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Talking about food: discussing attitudes towards food, health and obesity with adults with learning disabilities

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Abstract

Obesity and being overweight are known contributors to ill health and are subject to growing concern from health professionals and policy makers. The prevalence of obese and overweight adults is higher in the learning disability population than in the general population for reasons that are unclear. Food choice is influenced by many social and environmental factors. Constructions of health may also affect food choice, influencing the extent to which individuals believe it is worth acting upon healthy eating messages.

This thesis examines the attitudes towards food of adults with learning disabilities and the meanings they attached to health, to healthy eating and to food. Using data gathered from interviews with 23 people with learning disabilities in the Greater Glasgow area, it demonstrates the multiple meanings ascribed to food and the many barriers to food choice people with a learning disability experience. The data found that participants held complex, often competing ideas about health. Many did not believe that it was something over which they could exert any meaningful control and this negatively impacted on their actions to improve their health.

Choice and control were found to be the two most important elements in construction of food choice. Although almost all participants had a good basic knowledge of healthy eating guidelines, decisions about food and food choice were often taken by support workers, parents, family members or other gatekeepers. This lack of choice and control over food was reflected in their opportunities in their wider lives and impacted on their attitudes towards their general health. Participants became disengaged from the processes associated with food and some believed that they were not capable of developing their skills or implementing their dietary knowledge. Further, health was viewed as being subject to luck or the intervention of others. Without a sense of self-efficacy in their wider lives, people with learning disabilities might struggle to make positive changes for their health.

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Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Victoria Williams

30th September 2011

Abbreviations

BMI Body Mass Index

GP General Practitioner

I Interviewer

MRSA Multidrug-Resistant Staphylococcus Aureus- a bacterial infection in humans that is difficult to treat

NHS National Health Service

PA Personal Assistant

PEG Percutaneous endoscopic gastrostomy- a feeding tube leading directly into the stomach

R Respondent

SRV Social Role Valorization

UPIAS Union of the Physically Impaired Against Segregation

WHO World Health Organisation

Chapter 1. Introduction

Obesity is the subject of growing public and academic interest and there is increasing pressure to achieve a 'healthy' body weight. It has been identified by the Scottish Government as being both a serious personal and economic issue due to the social costs and associated health risks (Scottish Government 2010a). It was estimated that, in 2008, 26.8% of adults in Scotland were obese and 65.1% were overweight and, 'as overweight has become the norm, we have developed a distorted view of normal body shape and just how many people in Scotland are overweight and obese' (Scottish Government 2010a:1). Strategies aimed at the individual intend to promote healthy choices 'by communicating practical achievable steps towards the consumption of a healthier diet' and to 'increase access to healthier food choices, particularly for those on low incomes and provide support, education and skill development to allow people to break through barriers of food affordability and availability, and the negative impact of culture and lack of food skills' (Scottish Government 2008:20). Cultural and social norms are known to have a significant impact on eating habits and interpretations of healthy eating messages leading policy to conclude that the problem of obesity must therefore be tackled on a collective, as well as individual, level (Scottish Government 2010a).

The prevalence of overweight and obesity is known to be higher in the learning disability population, compared to the general population (Emerson and Baines 2010; Emerson 2005; Yamaki 2005; Hamilton et al 2007). As well as those barriers faced by the general population, people with learning disabilities potentially face additional barriers including a lack of accessible information and practical and attitudinal barriers to physical activity (Smyth and Bell 2006; Messent et al 1999). Research focussing on obesity rates in people with learning disabilities in Greater Glasgow found that 39.3% of women and 27.8% of men were obese. Given the wide-scale problem of obesity and its particular prevalence in the learning disability community, there is clearly a need to explore the food choices made by people with learning disabilities, the influences on them and the circumstances in which they take place.

Whilst the problems of obesity and overweight are recognised as problems throughout Scotland, they are a particularly significant issue in Glasgow. The diet in Scotland is recognised as being poorer than that of other European countries; for example, less fruit and vegetables are consumed in Scotland and more takeaways are eaten in Scotland compared to the rest of the UK and Europe (Fitzpatrick et al 2010). The quality of diet is known to be socially patterned, with those from higher socio-economic groups eating more lean meat and fish, whole grains and low-fat dairy produce, generally considered to be 'healthier' items, and those from lower socio-economic groups eating more energy dense, lower quality, less 'healthy' foods, including refined grains and added fats (Gray and Leyland 2008). The Glasgow area is the most economically disadvantaged in Scotland and, although high levels of illness and mortality occur across all social classes in the city, they are particularly concentrated in the lower socio-economic groups (Gray and Leyland 2008). The diet in Glasgow has been found to be 'unfavourable' when compared to the rest of Scotland, for reasons that are not always attributable to socio-economic status (Gray and Leyland 2008). It seems, therefore, that influences on diet reflect not only the effects of deprivation but also a wider culture that does not encourage healthy eating.

People with learning disabilities are likely to be particularly at risk of the effects of deprivation and are 'more likely to be to be exposed to common 'social determinants' of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination' (Emerson and Baines 2010:6). Historically, people with learning disabilities have been marginalised (Welshman 2006) but in recent years shifts towards community based care and the promotion of social inclusion have resulted in considerable improvements in their lives. In Scotland, people are not likely to live in institutional accommodation: in 2009, 61% of people with learning disabilities known to local authorities lived in mainstream accommodation, 24% in supported accommodation and only 11% in adult care homes. Of those who were in employment or training for employment (14%), 55% were in open employment (Scottish Consortium for Learning Disability 2010). 61% were reported to have

personal life plans. These plans, outlined in The Same As You? (2000)¹, are intended to use the views of friends, family and professionals, as well as the individual, to create a person-centred, long-term plan to enable the person to lead a fuller life. The plan should include any healthcare needs and should be reviewed on a regular basis to ensure that it is reflective of the individual's needs and goals (Scottish Executive 2000). However, despite UK and Scotland specific policy (Prime Minister's Strategy Unit 2005; Scottish Executive 2000) that aimed to improve the wellbeing of disabled people and promote their inclusion in the community, people with learning disabilities still face considerable health inequalities across a wide range of illnesses and their health needs have been found to be unrecognised and unmet (Emerson and Baines 2010).

Much work has been done on the influences on food choice of the general population but little has considered how people with learning disabilities determine what they eat or why the prevalence of obesity is so high (Melville et al 2008). The individual's relationship with food is often complex and food choice can be a way of expressing the self, an expression of attitudes towards health and a reflection of their cultural landscape (Lupton 1996). Simply providing accessible information is therefore unlikely to bring about substantial change. Instead, it is necessary to understand how and why they make their choices, what their influences are and what they consider to be 'normal'. An understanding of how health is conceptualised is also required as this will affect how health messages, such as those concerning food, are interpreted and whether or not they are implemented. This information is lacking in our knowledge about people with learning disabilities and it is this gap that this thesis aims to address.

It was the aim of this thesis that it be led by the ideas of people with learning disabilities. The genesis of this project came from a conversation I had with a participant during a different piece of research. He was keen to lose weight but was struggling to do so and seemed to find it hard to put his knowledge of healthy eating into practice. A discussion with representatives from Enable's user group, ACE, confirmed that healthy eating, obesity and weight loss were

¹ The Same as You? A Review of Services for People with Learning Disabilities (2000) was published by the Scottish Executive. It looked at service provision for people with learning disabilities and focussed on how these could be provided to support people to live in the community.

issues that they felt were important to their lives and that were in need of more attention and that attitudes towards food was a subject they were interested in. The research is grounded in the social model of disability and takes a participatory approach to the research process: it focuses largely on social and environmental barriers and on relationships with others, rather than looking to the individual's learning disability to provide an explanation for the findings. It is concerned with the lived experiences of the research participants and is informed by their views.

The research aims

Whilst the general aims of this research were set out in the original funding application made to the ESRC, they were refined throughout the course of the research and, in particular, following conversations with ACE group representatives and a review of the literature. Although it is hoped that the research presented in this thesis can contribute to wider discussions on the way people with learning disabilities make food choices and the way this interacts with their attitudes towards health, it should be noted that the study used data from participants in Greater Glasgow and that it is therefore primarily reflective of their experiences.

The research aimed to explore the role of food in the lives of people with learning disabilities in Greater Glasgow and how it interacted with their views of health. In order to achieve this, the following questions were identified:

How do adults with learning disabilities view food?

- What are their perceptions of a healthy diet?
- What do they know about healthy eating?
- Is this important to them?
- Where do they learn about it from? Who could they ask?
- What opportunities do they have to use this information

What food choices are available to adults with learning disabilities?

- What opportunities do participants have to make choices about the food they eat?
- Would they like more choice or less?

- Who/what influences their choices?
- How important is it to have choice and autonomy over food?

What does it mean to be healthy?

- What indicates health?
- What can be done to promote health?
- Can individuals have control over their health?
- What is the relationship between weight and health?

