence-based tailored interventions involving this population had been conducted (n=5 from the UK and Sweden), and that those identified were all relatively recent studies (conducted from 2011 to date). There is a need for more controlled and qualitative studies of evidence-based multi-component weight management interventions for adults with intellectual disabilities. Crucially, none of the review's identified studies had explored adults with intellectual disabilities' views and experiences of barriers and facilitators to evidence-based multi-component weight management interventions. None of the studies had fully examined whether any short-term weight loss outcomes had been maintained by participants in the longer-term (post-intervention). The research also found that a variety of outcome measures (e.g. BMI, waist circumference, waist-to-hip ratio, changes in levels of physical activity, and satisfaction surveys) are needed to measure the effectiveness of evidence-based multi-component weight management interventions for this population.

Phase One's review found other types of (non-evidence-based) weight management studies involving this population had been conducted: 31 studies of other types of weight management interventions involving this population (such as diet-only or physical activity-only interventions) were conducted between 1984 and 2015. However, these other studies – even the more recent ones – did not examine

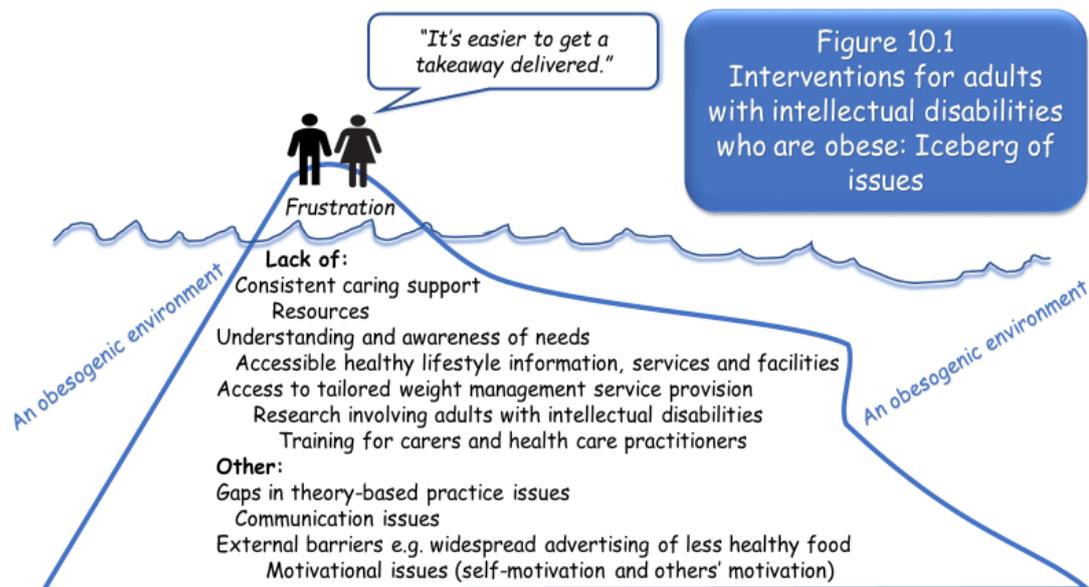
evidence-based multi-component weight management interventions. The review found a lack of information in the studies to describe the theories used to underpin weight management interventions for adults with intellectual disabilities. Those studies that did provide information on theories used to underpin their studies' interventions appeared to be reliant on behaviour change theories associated with an individual's responsibility for behaviour change. There was little cognisance of the impact of the socio-economic, demographic and environmental circumstances surrounding the individual with an intellectual disability. Phase One's mapping exercise also found insufficient routine provision of tailored evidence-based multi-component weight management interventions for adults with intellectual disabilities, despite evidence of a high prevalence of obesity in this population. Furthermore, there was an ad-hoc adherence to UK guidance on evidence-based multi-component weight management. Phase One's findings therefore imply that further national and international (controlled, qualitative and follow-up) studies of evidence-based multi-component weight management interventions for adults with intellectual disabilities are required. Future studies should also examine the wider socio-economic and environmental factors involved in weight management for this population. Future research studies should engage adults with intellectual disabilities, their carers, support workers and health care practitioners. Such research is needed to inform the future development of more practical guidance for health care and other practitioners (e.g. social services staff), service commissioners and service providers. However, this lack of research should not deter practitioners from using these emerging research findings and from involving adults with intellectual disabilities in approaches to inform in their day-to-day practice. Indeed, practical co-produced approaches involving this population may inform future research and the tailoring of evidence-based interventions and service provision, rather than the other way around.

Phase Two's findings highlighted many complex barriers to weight management for this population. Phase Two's participants expressed frustrations with these barriers which included frustrations with a lack of accessible healthy lifestyle information, a lack of resources, a lack of reasonable adjustments, inconsistencies in caring support, unmet training needs for carers and external barriers such as the

widespread availability of less healthy foodstuffs and the easy accessibility of fast-food takeaways. Participants also identified facilitators to weight management such as the provision of clear and accessible healthy lifestyle information, training for carers, support workers and health care practitioners, consistent caring support and the tailoring of services. Phase Two's findings highlighted the complexity of the challenges involved in obesity and weight management for adults with intellectual disabilities from the different perspectives of all those involved – health care practitioners, carers and support workers, as well as adults with intellectual disabilities themselves.

Phase Three's synthesised findings indicate that adults with intellectual disabilities experience inequitable support and inequities of access to accessible healthy lifestyle information and to tailored evidence-based multi-component weight management interventions. The synthesised findings imply that it is the socio-economic and environmental circumstances surrounding the individual with intellectual disabilities, rather than any poor lifestyle behaviour choices or any lack of motivation, which may inhibit this population from managing their weight if they want to. The findings highlight systems-related issues that act as barriers to implementing evidence-based multi-component weight management interventions for adults with intellectual disabilities. This existing situation is inappropriate for adults with intellectual disabilities, some of whom may require additional support to help them manage their weight if they want to, and some of whom may be frustrated by their relatively restricted environments.

Figure 10.1 illustrates an 'ice-berg' of issues involved in weight management interventions for adults with intellectual disabilities that has been uncovered by the phased programme of research conducted for this thesis.



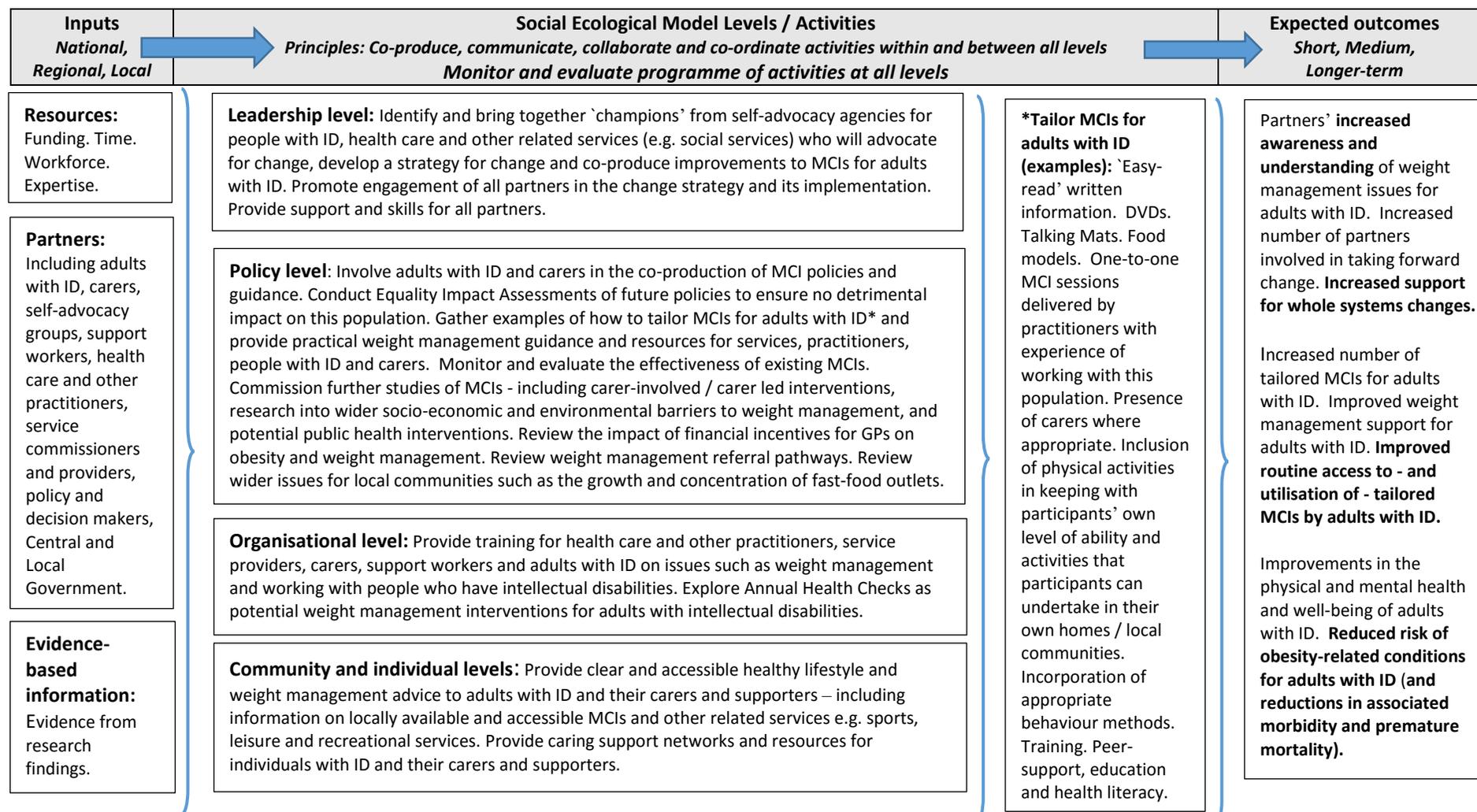
### *Whole systems approach*

The complexity of the systems-related barriers identified by this thesis highlight the need to look beyond the individual change theories underpinning weight management interventions towards the incorporation of wider systems-change theories as well. Whole systems approaches involve looking at the various components and barriers within a whole system and assessing the links and inter-relationships between these to consider ways of overcoming identified barriers to achieve required changes and outcomes (Leeds Beckett University, 2015). The Social Ecological Model (SEM) is a helpful theory-based framework for understanding the multiple levels of a whole system and the interactions between individual components and the wider environment within this whole system (Centers for Disease Control and Prevention [CDC], 2014). There are several levels of the SEM: individual, interpersonal, community, organisational and policy / enabling environment. Approaches to complex systems such as health care and public health systems may use a combination of activities at all these SEM levels (CDC, 2014). There is a corresponding need for communication strategies to engage all key partners (in this case: decision-makers, health care and other practitioners, service commissioners, service providers, adults with intellectual disabilities, carers and support workers) in dialogue and in the co-production of activities both within and between all these SEM levels to achieve required changes and agreed outcomes (CDC, 2014). Communication strategies may include advocacy, social

change communication, social mobilization, and behaviour change communication (CDC, 2014). Adults with intellectual disabilities, their carers and support workers should be proactively engaged in such a whole systems approach.

Logic models can illustrate the types of inputs and activities needed within the different SEM levels of a whole system to bring about change and movement towards collectively agreed outcomes (Community Tool Box, 2017). Figure 10.2 presents a logic model that has been informed by the synthesised findings of the research programme conducted for this thesis. The model depicts the types of inputs, activities and their interconnectivities needed to bring about whole systems changes. It indicates how outcomes are expected to be achieved within a whole systems approach. The model shows the types of inputs that a coalition of partners need to invest in to overcome identified barriers and effect change. These inputs include funding, other resources, partners themselves, and evidence-based information. Using these inputs, the partners can engage in a range of activities shown in the model at different SEM levels that can, in turn, reach certain communities, groups and individuals who then may be able to achieve certain changes themselves. This model recognises the varied contributions of partners at different SEM levels who need to be involved in overcoming identified barriers for adults with intellectual disabilities who want to manage their weight (and their carers and supporters). It provides a recommended route map for moving forward partnership activities within an integrated whole systems approach to encourage the tailoring and implementation of evidence-based multi-component weight management interventions for adults with intellectual disabilities. Co-production and communication within and between all levels is essential within this approach. This will help all partners buy into (and own) this programme of activities. If co-ordinated, co-produced, communicated and collaboratively undertaken and owned, this whole systems approach and associated activities may contribute towards reductions in the inequities experienced by adults with intellectual disabilities who want to manage their weight, and may lead to longer-term reductions in obesity-related morbidity and premature mortality in this population – a major source of health inequalities for this population.

**Figure 10.2: Logic Model: Evidence-based multi-component weight management interventions (MCIs) for adults with intellectual disabilities (ID) who are obese: a whole systems approach**



## 10.2 Summary of main findings

The overall findings from this phased programme of research highlight that there is a need for equitable support and equitable access to, and implementation of, tailored evidence-based multi-component weight management interventions for adults with intellectual disabilities. Adults with intellectual disabilities require equitable support and interventions tailored to meet their needs. This requirement is justified given the high prevalence of obesity in this population and the associated health risks that affect their health and wellbeing, including their quality of life and their life expectancy.

This research found that adults with intellectual disabilities (and their carers and support workers) experience several systems-related barriers to managing their weight. The fact that adults with intellectual disabilities experience barriers in accessing services within complex systems like the health service has already been documented elsewhere (Mencap, 2007). This thesis has highlighted the types of barriers that adults with intellectual disabilities and their carers experience in complex systems for weight management interventions (summarised in Figure 9.3 on page 185). However, this research also found that, if supported, adults with intellectual disabilities who want to manage their weight are more likely to access and utilise weight management interventions and some achieve their weight management goals.