The subject of choice emerged as a key theme in the data as it became apparent that participants frequently lacked the opportunity to make choices about what they ate, thus denying them the opportunity to make use of their knowledge of health and healthy eating. The theme of choice, and an exploration of those who controlled or facilitated choice, is referred to throughout the exploration of the data.

‘Choice’ in this thesis

In analysing the data it became clear that choice underpinned everything in this thesis. Much of the data focuses on choice: the opportunities participants had to choose, and what influenced these choices. ‘Choice’ refers to the action of deciding between two or more options or to the range of options available. The availability of choice is therefore dependent on several factors: that there is more than one option available and that the individual has the power to influence which is chosen (Harris 2003). The latter is particularly relevant when considering choice-making by people with learning disabilities as this is often restricted, not only by the limited availability of options available but because they might be unaware of the extent to which choice is available at all (Harris 2003). Further, a lack of experience of making choices may make people fearful that they will make the ‘wrong’ choice whilst limited communication skills can also be a barrier (Harris 2003). The right to make ‘real’, meaningful choices has been written into policy (Scottish Executive 2000) while choice and control are identified as key components in achieving independent living (Prime Minister’s Strategy Unit 2005). It is identified as ‘a way of asserting one’s identity’ (Jenkinson 1993:361) and as an important influence on quality of life (Stalker and Harris 1998). Several factors must be taken into consideration if choice is to

be facilitated. Historically, choice has often been restricted for people with learning disabilities and ‘too often, autonomy in decision-making is withheld on the grounds of lack of competence or poor judgement, or failure to meet some ideal model of decision-making’ (Jenkinson 1993:364). However, whilst the individual’s capacity to make decisions will be influenced by their ability to take ‘intentional action’ (Harris 2003), opportunities to make choices must be considered in the circumstances in which they occur: difficulty making choices about the long-term does not mean a person cannot make meaningful choices about concrete objects in the short-term (Stalker and Harris 1998). In addition, the way in which choices are made should be considered. Whilst some may be based on an objective analysis of the available information and potential outcomes, choices are also made according to personal preferences, previous experiences, and external influences (Harris 2003). Finally, the ability to make choices independently does not necessarily mean making decisions without the help of others. ‘Real’ choices can also be made with support, in collaboration with others, and with the use of accessible information. For the purposes of this thesis, choice is used to mean the options available to the individual and the process of deciding between them.

The term ‘learning disability’ is used throughout this thesis. This is primarily because it is the dominant term used in Scotland by organisations and in policy documents and is therefore recognisable to academics, those working in the field and by people with learning disabilities themselves. I have not included a definition of ‘learning disability’ and did not apply any sort of test for those willing to take part in the research. Those within the category are a heterogeneous group and therefore labels and definitions cannot tell us who the person is. The people who took part in the research are mostly referred to as ‘participants’ (or by their pseudonym), reflecting the active part they took in directing and informing the research. When talking more generally, the term ‘people with learning disabilities’ is used.

The structure of the thesis

The thesis consists of two literature chapters, a chapter describing the methods used for the data collection and the rationale behind these methods and four data chapters. It concludes with a discussion chapter that draws together the

main themes of the thesis and presents the final conclusions. The chapters are outlined below.

Chapter Two: *Models of Disability: from personal tragedy to equal access*

explores differing approaches to disability and places the research within the social model of disability. The chapter focuses on the medical model, normalisation and the social model of disability, giving an insight into the background to policy development. It then turns to look at critiques of the social model, including the absence of impairment, and considers attempts to rectify this, giving particular consideration to the development of a social-relational model and the concept of psycho-emotional disablism. Finally, it considers the potential exclusion of people with learning disabilities within the social model before considering how it can be used to analyse their experiences.

The second literature chapter, **Chapter Three: *Obesity, food choice and people with learning disabilities*** looks at obesity and general health and considers some of the health issues specific to people with learning disabilities. It problematises the issue of obesity in the learning disability community, exploring its prevalence and causes as suggested in the literature. It then examines some of the influences on food choices both in the general population and people with learning disabilities. It establishes that influences on food choice are complex and multiple and include environmental, social and personal factors which are mediated by the extent to which the individual is able to exercise choice and control.

Having contextualised this research in relation to existing work, **Chapter Four: *Methodology*** focuses on the research methods used. It starts with a discussion of the theoretical starting point of the research, outlining the reasons for committing to a participatory research approach. It then explores methodological issues relevant to doing research with people with learning disabilities and considers what adjustments might be required to ensure that they are able to contribute. The chapter then looks at the research design for this thesis: information-gathering focus groups, followed by several in depth interviews with twenty three participants and a grounded theory approach to the analysis. It explores ethical issues related to doing research with people with

learning disabilities and reflexively considers the role of the researcher in the research process.

The following four chapters present the findings from the data analysis. Chapters five and six, the first two data chapters, look at food in the lives of the participants. **Chapter Five: *Food: control and choice*** starts by looking at the opportunities participants had to exercise choice and control in their lives, focussing on food choice. The influence of others in mediating choice is explored and a gatekeeping role is established. Attitudes towards food choice are then explored and it is demonstrated that, while some participants were keen to have more control over what they ate, others doubted their own ability to become more involved with food.

The second data chapter, **Chapter Six: *Food: influences and understanding***, explores the meanings and roles participants ascribed to food. In particular, the way participants distinguished between ‘healthy’, ‘unhealthy’ and ‘ordinary’ food is discussed and the effect that this had on food choices is examined. The second half of the chapter looks at the broad influences on food choice, including other people, established norms, time and healthy eating information. It concludes by looking at participants’ responses to a campaign to promote consumption of fruit and vegetables.

Chapters seven and eight explore the participants’ concepts of health. **Chapter Seven: *Health concepts and control*** starts by looking at participants’ notion of control over their own health and the extent to which they felt they were able to influence it. It identifies three sets of beliefs. Some participants believed that they could positively influence their health; others believed that they might be able to with input from others, such as health professionals; finally, some participants believed that health was controlled by fate and so was not something they could influence although they did believe it was worthwhile seeking treatment if they were unwell. The chapter then considers participants’ concepts of health, drawing on the work of Blaxter (1990).

The final data chapter looks at the actions participants thought could improve health. **Chapter Eight: *Improving health, losing weight*** explores motivations for

taking action to improve their health and the barriers that prevented it. Weight was frequently connected to concepts of health and this relationship is explored. It looks at the effects being overweight had on the participants lives, whether or not they wished to lose weight and what prevented them from doing so. It concludes by considering how concepts of health impacted on their views on weight loss and diet.

Finally, **Chapter Nine: *Discussion and conclusion*** presents conclusions from the research and a discussion on the overarching themes to emerge from the data analysis. It highlights the importance of considering the opportunities for choice and control available to the participants and their experiences of psycho-emotional disablism when identifying the influences on their food choices. The implications for policy and some limitations of the study are discussed. Future areas of research are suggested; in particular it is proposed that further research into people with learning disabilities experiences of psycho-emotional disablism could give a useful insight into their experiences and highlight many of the barriers to being that they face. It concludes that choice is a key issue for many people with learning disabilities and that a lack of control over everyday matters, such as diet, results in a failure to believe that they can affect change in the long term.

Chapter 2. Models of disability: from personal tragedy to equal access

This chapter aims to explore how the social sciences have approached disability in order to contextualise the place of people with learning disabilities within policy and methods of service delivery. It also outlines the theoretical context within which this research has been conducted.

There have been a number of ways in which disability has been viewed, affecting the treatment of and opportunities available for disabled people. This chapter begins by looking at the medical, or individual, model of disability. This model has been dominant in shaping beliefs and expectations of disabled people and has contributed to the oppression and discrimination they have experienced. The chapter then explores the normalization principle, a highly influential force in service provision for adults with learning disabilities. Whilst this principle is not applied in this thesis it is important to be aware of the main points as its impact is seen in much of the service provision for adults with learning disabilities and in the approaches of professionals. This is followed with a critique of the principle which highlights the theory's failure to adequately represent the experiences of disabled people.

The chapter then moves on to look at the social model of disability. This is the approach that frames this research and its theory of disability will be outlined. This will be followed by criticisms of the model, in particular that it does not take into account the impact of impairment. Finally, the social model as applied to learning disability will be examined. Although some proponents of the social model might argue that specific impairments should not be discussed (for example Oliver 1999) it is necessary to explore how the model can be applied to this group if it is to inform the data analysis for this research.

2.1 The medical model

The medical model, also known as the individual or personal tragedy model, was the dominant model of disability until challenged by the disability movement

and critiqued by a social model analysis. It refers to a collection of approaches to disability and the impaired individual that associate disability with specific, diagnosed conditions characterised by bodily impairments (Barnes and Mercer 2010). This section will look at these approaches and the influence they had on the treatment of disabled people and their role in society before considering why the disability movement developed an alternative model.

Oliver argued that ‘almost all studies of disability have a grand theory underpinning them. That grand theory can be described as “the personal tragedy theory of disability”’ (Oliver 1990:1) and is an inherent part of the medical model approach. It is this that he and others have challenged in political and theoretical terms with the social model of disability. The theory locates disability in the individual and focuses on the apparent functional limitations of the disabled person. This is then reflected in public policy and society’s views of disabled people leading them to ‘be treated as if they are the victims of some tragic happening or circumstance’ (Oliver 1990: 2) both in social relations and in public policy.

The basis of the medical model is that disability is an individual problem, arising from impairment, to be treated through healthcare and managed through the welfare system: ‘the assumption is, in health terms, that disability is a pathology and, in welfare terms, that disability is a social problem’ (Oliver 1996b:30). Functional limitations experienced by the individual are believed to arise from their impairment, a view widely accepted by medical and allied professionals as well as wider society (Barnes and Mercer 2010). Disability is therefore assumed to be a medical, rather than social, issue and it is assumed that the appropriate response to disability is to work towards a cure or rehabilitation whilst the individual is ‘looked after’ by the social care system. The expectation is that disabled people will submit to treatment of the impairment regardless of the impact of such treatment on aspects of their wider lives (Oliver and Barnes 1998).

Disabled people have been subjected to classification to determine their eligibility for state support in the modern industrialised world (Oliver and Barnes 1998), leading to the categorisation of impairment and specific aspects of

functional ability by professional experts. A three tier definition was developed and used, most notably by the World Health Organisation in 1980. This separated impairment, disability, and handicap. 'Impairment' constituted 'those parts or systems of the body that do not work properly' (Barnes and Mercer 2010:20), whilst 'disability' 'centres on the (functional) activities that an individual cannot accomplish' (Barnes and Mercer 2010:20) as a result of the impairment. 'Handicap' was defined as the disadvantage that arises because of impairment or disability (Barnes and Mercer 2010). The framework was redeveloped and the International Classification of Functioning, Disability and Health was officially endorsed by the World Health Organisation (WHO) in 2001. It focuses on the notion of function and the ways in which bodily and interpersonal functions interact with the individual's environment, thus attempting to capture a wider sense of the lived experience of health. Function and disability are conceptualised as being part of a broader continuum of health. However, whilst the definition takes into account the impact of social disadvantage, the root of barriers to participants is still associated with the individual impairment.

The assumption of impairment as an individual problem compounded the social exclusion of disabled people, who are regarded as 'passive objects of intervention, treatment and rehabilitation' (Oliver 1990: 5). Thus it is argued that the medical model causes the oppression of disabled people as they are defined according to their impairment which, in turn, is assumed to be the cause of their disability (Oliver 1990). This has historically led to the exclusion of disabled people from a society they are unable to participate in due to its failure to accommodate their impairments and the organisation of services that look at treatment and managing the needs of individuals rather than the barriers that prevent inclusion.

The dominance of the medical profession in the lives of people with learning disabilities was demonstrated when the newly founded National Health Service (NHS) became responsible for the institutions previously run by local authorities, voluntary organisations and private providers in 1948 (Welshman 2006). Once diagnosed, a learning disability was frequently regarded as an individual's dominant characteristic. People with learning disabilities were viewed as individuals whose 'passivity and neediness were unquestioned. They were seen

as people who needed physical care and control, either within institutions or carefully policed within their families on the basis of an unchanging and unchangeable individualised pathology' (Welshman 2006:17). The view of learning disability as a static condition began to be challenged but despite research that argued that people with learning disabilities could, in fact, benefit from education and training the focus remained on the limiting effects of the impairment rather than truly providing opportunities for the individual (Welshman 2006).

Impairment classification, the potential for rehabilitation and institutionalisation were dominant approaches to learning disability until critiques of institutional care by sociologists in the 1960s (Welshman 2006, Walmsley 2006). These studies 'painted a bleak picture of isolation, meaningless routines, impoverished surroundings and demoralised residents' (Walmsley 2006: 41), whilst it was found that many did not require the level of medical care that had previously been assumed. These findings helped fuel the demand for a move away from care in large institutions and into smaller hostels in towns and cities as part of a method of service provision known as care in the community (Welshman 2006). The ideology of service provision shifted from being focussed on bricks and mortar institutions to one that promoted care in a community setting and, increasingly, independent living and individualised support. Initially, it focussed on providing services that supported family carers and care within the home whilst enabling disabled people to live 'ordinary' lives within their local community (Dalley 1989). However, it was criticised for failing to achieve the latter as services were organised in ways that allowed disabled people little control or choice, restricting their work and leisure opportunities and creating a complex array of services, providers and settings (Barnes and Mercer 2003). The system was reformed in the early 1990s with the Community Care Act (1990) which created a 'mixed economy of care', combining private, voluntary and public sector services with the aim of improving consumer choice in the social care market (Barnes and Mercer 2003). Disability activists have lobbied for increased control of social care provision with some success (see, for example, the Community Care (Direct Payments) Act (1996) Barnes and Mercer 2010). These legislative changes were intended for all user groups. (Walmsley 2006). However, whilst people with learning disabilities 'were included in ideological

shifts in the meaning of Community Care... learning disability retained a distinct identity' (Walmsley 2006:41). This is perhaps because another model was developed, largely by practitioners, which aimed to integrate people with learning disabilities into mainstream society. The normalization model and the subsequent theory of Social Role Valorization (SRV) influenced the development of services and the way that learning disability is viewed and managed and it is this that will be examined next.

2.2 Normalization

The impact of normalization on the lives of people with learning disabilities is considerable. It has variously been described as 'probably the most decisive influence on late twentieth-century services and thinking about learning disability' (Walmsley 2006:42), 'a dominant force in social and educational policy' (Culham and Nind 2003:65) and is 'perhaps the key theoretical position' for services for people with learning disabilities (Yates et al 2008:247).

Normalization and SRV are ideologies that are intended to be directly applied to service design and delivery. They look beyond medical treatment and rehabilitation to consider promoting the social integration of people with learning disabilities. The concept of SRV builds on the principle of normalization and provides guidelines on how people with learning disabilities can be helped to overcome the negative stereotypes they face and achieve greater social interaction. This section of the chapter looks at the meaning of normalization and SRV and the impact they have had on the way learning disability is viewed.

The aim of normalization is to make it possible for disabled people to access 'those patterns of life and conditions of everyday living that are as close as possible to, or indeed the same as, the regular circumstances and ways of life of their communities and their culture' (Nirje 1999:17). Eight areas which a disabled person should be able to experience 'normally' were identified. These were:

1. A normal rhythm of the day.
2. A normal rhythm of the week.
3. A normal rhythm of the year.

4. The normal experience of the life cycle.
5. Normal respect for the individual and the right to self-determination.
6. The normal sexual patterns of their culture.
7. The normal economic patterns and rights of their society.
8. The normal environment patterns and standards in their community.

(Nirje 1999:17)

In practice this meant the integration and inclusion in society of people with learning disabilities and the opportunity to have the same standard of living as other members of the community. In particular, it was intended to bring an end to institutional living. 'Normal' is used to mean what the average member of society would want for themselves (Nirje 1999) and should be interpreted in a way that is culturally appropriate for the specific circumstance. The principle was developed to influence policy and service provision on a broad level whilst also providing a set of goals for disabled people and service providers when planning support for individuals.

The principle of normalization has been adopted and expanded by others, in particular by Wolf Wolfensberger who developed the theory of SRV (Walmsley 2006). Bengt Nirje had focussed on the arrangement of services, based on the assumption that the individual had the right to participate in society; indeed, this iteration placed integration secondary to the issues of human rights and equality (Culham and Nind 2003). Wolfensberger developed the concept of normalization further. He felt that people with learning disabilities were devalued by society and argued that, if true 'normalization' were to occur, segregation must end and social interaction must take place whilst 'culturally valued means' must be employed 'to enable, establish, and/or maintain valued social roles for people' (Wolfensberger and Tullman 1982:131). The concepts of deviancy, stigma and public perception were central to Wolfensberger's work and he argued that, in addition to changes to everyday living proposed in the Scandinavian model, people with learning disabilities should 'engage in a positive way with socially valued activities, thus giving people a positive social role, enhancing their personal competencies and bolstering their social image' (Yates et al 2008:248).

The creation of valued social roles is particularly important as ‘handicapped individuals are frequently perceived as deviant’ (Wolfensberger 1972:13) due to differences or significant characteristics that are negatively valued by a section of society which holds power or defines what is ‘normal’ (Wolfensberger and Tullman 1982). When viewed this way, in contrast to an impairment-based view of disability, learning disability becomes ‘an acquired social status, defined and perceived according to the type of performance expected of persons holding that status’ (Manion and Bersani 1987:237). Wolfensberger suggests that ‘devalued people will be treated badly’ and will internalise the low expectations that others have of them, limiting their behaviour accordingly (Wolfensberger and Tullman 1982:132). However, he argues that devaluation often occurs subconsciously and so the resulting discrimination is not deliberate and wider social change is hard (Wolfensberger and Tullman 1982). So, although the effect society has on the lives of people with learning disabilities is acknowledged, SRV emphasises individual change to enhance social status and shake off the ‘deviant’ tag rather than broader social change.