Adults with intellectual disabilities require weight management (and healthy lifestyle) information, interventions and services that are of an equal quality to their non-disabled peers. Adults with intellectual disability have the same right to access evidence-based weight management interventions as their non-disabled peers. This requires additional support and resources for them (Northway, 2016). The provision of more resources for this population is justified since simply providing the same 'universal' weight management interventions for all population groups is not fair or equitable (Northway, 2016). Other authors have suggested that the provision of 'universal' services as opposed to 'tailored' services may continue to result in the needs of populations, such as this population, not being addressed

(Tudor Hart, 1971; Victora et al., 2000; White, Adams and Heywood, 2009). It may even result in a widening of a health inequalities gap between those with intellectual disabilities and those without intellectual disabilities – particularly if adults without intellectual disabilities can access and obtain benefit from these ‘universal’ services, whilst their disabled peers do not have access or do not obtain benefit (White, Adams and Heywood, 2009).

The findings from this research programme imply that broader public health interventions, that seek to change the socio-economic and environmental context surrounding individuals with intellectual disabilities are also required, rather than the current reliance on provision of clinical non-evidence-based interventions which mainly focus on an individual’s responsibility for behaviour changes in one or two areas (such as diet-only or physical activity-only interventions) to achieve short-term weight loss outcomes. The findings indicate the need for a whole systems approach incorporating both individual behaviour change and systems-change theories. The Logic Model (outlined in Figure 10.2) illustrates the types of inputs and activities that are needed at several levels of the Social Ecological Model which - if co-produced, co-ordinated, communicated and collectively actioned - may steer partners towards the whole systems changes needed to achieve improvements in the tailoring and implementation of weight management interventions and outcomes for adults with intellectual disabilities who are at risk of obesity-related medical conditions.

### **10.3 Summary of the main strengths and limitations of overall research**

Table 10.1 summarises the main strengths and limitations of this phased programme of research.

**Table 10.1 Summary of main strengths and limitations of methods used in the phased programme of research**

Methods	Main strengths	Limitations	Comments
<b>Integrative review</b>	<p>First known published integrative review of evidence-based multi-component weight management interventions for adults with intellectual disabilities.</p> <p>This review used a systematic approach to investigate the state of research knowledge in this field.</p>	<p>Included only studies published in the English language and studies involving adults with intellectual disabilities.</p> <p>Few studies identified (n=5).</p>	<p>The review identified a lack of research concerning evidence-based multi-component weight management interventions for adults with intellectual disabilities.</p> <p>The review found no qualitative research studies involving adults with intellectual disabilities to explore their views and experiences of multi-component weight management interventions.</p>
<b>Exploration of theories used to underpin studies' weight management interventions</b>	<p>This exploration found that few identified weight management intervention studies involving adults with intellectual disabilities included information on the theories used to underpin their studies' interventions.</p> <p>The exercise highlighted that future studies should include such information.</p>	<p>Findings are limited because few studies (n=8/36) provided information on the theoretical underpinning of their studies' intervention.</p>	<p>Weight management intervention studies that did provide information on underpinning theories appear to be reliant on behaviour change strategies. There appears to be a lack of cognisance of the impact of wider environmental and socio-economic factors on weight management for adults with intellectual disabilities.</p>
<b>Mapping exercise involving email enquiries and interviews</b>	<p>One of only two local mapping exercises conducted to explore the extent of weight management provision for adults with intellectual disabilities.</p> <p>Enabled an in-depth description of a local context.</p>	<p>Small sample of service commissioners and providers from one county in the North West of England (n=6).</p>	<p>Highlighted gaps in service provision and ad-hoc adherence to UK guidance on evidence-based multi-component weight management interventions despite the high prevalence of obesity in adults with, and without, intellectual disabilities in geographical setting for the mapping exercise.</p>
<b>Qualitative study involving interviews with health care practitioners</b>	<p>First known study to explore health care practitioners' views and experiences of this topic.</p>	<p>Small sample of health care practitioners from the North West of England (n=14).</p>	<p>Flexible, face-to-face, semi-structured interview approach that enabled exploration and clarification of issues raised by interviewees.</p>
<b>Co-produced focus group study involving adults with intellectual disabilities</b>	<p>First known co-produced focus group study to explore the views and experiences of adults with intellectual disabilities on this topic. Inclusive, collaborative, co-produced research. Generated new knowledge.</p>	<p>Small sample of self-selected adults with mild-to-moderate intellectual disability from the North West of England (n=19).</p> <p>Presence of carers and postgraduate student may have led to positive response bias.</p>	<p>People with intellectual disabilities have a right to be involved in research into matters that affect their day-to-day lives.</p> <p>Some of the challenges experienced by other researchers who have conducted research involving this population</p>

	Research was not restricted to adults with intellectual disabilities who are obese or overweight, or adults with intellectual disabilities accessing weight management services. Findings therefore importantly captured views of some who were not overweight or obese and highlighted challenges they face remaining so.		were not encountered by this study. Strategies used to mitigate or reduce risks are highlighted previously in Table 7.2. These strategies could be adopted in future research.
<b>Survey of carers and support workers</b>	Quick and easy method for use with busy carers and support workers who did not have time to participate in interviews or focus groups.	Small sample of self-selected carers and support workers from the North-West of England (n=19).	Enabled a snap-shot of participants' views and experiences. All respondents used the on-line web-based version of the survey rather than postal or email versions. This strategy could be used in similar research.
<b>Synthesis of findings</b>	Enabled a rich, in-depth comprehensive picture of the issues involved in the topic from several perspectives.	Small non-probability sampling techniques used in studies.	Highlights the issues involved in this topic and highlights implications for future research, policy and practice.

#### 10.4 Contribution to original knowledge

Significantly, the research programme for this thesis has, for the first time, pro-actively engaged adults with intellectual disabilities in co-produced qualitative research to explore and present their views and experiences of barriers and facilitators to eating well, living well and weight management interventions. Previously, there has been no known qualitative, co-produced research involving adults with intellectual disabilities in this field. The research programme also explored the views and experiences of carers, support workers, health care practitioners, service commissioners and providers. A rich comprehensive picture has emerged from this research to highlight the complex systems-related barriers and challenges involved in weight management interventions for adults with intellectual disabilities from the different perspectives of all of those involved (service commissioners, service providers, health care practitioners, adults with intellectual disabilities, their carers and support workers). The findings have highlighted the wider socio-economic and environmental barriers to weight management for this population, and the need for a whole systems approach

including further exploration of wider public health interventions, rather than the current reliance on non-evidence-based clinical interventions focused on individual behaviour change strategies which may be inappropriate for this population. This thesis has contributed to research knowledge by presenting a whole systems approach and logic model which recommend the types of activities that are required at several systems-related levels to encourage the tailoring and implementation of evidence-based multi-component weight management interventions for adults with intellectual disabilities. This approach and model are informed by findings from the comprehensive programme of research conducted for this thesis.

There have been other studies and reviews of other types of weight management interventions involving this population. However, there has been a lack of controlled and qualitative studies and reviews exploring evidence-based multi-component weight management interventions for this population. The research conducted for this thesis involved the first known published integrative review of evidence-based multi-component weight management interventions for adults with intellectual disabilities. This thesis has therefore added to research knowledge in this field. The findings have implications for future research, policy and practice. Detailed recommendations for future research, policy and practice that have arisen from each stage of this comprehensive programme of research are summarised in the following two sections of this concluding chapter.

## **10.5 Recommendations for future research**

Detailed recommendations for future research arising from each phase of the programme of research for this thesis are summarised in Table 10.2.

**Table 10.2: Recommendations for future research**

<b>Chapter Two (Integrative Review): Research recommendations</b>	
1.	Information on the theoretical underpinning for weight management interventions should be included in future published studies.
2.	Published studies should provide more detail regarding the actual components of the weight management interventions under investigation.

3. Further studies should explore the organisational culture and resources that enable staff to implement interventions over time.
4. Justification for sample sizes needs to be included in future studies, and the sampling and settings used in studies should reflect that people with intellectual disabilities are not a homogeneous group.
5. Further controlled studies of multi-component weight management interventions including cluster-randomised designs - based on MRC guidelines for complex interventions and CONSORT guidance for trials.
6. Systematic reviews of multi-component weight management interventions for all adults who are obese (including adults from different population groups).
7. Further qualitative studies seeking the views and experiences of adults with intellectual disabilities, their carers (and or support workers) and service providers to improve understanding of the barriers and facilitators to weight management.
8. Research to explore the longer-term effectiveness of multi-component weight management interventions for adults with intellectual disabilities (and other different population groups).
9. A range of outcome measures (e.g. BMI, waist circumference, dietary quality, physical activity levels, and satisfaction with life surveys) may be needed in future studies.
10. Any unintended consequences of an intervention should be reported in future studies.
11. An intervention may need to be adapted during implementation to suit local settings and a description of any such adaptation should be described in the study's findings.

#### **Chapter Four (Mapping exercise): Research recommendations**

1. Further research to explore reasons for gaps in specialist weight management services including tier 3 weight management service provision for all adults who are morbidly obese (with, and without, intellectual disabilities).
2. Research to clarify the obesity referral pathways for all adults (with, and without intellectual disabilities) requiring weight management services.

#### **Chapter Six: Study One (Interviews with health care practitioners): Research recommendations**

1. Further research to explore the effectiveness of Annual Health Checks in identifying obesity as a risk factor and to explore whether such checks can be used as a method of intervention.
2. Research to explore GP brief interventions for weight management (for adults with, and without, intellectual disabilities).
3. Review of available weight management services to assess whether they are accessible, appropriate and effective for different population groups including people with intellectual disabilities.
4. Qualitative research to explore weight related self-perceptions in overweight or obese individuals with intellectual disabilities from different sub-groups.
5. Studies of carer-led and or carer-involved interventions to promote, improve and monitor health and weight management in this population group.

#### **Chapter Seven: Study Two (Co-produced focus groups involving adults with intellectual disabilities): Research recommendations**

1. Further research to explore issues for intellectual disabilities' sub-group populations (by age, sex, ethnicity, type and level of intellectual [and physical] disability, weight status, residential setting, geography, and socio-economic status).
2. Co-produced, collaborative research to develop better and more accessible healthy lifestyle information for people with intellectual disabilities.
3. Research into the wider socio-economic and environmental barriers that affect the health and wellbeing of people who have intellectual disabilities.

4. The development and evaluation of 'buddying' support systems or schemes for this population.

**Chapter Eight: Study Three (Survey of carers and support workers): Research recommendations**

1. Research to establish how to involve carers and people with intellectual disabilities in the design and delivery of weight and health-related interventions for people with intellectual disabilities.
2. Research to explore the role of carers and support workers in promoting access to tailored weight management services for people with intellectual disabilities (and other related services and activities such as health promotion services and physical exercise activities).
3. Further qualitative research involving carers and support workers of individuals with intellectual disabilities from different sub-group populations e.g. by age, gender, ethnicity, type and level of intellectual and or physical disability - to explore whether there are similar or different issues associated with eating well, living well and weight management for each of these sub-group populations.

**Chapter Nine: Synthesis of studies' findings: Research recommendations**

1. Research to explore broader public health interventions and the impact of such interventions on the population of people with intellectual disabilities e.g. restrictions on the growth of fast-food outlets, placing higher levels of tax on unhealthier foods, and redesigning local neighbourhoods to promote physical activity measures such as walking.

## 10.6 Recommendations for future policy and practice

Detailed recommendations for future policy and practice arising from the phased programme of research conducted for this thesis are summarised in Table 10.3.

**Table 10.3: Recommendations for future policy and practice**

<p><b>Chapter Four (Mapping exercise): Policy and practice recommendations for service commissioners and providers</b></p> <ol style="list-style-type: none"> <li>1. Specific involvement of adults with intellectual disabilities in any new weight management policies, interventions and guidance.</li> <li>2. Equality impact assessments of any new weight management policies, interventions or guidance to assess whether these have any negative effects for adults with intellectual disabilities, and planned action to mitigate against, or reduce, any risks.</li> <li>3. Routine monitoring and evaluation of weight management services to ensure they are accessible, appropriate and effective for adults with intellectual disabilities who are obese or overweight.</li> <li>4. Provision of resources for tailored weight management interventions for adults with intellectual disabilities.</li> <li>5. Service commissioners to enter discussions with Public Health England and the Department of Health to explore concerns over ongoing funding and joint commissioning challenges for weight management services for all adults.</li> </ol>
<p><b>Chapter Six: Study One (Interviews with health care practitioners): Policy and practice recommendations</b></p> <ol style="list-style-type: none"> <li>1. Review of UK guidance on obesity and weight management for adults to include more practical support and guidance for health care practitioners.</li> <li>2. Review of QOF and financial incentives for GPs to deliver weight management services or make referrals to weight management services and encouragement of a more pro-active approach to the prevention and treatment of obesity in patients.</li> <li>3. General awareness raising of the barriers to weight management experienced by adults with intellectual disabilities.</li> </ol>

4. Enhancing the capacity of adults with intellectual disabilities to access weight management services, whilst, at the same time, ensuring that such services can respond appropriately to their needs.
5. Training for trainee GPs and GPs on obesity and weight management and how best to communicate with patients on this subject – including how best to engage and communicate with patients who have intellectual disabilities.
6. Training for carers and support workers on weight management issues for people with intellectual disabilities.
7. Training for health care practitioners and training for carers to involve people with intellectual disabilities so that practitioners and carers can learn from this population group.
8. Raising awareness of available (non-commercial and commercial) weight management interventions and services amongst GPs, health care practitioners, adults with intellectual disabilities, their carers and support workers.
9. Raising awareness of examples of tailored weight management interventions for adults with intellectual disabilities.
10. Improvements in GP referral processes to evidence-based multi-component weight management services.
11. Provision of accessible (easy-read) health and weight related advice and information for people with intellectual disabilities in primary health care.
12. Improving the provision and take up of Annual Health Checks for adults with intellectual disabilities in primary health care.
13. Greater collaborative and inter-disciplinary working between health practitioners and intellectual disabilities practitioners.
14. Action to address any negative or discriminatory attitudes towards people with intellectual disabilities.