The model aims to tackle this by constructing services to help people with learning disabilities to take on roles that are positively valued and shed the behaviour and characteristics that are negatively valued and cause them to be seen as deviant. This, it is argued, will make social acceptance more likely. Dressing appropriately and avoiding socialising with other devalued groups or individuals should be encouraged (Wolfensberger and Tullman 1982) whilst using services for the general public rather than those specifically for disabled people is advocated as this will confer positive images and encourage socially appropriate behaviour in line with the ‘norm’ (Yates et al 2008). The initial action by the individual will then provoke action in socially valued areas, such as workplaces and generic community services, and on a societal level by changing laws and social expectations (Yates et al 2008). These actions will enable people to become ‘valued’ members of society.

2.2.1 Influence of normalization and SRV in the UK

The influence of normalization and SRV has been seen since the 1970s in service provision. It has contributed to the introduction of a rights-based discussion on service provision for adults with learning disabilities (Walmsley 2006) and ‘it is

difficult to deny that for many people there has been a tremendous shift towards a more “normal” way of life’ (Culham and Nind 2003). Normalization has allies in the UK who have campaigned for policy makers to adhere to its principles (Walmsley 2006) and ‘in the circumstances in which it was coined, when many people with learning disabilities were confined to large-scale specialist residential institutions, it made a good deal of sense to review service philosophies with ‘normalization’ in mind’ (Brown and Walmsley 1997:227). Its influence can be seen in various areas of policy including the Scottish policy document *The Same as You? A review of services for people with learning disabilities* (2000), which states that ‘people with learning disabilities should be able to lead normal lives’, and the emphasis on community participation in the recent drive for Self Directed Support (Scottish Government 2010). Services for adults with learning disabilities are now closer to those espoused by advocates of normalization: people are likely to live in their own homes and are more likely to be engaged in activities tailored to their preferences, although day centres and adult training centres still operate.

The move to house people with learning disabilities in the community in ‘ordinary’ houses, rather than hospitals or hostels, reflects the principles of integration seen in normalization and was encouraged by its supporters (Brown and Walmsley 1997). However, although dismantling the large institutions and re-housing people in the community does not itself necessarily result in an end to exclusion it was often emphasised as a goal in its own right and this contributed to a lack of adequate support in the community for some people with learning disabilities (Brown and Walmsley 1997). Applying the principles of normalization on an individual level can also be problematic as staff are more likely to be working alone or as part of a small team and so are left to interpret the policy behind service design with fewer opportunities to learn best practice from others (Brown and Walmsley 1997).

2.2.2 Criticisms of normalization

There have been various critiques of the principles of normalization and SRV. These include its inability to adequately account for the experiences of disabled people or their oppression because it is underpinned by medical model ideology (Oliver 1999), the failure to challenge power held by service providers and

professionals (Chappell 1992, Culham and Nind 2003) and a lack of detail as to how political change can be brought about (Chappell 1997, Oliver 1999). The principle is also criticised for continuing the normal/abnormal dichotomy through the discussion of normalization and valued social roles (Chappell 1992, Culham and Nind 2003). The main points of these critiques will be outlined here before the chapter explores the social model, a theory that aims to provide an explanation for the oppression of disabled people.

Professional / service user power balance

Normalization has been criticised for failing to bring a radical change in the balance of power between professionals and disabled people:

...the status quo... has been largely unchallenged. The power dynamic in which professionals hold on to key decision-making is unthreatened. (Culham and Nind 2003:70).

Chappell takes this argument further, stating that normalization ignores the power relationship between practitioner and service user and starts with the assumption that people with learning disabilities need professionals (Chappell 1992). This is a reflection of the fact that the theory is for and by practitioners who work with people with learning disabilities: much of the writing looks at the implementation of normalization whilst various key features, such as the definitions of quality of life and quality of care, have been defined according to the normalization principle rather than the views of service users (Chappell 1992).

Normalization has been described as offering 'a theory of services, but not a theory of disability' (Chappell 1992:40) as it aims to work with existing structures, albeit to bring change, and does not examine the assumptions on which they are based. Whilst service delivery might have changed, this has not automatically brought about changes in attitudes or approaches nor has normalization given people the power to determine their own support: 'the material fact remains, it is still professionals doing it, whatever 'it' is called, to disabled people' (Oliver 1999:166). Further, the blame for the assumed social devaluation in the SRV model has fallen on people with learning disabilities,

seemingly confirming the need for practitioners to take responsibility for helping them to achieve social acceptance (Culham and Nind 2003).

The zeal of normalization advocates has meant that to criticise the ideology was assumed to mean a negative attitude towards people with learning disabilities and it was suggested that ‘those who are sceptical about normalization have failed to acknowledge their own subconscious fears and negative values about people with learning difficulties’ (Chappell 1997: 3). The association of the theory with the move away from institutionalisation also made it hard to criticise normalization for fear of undermining the move away from institutional care. Further, as normalization is concerned with the provision of human services their existence, and that of the practitioner, is inherent in the theory and thus they are written into new models of practice post deinstitutionalisation (Chappell 1992).

Perpetuating notions of the ‘abnormal’ individual

The theories of normalization and SRV have been criticised for continuing the normal/abnormal dichotomy whilst failing to bring about rights-based change. SRV assumes that society views people with learning disabilities as being deviant and offers a way for them to overcome this negative image. Oliver argues that rather than providing a way to challenge social expectations this continues the theme of control that was present in the institutions as people should be ‘normalised’ before they are integrated into society. Further, continuing to talk about people with learning disabilities as ‘deviant’, or ‘abnormal’ can perpetuate the view that they, indeed, are deviant or abnormal, even if it is intended that this view is understood to be a social construction rather than a characteristic of the individual (Oliver 1999:167).

The distinction between ‘normal’ and ‘abnormal’ is criticised as too blunt a tool to describe a society characterised by difference. Although its proponents argue that normalization is not about making the individual ‘normal’², but is instead

² ‘Probably the most common misinterpretation of the normalization principle is the mistaken belief that it means mentally handicapped people [sic] must be expected to, indeed be forced to, act ‘normal’, to conform in all respects to society’s statistical norms for all dimensions of behaviour... normalization does not mean normalcy; it does mean that people should be normalised... normalization means the acceptance of a person with their handicap within ‘normal’ society’ (Perrin and Nirje 1985:69-70, quoted in Culham and Nind 2003).

about making ‘normal’ patterns of life available whilst creating conditions in which ‘normal’ society is accepting of difference, Oliver suggests you cannot do that without also implying that a person is being made ‘normal’ (Oliver 1999). Further, although the theoretical model might be clear that normalization is about acceptance of difference in ‘normal’ society (Perrin and Nirje 1985, quoted in Culham and Nind 2003) and is intended to be ‘more “nuanced”, balancing ideals of decreasing devaluation and respecting the choices of people with learning difficulties themselves’ (Yates et al 2008:249) this is not necessarily how it has been interpreted by practitioners who took it to mean that conformity was valued over difference (Culham and Nind 2003).

The argument that people are not asked to change themselves is somewhat undermined by elements of SRV which require the individual to shed characteristics associated with their (devalued and devaluing) impairment, including socialising with other devalued people, and to adopt ‘valued’ roles and actions. Chappell argues that, by constructing valued social roles, services are ‘in danger of failing to support the valuable characteristics of people with learning difficulties. The emphasis was on making them conform rather than on unconditional acceptance’ (Chappell 1997:3). This is particularly the case when the model rests on the belief that people with learning disabilities are stigmatised:

[Normalization] demonstrates an unquestioning acceptance of the concept of stigmatised identities. There is no recognition of stigma itself as a social construct: a mark imposed by an economically, socially and politically powerful group on one which is economically, socially and politically disempowered. (Chappell 1997:4)

Normalization therefore does not explain why disabled people came to occupy a stigmatised place in society and it is this criticism of the principle that is considered next.

Normalization and social and political change

A fundamental critique of normalization is that ‘it offers no satisfactory explanation of why disabled people are oppressed in capitalist societies and no

strategy for liberating us from the chains of that oppression.’ (Oliver 1999:164). The principle fails to take account of the material constraints faced by disabled people and the reasons why a stigmatised identity is constructed (Chappell 1992). Normalization assumes the problems associated with a learning disability stem from that impairment but when considered in a social model framework, cognitive impairment becomes problematic ‘only when the society in which [the individual] is resident is materially organised in such a way that particular qualities become important’ (Chappell 1992:44). People with learning disabilities are not just disabled by others’ attitudes towards them or their impairment but because of a complex interaction of factors, including poverty, marginalisation and disempowerment; normalization does not help to explain why this is (Chappell 1992). It is these factors that need to be addressed if people with learning disabilities are to achieve some sort of social parity. These issues are key to the social model of disability, which will be looked at in much greater detail in the following section.

Whilst normalization represented a radical change to the previous approaches to learning disability, and in particular the dominance of separation and containment, it is argued that it does not tackle the underlying devaluing of people with learning disabilities but instead focuses on what can be done to fit them into mainstream society. The determination to be rid of characteristics associated with disability which, according to SRV, devalue the individual can result in the denial of real need: Brown and Walmsley (1997) cite the discouragement of wheelchair use, for example. Normalization could, ‘if unchecked, lead to a desire to “normalise” people’s individual differences and a requirement that they should conform in order to gain acceptance’ (Walmsley 2006). Normalised behaviour cannot guarantee inclusion and people living ‘normal’ lives can still be subjected to harassment or social isolation. Further, the approach does not take account of the fact that ‘social norms are not neutral’ and even ‘reproduces other discriminatory norms’ (Chappell 1997:3) thus not contributing to lasting social change for people with learning disabilities.

The theory has been criticised for failing to speak for disabled people or reflect their experiences. Oliver suggests this is demonstrated by the fact that, at the

time of writing, the principle had not been adopted by any organisations of disabled people (Oliver 1999). This is important if disabled people are to be instrumental in defining how they are regarded. Chappell also notes that the principle did not resonate with disabled people despite normalization's claim to articulate their experiences (Chappell 1997). In particular, the very notion of a 'normal' life as something that disabled people should aspire to has been challenged:

... one of the most offensive features of prejudice which disabled people experience is the assumption that we want to be other than we are; that is, we want to be normal (Morris 1991:34).

Normalization is criticised for not detailing how political change can be brought about:

One can only assume from normalization writings that political change will be a gift from the powerful to the powerless once they have come to a true understanding of disability through exposure to the teachings of normalization and social role valorization (Oliver 1999:171).

As normalization focuses on redesigning service provision the continued control of service providers is implicit in the theory. Relationships with other disabled people are thought to contribute to social devaluation and reinforce stigmatised identities as 'evidence of a failure to integrate into able-bodied society' (Chappell 1992:45), denying the positive experiences such relationships can bring and reducing opportunities for collective action.

Normalization largely focussed on service provision which has meant that the views of professionals have often been prioritised over those of disabled people (Chappell 1992) and the medical model of disability has been upheld. Normalization argues for the transformation of services without adequately exploring why services are required or whether they reflect the needs of people with learning disabilities (Chappell 1992). Although the philosophy promoted the notion that people with learning disabilities had the right to be active citizens it

has concentrated on the individual, rather than addressing the wider issues of discrimination and social barriers to participation faced by disabled people. It is primarily a model of service provision that focuses on meeting the needs of people with learning disabilities. The fundamental critique of normalization, therefore, is that it ‘fails to provide a theory of *disability* that takes account of the material constraints in the lives of people with learning difficulties’ (Chappell 1992:39). This is a critique that has been levelled at the individual and medical models of disability and forms the basis of the social model approach which, in contrast aims to be emancipatory, creating a model of disability that is of use to all disabled people. It is this that the chapter explores next.

2.3 The social model of disability

The social model of disability offered a radical new perspective on disability and was a political response to the dominance of the medical model. The following section outlines the challenges the model made to the dominant views of disability before discussing the approach it introduced.

Inspired by other social movements in the 1960s and 1970s, disability activists began to campaign for fairer treatment and to highlight the discrimination they experienced. Rather than look at reforming welfare provision disabled people, like the feminist and civil rights campaigners, began to frame their needs in terms of rights and equal opportunities. It was from this change in perspective that the social model of disability emerged.

The new campaign groups were controlled by and made up of disabled people unlike previous disability interest groups that had spoken on behalf of those they claimed to represent. They campaigned on issues such as institutionalisation and exclusion from the workplace and highlighted the discrimination that occurred (Thomas 2002). The Union of the Physically Impaired Against Segregation (UPIAS) was one such organisation of disabled people which sought to raise disability issues on the political agenda (Oliver 1996). Its statement separating disability from impairment has been central to the formation of the social model. In summary, impairment is defined as:

Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.

In contrast disability is defined as:

The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

(Barnes et al 2000:28, from UPIAS 1976)

Unlike the WHO definition mentioned at the start of the chapter, disability does not stem from impairment, and therefore the individual. Instead the 'definition locates the causes of disability squarely within society and social organisation' (Oliver 1990:11).

These ideas were taken forward by academics, many of whom were also part of the disability movement. It was argued that previous academic disciplines had failed to provide adequate theories of impairment and disability, instead grounding discussions in the individual model and even acting as 'a hindrance rather than a help to disabled people' (Abberley 1987:5). A new discipline, Disability Studies, was developed to explore this gap in understanding using the social model.

Whilst there are various interpretations of the social model there are four themes central to each version (Burchardt 2004). First is the distinction between impairment and disability, described above. Disability is no longer regarded as stemming from individual impairment but is recognised as 'the outcome of an oppressive relationship between people with impairments and the rest of society' (Finklestein 1980:47). When disability is framed this way, external barriers, rather than impairment, are highlighted as the main cause of the exclusion from the participation in society of disabled people, leading to calls for greater accessibility to the built environment, employment and personal interaction, for example. It is not acceptable to ask that the individual adapt or

change when they are excluded by a structure imposed upon them. As Gleeson argues,

...the social construction of physically impaired people as *disabled* people arises, in the first instance, from the specific ways in which society organises its basic material activities (work, transport, leisure, domestic activities). Attitudes, discourses and symbolic representations are, of course, critical to the reproduction of disablement, but are themselves the product of the social practices which society undertakes in order to meet its basic material needs.
(Gleeson 1997:194).

Within the model is the understanding that the demand for inclusion and accessibility is rights-based: if disability is a result of social barriers, rather than individual impairment, 'it is a matter of social justice that these barriers should be dismantled' (Burchardt 2004:736). Finally it is recognised that social change is required to end discrimination and that this requires collective action from disabled people. Importantly, it needs people with impairments to identify themselves as disabled in a political sense and to identify with the social model rather than the viewing their disability as a personal tragedy (Burchardt 2004). This can be achieved by acknowledging a collective experience of cultural and material oppression (Abberley 1987; Priestley 1998).

To understand how people came to be disabled it is necessary to look at the way disabled people have been treated historically. Oliver (1990) applies a materialist analysis to the recent history of disabled people and attributes their exclusion from modern society to industrialisation and the rise of capitalism, stating that 'the individualisation of life under capitalism has contributed to the individualisation of disability' (Oliver 1990:42).

The movement of work from the home into more standardised settings and tasks made it harder for people who did not conform to these 'standards' to obtain employment. Disabled people were not considered to be responsible for their inability to work and so, with confirmation from the medical profession, were determined to be eligible for public assistance (Barnes and Mercer 2010). State

responses, such as institutions and welfare payments, legitimised exclusion from employment and the creation of a physical norm which it was assumed that the disabled person would aspire to (Oliver 1990). The provision of welfare in institutions removed disabled people from the community and, by grouping them with other, apparently less ‘deserving’ recipients of benefits, caused them to be stigmatised (Barnes and Mercer 2010). Even when support is provided in the community it often leaves the recipient financially unable to participate in society. As a result, disabled people have been marginalised, a position that is reinforced by the medicalisation of difference.

The dominance of the medical profession in defining disability contributed to the oppression of disabled people and belief in the personal tragedy approach (Oliver 1990, Barnes and Mercer 2003). The assumption was that medical treatment was progressive as it aimed to cure or ameliorate the ‘problem’ of impairment and so the involvement of the medical profession went largely unquestioned. However, the concentration on impairment leads to a very narrow view of the lives of disabled people and whilst treatment might alleviate a specific condition it does not guarantee it is in the best interest of the person (Oliver 1990). Instead, it continues the assumption that what is required is rehabilitation or cure so that the person is better able to conform to ‘the ideology of the able-bodied and able-minded individual’ (Oliver 1990:55). The involvement of doctors and other health professionals went beyond diagnosis, treatment and management of medical conditions into, amongst other areas, ‘assessing driving ability, prescribing wheelchairs, determining the allocation of financial benefits, selecting educational provision and measuring work capabilities and potential; in none of these cases is it immediately obvious that medical training qualifications make doctors the most appropriate persons to be so involved’ (Oliver 1990: 48). Not only does the focus on impairment ignore the disabling effects of an inaccessible society but the deference to the ‘expert professional’ excludes disabled people and renders them passive participants in their own lives.