**Chapter Seven: Study Two (Co-produced focus groups involving adults with intellectual disabilities): Policy and practice recommendations**

1. Provision of consistent caring support for adults with intellectual disabilities to assist them with access to services, resources and activities to help them manage their weight if they want to, and to promote healthier lifestyles.
2. Provision of clear and accessible information on weight management and healthy lifestyles for adults with intellectual disabilities.
3. Training for carers and support workers on *how* to support people with intellectual disabilities to eat well and live well and *why* this is important.
4. The greater involvement of carers and support workers in weight management interventions to support people who have intellectual disabilities.
5. Reasonable adjustments to existing mainstream weight management and healthy lifestyle activities and services so they are accessible to people who have intellectual (and physical) disabilities.
6. Improvements in referrals of adults who have intellectual (and physical) disabilities to mainstream weight management services - including reasonable adjustments or the tailoring of such services to meet the needs of this population.

**Chapter Eight: Study Three (Survey of carers and support workers): Policy and practice recommendations**

1. Improved health care practitioners' training to develop or enhance communication skills and competence in meeting the needs of people with intellectual disabilities, and to discuss weight management with all adult patients (with and without intellectual disabilities).
2. Involvement of adults with intellectual disabilities, carers and support workers in training for GPs, health care practitioners, carers and support workers.

### *Concluding remarks*

This thesis has demonstrated that obesity is a significant health inequality issue for adults with intellectual disabilities, yet there is a lack of (controlled and qualitative) research exploring how evidence-based multi-component weight management interventions can be tailored and implemented for this population and an associated lack of policy and guidance to inform service provision and practice. The programme of research for this thesis found that evidence-based multi-component weight management interventions are not tailored routinely for this population (or monitored), and that there is insufficient service provision of evidence-based multi-component weight management interventions - despite evidence to indicate a high prevalence of obesity in this population. To date, adults with intellectual disabilities have been largely excluded from evidence-based multi-component weight management research, policy and practice.

The overall findings from this phased programme of research imply that there is a need for equitable support for adults with intellectual disabilities who want to manage their weight. This population requires equitable access to, and routine provision of, tailored evidence-based multi-component weight management interventions, and associated healthy lifestyle information. The findings imply that broader public health interventions, that create healthier environments to prevent or reduce obesity in this population, are also required. To date, there appears to have been an over-reliance on non-evidence-based weight management interventions (such as diet-only or physical activity-only interventions) focused on individual behaviour change strategies designed to achieve short-term weight loss goals. Weight management interventions that primarily focus on individual behaviour change may be inappropriate for some adults with intellectual disabilities. This research found that barriers to weight management go beyond the control of the individual and the individual change theories underpinning existing weight management interventions. It has found that there are other wider socio-economic and environmental issues at play. This thesis has highlighted the need to understand barriers to complex interventions such as weight management using a whole systems approach. It presents a logic model which outlines the types of

inputs and activities needed within a whole systems approach to achieve desired outcomes.

Future obesity and weight management intervention research, policy and practice requires more collaborative and co-ordinated activities (and communication) within a whole systems approach. Adults with intellectual disabilities (and their carers and support workers) should be proactively engaged in the co-production of these activities and approach. Adults with intellectual disabilities have a right to be visible and engaged in co-produced whole systems approaches designed to improve their own health and wellbeing.

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## APPENDIX 1: TABLE OF EXCLUDED STUDIES AND REASONS FOR EXCLUSION

	<b>Excluded study</b>	<b>Reasons for exclusion</b>
1.	Antal et al (1988)	Study not available (German journal)
2.	Attux et al (2011)	Not related to people with intellectual disability
3.	Barnes et al (2013)	Not an intervention study
4.	Beeken et al (2013)	Duplicate. Same study described in 2 different journals.
5.	Beeken et al (2013)	Protocol
6.	Beeken et al (2015)	Not a multi-component weight management intervention
7.	Bell and Bhate (1992)	Not an intervention study
8.	Bhaumik et al (2008)	Not an intervention study
9.	Biswas et al (2010)	Not an intervention study
10.	Bryan et al (2000)	Not an intervention study
11.	Bryan et al (1998)	Not an intervention study
12.	Cohen et al (2003)	Not an intervention study
13.	Crocker et al (2012)	Conference paper – not available
14.	De Winter (2009)	Not an intervention study
15.	De Winter (2012a)	Not an intervention study
16.	De Winter (2012b)	Not an intervention study
17.	Donnelly et al (2013)	Protocol
18.	Doody and Doody (2012)	Not an intervention study
19.	Ells et al (2006)	Not an intervention study
20.	Emerson (2005)	Not an intervention study
21.	Flanagan (2013)	Full text not available
22.	Fleming et al (2008)	Not an intervention study
23.	Fornieles et al (2013)	Not an intervention study
24.	Fox et al (1982)	Not an intervention study
25.	Fox et al (1983a)	Not an intervention study
26.	Fox et al (1983b)	Not an intervention study
27.	Frey and Rimmer (1995)	Not an intervention study
28.	Gaziazova et al (2012)	Not an intervention study
29.	Georgia et al. (2005)	Full text not available
30.	Giannopoulou et al (2014)	Not related to people with intellectual disability
31.	Golden and Hatcher (1997)	Full text not available
32.	Gravestock et al (2000)	Not an intervention study
33.	Griffin et al (2009)	Not an intervention study
34.	Guidetti et al (2010)	Not an intervention study
35.	Haider et al (2013)	Not an intervention study
36.	Hallawell et al (2012)	Not an intervention study
37.	Havercamp et al (2004)	Not an intervention study
38.	Havercamp et al (2015)	Not an intervention study
39.	Heinberg et al (2014)	Surgery
40.	Heller and Sorenson (2013)	Not an intervention study
41.	Hithersay et al (2014)	Not an intervention study
42.	Hogan and Evers (1994)	Not an intervention study
43.	Hogan and Evers (1997)	Study involved children
44.	Hove (2004)	Not an intervention study
45.	Hsieh and Rimmer (2012)	Not an intervention study
46.	Hsieh et al (2014)	Not an intervention study
47.	Humphries, Traci and Seekins (2010)	Full text article not available.
48.	Izquierdo-Gomez et al (2015)	Not an intervention study
49.	Jackson and Thorbeck (1982)	Full text paper missing
50.	Jensen et al (2013)	Not an intervention study

51.	Johnson et al (2011)	Not an intervention study
52.	Johnson et al (2011)	Duplicate and not an intervention study.
53.	Kremers et al (2010)	Not specific to people with intellectual disabilities
54.	Lahtinen et al (2007)	Not an intervention study
55.	Lante et al (2012)	Not an intervention study
56.	Lea (1999)	Not an intervention study
57.	Levy et al (2007)	Not an intervention study
58.	Lewis et al (2002)	Not an intervention study
59.	Lin et al (2012a)	Not an intervention study
60.	Lin et al (2012b)	Not an intervention study
61.	Martin (2003)	Not an intervention study
62.	Martinez-Leal et al (2011)	Not an intervention study
63.	McCarron et al (2012)	Not an intervention study
64.	McDermott et al (2007)	Not an intervention study
65.	McGuire et al (2007)	Not an intervention study
66.	Melville et al (2005)	Not an intervention study
67.	Melville et al (2007)	Not an intervention study
68.	Merrick (2000)	Not an intervention study
69.	Merriman et al (2005)	Not an intervention study
70.	Messant et al (1998)	Not an intervention study
71.	Messinger-Rapport and Rapport (1997)	Not an intervention study
72.	Mikulovic (2014a)	Not an intervention study
73.	Mikulovic (2014b)	Not an intervention study
74.	Molteno et al (2000)	Not an intervention study
75.	Moore et al (2004)	Not an intervention study
76.	Moran et al (2005)	Not an intervention study
77.	Mulrooney (2014)	Not an intervention study
78.	Ordonez et al (2014)	Concerned with metabolic syndrome
79.	Perez et al (2015)	Not an intervention study
80.	Pett et al (2013)	Study involving young people with ID
81.	Pitetti (1993)	Not an intervention study
82.	Podgorski et al (2014)	Not a weight management intervention study
83.	Polednack and Auliffe (1976)	Not an intervention study
84.	Pommering et al (1994)	Not a weight management intervention study
85.	Prasher (1995)	Not an intervention study
86.	Prasher et al (2004)	Not specifically related to people with intellectual disabilities
87.	Ptomey et al (2015a)	Not an intervention study
88.	Ptomey et al (2015b)	Technology study
89.	Ptomey et al (2013)	Not an intervention study
90.	Reiner et al (2013)	Not an intervention study
91.	Rimmer et al (1992)	Not an intervention study
92.	Rimmer et al (1993)	Not an intervention study
93.	Rimmer et al (1994a)	Not an intervention study
94.	Rimmer et al (1994b)	Not an intervention study
95.	Rimmer et al (2006)	Not an intervention study
96.	Robertson et al (2000)	Not an intervention study
97.	Rotatori (1978)	Full text paper unavailable
98.	Rotatori et al (1981)	Full text paper unavailable
99.	Rubbert (2014)	Not an intervention study
100.	Rubin et al (1998)	Not an intervention study
101.	Shih and Chiu (2014)	Concerned with children and a dance mat
102.	Shoneye (2012)	Not an intervention study
103.	Smallman et al (2011)	Not an intervention study

104.	Smith et al (2013)	Not an intervention study
105.	Smyth and Bell (2006)	Not an intervention study
106.	Sohler et al (2009)	Not an intervention study
107.	Soler and Xandri (2011)	Not an intervention study
108.	Spanos et al (2014)	Duplicate. Same article published in 2 different journals
109.	Stancliffe et al (2011)	Not an intervention study
110.	Stancliffe et al (2012)	Not an intervention study
111.	Stedman and Leland (2010)	Not an intervention study
112.	Swartz (2014)	Full text not available
113.	Taggart et al (2013)	Not an intervention study
114.	Temple et al (2010)	Not an intervention study
115.	Thompson and Muir (1993)	Not an intervention study
116.	Wallace and Schulter (2008)	Not an intervention study
117.	Wee et al (2015)	Not an intervention study
118.	Wells et al (1997)	Not an intervention study
119.	Winter et al (2015)	Not an intervention study
120.	Wodarski (1985)	Not an intervention study
121.	Yamaki (2005)	Not an intervention study
122.	Yen (2005)	Not an intervention study
123.	Zoppo and Asteria (2008)	Letter to editor
124.	Position of the American dietetic association	Position statement
125.	Providing nutrition for infants	Position statement

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## APPENDIX 2: EXAMPLE OF A COMPLETED STUDY APPRAISAL

**Summary criteria for appraising qualitative and quantitative research studies**  
 Adapted from the Critical Appraisal Skills Programme (CASP) tool [www.casp-uk.net](http://www.casp-uk.net); Walsh and Downe (2006) 'Appraising the Quality of Qualitative Research' *Midwifery*. 22(2):108-19, and CONSORT.

### Title of study and reference

Spanos D., Hankey C., Boyle S., and Melville C. (2014) Comparing the effectiveness of a multi-component weight loss intervention in adults with and without intellectual disabilities. *Journal of Human Nutrition and Dietetics*, 27:22-29.

### Description

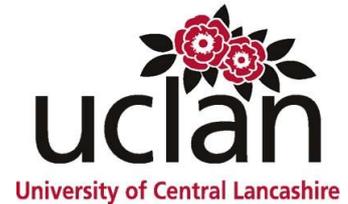
Spanos *et al* (2014) evaluated a 16 week specially designed multi-component weight management intervention (TAKE 5) for obese adults with intellectual disabilities. 52 participants with intellectual disabilities on the TAKE 5 intervention were matched with participants without intellectual disabilities taking part in the Glasgow and Clyde weight management intervention. (TAKE 5 was adapted from the Glasgow and Clyde intervention). At the end of the 16 weeks there were no differences between the groups in the amount of weight loss (median: 3.6kg vs 3.8kg), change in BMI (median: -1.5kg/m<sup>2</sup> vs -1.4kg/m<sup>2</sup>), success of achieving a 5% weight loss (41.3% vs 36.8%) or the rate of weight loss.

	Scope and Purpose	Issues to consider	Yes / No / Unclear and Comments
1	Clear statement of, and rationale for research questions /aims / purposes?	What was the goal of the research? Why it is important and relevant?	Yes. To compare the effectiveness of weight management in those with and without intellectual disabilities who completed nine sessions of a multi-component weight management programme.
2	Clear overview of intention given with appropriate outcome measures?	Has the researcher outlined the intention of the research and appropriate outcome measures?	Yes.
3	Study thoroughly contextualised by existing literature?	Is there a background context, theory and rationale provided?	Yes. This author had previously undertaken a Systematic Review of weight management interventions for people with intellectual disabilities.
	<b>Design</b>		<b>Yes / No / Unclear and Comments</b>
4	Method / design apparent and consistent with research intent?	Is the research method and design justified? Has a rationale been provided?	Yes.
5	Data collection strategy apparent and appropriate?	How have the researchers decided which methods to use? Were the data collected in a way that addressed the research question?	Yes. Comparisons in terms of weight and BMI change and rate of weight loss were made for those who attended all sessions.
	<b>Sampling strategy</b>		<b>Yes / No / Unclear and Comments</b>
6	Sample size given (for quantitative studies) or number of participants given (for qualitative studies)?	Has the researcher explained how and why participants were selected?	