The social model conceptualised the marginalisation of disabled people by framing disability as being caused by social and material barriers to participation (Oliver 1990). This model grew out of the disability movement and has been

developed by and for disabled people and this is perhaps the most powerful reason for employing it in research with disabled people. However the model is by no means flawless and has been criticised for failing to account for the impact of impairment. The chapter will next turn to explore critiques of the social model of disability before looking at how it can be applied to the experiences of people with learning disabilities.

2.4 Critique of social model

Whilst the social model of disability is heralded as a powerful political tool for social change it has been criticised as a research model for having ‘an overly narrow and flawed conception of disability’ (Shakespeare 2006:9). The success of the model in achieving legislative change has led it to be described as the ‘sacred cow’ of the disability movement, making others reluctant to criticise it (Shakespeare and Watson 2002) whilst rigid adherence to the social model framework is criticised for contributing to the stagnation of the disability movement and the exploration of what it means to be disabled (Shakespeare 2006).

The mainstream models of disability are criticised for no longer being adequate in capturing the range of issues and experiences of disabled people:

Both the medical model and the social model seek to explain disability universally, and end up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people’s lives and of their knowledge. The global experience of disabled people is too complex to be rendered within one unitary model or set of ideas. (Corker and Shakespeare 2002:15)

Proponents of the social model have used the framework to identify barriers to inclusion and participation with the aim of bringing about social change and have concentrated on looking ‘outwards’ rather than considering the experiences of disabled people living with impairment (Thomas 2001). Social barriers have been identified as the cause of disability and the effects of impairment have tended to be ignored. The social model has been criticised for presenting disability and

impairment as a dichotomy (Thomas 2001, Shakespeare 2006) thus preventing meaningful discussion about the experience and impact of impairment. It has been criticised for being too narrow in its exploration of barriers to inclusion (Thomas 1999). Critiques have concerned the absence of impairment and individual experience (Shakespeare 2006, Morris 1991, French 1993) in the social model framework and for not taking sufficient account of factors that contribute to the oppression of disabled people (Stuart 1992). Further, it has been criticised for its implicit focus on physical impairment and subsequent lack of engagement with people with learning disabilities (Chappell 1997; Chappell et al 2001), and this is explored in more detail in a later section of this chapter. Whilst Oliver states that the focus of the social model was at least, in part, intended to maintain the emphasis on political and social change (Oliver 1996c) it is argued that this ultimately weakens the model. The following section will look at these critiques before outlining how it has been suggested that the social model might be developed.

2.4.1 Individual experiences of disability

As discussed earlier in the chapter, Oliver's (1990, 1996) theory of disability focuses on materialist oppression and reasons that disability is caused by social organisation. Disabled people were assumed to be united in their oppression and able to recognise that they were disabled by external barriers. Whilst this helped to put across a powerful message it is problematic:

...[disabled people] are geographically dispersed and socially and culturally dissimilar; in addition they are one of the most powerless groups in society and may themselves have negative attitudes about disability and towards people with dissimilar impairments to their own, leading to considerable distancing between them (French 1993:22).

Feminist academics have contributed to the critique of the social model through the application of feminist epistemology to disability (Thomas 2001) By applying the idea that 'the personal is political', they have criticised the social model for failing to include personal accounts of disability (see, for example, Morris 1991, Thomas 2001, Wendell 2001). In doing so, the model risks presenting disabled people as a homogenous group, denying individual identity and overlooking the

fact that, at an individual level, 'disablement is felt as the outcome of the withholding of social and cultural recognition' rather than simply as a lack of material opportunities (Watson 2004).

Individuals might identify with other characteristics, such as gender or ethnicity, that they feel have equal or greater impact on their lives. Feminist writers have spoken of the marginalisation of women in the disability movement and the need to consider how disability and gender interact so that the differing experiences of men and women can be explored (Morris 1993). There have also been calls to consider the experience of black disabled people who have been described as experiencing a 'simultaneous oppression' (Stuart 1992:179), distinct from that experienced by other disabled people or other black people and which separates them both from white communities and non-disabled black communities (Stuart 1992, 1993). Research exploring the 'reality' of living as a disabled person would contribute towards a more comprehensive theory of disability. Such research challenges common notions of what it means to be disabled: '[it] establishes disabled people as active agents, as subjects rather than objects and allows disabled people to see themselves as a member of a social group who can accomplish things and whose worth is recognised by all members of society' (Watson 2004:119).

2.4.2 Social relational model of disability and psycho-emotional disablism

Thomas (1999) aimed to broaden the social model framework by developing a social relational model. First, she builds on the definition put forward by UPIAS by framing disability as a form of social oppression: it is 'an unequal social relationship between those who are impaired and those who are non-impaired, or 'normal', in society... so the concept of disability refers to the relationship of ascendancy of the non-impaired over the impaired' (Thomas 1999:40). Disability occurs as a result of 'the social imposition of restrictions of activity on impaired people' and 'manifests itself through exclusionary and oppressive practices- *disablism*- at the interpersonal, organisational, cultural and socio-structural levels in particular social contexts' (Thomas 1999:40). Whilst the effects of impairment do not necessarily constitute disability, they may result in restrictions of activity if these effects cause others to assume that the disabled person is not capable of other actions. Thus, the effects of impairment need not

be ignored within the model but should not be assumed to be the cause of disability (Thomas 1999).

The social model focuses largely on barriers to 'doing' and does not, Thomas argues, help to understand the social barriers to 'being' (Thomas 1999). In addition to barriers to participation, disablism operates to 'shape personal identity, subjectivity or the landscapes of our interior worlds' (Thomas 1999:46). This effect is termed the 'psycho-emotional dimension of disablism':

...psycho-emotional disablism involves the intended or unintended 'hurtful' words and social actions of non-disabled people (parents, professionals, complete strangers, others) in inter-personal engagements with people with impairments. It also involves the creation, placement and use of denigrating images of 'people with impairments' in public spaces by the non-disabled. (Thomas 2007:72).

This type of disablism can result in internal barriers:

...the cumulative impact of psycho-emotional disablism can lead to 'barriers to being' meaning restrictions on who an individual feels they can be or become, their inner worlds, sense of self and social behaviours being negatively shaped by these experiences (Stalker, 2012 forthcoming:3).

Although the heterogeneity of disabled people means that there will not be a uniform response to societal views, the disabled person may accept the prejudices held about them by wider society, affecting their thoughts and actions on a subconscious level (Reeve 2002; 2004). This results in an internalised oppression which can be as great a barrier to participation in society as structural barriers (Reeve 2002). Stalker (2012 forthcoming) suggests that this approach to exploring disability is particularly relevant when looking at the experiences of people with learning disabilities, who are known to face attitudinal barriers. Thomas' model allows for the impact of impairment to be taken into consideration without detracting from the implications of disablement: the difficulties associated with a cognitive impairment can be

recognised but should not be a reason for negative assumptions about the individual. The ensuing feelings caused by these negative assumptions should not be confused with the effects of impairment, though. The causes of psycho-emotional disability 'are just as 'social' in origin as are the 'restrictions of activity' experienced in the labour market, in transportation, in education, in housing, in leisure pursuits, or wherever' (Thomas 1999:48) and, when experienced in conjunction with structural and material barriers, can cause the individual to feel that they have little hope of overcoming them.

However, although this approach broadens the notion of social barriers and the restrictive effect society can have on a disabled person, it has been criticised for suggesting that effect of negative social relations on a person's sense of well-being can be separated from the effect of the impairment (Shakespeare 2006). The effect of impairment and its role in disability will be considered next.

2.4.3 The impairment-disability dichotomy

The separation of disability and impairment has been described as a distinction that is 'conceptually and empirically very difficult to sustain' (Shakespeare 2006:34). There were fears that to talk about problems associated with impairment would weaken the political force of the social model or confirm the disablist views of the general population, leading French to confess that writing about impairment effects felt 'dangerous' (French 1993:20). However, to ignore impairment has, for some, been to deny an integral part of the self and their experience:

In asserting our right to exist, we have sometimes been forced into the position of maintaining that the experience of disability is totally determined by socio-economic factors and thus deny, or play down, the personal reality of disability... In this way, an assertion of our worth becomes tied up with a denial of our bodies and an attempt to 'overcome' the difficulties which are part of being disabled. We can thus fall into the trap of trying to prove that our lives are worth living by denying that disability sometimes involves being ill, in pain, dying or generally experiencing a bloody awful time (Morris 1991:70).

This can prevent disabled people identifying with the social model (French 1993, Thomas 2001). French states that when impairment is not acknowledged, ‘my experiences are compartmentalised, with someone else being the judge of which are and which are not worthy of consideration. This gives rise to feelings of estrangement and alienation.’ (French 1993:19). As a result, the disability movement is accused of continuing the oppression of those it aims to represent (Morris 1991, Crow 1996).