7	Selection bias: Are the individuals selected likely to be representative of the target population? What percentage agreed to participate?	Very likely. Likely. Not likely.	Likely to be representative. 54% agreement to participate. 47% completion.
8	Evidence of steps taken to limit sampling bias e.g. power calculation or sample size calculation?	Any discussion around sampling?	Unclear.
9	Allocation bias: Randomisation method used in sample selection (quantitative studies) or recruitment of participants adequately described (in qualitative studies)?	Any discussions around method of random allocation?	Unclear.
10	Confounders: prior to intervention were any difference between groups reported in the paper? (quantitative studies)	Any other confounders not reported in the paper?	Unclear.
11	Blinding: were the assessors blinded to the intervention or exposure status of participants?		Data collection was carried out by a research assistant who was not involved in the delivery of the intervention. The same research assistant was involved in pre- and post-intervention measurements and therefore was not blind to which measurement was being made.
	<b>Data collection and analysis</b>		<b>Yes / No / Unclear and Comments</b>
12	Were data collection tools shown? Are they known to be valid and reliable?		Yes.
13	Attrition rate from intervention recorded? Any indication of percentage of participants completing the study?	Any discussion around why participants did not start or complete the intervention?	No.
14	Outcomes of intervention clearly described?	Where outcomes clearly described?	Yes.
15	Data analysis adequately described and rigorous?	Is there an in-depth description of the analysis process?	Yes.

	<b>Interpretation</b>		<b>Yes / No / Unclear and Comments</b>
16	Context described and taken into account of interpretation?	Evidence that the researcher spent time with the data and interrogating it for competing / alternative explanations of phenomena?	Yes. Limitations of study also discussed.
17	Data used to support interpretation?	Is sufficient data presented to support findings? Are findings explicit? Are results / conclusions supported by evidence? Is interpretation plausible? Does it 'make sense'?	Yes. Including detailed discussion and use of tables to highlight findings.
	<b>Reflexivity</b>		<b>Yes / No / Unclear and Comments</b>
18	Researcher reflexivity demonstrated?	Has the researcher examined their own role, potential bias and influence during the research?	Yes. No conflict of interest reported. The TAKE 5 study was funded by the Scottish Government.
	<b>Ethical dimension</b>		<b>Yes / No / Unclear and Comments</b>
19	Demonstration of sensitivity to ethical concerns?	Are there sufficient details of how the research was explained to participants? Has approval been sought from ethics committees?	No information provided. The weight management service itself is thanked but no acknowledgements for the participants themselves.
	<b>Relevance / transferability</b>		<b>Yes / No / Unclear and Comments</b>
20	Replicability based on detailed description of intervention?	Can the study be replicated? Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies? Discussion of how explanatory propositions / emergent theory may fit other contexts? Limitations / weaknesses of study clearly outlined?	Yes. Relevant and transferable. The study showed that TAKE 5, a multi-component weight management intervention adapted for individuals with intellectual disabilities was equally effective in this group as in adults without intellectual disability. The programme may therefore potentially tackle disparities in the provision of weight management interventions for people with intellectual disabilities. However, a larger randomised controlled trial is needed to provide more robust results.
<b>Rating: Strong.</b>			

**APPENDIX 3a: ETHICAL APPROVAL FOR INTERVIEWS WITH HEALTH CARE  
PRACTITIONERS (UCLan)**



20th October 2015

Josephine Gibson/Alison Jayne Doherty School of Nursing University of Central Lancashire

Dear Josephine/Alison,

Re: STEMH Ethics Committee Application Unique Reference Number: STEMH 393

The STEMH ethics committee has granted approval of your proposal application 'Interventions for obese adults with intellectual disabilities'. Approval is granted up to the end of project date\* or for 5 years from the date of this letter, whichever is the longer.

Please note that this approval is subject to the following condition being met: Edit Section 2.6 on the Ethics Form (How long will the participants have to decide whether to take part in the research?) to "At least 5 working days". Please provide evidence of this change prior to data collection.

It is your responsibility to ensure that:

- the project is carried out in line with the information provided in the forms you have submitted
- you regularly re-consider the ethical issues that may be raised in generating and analysing your data
- any proposed amendments/changes to the project are raised with, and approved, by Committee
- you notify roffice@uclan.ac.uk if the end date changes or the project does not start
- serious adverse events that occur from the project are reported to Committee
- a closure report is submitted to complete the ethics governance procedures (Existing paperwork can be used for this purposes e.g. funder's end of grant report; abstract for student award or NRES final report. If none of these are available use e-Ethics Closure Report Proforma).

Yours sincerely,

Arati Iyengar Deputy Vice Chair STEMH Ethics Committee

\* for research degree students this will be the final lapse date

## APPENDIX 3b: ETHICAL APPROVAL FOR INTERVIEWS WITH HEALTH CARE PRACTITIONERS (NHS R&D)

**From:** stephen.harwood2@nihr.ac.uk [stephen.harwood2@nihr.ac.uk] on behalf of CSP Unit [crncc.cspunit@nihr.ac.uk]  
**Sent:** 02 March 2016 18:54  
**To:** Josephine Gibson  
**Cc:** North West Coast  
**Subject:** NIHR CSP - Ref. 197599 - R&D Submission Confirmation

Dear Josephine Gibson,

**Re: 197599 - Interventions for obese adults with intellectual disabilities**

Thank you for your R&D submission.

We are pleased to confirm that your study is proceeding through NIHR CSP.

Any other LCRNs participating in your study will contact the Principal Investigators listed in the R&D Form, in order to provide assistance with the SSI Form submissions for the other study sites.

Please contact the Lead LCRN, *NIHR CRN: North West Coast*, for this study if you require any further information.

If new research sites or PICs are added to the study, you should amend the list of sites in Part C of the R&D Form and resubmit via IRAS. Please inform the Lead LCRN at this time.

Further information on NIHR CRN Portfolio and NIHR CSP can be found at <http://www.crncc.nihr.ac.uk>.

Should you decide not to proceed with this study, please inform the Lead LCRN as soon as possible.

Kind regards

*Stephen Harwood*

Research Approvals Facilitator, CSP Unit

**CSP Unit**



**National Institute for  
Health Research**

t. 020 3328 6706 | e. [crncc.cspunit@nihr.ac.uk](mailto:crncc.cspunit@nihr.ac.uk)

a. CRN National Coordinating Centre, Minerva House, 5 Montague Close, London

## APPENDIX 4: PARTICIPANT INFORMATION SHEET FOR INTERVIEWS WITH HEALTH CARE PRACTITIONERS



### Interventions for obese adults with intellectual disabilities

#### Participant Information Sheet

##### Invitation to participate

We would like to invite you to take part in a research study. Before you decide if you would like to take part, it is important for you to understand why the research is being carried out and what it will involve. Please take the time to read the following information. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like further information.

##### What is the purpose of the study?

The purpose of this study is to explore how Health Care Practitioners identify obesity in adults with intellectual disabilities and how they manage interventions for obese adults with intellectual disabilities. The research forms the basis of a post-graduate degree.

##### What will this research involve?

The research will involve a telephone or face-to-face interview in order to ascertain your views and experiences of delivering interventions to obese adults with intellectual disabilities. A second interview may be required to clarify any issues raised in the first interview. Each interview may last for up to sixty minutes.

##### Why have I been invited?

You have been invited to take part in this study because you are a Health Care Practitioner and you are - or have been - involved in identifying obesity in adults with intellectual disabilities, and / or managing interventions for obese adults with intellectual disabilities. Your views will be used to inform knowledge and understanding of interventions for obese adults with intellectual disabilities.

##### Why is this research needed?

We wish to understand how Health Care Practitioners identify obesity in adults with intellectual disabilities and how they manage interventions for obese adults with intellectual disabilities. We also wish to explore Health Care Practitioners' views on whether any additional training, guidance or resources are needed in this field.

##### Do I have to take part?

It is your decision whether or not to take part in the research. We will explain the study to you and give you this information sheet to keep.

We will ask you to sign a consent form to show that you have an understanding of the research and have agreed to take part in the research. The consent form will also ask for permission to use anonymised information from the interview. You are free to withdraw at any time, without giving a reason.

**Will my taking part in the study be kept confidential?**

All of your information will be kept confidential. The only people who will have access to your personal information will be the postgraduate Researcher (Alison Doherty) and her supervisory team at the University of Central Lancashire.

All your information will be treated and stored according to the Data Protection Act (1998). Electronic anonymised data will be password protected and stored securely on a computer for 10 years in line with recommendations of the Medical Research Council document 'Good Research Practice' (2000). Other data (e.g. paper-based) will be stored in a locked cabinet in a post-graduate research room (also locked).

All participants who consent to take part will be allocated a code number and all data recorded about them (including voice recordings) will be identified by their code number. All personal data will be stored in a locked filing cabinet separate from all other data in a locked room and will be destroyed once you have received the results at the end of the study. Voice recordings will be destroyed after the results of the study are published. We may use information that you supply us with in future publications, presentations and teaching. All your personal information will be removed prior to its use in any future publications, projects or presentations.

**What will happen to the results of the research?**

The draft findings from your interview will be shared with you for checking and validation. Once these are agreed with you then the final findings will be published in a research report. Data in the research report will be anonymised so that individual participants and their individual views will not be identifiable from the research findings or any subsequent publications.

**What are the possible disadvantages of taking part?**

No potential harm to participants is expected from this research. However, there will be a time commitment for participants involved in the telephone or face-to-face interviews. It is possible that concerns about unsafe or unprofessional practice may be disclosed during the interviews. The participants will be advised to report any such concerns they may have about unsafe or unprofessional practice to their employing organisation's established professional governance system. The postgraduate Researcher will discuss the concerns and action taken with the supervisory team at the earliest opportunity.

**What will happen if I do not want to carry on with the study?**

You are free to withdraw from the study at any time without giving a reason. To withdraw from the study, please contact Alison Doherty (email: [ajdoherty@uclan.ac.uk](mailto:ajdoherty@uclan.ac.uk) / tel: 07580850616). We will give you the opportunity to have your data removed from the project. Please note that there will be a period of up to 72 hours after an interview before data is anonymised and aggregated during which time a participant may, upon reflection, wish to withdraw. However, if the data have already been anonymised and aggregated with other data then this may not be possible – but please note that once anonymised and aggregated it will not be possible for you to be identified from any of the information used.

**What if there is a problem?**

Please contact Alison Doherty in the first instance. She will do her best to answer any queries or concerns: Alison Doherty, Brook Building BB418, University of Central Lancashire, Preston. PR1 2HE. Email: [AJDoherty@uclan.ac.uk](mailto:AJDoherty@uclan.ac.uk) Telephone: 07580 850 616  
However, if you remain unhappy and wish to make a formal complaint, you can do so by contacting the Supervisory Team c/o Dr. Josephine Gibson [jgibson4@uclan.ac.uk](mailto:jgibson4@uclan.ac.uk) / 01772

895 144 or the University Officer for Ethics, University of Central Lancashire, Preston. PR1 2HE. Email: [OfficerForEthics@uclan.ac.uk](mailto:OfficerForEthics@uclan.ac.uk) Telephone: 01772 893 700

**Who is organising and funding the research?**

This research forms the basis of a post-graduate degree and is part of a wider project being undertaken by the University of Central Lancashire. The research studentship is funded by the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC, North West Coast).

**Who has reviewed the study?**

All research is looked at by an independent group of people, called an Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed by the University of Central Lancashire Research Ethics Committee.

**Contact for further information:**

Alison Doherty, Postgraduate Researcher, Brook Building, BB418, University of Central Lancashire, Preston, PR1 2HE. Mobile: 07580 850 616. Email: [AJDoherty@uclan.ac.uk](mailto:AJDoherty@uclan.ac.uk)

**Thank you for taking the time to read through this information and for considering this request.**  
**You may keep this information sheet and you will be given a signed consent form to keep.**

**APPENDIX 5: CONSENT FORM FOR INTERVIEWS WITH HEALTH CARE PRACTITIONERS**

**Title of Study: Interventions for obese adults with intellectual disabilities**

**Consent Form**

- Name of Researcher: Alison Doherty **Please initial  
the box**
1. I confirm that I have read and understood the Participant Information Sheet for the above study (version 1 dated 16.10.15) and understand that my involvement will include being interviewed at a time and place to suit me. I have had the opportunity to ask questions.
  2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my rights being affected.
  3. I agree to the above researcher from the University of Central Lancashire who is working on the project to having access to my contact details.
  4. I agree that any anonymised data arising from this study may be used for further secondary analysis, presentations or teaching.
  5. I agree to being contacted again for a second interview should the need arise.
  6. I agree to interviews being audio-recorded.
  7. I agree to written notes of interviews being taken.
  8. I agree to take part in the above study.
  9. I would like to receive a summary report of the study.

Name of Participant (in block capitals):

Signature of Participant: (Date):

\_\_\_\_\_

\_\_\_\_\_

Name of Researcher (in block capitals):

Signature of Researcher: (Date):

\_\_\_\_\_

\_\_\_\_\_

**APPENDIX 6: THEMATIC ANALYSIS FRAMEWORK: MAPPING WEIGHT MANAGEMENT SERVICES FOR ADULTS**

<b>Open coding</b>	<b>Issues arising from interviews</b>	<b>Basic themes identified</b>	<b>Organising themes</b>	<b>Global themes</b>
Funding.	Problems identifying and providing ongoing funding for weight management services for adults.	A lack of ongoing funding.	Funding and joint commissioning barriers.	Barriers to weight management service provision.
Joint commissioning.	Joint commissioning challenges between local authorities and CCGs.	Joint commissioning challenges.		
Non-statutory status of weight management services.	Weight management services are not statutory services. Local authorities do not have a duty to provide weight management services.	A lack of priority for weight management services for all adults (not just adults with intellectual disabilities).		
Gaps in weight management service provision.	Gaps in tier 3 weight management service provision for adults with BMI $\geq$ 35 in Lancs.	Lack of service provision for adults with severe obesity.	Lack of more specialist weight management service provision.	
Tailored weight management services for adults with intellectual disabilities.	Evidence of tailored weight management services for adults with intellectual disabilities. However, these are not routinely provided because adults with intellectual disabilities seen as requiring more time and staffing resources and funders require providers to see 'masses'.	Lack of resources for tailored weight management services for adults with intellectual disabilities who are obese.		
Performance monitoring.	Lack of performance monitoring data relating to tailored weight management service provision for adults with intellectual disabilities.	Lack of performance monitoring data for adults with intellectual disabilities.	Lack of monitoring and evaluation of existing services.	

## APPENDIX 7: COVERING LETTER FOR INTERVIEWS WITH HCPs



School of Health  
University of Central Lancashire  
Preston PR1 2HE  
Tel: (Office) 01772 893419  
email: [ajdoherty@uclan.ac.uk](mailto:ajdoherty@uclan.ac.uk)  
[www.uclan.ac.uk](http://www.uclan.ac.uk)

4<sup>th</sup> April 2016

Dear Colleague,

**Title of Study: Interventions for obese adults with intellectual disabilities**

We are writing to invite you to participate in a research study to explore the views of Health Care Practitioners in primary care who are (or who have been) involved in the identification of obesity in adults with intellectual disabilities, and in the management of interventions for obese adults with intellectual disabilities.

Please find attached a Participant Information Sheet which provides information about the study.

The research is part of a post-graduate degree and is funded by the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC, North West Coast). Ethical approval has been obtained from the University of Central Lancashire to conduct this study.

If you are interested in taking part then please contact the postgraduate Researcher (Alison Doherty) by email: [ajdoherty@uclan.ac.uk](mailto:ajdoherty@uclan.ac.uk) or by telephone: 07580 850 616.

Thank you for considering this request.

Yours faithfully,

A handwritten signature in black ink that reads "A. J. Doherty".

Alison Doherty,  
Postgraduate student



26<sup>th</sup> September 2016

**Title of project: Finding out what people think about eating and living well**

	<p>Hello. My name is Alison Doherty.</p> <p>I am a student in the School of Nursing, University of Central Lancashire (UCLan).</p>
	<p>I wish to find out what you think about eating and living well.</p> <p>I would also like to talk to your carer or the person who routinely supports you, if you agree.</p>
	<p>Information about the project is attached.</p>
	<p>If you wish to take part in the project, please contact Alison Doherty.</p> <p>Email: <a href="mailto:ajdoherty@uclan.ac.uk">ajdoherty@uclan.ac.uk</a></p> <p>Telephone: 07580 850 616.</p>

Thank you.



**Title of project: Finding out what people think about eating well and living well**  
**Participant Information Sheet**

	<p>You are invited to take part in a project.</p>
	<p>Before you decide, it is important you understand why the project is being carried out and what it will involve.</p> <p>Please take the time to read the following information.</p>
	<p><b>Who is the project for?</b></p> <p>This project is being undertaken by Alison Doherty.</p> <p>Alison Doherty is a student in the School of Nursing, University of Central Lancashire (UCLan).</p>

	<p>The project is for her studies.</p>
	<p><b>What is the aim of the project?</b></p> <p>To find out what people with learning disabilities think about eating well and living well.</p>
  	<p><b>Why is this project needed?</b></p> <p>To find out <b>what helps</b> people with learning disabilities to eat well and live well, if they want to.</p> <p>To find out <b>what makes it hard</b> for people with learning disabilities to eat well and live well, if they want to.</p>

**YOU  
DECIDE**

## Do I have to take part?

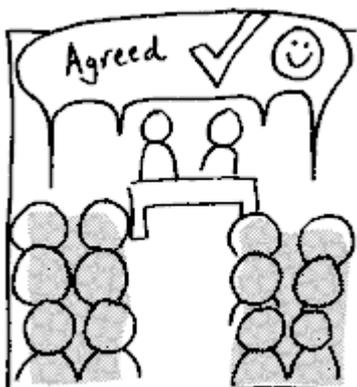
It is your decision whether you take part in the project or not.

Take your time to understand the information. Ask people about it if you want to.

**Choosing YES or NO is your choice.**



If you say **NO**, I don't want to take part  
That's ok. It is your choice. You do not have to take part. No-one will mind. You will not be treated any differently.



If you say **YES**, I want to take part then this is what will happen:

You can discuss the research with others in the group if you want.

You will have the opportunity to ask Alison Doherty any questions.



You will be invited to take part in a group discussion. Alison Doherty will explain the project to you and to others in the group. You can discuss the research with others in the group if you want.



You will have the opportunity to ask Alison Doherty any questions.

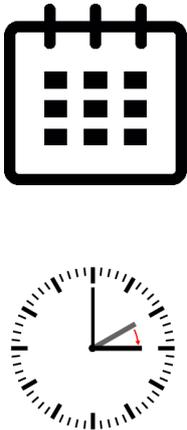


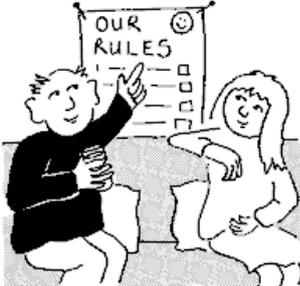
If you want to take part then you will be asked to sign a consent form.

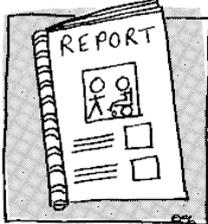
The consent form says that you understand what your involvement in the project includes and that you have agreed to take part in the research.



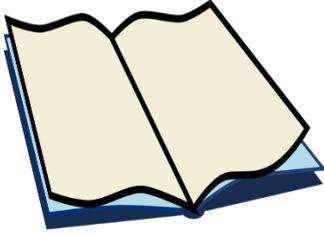
However, once you have signed the consent form, you can still withdraw from the research at any time from the start to the end of the group.

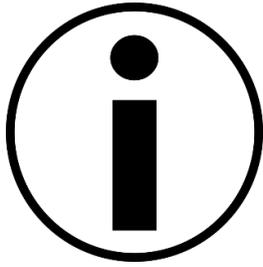
	<p>The group will involve 4 or 5 other people with learning disabilities and their carers or the people who support them.</p> <p>You can have someone with you if you want.</p> <p>Carers who do not wish to take part in the project can still stay with you.</p> <p>People called facilitators will help run the group.</p>
	<p>There will be another separate group just for carers.</p>
	<p>The group will take place on a date and time that is okay for most of the people involved.</p> <p>The group will be held in place that is easy for people to get to.</p>

	<p>The group will last about an hour.</p>
	<p>There will be a break.</p> <p>Healthy refreshments will be available.</p>
	<p>Ground rules will be set for the group and how important it is not to talk about anything that is said in the group with anyone else. However, we cannot be 100% sure that other members of the group will not discuss anything with anyone else outside of the group.</p>
	<p>The group's discussion will be tape recorded.</p>
	<p>Written notes of the group's discussion will also be taken.</p>

	<p><b>What will happen to the information I give?</b></p> <p>Alison Doherty will make sure that other people do not know that you took part in the research. She will not share your name or address with anyone.</p>
	<p>The only time Alison Doherty or the facilitator may tell someone what you said is if you talk about abuse by someone who works in services.</p> <p>Any abuse or very bad practice by services would be reported to the people who inspect those services.</p>
	<p>Information from the group will be put on to a computer.</p>
	<p>A report will be written about findings from the project.</p>

	<p><b>What will happen to the results of the project?</b></p> <p>The report will be shared with you and other people who have taken part in the project.</p>
	<p>Your name and address will not be published in the report.</p> <p>No one who reads the report will know it was you.</p>
	<p>The report will be shared with health care staff and other staff involved in providing services.</p> <p>This is so that staff can learn from you.</p>
	<p>The report will also be shared at meetings and conferences for people with learning disabilities, their carers.</p> <p>This is so that other people can learn from you.</p>

	<p>The student may want to put the project's findings in journals. A journal is a type of book.</p> <p>This is so that an even wider range of people can learn from you</p>
	<p>No one will know from the journals, meetings or conferences it was you that took part in the project.</p>
	<p>The findings from this project will also be included in information for Alison Doherty's studies.</p> <p>No-one will know from Alison Doherty's information that it was you that took part in the project.</p>
	<p><b>What are the advantages or disadvantages of taking part in the project?</b></p> <p>There are no advantages from taking part in this project.</p> <p>There are no disadvantages from taking part in this project.</p>



**You can talk to other people about the project...**

To ask for more information.



You can say if you do not understand something.



The best person to speak to about the project is Alison Doherty:

Alison Doherty  
Student, School of Nursing  
BB418, Brook Building  
University of Central  
Lancashire  
Preston  
PR1 2HE

Email:

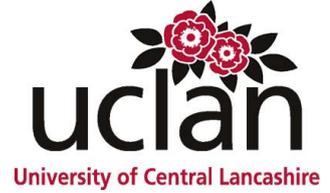
[AJDoherty@uclan.ac.uk](mailto:AJDoherty@uclan.ac.uk)

Telephone: 07580 850 616

   	<p style="text-align: center;"><b>What to do if you have a complaint about the project</b></p> <p>If you are unhappy and wish to make a complaint about the project, you can do so by contacting:</p> <p>The University Officer for Ethics  University of Central Lancashire  Preston, PR1 2HE</p> <p>Email: <a href="mailto:OfficerForEthics@uclan.ac.uk">OfficerForEthics@uclan.ac.uk</a></p> <p>Telephone: 01772893700</p>
	<p style="text-align: center;"><b>Who is organising the project?</b></p> <p>This project is organised by the School of Nursing in the University of Central Lancashire.</p>

	<p style="text-align: center;"><b>Who is funding the project?</b></p> <p>The student is funded by the National Institute of Health Research's Collaboration for Leadership in Applied Health Research and Care North West Coast (NIHR CLAHRC NWC).</p> <p>There is a one-off £25.00 payment for individuals taking part in the project.</p> <p>There will be a contribution towards the costs of the room hire, healthy refreshments and facilitation of the group.</p>
	<p style="text-align: center;"><b>Thank you for reading this information.</b></p> <p style="text-align: center;"><b>Thank you for considering this request.</b></p>

All images used in this participant information sheet were obtained from Google images and were labelled as licensed for reuse.



## Consent Form

**Name of student:** Alison Doherty

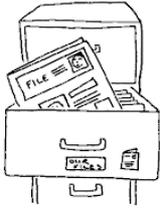
**Title of project:** Finding out what people think about eating well and living well

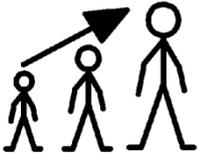


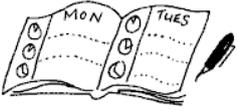
	<b>Please write your initials in the end boxes</b>	
		<b>Initials</b>
	1. I have read and understood the information sheet for this project.	
	2. I have had the opportunity to think about the information and ask questions.	

	<p>3. I understand that I will be involved in a group discussion.</p>	
	<p>4. I am taking part of my own free will.</p>	
	<p>5. I understand that I can change my mind and withdraw at any time from the start to the end of the group.</p>	
	<p>6. I understand that I do not have to give a reason if I change my mind and that nothing will happen to me if I do change my mind.</p>	
	<p>7. If I change my mind, I understand that the information I gave before I changed my mind can still be used but any</p>	

	information about me will be kept private.	
	8. I agree to group discussions being taped.	
	9. I agree to written notes of the group discussions being made.	
	10. I understand that the information about me will be kept private.	
	11. I give permission for the student and her team to see my information.	
	12. I understand that my name will not be published in the project's report, and no one who reads the report will know it was me.	

	<p>13. I agree for the information I give in the project to be used for future meetings, conferences or journals.</p>	
	<p>14. I agree to take part in the project.</p>	

	<p>Your name</p>	
	<p>Your age</p>	
	<p>Gender</p>	
<p><b>Carers only:</b> Relationship to the person with learning disability</p>		

	<p><b>Date</b></p>	
	<p><b>Signature</b></p>	

---

**For Office Use**

Name of person taking consent:

Date:

Signature:

## **APPENDIX 11: STUDY ONE – STUDY TOPIC GUIDE**

### **Interventions for obese adults with intellectual disabilities**

#### **Study Topic Guide**

##### **Study Aims**

To explore how Health Care Practitioners in primary health care (primarily, but not limited to, General Practitioners and General Practice Nurses) recognise obesity in adults with intellectual disabilities, and how they manage interventions for identified obese adults with intellectual disabilities.

To explore whether there are any differences in the ways in which obese adults with intellectual disabilities are identified and managed by Health Care Practitioners compared to obese adults without intellectual disabilities.

##### **Objectives**

To explore:

- How Health Care Practitioners in primary health care recognise (and record) obesity in adult patients with intellectual disabilities, and in adult patients without intellectual disabilities.
- What types of interventions are offered and / or delivered to obese adult patients with intellectual disabilities, and to obese adult patients without intellectual disabilities.
- Health Care Practitioners' experiences of offering and / or delivering interventions to obese adults with intellectual disabilities and without intellectual disabilities.
- Aspects considered to be important to the specific implementation of interventions for obese adults with intellectual disabilities, as perceived by Health Care Practitioners.
- Health Care Practitioners' views on what, if any, training, guidance or resources they would like to enable them to better engage with obese adults with intellectual disabilities on interventions to manage their obesity.

##### **Interview schedule**

###### **Introduction**

Make it clear who I am, why I am there, and why I am asking them. Go through consent, audio-recording, written notes, housekeeping. Brief reminder of the research and participant information sheet; including how information will be recorded, stored and used, confidentiality issues, and thanking them for participating in the research. Ask if they have any questions before we begin the interview.