To overcome this, there have been calls for the acknowledgment of personal experiences of impairment (Morris 1991, Crow 1996). This does not negate the impact of social barriers but instead includes those who ‘very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it’ (Wendell 2001:18). Acknowledging the impact of impairment would empower disabled people to both identify individual needs and confront disabling barriers collectively (Crow 1996, Thomas 2001). By including the impact of impairment in discussions of what it means to be disabled the disability movement ‘can truly challenge the way non-disabled people make judgements about our lives because in so doing we will take charge of the way in which disability is defined and perceived’ (Morris 1991:71).

The social model has been criticised for ignoring the relationship between impairment and disability. These arguments do not intend to deny the role society plays in disabling the individual but instead aim to demonstrate that it is not possible to separate impairment from disability:

...it is necessary to have an impairment to experience disabling barriers. Impairments may not be a sufficient cause of the difficulties which disabled people face, but they are a necessary one (Shakespeare 2006:34).

Impairment can be both caused and exacerbated by social arrangements (for example, poverty) whilst what is considered an impairment is determined by social judgement (Shakespeare 2006). Impairment is therefore ‘always already social’ (Shakespeare 2006:35). Unlike other forms of oppression, such as racism or gender inequality, there are aspects of impairment that are negative for some

disabled people and that might be more disabling than the social barriers faced (French 1993). Further, different impairments impact on individuals in different ways, both in terms of health and in cultural and social implications (Shakespeare and Watson 2002). Eliminating social barriers therefore does not automatically alleviate disability (Morris 1991:71; French 1993) whilst choosing only to look at social barriers is to only consider part of the issue as without an impairment the restriction would not apply (Shakespeare 2006). Failing to discuss impairments and their effects can cause them to become taboo (Crow 1996), making it harder to demand the support required to manage the impairment. In addition, the removal of barriers for all disabled people is simply not possible: ‘Even if it were possible to transform the world to eliminate the disabilities of a small minority of people, would there not be a danger of disabling the rest of the population, including many of those with similar impairments?’ (French 1993:21, see also Shakespeare 2006).

This has led to calls for a theory of disability *and* impairment as ‘whilst they can exist independently of each other, there are also circumstances where they interact’ (Crow 1996:218). Shakespeare (2006) takes this argument further, suggesting that it is virtually impossible to completely separate disability and impairment. This is not just because of physical implications of impairment, such as pain, but because of the ‘interpenetration of impairment and disability’ that can frequently be found in the accounts of disabled people’s experiences (Shakespeare 2006:37). That many people say that their impairment is central to their experience of disability is a reason, Shakespeare argues, why it should not be excluded from a model of disability (Shakespeare 2006).

2.5 The social model of disability and people with learning disabilities

Much of the critique of the social model and the attempts to develop the framework has argued for an acknowledgement of the effects of impairment on the individual both physically and emotionally. Learning disability, it has been suggested, has been treated differently to other impairments by the disability movement (Chappell et al 2001, Goodley 2001).

Explicit discussion of the social model and learning disability is limited: 'the majority of research has not attempted to explicitly use the social model as a tool for analysing the views and experiences of people with learning difficulties, nor invited people so labelled to inform a social model' (Chappell et al 2001:45; Goodley 2001). There has been some discussion of the limiting effects of oppression by wider society on the lives of people with learning disabilities and that 'being so labelled reflects societal expectations as much as any direct results of neurological impairment' (Brechin and Walmsley 1989:73) but their experiences have tended to be missing from social model analyses and they have been marginalised in the disability movement (Chappell 1997, Chappell et al 2001). However it has been argued that the social model has much to contribute when applied to the lives of people with learning disabilities and that failing to include learning disability in a theory of disability weakens that model (Chappell 1998).

Assumptions about 'impairment' have been put forward as a reason for the marginal position of learning disability within the disability movement. The initial definition of disability put forward by the UPIAS referred only to physical impairment, although it has since been amended to include those with learning disabilities and mental health problems (Barnes et al 2000). Impairment has often been assumed to refer to physical, rather than cognitive, function, something emphasised by the use of the term 'able-bodied' as the opposite of disabled (Chappell 1997, 1998). This has implicitly excluded learning disabilities from the discussion and meant that people with learning disabilities do not identify with the social model. Further, suggestion that the model should be developed by including impairment experience, as discussed above, implies that 'it is the bodily pain of impairment that is referred to' (Chappell 1997:55) again excluding the experience of living with a learning disability. This is not just an academic distinction: research with people with learning disabilities found that they did not necessarily identify as being 'disabled' as disability was associated with physical impairment (Goodley 2000).

Associating disability with physical impairment also affects the efficacy of anti-discrimination legislation. The Disability Discrimination Act (1995) was passed following lengthy campaigns by groups of disabled people (Shakespeare and

Watson 2001). Although the Act was originally criticised for failing to deliver adequate or enforceable protection of civil rights (Shakespeare and Watson 2001) amendments to the Act in 2003, prohibiting harassment, and the introduction of the Disability Equality Duty in 2005, requiring the promotion of disability equality in almost all public sector bodies, have particular relevance for people with learning disabilities who are reported as experiencing a high level of bullying and harassment (Stalker and Lerpiniere 2009). The requirement to provide accessible goods and services has the potential to be beneficial for people with learning disabilities if it means that information will be provided in an accessible format. However, research found that “reasonable adjustments” made by service providers have mostly been limited to physical adaptations... with many providers wrongly assuming their services were then fully accessible to all customers’ (Stalker and Lerpiniere 2009:830). Further, people with learning disabilities and family members also tended to assume that the legislation referred to those with physical and sensory impairments and were not aware of the legal force of the Act or how they could make use of it. Case studies carried out as part of the same research found that few people made use of the Act despite people with learning disabilities experiencing discriminatory treatment regarding the provision of goods and services (Lerpiniere and Stalker 2009). The association of disability with physical or sensory impairment therefore affects not just the political identity of people with learning disabilities but also the recognition of them as disabled people in the context of anti-discrimination legislation. This, in turn, can have negative repercussions on their opportunities to participate in society.

It is necessary to find a way to include the experiences of people with learning disabilities and for them to contribute to disability studies as without them ‘any analysis of the meaning of impairment will be incomplete’ (Chappell 1997:55). Assumptions about people with learning disabilities have resulted in their views being excluded from research as they are deemed to be unreliable (Goodley 2001). However, by gathering the experiences and views of people with learning disabilities the barriers that they face can be explored, bringing a move away from the assumption that their disability stems solely from their impairment. Whilst research is now far more likely to include the views of people with learning disabilities it is rare for them to contribute to academic debate.

However there have been calls for people with learning disabilities to become involved in analysing their own experiences. Achieving this is not straightforward and there are issues of access and power, amongst others (Walmsley 1997). Environmental manipulation can take place so that material is accessible, but this would impact on the development of disability studies. The acknowledgment that cognitive impairment restricts the individual's ability to contribute without support could allow mechanisms to be employed that enable them to articulate their view but this risks placing people with learning disabilities in a passive role (Chappell 1997). How to involve people with learning disabilities in research is a matter of ongoing discussion and will be considered in the methods chapter of this thesis.

The influence of normalization has perhaps also prevented social model uptake in learning disability communities. As discussed earlier in the chapter, the principle dominated ideas about learning disability but focused on changing service provision and the stigma associated with the learning disability label rather than tackling wider social issues (Chappell et al 2001). It thus gave the impression of bringing about social change for people with learning disabilities without tackling social barriers, including attitudes towards learning disability, and advocated methods of integration that were the 'antithesis' of the social model approach (Walmsley 1997:64). The concentration on promoting socially valued roles for those 'devalued' by the learning disability label 'compounded the already difficult and complex process of positive identification for disabled people' and potentially led them to internalise their 'devalued' status (Dowse 2001:134). Normalization 'helped at least some disabled people learn to develop solidarity with one another, to revalue themselves as equal citizens, and to attribute their oppression and exclusion to social barriers, much broader than labelling' but its approach has meant that 'there is still a hesitancy in adopting the positive stance to disability which characterises the broader disability politics' (Walmsley 1997:64-5), preventing engagement with the social model.

Self advocacy has been held up as a method by which people with learning disabilities can be supported to discuss their experiences and express their views both on a personal and political level (Goodley 2000). It includes 'speaking up for yourself; standing up for your rights; making choices; being independent;

taking responsibility for oneself' and requires the individual to 'resist practices which oppress you by challenging people in power; have the right to challenge others and be angry; challenge carers when the need arises' (Apsis 1997:648). Self advocacy has tended to focus on developing the ability to make or challenge decisions relating to the individual, rather than looking outwards to challenging societal barriers. However 'the problem with running these courses is that people do not gain the confidence to speak up in their own lives outside the course' whilst 'courses do not include teaching students how to gain effective change through challenging policies and the law. There is also no examination of power relationships between self-advocate and institution or government staff or elected members' (Apsis 1997:648-9). This makes it seem less likely that they will find the confidence to campaign on a broader level even if they do become engaged in disability politics. Research found that people did not always adopt the concept of learning disability when describing themselves or their experiences (Finlay and Lyons 1998; Davies and Jenkins 1997). The tendency not to incorporate learning disability into personal identity impacts on groups such as these, both in regard to what they can achieve and to their very existence:

... given the political potential inherent in the self-advocacy movement, any such emerging politics of identity could only be enhanced if its broader constituency were full participants in the discourse relating to their categorical identity and thereby made more aware of its organisational potential (Davies and Jenkins 1997:108)

Rather than becoming a tool for the emancipation of people with learning disabilities, Apsis argues that self advocacy has become 'a tool to support people with learning difficulties to accept their position in society' (Apsis 1997:653): it is frequently managed by those who have power over people with learning disabilities and whilst it might teach them how to negotiate on an individual level it does not necessarily equip them with the skills to agitate for real change or even positively identify themselves as a disabled person.