1. What do you think the role of [*insert title of Health Care Practitioner*] should be in weight management for obese adults generally? Is this any different for an obese adult with an intellectual disability?
2. When you see an obese adult patient in your consulting room, how often would you raise the issue of obesity with that patient? And, if that obese adult patient in your consulting room has an intellectual disability, would this make a difference to how you would raise the issue with them? Give options: when there is a medical problem linked to obesity or when there is no medical problem identified?
3. Can you describe any challenges that may make it difficult generally to discuss a patient's obesity? What if a patient had an intellectual disability? Would this make a difference?
4. Do you conduct any specific tests to identify (and record) obesity in patients? If so, what do you do? Do you carry out the same tests for an individual with an intellectual disability?
5. Do you offer and / or deliver any interventions for adult patients with obesity? What types of interventions do you offer and / or deliver? Do you offer and / or deliver the same interventions for obese adults with intellectual disabilities?
6. Has anything helped or hindered you in offering or delivering interventions specifically to obese adults with intellectual disabilities? What kind of things have helped or hindered you?
7. Could you tell me about other services / interventions that are available in your area for adults with obesity? Do you refer your patients with obesity to these other services / interventions? Do you refer patients with an intellectual disability to these services or interventions? If not, why not?
8. What factors do you think are important to consider in the implementation of interventions specifically for obese adults who have intellectual disabilities?
9. Who do you think is best placed to provide interventions for obese adults with intellectual disabilities? Reasons for answer:
10. On a scale of 1-10, with 1 being the lowest and 10 being the highest, how confident are you that you can generally support an obese adult to achieve and maintain a healthy weight? And, again on a scale of 1-10, with 1 being the lowest and 10 being the highest, how confident are you that you can support an obese adult with an intellectual disability to achieve and maintain a healthy weight?
11. How would you approach improving interventions for obese adults with intellectual disabilities?

**Finally, I am also interested in things external to the patient encounter—such as clinical guidelines...**

12. Have you accessed any training or resources as part of your work in identifying obesity and in managing interventions for obese adults? E.g. UK guidelines. If so, what kind of training or resources?
13. Are you aware of the UK obesity and weight management guidelines?
14. How useful do you find existing UK guidelines on obesity and weight management interventions for your work with obese adults generally? How useful do you find the UK guidelines for your work specifically with obese adults who have an intellectual disability? Reasons for answer:
15. What training, guidance and / or resources would you like to be able to access to enable you to better engage with adults with intellectual disabilities on weight management issues and interventions?
16. Any other comments?

Many thanks for taking part. Your interview notes will be transcribed. A draft copy of your interview notes will be provided to you for verification and agreement. Any amendments will be made if necessary and these will be shared with you again for agreement. Your anonymised notes will then be analysed along with other participants' interview notes and results synthesised along with findings from the literature review. A final copy of findings will be available to you on request. Thank you once more for your participation in this research.

## Study Topic Guide

**Focus groups involving adults with learning disabilities and their carers, or people who routinely support them**

**Title of project: Finding out what people think about eating well and living well**

### **Question 1**

	<b>Question</b>	<b>Answer</b>
	Do you think you are healthy? Yes or No	
	If your answer is yes. What do you do to keep healthy?	
	If your answer is no. Why don't you think you are healthy?	

## Question 2

	Question	Answer
	Do you want to eat well?	
	Do you want to live well?	

## Question 3

	Question	Answer
 	Is there anything which <b>helps</b> you eat well, if you want to?	
	If your answer is yes. What helps?	
 	Is there anything which <b>helps</b> you live well, if you want to?	
	If your answer is yes. What helps?	

### Question 4

	Question	Answer
	Is there anything which <b>stops</b> you from eating well, if you want to?	
	If your answer is yes, what sort of things?	
	Is there anything which <b>stops</b> you from living well, if you want to?	
	If your answer is yes, what sort of things?	

### Question 5

	Question	Answer
	Do you have any concerns about your health?	
	If your answer is yes, what concerns do you have?	

## Question 6

	Question	Answer
	Do you have any concerns about your weight?	
	If your answer is yes, what concerns do you have?	

## Question 7

	Question	Answer
	<p>Have you ever been referred to any weight loss services? Like slimming world, a dietician, exercise classes?</p>	
	<p>If you answer is yes:-</p>	
	<p>What types of weight loss services have you been referred to? (prompt - dietician, exercise classes, Slimming World).</p>	
	<p>Did you go to these services?</p>	
	<p>If not, why did you not go?</p>	
	<p>If you went to these services, did you find them helpful or not helpful?</p>	
	<p>If they were helpful, what helped?</p>	

	<p>If they were not helpful, what did not help?</p>	
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**Question 8**

	<b>Question</b>	<b>Answer</b>
	<p>What do you think can be done to improve the health and wellbeing of people with learning disabilities?</p>	

Things I like to eat....



Activities I like to do...



What helps people eat well?



What helps people live well?

This is a picture of me...

Things that can be done to improve people's health and wellbeing ...



What makes it difficult for people to eat well?



What makes it difficult for people to live well?

*Ref: Worksheet adapted from Warm and Well Families research project 2013*

**APPENDIX 13: STUDY THREE - SURVEY QUESTIONNAIRE FOR CARERS AND  
SUPPORT WORKERS**

**What helps people with learning disabilities to eat well and live well?  
Survey of carers or supporters of people with learning disabilities**

1. Are you a carer (someone who cares, unpaid, for a friend or family member with a learning disability); or are you someone who is formally paid to support a person(s) with a learning disability? Yes / No / Don't know
2. Is there anything which you think **helps** a person with learning disabilities to **eat well**, if they want to? If yes, what helps?
3. Is anything which you think **stops** a person with a learning disability from **eating well**, if they want to? If yes, what sort of things?
4. Is there anything which you think **helps** a person with learning disabilities to **live well**, if they want to? If yes, what helps?
5. Is there anything which you think **stops** a person with learning disabilities from **living well**, if they want to? If yes, what sort of things?
6. Do you have any concerns about the weight of the person(s) with learning disabilities that you support? Yes / No / Don't know
7. Has the person(s) with learning disabilities that you support ever been referred to any weight loss services? Yes / No / Don't know
  - a. If yes:
    - i) What types of weight loss services have they been referred to? (Please describe these services, if known)
    - ii) Did they go to these services? Yes / No / Don't know
      - If not, do you know why they did not go?
    - iii) If you went to these services to support the person with learning disabilities, did you find them helpful or not helpful?
      - If helpful, what helped?
      - If they were not helpful, what did not help?
8. Is there anything which you think can be done to improve the overall health and wellbeing of people with learning disabilities? (Please provide some of your ideas / suggestions):



University of Central Lancashire

**Title of project: Finding out what people think about eating and living well**

**Survey of carers or supporters of people with learning disabilities**

### **Participant Information Sheet**

<p><b>Introduction</b></p> <p>You are invited to take part in the above project. Before you decide, it is important for you to understand why the project is being carried out and what it will involve. Please take the time to read the following information.</p> <p>This project is being undertaken by Alison Doherty, a student based in the School of Nursing, University of Central Lancashire (UCLan). The project is for her studies.</p>
<p><b>What is the aim of the project?</b></p> <p>To explore the views of carers or supporters of people with learning disabilities.</p>
<p><b>Why is this research project needed?</b></p> <p>To find out what carers or supporters think <b>helps and what makes it hard</b> for people with learning disabilities to eat well and live well, if they want to.</p>
<p><b>Do I have to take part?</b></p> <p>It is your decision whether or not to take part in the project or not. Take the time to understand the information. Ask people about it if you want to. Choosing yes or no is your choice.</p>
<p><b>What will this project involve?</b></p> <p>The research project will involve a survey questionnaire. The survey may be completed on-line via a web-link, <b>or</b> it may be completed electronically and emailed back to <a href="mailto:ajdoherty@uclan.ac.uk">ajdoherty@uclan.ac.uk</a>, <b>or</b> it may be completed on paper and posted back to Alison Doherty using a freepost envelope (available on request).</p>

**Do I have to take part?**

It is completely your decision whether you take part in the project or not. You do not have to take part. No-one will mind.

**What will happen to the information I give?**

The survey does not ask you to provide any personal details such your name, age or home address. Your responses will be treated in the strictest confidence. Alison Doherty will make sure that other people do not know that you took part in the research.

Electronic data will be password protected and stored securely on a computer in line with recommendations of the Medical Research Council document 'Good Research Practice' (2000). All paper-based personal data will be stored in a locked filing cabinet separate from all other data in a locked room and will be destroyed at the end of the study.

Alison Doherty will use the information that you provide to inform her studies. Alison may use the information that you provide in future publications, conferences and teaching.

**What will happen to the results of the project?**

The results will inform Alison Doherty's studies and be included in her thesis. A summary report will be written about the findings from the survey. The report will be shared with representatives from self-advocacy groups for people with learning disabilities. The report may also be shared with health care staff and other staff involved in providing services so that they can learn from the views and experiences of carers and supporters of people with learning disabilities.

**What are the possible disadvantages or benefits of taking part?**

We feel that there are no potential benefits, disadvantages or risks to taking part in this project. You will, however, be required to give up about 15 minutes of your time to complete the survey.

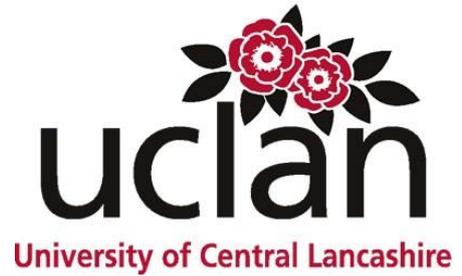
**Who is organising and funding the project?**

This research will inform projects being undertaken by the School of Nursing, University of Central Lancashire (UCLan).

Alison Doherty is funded by the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC, North West Coast) as part of a postgraduate degree (PhD).

There is no payment for individuals taking part in the survey.

**Thank you for taking the time to read through this information and for considering this request.**



12th September 2016

Josephine Gibson/Alison Jayne Doherty School of Nursing University of Central Lancashire

Dear Josephine/Alison,

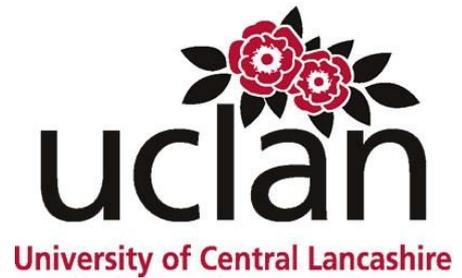
**Re: STEMH Ethics Committee Application Unique Reference Number: STEMH 502\_amendment**

The STEMH Ethics Committee has approved your proposed amendment to your application 'Finding out what people with learning disabilities and their carers think about eating and living well'.

Yours sincerely,

Kevin Butt Vice-Chair STEMH Ethics Committee

APPENDIX 16: STUDY THREE - ETHICAL APPROVAL LETTER



11 November 2016

Jo Gibson / Alison Doherty School of Nursing University of Central Lancashire

Dear Jo / Alison

**Re: STEMH Ethics Committee Application Unique Reference Number: STEMH 502\_amendment**

The STEMH Ethics Committee has approved your proposed amendment – carer's questionnaire - to your application 'Finding out what people with learning disabilities and their carers think about eating and living well'.

Yours sincerely

Kevin Butt Vice-Chair STEMH Ethics Committee

**APPENDIX 17: STUDY ONE – THEMATIC CODING FRAMEWORK**

<b>Codes</b>	<b>Basic themes and sub-themes</b>	<b>Global themes</b>
<p>Challenges in raising the subject of obesity:</p> <p>Sensitivities concerning overweight staff giving weight loss advice. Link between mental health and obesity. Tone of comment relating to modelling of health behaviours by health practitioners.</p> <p>Carers (having to communicate through a carer who may be overweight themselves). Diluted messages.</p> <p>Obesity as product of environment, not an individual failing.</p> <p>GPs' time constraints. Prioritisation of medical conditions over obesity.</p> <p>Annual health checks.</p> <p>Time and effort Vs. ? results.</p> <p>Diagnostic overshadowing in patients with mental health issues.</p> <p>Patients in denial. 'Eager to please' patients with or without intellectual disabilities providing staff with incorrect info on their eating habits.</p> <p>Cultural issues (including issues over access to services).</p> <p>Challenges involved in explaining complex information to patients both with and without intellectual disabilities.</p>	<p>Challenges in communication:</p> <p>Obesity seen as sensitive issue to raise. Patients may have to raise the issue.</p> <p>Communication barriers (GP and patient, GP and carer, GP and service providers).</p> <p>Time.</p> <p>Motivation.</p> <p>Culture.</p> <p>Lack of resources.</p> <p>Assumptions.</p> <p>External environment.</p> <p>Lack of knowledge of causes of death in people with intellectual disabilities.</p>	<p>Communication.</p>

<p>Lack of awareness of service provision. Communication issues between GP and service providers.</p> <p>Role of others in weight management. Team approach needed. GP is not central.</p> <p>Assumptions. Therapeutic nihilism. Lack of awareness of causes of death in the ID population. Extremes of the problem and solution are being normalised. Obesity seen as individual's fault and that people have agency to fix themselves (or not).</p> <p>Too fat to fix myself feeling?</p>		
<p>Patients' lack of awareness (of links between obesity and serious medical conditions).</p> <p>Ability or inability to act (upon knowledge, information and advice given). Awareness of obesity exists but barriers are preventing change.</p>	<p>Knowledge and understanding barriers.</p>	<p>Knowledge and understanding.</p>
<p>Carers and support workers (their importance in weight management interventions for people with intellectual disabilities).</p> <p>Continuity of quality caring support (is important – but high support staff turnover). Just one carer's input could undermine the process. Lots of ways in which continuity is important. Gaps in guidance, training, resources and support for carers.</p> <p>Knowledge, skills, attitudes. Or, capability, opportunity, motivation for carers as well as individuals.</p>	<p>Carers and support workers. Continuity of caring. Training. Knowledge, skills, attitudes.</p>	<p>Support networks.</p>
<p>Lack of priority and lack of financial incentives for weight management services.</p> <p>Is giving out advice and info enough though? Wider environmental issues.</p>	<p>Lack of resources. Lack of specialist services.</p>	<p>Resources.</p>

<p>Lack of specialist weight management services and resources for people with intellectual disabilities. Simplified, accessible resources needed.</p> <p>Not just a priority for specialists. Need for health care staff, carers and service users to develop and share weight management resources for people with intellectual disabilities. Pool resources.</p> <p>Lack of time and resources for specialist weight management.</p> <p>Value for Money for commissioners / funders – services that are time intensive for a small population are at risk.</p> <p>Staff developing adaptations for people with intellectual disabilities.</p> <p>Little evidence of what works in the longer-term.</p> <p>Guidance (not seen as particularly helpful or practical for health care practitioners on a day-to-day basis).</p> <p>Training needs.</p>	<p>Need to address wider environmental issues.</p> <p>Time.</p> <p>Guidance.</p> <p>Training.</p> <p>Lack of forum for development and pooling of multi-agency resources.</p> <p>Value for Money considerations.</p> <p>Lack of evidence as to what works in the longer-term.</p> <p>Existing guidance unhelpful.</p>	
<p>GP's role: identification of obesity, investigation, brief advice, medical interventions, referral to other services.</p> <p>Weight management service staff role:</p> <p>Gaps in specialist services.</p> <p>Sports and leisure accessibility issues.</p> <p>Gender-specific programmes.</p> <p>Lack of tailored evidence-based weight management services for people with intellectual disabilities.</p> <p>Psychologists, psychotherapists, nutritionists, dieticians.</p> <p>Multi-disciplinary appointments.</p>	<p>Staffing skills and experience.</p> <p>Interventions offered (including tailoring).</p> <p>Accessibility.</p>	<p>Interventions</p>

<p>Community programmes. Group programmes.</p> <p>Motivational interviewing. Behavioural change.</p>		
<p>Socio-economic, environmental and individual barriers.</p> <p>Power of advertising. Role of media.</p> <p>Mental health problems.</p> <p>Individual priorities.</p> <p>Demographics.</p> <p>Co-morbidities.</p> <p>Poor weather.</p> <p>Inaccessible services.</p> <p>Obesogenic environment.</p> <p>Medication given to people with intellectual disabilities.</p>	<p>Socio-economic factors.</p> <p>Environmental factors.</p> <p>Poverty.</p> <p>Mental health.</p> <p>Attitudes.</p> <p>Medication.</p>	<p>External barriers.</p>
<p>Self-motivation. Motivation of others. Beyond weight and incentives for change (not just about calorie counting).</p>	<p>Motivation (self and others).</p> <p>Confidence. Incentives for change needed.</p>	<p>Motivation.</p>

**APPENDIX 18: STUDY ONE - DRAFT REPORT OF FINDINGS FOR STUDY ONE PARTICIPANTS**  
**Qualitative study exploring how health care practitioners recognise and manage obesity in adults**  
**with intellectual disabilities**

**Summary of Key Findings**

**Alison Doherty, Postgraduate Student, University of Central Lancashire [ajdoherty@uclan.ac.uk](mailto:ajdoherty@uclan.ac.uk)**

This report summarises key findings from a qualitative study conducted in 2016 which aimed to explore how health care practitioners (principally – but not limited to - General Practitioners) recognise, and manage, obesity in adults with intellectual disabilities.

14 health care practitioners from North West England participated in semi-structured interviews for the study. These included 7 GPs, 1 General Practice Nurse, and 6 other health professionals involved in the delivery of weight management interventions.

Analysis of findings highlighted 6 key themes. There was no ranking or hierarchy of importance as all themes appear equally important and interconnected. The analysis highlights the complexity of the issues involved in obesity and weight management for adults with intellectual disabilities.

**Theme 1: Communication**

Participants indicated that it was the role of the GP or GP nurse in primary care to raise the subject of obesity with any patients (with or without intellectual disabilities) who appeared to be obese. However, participants highlighted time constraints and the need to prioritise patients' presenting medical conditions in primary care. Participants also commented that obesity was a sensitive issue to raise - particularly if health care practitioners were overweight themselves.

Participants commented on challenges involved in having to have a three-way conversation with carers or support workers as well as individual patients with intellectual disabilities. This could be especially challenging if carers or support workers were overweight or obese themselves and / or if the carers or support workers kept changing and they were not fully aware of the needs of the individual they were supporting.

Participants highlighted a lack of accessible resources in primary health care to aid discussions about obesity and weight management with patients who have intellectual disabilities.

Participants highlighted that some patients were 'eager-to-please' health care practitioners and that they may communicate incorrect information about their lifestyle behaviours and or that they may be in denial about their weight and unmotivated to change.

Some participants also commented on cultural issues that may form a barrier to weight management in patients from BME communities.

## **Theme 2: Knowledge**

GPs' overall knowledge and awareness of locally available weight management services was poor. GPs stated that these services kept changing and they spoke about their need for information on services available in their localities.

None of the participants found the UK obesity and weight management guidelines particularly useful in their day-to-day practice. For example, they suggested there was insufficient information provided on different population groups and too much emphasis on BMI rather than on other incentives for change e.g. mental health benefits, image and appearance.

## **Theme 3: Carers support**

All participants spoke about the importance of caring support for people with intellectual disabilities. Many suggested that carers and support workers need more support and training in how to support people with intellectual disabilities with their weight management.

## **Theme 4: Resources**

Some participants stated that there was a need for specialist services for people with intellectual disabilities. However, they commented that commissioners primarily focus on universal weight management services rather than on targeted specialist services.

Participants spoke about their training needs – including training on weight management generally and on how to improve communication with people who have intellectual disabilities. However, they acknowledged that such training might not be a high priority and that practitioners need to be motivated to undertake training especially given the constraints on their time.

The participants provided a range of interventions for people with intellectual disabilities. For example, annual health checks in primary care. Weight management practitioners provided simplified information and resources, smaller group or one-to-one sessions, involved carers (if appropriate) in sessions, held confidence building activities, rapport building and matched the personalities of staff with patients who have intellectual disabilities. However, they suggested that more was needed for this population group.

Participants also spoke about how GPs receive financial incentives for conducting Annual Health Checks for people with intellectual disabilities, and for placing patients on an Obesity Register. However, they were not aware of any financial incentives for GPs to deliver weight management interventions and or to refer any obese patients (with or without intellectual disabilities) to weight management services.

**Theme 5: External barriers**

Participants spoke about an obesogenic environment which acted as a barrier to people's efforts at weight management. They stated that obesity is more a product of the environment rather than any individual 'failing'. They commented that more policy focus was needed around these external barriers. They also spoke about prevailing attitudes and assumptions about people with intellectual disabilities that can make it difficult to manage weight management interventions with this population group. For example, overfeeding people with intellectual disabilities to prevent boredom or conflict.

**Theme 6: Motivation**

Participants raised the issue of motivation in weight management and how this might be difficult for a person with intellectual disabilities who also need the support and motivation of others (including carers and health care practitioners) as well.

**Recommendations**

The findings from this study have highlighted some areas for the attention of future research and practice. These are summarised in Table 1.

**Table 1: Future research and practice recommendations**

<b>Future research: recommendations</b>
<ol style="list-style-type: none"><li>1. Further research into possible explanations for the differences in GP provision of, and low take-up of, Annual Health Checks for people with intellectual disabilities across England.</li><li>2. Further research into GP brief weight management interventions for adults with and without intellectual disabilities.</li><li>3. Review of existing weight management services to assess whether they are accessible, appropriate and effective for different population groups including people with intellectual disabilities and people from BME communities.</li><li>4. Studies of carer-led and or carer-involved interventions to promote, improve and monitor health and weight management in this population group.</li></ol>
<b>Future practice: recommendations</b>
<ol style="list-style-type: none"><li>5. Training for trainee GPs and GPs on obesity and weight management and how best to communicate with patients on this subject – including how best to engage and communicate with patients who have intellectual disabilities.</li><li>6. Training for carers and support workers on weight management.</li><li>7. All training to involve people with intellectual disabilities so that practitioners and carers can learn from this population group.</li><li>8. Improvements to increase GPs' knowledge and awareness of locally available evidence-based weight management services.</li><li>9. Improvements in GP referral processes to evidence-based weight management services.</li><li>10. Review of financial incentives for GPs to deliver weight management services or make referrals to weight management services.</li><li>11. Provision of accessible (easy-read) healthy lifestyles advice and information for people with intellectual disabilities in primary health care.</li><li>12. Review of UK guidance on obesity and weight management for adults to include more practical support and guidance for health care practitioners.</li></ol>

**Next steps:** Study findings will be compared with other studies involving people with intellectual disabilities and their carers and support workers.

## APPENDIX 19: STUDY TWO - THEMATIC CODING FRAMEWORK

Codes	Issues arising from focus groups	Basic themes identified	Organising themes	Global themes
Caring	Participants stressed the importance of caring support. Carers and or support workers help people with intellectual disabilities to eat the right kinds of foods and help them to access the types of activities which they enjoy such as walking, cycling, dancing, keep-fit and socialising with others. Some participants who wanted to lose weight stated that they lacked the support to enable them to routinely attend weekly weight loss groups. They were frustrated by this.	<b>Caring support</b> as enabler to eating well and living well (including losing weight, if required). Lack of support as barrier. Also, <b>frustration</b> amongst some participants over the lack of support.	<b>Support networks</b>	<b>Control and choice</b>
Group support	Participants commented on the value of being with others who wanted the same weight loss goals. People with intellectual disabilities also liked to be matched with support workers who had the same interests as them e.g. supporting the same rugby or football club.	<b>Group support</b> helps people with intellectual disabilities to eat well and live well.		
Better, clearer, more accessible information	Participants spoke about conflicting health messages and stressed the need for better, clearer and more accessible (e.g. 'easy-read') information, carers' training and resources on <i>how</i> to eat well, live well and lose weight if they need and want to, and <i>why</i> this is important.	<b>Clear, accessible information and training</b> as enabler to eating well and living well. <b>Frustration</b> over a lack of clear and accessible information.	<b>Resources</b>	
Money	Participants commented on the need for money to enable them to pay for routine caring support and for food and activities to help them eat well and live well. Participants spoke with frustration about how their personalised budgets to pay for caring support is being cut.	<b>Money</b> facilitates the ability of people with intellectual disabilities to eat well and live well. <b>Frustration</b> over budget cuts.		
Mental health and wellbeing	Participants mentioned the need to improve their mental health and wellbeing as well as their physical health.	Over half of participants with intellectual disabilities <b>recognised their own health and weight concerns</b> . However, they identified	<b>The ability or inability to act upon recognised concerns</b>	
Health concerns	More than half of the participants were concerned about their own health.			

Weight concerns	More than half of the participants were concerned about their own weight and they were frustrated over not being able to do something about this.	<b>barriers which reduced their ability to act</b> on these concerns. This was <b>frustrating</b> .		
Advertising	The advertising of less healthy foodstuffs was also discussed. Participants expressed frustration over the advertising of less healthy food during the showing of the Paralympics on television.	The influence of <b>advertising</b> . <b>Frustrations</b> over advertising expressed.	<b>External factors</b>	

**Eating Well and Living Well**  
 Focus group of people with Learning disabilities and their carers or support workers.  
 26th September 2017  
 Accrington

**What stops people with learning disabilities eating well and living well?**

**Having the right support is important**

- To help us to eat well**
  - Some carers and support workers need training in things like cooking
  - It helps if support workers share our interests - like the gym or football
  - People need easy read information on **HOW** to eat well, live well, lose weight and **WHY** this is important
  - Some places are not accessible for people who have a physical disability as well as a learning disability
- To help us to keep active**
  - People want to improve their mental health as well as their physical health
  - People like being in groups with others who want to lose weight
  - Some people can't afford to go to a weight loss service - this annoys them
  - one person got a summer of the year award at a local support service
  - Too much advertising for unhealthy foods - even during the Paralympics

**Other issues:**

- People need money to pay for support, food and activities BUT some people have had their money cut and they have less choice
- Lots of people are worried about being overweight
- Sometimes the information and advice people get is confusing and clashes

**Next steps**

- Better understanding of healthy eating and why it is important
- Make sure that people are eating healthily
- Good information on how to keep healthy
- Easy to understand
- Easy to access
- Using 5 ways to Wellbeing
- Information in easy read - support workers need to be trained up
- Talk to people - have easy to understand information workshops
- More awareness between carers about services in your local area and between agencies
- 5 Ways to Wellbeing make sure people know about it
- More support - help with relationships - sex education and support
- Awareness, guidance, support
- Understanding
- What people in the North West had to say will be compared to other areas
- All the information will be used to design weight loss services for people with learning disabilities

**APPENDIX 21: STUDY THREE - THEMATIC CODING FRAMEWORK**

<b>Codes</b>	<b>Issues arising from survey of carers</b>	<b>Basic themes identified</b>	<b>Organising themes</b>	<b>Global themes</b>
Support, Encouragement, support with food.	Encouraging them to choose healthy foods that they like so that they'll seek these foods themselves at regular times of the day. Having people around them who encourage them to live well and demonstrate what living well is. Positive praise, encouragement. Having whoever supports them support them to access healthy eating options. There is also a need to have a consistent approach from all involved in supporting the individual. Empowering individuals to take control. Positive support for weight loss. Experienced supportive staff / carers. Helping, support someone, prepare meals for themselves. Friendship. Peer support. Eating with others and not alone. Motivation and support. Informed and engaged staff. Advocacy and support with rights. Good support to ensure the person is enabled to purchase, prepare and eat a good diet. Having support staff who are really committed to sharing the person's life. Staff not being fully supported in how they assist a person to eat healthily, as often they don't themselves.	Encouragement. Consistent support. Experienced carers. Sharing meals. Peer support. Motivation. Shared interests. Support for carers needed too.	<b>Consistent caring support.</b> <b>Encouragement.</b> <b>Shared interests.</b>	<b>Supportive caring networks.</b>
Training	GPs have no correct training around this area. Better education around healthy eating in schools / colleges with healthy choices being the first choice. Lack of staff / carers training. Inability of person and carers to cook.	Training needs for people with intellectual disabilities, their families, carers, support staff, and GPs.	<b>Training for all involved in care of people with intellectual disabilities.</b>	<b>Training for all involved in caring for people with intellectual disabilities.</b>

Surroundings	<p>Surroundings.  Social setting.  Tasty food, well presented.  Environment.  People's reaction to them in public.  Good role models all sit together to eat.  Quiet calm mealtimes.  Pressure on people to go for unhealthy meals out and income restrictions on buying better choices. Also, poor labelling.  Opportunities to connect with their communities. Feeling safe.</p>	<p>Social setting for mealtimes is impactive.  Surrounding environments limiting choices.  Societal attitudes.</p>	<p><b>Social settings and surrounding environments.</b></p>	<p><b>Social settings and surrounding environments.</b></p> <p><b>Choice and control.</b></p>
Choice	<p>Not having choice. Same menu each week.  Be involved in menu planning and shopping.  Unhealthy menu choice or planning.  Poor diet choice. Lack of access to support services.  Having a range of healthy options to choose from.  Lack of choice.  Lack of opportunities to socialise and access sport / leisure activities.  Choices may be limited to staff skill level.  Lack of money.  Lack of aids and adaptations to assist eating.</p>	<p>Poor or limiting choices in social settings.  Lack of money.</p>	<p><b>Choice and control.</b></p>	<p><b>Choice and control.</b></p> <p><b>Social settings and surrounding environments.</b></p>
Mental health and emotions	<p>Working around things they like and keeps them happy and content.  Behaviour related to bad routine and things not working well.  Being ill an underlying issue that is not recognised which then relates to behaviour.  Anxiety and having to provide for themselves.  Benefits being stopped when having a long stay in hospital. Causes huge anxieties.  Monitoring if someone has psychological issues surrounding eating too much or too less.  Poor health.  Feeling pressured.</p>	<p>Behaviour may be linked to underlying poor health.  Disruption to routines may be stressful.  Mental health, stress, anxiety, emotional issues.  Money worries.</p>	<p><b>Stress and anxiety impacting on health.</b></p>	<p><b>Mental health issues.</b></p>

Helpful services	<p>Good monitoring and keeping up to date with a person's wellbeing. Being aware of the person and any bodily changes or behaviour changes related to a person needing support and help.</p> <p>UNDERSTANDING the person's individual needs and them as a person and then to be proactive.</p> <p>Always successful if the interest in a healthy diet or (X name of commercial weight management service) is shared.</p> <p>Annual health checks, mention weight and options.</p>	<p>Annual health checks.</p> <p>Understanding and having an interest in the person.</p> <p>Monitoring.</p> <p>Having shared interests with the person.</p>	<p><b>Routine monitoring.</b></p> <p><b>Specialist services.</b></p> <p><b>Having an interest in the person.</b></p> <p><b>Sharing interests with the person.</b></p>	<p><b>Shared interests.</b></p> <p><b>Routines.</b></p> <p><b>Specialist services.</b></p>
Routine	<p>By keeping a routine and don't confuse the situation.</p> <p>Behaviour related to bad routine and things not working well.</p> <p>Having regular mealtimes.</p> <p>Being offered food they don't like at fixed times when not hungry.</p> <p>Regular work or activities.</p> <p>Also, habits are sometimes difficult to change.</p>	<p>Regular routines and schedules.</p> <p>Less healthy habits may be difficult to change.</p>	<p><b>Routines are an important factor in the lives of people with intellectual disabilities.</b></p>	<p><b>Routines.</b></p>
Adaptations	<p>Adapted cutlery e.g. plastic plates, cups, cutlery etc. Even bibs for some.</p> <p>Pictures of food or plated meal and pictures of a happy healthy person and where the food helps....social stories.</p> <p>Adverts on TV or the boxes that imply it's healthy...so (X name of a cereal) for example is not too bad but still has a lot of sugar...I'd like to see a sugar cube(s), easy read chart on all cereals.</p> <p>Easy read labels and traffic lights.</p> <p>Accessible information to ensure people have the knowledge about healthy eating. People should be given the information in a way which they understand. Accessible, easy read with pictures and symbols etc. Multi-media. Films really work to assist people to understand.</p>	<p>Aids and adaptations.</p> <p>Surrounding environmental factors.</p>	<p><b>Accessible aids and adaptations.</b></p> <p><b>Social surroundings.</b></p>	<p><b>Accessible adaptations.</b></p>
Unhelpful services	<p>I was already doing what they said.</p> <p>Weight loss service implied I should have waited until they were heavier but I wanted to be referred before it got that bad - to prevent it getting that bad.</p> <p>Staff haven't followed the programme so little results were seen and also conflicts within staff team on a person's weight.</p> <p>However, they were in some respects using inaccessible language, He is 23 stone and I am trying to find people to help me.</p>	<p>Unhelpful advice.</p> <p>Inaccessible services.</p> <p>Conflicting views and action by different support staff involved.</p>	<p><b>Inaccessible services.</b></p> <p><b>Inconsistencies in staffing support.</b></p>	<p><b>Accessibility.</b></p> <p><b>Routines.</b></p>
Prejudice	<p>Not being accepted, included or others having an understanding of their disability. People's reaction to them in public.</p> <p>Awareness...it's quite easy to say "well bless what do you expect they have learning disabilities". NO NO NO!! WE ALL have a part to play in helping our</p>	<p>Social surroundings.</p> <p>Attitudes, beliefs and behaviour of others limiting</p>	<p><b>Inclusive communities needed.</b></p>	<p><b>Inclusion.</b></p>

	<p>people with learning disabilities to live a healthy life.          Prejudice. Limiting beliefs from others.          Don't exclude those who are just outside the 70IQ range or those with autism as they need help just as much.          Opportunities to connect with their communities. Feeling safe.</p>	<p>opportunities for people with intellectual disabilities.</p>		
Convenience	<p>Cost of `healthy' food and possibly the disadvantage of healthy often meaning cooking from scratch.          Convenience for staff choosing unhealthy food options.          Money. It's cheaper to follow a poor diet and buy convenience food.          Inability to source and prepare healthy food.</p>	<p>Less healthy food perceived to be cheaper and more convenient to access than healthier foods.          Convenience foods desirable.</p>	<p><b>Money and convenience factors limiting food choices.</b></p>	<p><b>Choice and control.</b></p>
Communication	<p>Communication can be very poor in services.          Staff taking notice of their likes/interests and info from family if person cannot communicate their wishes very well.          The major obstacle is not listening to the person, care providers' rules and regulations often get in the way.</p>	<p>Poor communication skills amongst staff.          Surrounding environment important.</p>	<p><b>Staff with poor communication skills.</b></p>	<p><b>Poor communication.</b></p>

**What helps and what makes it difficult for people with learning disabilities to eat well, live well and manage their weight, if they want to?**

**Survey of carers’ and support workers’ views: draft summary of key findings**

**Alison Doherty, Postgraduate Student, University of Central Lancashire [ajdoherty@uclan.ac.uk](mailto:ajdoherty@uclan.ac.uk)**

This report summarises key findings from a survey of carers and support workers conducted in 2016/17 which aimed to explore their views of what helps and what makes it difficult for people with learning disabilities to eat well, live well and manage their weight, if they want to. 19 carers and support workers from across the North West participated in the survey.

**Barriers and facilitators to eating well: main themes**

Respondents commented that a complexity of issues acted as barriers to eating well amongst people with learning disabilities: a lack of money, poor support, a lack of accurate advice and or support for healthier eating, a lack of choice, disruption to routines, unsupportive environments, emotional issues and underlying health issues.

Respondents highlighted that facilitators to eating well for people with learning disabilities included aids and adaptations, reasonable adjustments, routinely sharing meals with familiar people, praise and encouragement, and consistent quality support.

**Barriers and facilitators to living well: main themes**

Respondents commented that a lack of understanding, a lack of opportunities, poor support, financial issues, motivational issues and underlying health issues acted as a barrier to living well for people with learning disabilities.

Facilitators were thought to include consistent quality support from people with shared interests as the people they were supporting, routines, opportunities to socialise and to access sports and leisure activities, and clear accessible health information, advice and education.

**Weight management: main themes**

Most respondents were concerned about the weight of the person(s) with learning disabilities whom they supported. Respondents highlighted that underweight is an issue for people with learning disabilities as well as overweight and obesity. Despite carers’ concerns about the weight of the person they supported, the survey found that few of the people with learning disabilities supported by the carers had been referred to weight management services and even fewer had attended.

Respondents commented on the difficulties they had encountered. For example:

*“Weight loss service implied I should have waited until they were heavier but I wanted to be referred before it got that bad - to prevent it getting that bad.”*

*“He is 23 stone and I am trying to find people to help me.”*

*“Families may be trying very hard at home to assist the person to eat healthily, only for a provider of e.g. day services work totally contrary. This is often down to staff not being fully supported in how they assist a person to eat healthily, as often they don't themselves.”*

The underlying message is that improvements in weight management interventions are needed for people with learning disabilities who have weight concerns and issues.

#### **Improving overall health and wellbeing: themes**

Respondents commented on the need for better support not only for people with learning disabilities but also for their families and carers. Respondents emphasised the need for improved opportunities to access social, sports and leisure activities (that are accessible for people with physical as well as learning disabilities). Respondents emphasised the role of accessible (easy-read) information, education and training. The respondents indicated that training should involve everyone who has an involvement in providing support to people with learning disabilities, and that people with learning disabilities should be involved in such training so that there is raised awareness and shared understanding of issues and concerns.

The findings from this survey are limited. It included a small sample of carers and support workers and do not represent the views of all carers and supporters of people with learning disabilities.

#### **Summary**

The survey highlighted carers' views on the importance of consistent quality support from staff, family, other carers, support workers and peers with a shared interest in the person with a learning disability. The survey found a need for more supportive and accessible activities, services, resources, information, education and training. Respondents stressed the importance of involving everyone with an interest and involvement in the lives of people with learning disabilities in measures to improve the overall health and wellbeing of people with learning disabilities.

#### **Next steps**

Further feedback or reflections from carers and support workers on the draft findings is welcomed. The final findings from this survey will be synthesised with findings from other studies being conducted involving adults with learning disabilities and health care practitioners. Thank you to all of those who participated in the survey.

**Please send any further feedback, comments, observations or reflections to Alison Doherty via email: [ajdoherty@uclan.ac.uk](mailto:ajdoherty@uclan.ac.uk)**  
**Thank you.**

**APPENDIX 23: THEMATIC ANALYSIS FRAMEWORK – SYNTHESISED STUDIES**

<b>Study</b>	<b>Basic themes</b>	<b>Organising Themes</b>	<b>Global Themes</b>	<b>Central Themes</b>
1. Interviews with health care practitioners.	Raising the subject of obesity. Communicating through a third party. Lack of resources to aid communication. Time and prioritisation. Culture. Lack of specialist services. Training and guidance. Interventions offered. Financial incentives. Demographic factors. Environmental factors. Attitudes and assumptions. Self-motivation. Others' motivation. Incentives for change.	Challenges in communication.  Knowledge.  Carers and support networks.  Resources.  External barriers.  Motivation.	Communication.  Knowledge.  Support networks.  Resources.  External barriers.  Motivation.	<ol style="list-style-type: none"> <li>1. Caring support networks</li> <li>2. Resources</li> <li>3. Communication and understanding</li> <li>4. Motivation vs frustration</li> <li>5. External barriers.</li> </ol>
2. Focus Groups involving people with intellectual disabilities.	Caring support. Group support. Clearer, accessible info and training. Money. Recognition of health and weight concerns. External barriers.	Support networks. Resources. Choice. External barriers.	Frustration.	
3. Survey of carers and support workers.	Motivation. Support. Training. Social settings. Limited choices. Lack of resources. Inaccessible services. Communication. Mental health issues. Prejudice.	Support. Training. Choice. Resources. Communication. Mental health issues. Prejudice.	Frustration.	

**APPENDIX 24: THEMATIC ANALYSIS FRAMEWORK – SYNTHESIS OF PHASES ONE AND TWO**

<b>Phase</b>	<b>Themes</b>	<b>Central themes</b>	<b>Conclusions</b>
Phase 1 Integrative review	Lack of (qualitative and controlled) studies involving adults with intellectual disabilities and their carers to explore their views and experiences of weight management interventions Emerging evidence to suggest multi-component weight management interventions can be tailored and effective for adults with intellectual disabilities Carers pivotal role in weight management Lack of accessible resources	Carers' pivotal role in weight management for this population but lack of research involving adults with intellectual disabilities and their carers.  Lack of accessible weight management interventions, services and resources for adults with intellectual disabilities	The overall synthesised findings imply a need for more equitable support relative to the needs of adults with intellectual disabilities.  Implications for further research, policy and practice in this field.
Phase 1 Exploration of theories	Lack of information on theories used to underpin studies' interventions Gaps in theory-based practice	Lack of financial and other resources for the routine provision of tailored weight management services for this population	
Phase 1 Mapping exercise	Insufficient tailored weight management services for adults with intellectual disabilities Lack of service monitoring and evaluation	Challenges for service commissioners, providers, health care practitioners, adults with intellectual disabilities and their carers	
Phase 2 Synthesised findings from studies involving health care practitioners, adults with intellectual disabilities, and carers	Caring support networks Lack of resources Communication issues and lack of understanding Motivation vs frustration External barriers e.g. widespread availability of less healthy foodstuffs	Frustration with barriers - rather than lack of motivation	

## APPENDIX 25: PUBLISHED JOURNAL ARTICLE

Doherty, A.J., Jones, S.P., Chauhan, U., and Gibson, J.M.E., (2017) [An integrative review of multicomponent weight management interventions for adults with intellectual difficulties.](#) *Journal of Applied Research in Intellectual Disabilities*. pp. 1-13. ISSN 1360-2322