Although people with learning disabilities might not have been engaged with the social model it should not be ignored as an analysis framework when looking at

their experience. Goodley suggests that there has been ‘a tacit acceptance of naturalised impairment’ in people with learning disabilities:

...whereas people with physical impairments are rightfully afforded a socio-historical position in the social model... people with ‘learning difficulties’ are consistently underwritten. Thrown into the category of naturalised, irrational ‘other’. Closed in, isolated and confined by a ‘mental impairment’ devoid of meaning and history, presocial, inert and physical. People with ‘learning difficulties’ are personal tragedies of the unchangeable ‘organic impairments’ (Goodley 2001:211).

It has been suggested that even within the disability movement an individual model of disability has been applied to people with learning disabilities (Chappell et al 2001). Goodley argues that learning disability can be understood as ‘a creation of culture, politics and society’ (Goodley 2001:212). This occurs when social expectations are attached to the impairment, which can then lead to significant restrictions being placed on lives of people with learning disabilities. Normal behaviour becomes ‘a naturalised, individualised embodied pathology’ (Goodley and Rapley 2002:138), leading people with learning disabilities to feel that they must be more ‘normal’ than non-disabled people if they are to be accepted (Goodley 2001). The social model can provide a framework for exploring these restrictions and the experiences of people with learning disabilities. When applied to service provision, adherence to social model principles can result in a service that is respectful and accepting of the individual and supports them ‘to live as full a life as possible... changing the context or environment, rather than the person’ (Cole 2001:506). Thus, whilst impairment might impact on the individual’s ability to contribute to academic debate, a social model analysis is beneficial when exploring the experiences of people with learning disabilities just as it is when considering those with other impairments.

2.6 Conclusion

This chapter has explored three influential models of disability: the individual or personal tragedy approach, normalization and social role valorisation and the

social model. The medical model has been the dominant approach to disability and continues to be influential. However by locating the problems faced by disabled people as the result of their impairment it has done little to identify or explain the barriers to participation in social life. Instead it has perpetuated the view of disabled people as the victims of their impairments. This has resulted in impairment and, by association, the disabled person being viewed negatively. The principles of normalization and social role valorisation attempted to change this by focussing on designing community-based services for people with learning disabilities that helped them to achieve 'valued social roles'. These were intended to facilitate a 'normal' life for the individual, integrated in the community, and to remove the stigma attached to learning disability. Normalization and social role valorisation have been very influential in service design and the way learning disability is thought about in the UK in the late twentieth century. They contributed to the drive to move people with learning disabilities from institutions to the community and advocated giving people more control over the direction of their lives. However, as this chapter has described, there have been criticisms of normalization. In particular, it is criticised for failing to address the causes of the social disadvantages faced by people with learning disabilities, focussing instead on models of service provision, and thus not contributing the emancipation of disabled people.

In contrast to the medical model and the principles of normalization and social role valorisation, the social model of disability placed the emancipation of disabled people at its heart. It looked away from the individual to identify those barriers which prevented the participation of disabled people in society. It primarily focussed on material barriers and stated that it was these, not impairment, that disabled the individual but has since been expanded to include attitudinal and prejudicial barriers that impact on the individual's sense of self. The social model was not only radical in its stance. Unlike other approaches, it was conceptualised and developed by disabled people rather than being imposed upon them by medical professionals, service providers or other outside parties and this is perhaps one of the most powerful arguments for using it to analyse the experience of disabled people. However, as the final sections of the chapter show, the model has been criticised for its treatment of impairment and personal experience and has not always engaged people from the learning

disability community. Whilst the disability movement has been successful in lobbying for legislation that promotes the civil rights of disabled people, the legislation can only be effective if it is recognised that these rights are extended to people with learning disabilities. As a framework for analysis the social model is a useful tool when looking at the experiences of people with learning disabilities and doing so can help to create a fuller understanding of disability. However it is also important to understand that people with learning disabilities might not be engaged with the social model but instead be using both medical and social services characterised by an approach that places impairment at the centre of their experiences.

This thesis takes a broadly social model approach, incorporating Thomas' (1999, 2007) concept of psycho-emotional disablism, to look at the influences on the food choices of people with learning disabilities and their concepts of health. The following chapter looks at what is known about obesity in the learning disability population. It then looks at influences on food choice before focussing on issues specific to people with learning disabilities.

Chapter 3. Obesity, food choice and people with learning disabilities

The aim of this thesis was to explore attitudes towards food and health with adults with learning disabilities in light of the prevalence of obesity in this group. Obesity is currently a growing health issue in the UK and ‘the vast majority of studies report higher levels of obesity in adults with intellectual disabilities, in comparison with data derived from general population studies’ (Melville et al 2008:426). The causes of obesity are complex and a number of risk factors have been identified. These include gender, level of impairment and living arrangements (Melville et al 2008). However, while the prevalence of obesity in the learning disability population has been explored there is a need for more information about how this group make choices about food which this thesis hopes to address.

This chapter looks at the problem of obesity³ in the learning disability population and issues around food choice for both people with learning disabilities and the general population. It first looks at some of the broad issues that affect the health of people with learning disabilities. It then outlines the problems associated with obesity and general health before turning to look at issues specific to people with learning disabilities in general and to those in Glasgow, the location in which this research was conducted. Eating habits are closely linked to body weight and multiple influences on food choice have been identified. These include environmental, social and personal factors whilst the element of control and opportunity to make decisions is particularly relevant to many people with learning disabilities. The chapter explores the literature looking at these influences before turning to look at issues specific to the learning disability population, including understanding of healthy eating messages, the influence of others, and their opportunities to exercise choice.

³ Throughout this thesis obesity is defined as a body mass index (BMI) of over 30 and overweight is defined as a BMI of 25 to 30. BMI is a measure based on the relationship between height and weight and is calculated by dividing weight in kilograms by height in metres squared. It is the measure commonly used in epidemiology (Scottish Government 2010a).

3.1 Obesity

3.1.1 General health of adults with learning disabilities

People with learning disabilities tend to have poorer health than that of non-disabled people (Emerson and Baines 2010). However, research into the health and lifestyles of adults with learning disabilities has had limited scope, tending to focus on specific conditions or circumstances rather than building a comprehensive picture (Robertson et al 2000). This section aims to explore the literature and highlight the key health issues for this group.

Adults with learning disabilities account for approximately two percent of the UK population (Cooper et al 2004). As a group, they tend to have a higher level of health care needs, and these are often ‘unrecognised and unmet’, contributing to ‘ongoing health inequality, chronic ill health, and premature death’ (Cooper et al 2004:14). They are more likely to be at risk from the social determinants of poor health, including ‘poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination’ (Emerson and Baines 2010:6). Changes in socioeconomic conditions and neonatal care have contributed to improved survival rates but, while life expectancy has increased considerably in the second half of the twentieth century, it still remains lower than that of the general population (Emerson and Baines 2010; Cooper et al 2004; Patja et al 2000; Kappell et al 1998) and has been found to decrease as the level of impairment increases (Patja et al 2000). This is not thought to be entirely attributable to health issues associated with impairment:

...at least some of the deaths in these individuals are potentially preventable. Attention to factors such as regular health surveillance... would not only help to reduce mortality, but would also improve the health of this vulnerable population. (Durvasula et al 2002:263)

The health needs of people with learning disabilities differ somewhat to those of the general population: they have been found to have a greater prevalence of certain conditions as well as comparable rates of age related conditions (Cooper et al 2004; Kappell et al 1998). However it seems that these are not being met by healthcare services. Research found that ‘if a community-based population of

people with intellectual disability receiving primary care were examined, one was likely to uncover... untreated, yet treatable, simple medical conditions; untreated specific health issues related to the individual's disability; and a lack of uptake of generic health promotion' (Lennox and Kerr 1997:366). In addition, people with learning disabilities have been found to experience barriers to using health services (Emerson and Baines 2010; Cooper et al 2004) despite visiting their general practitioner as regularly as the general population and using specialist services more frequently (Lennox and Kerr 1997).

Those living independently, such as people with mild learning disabilities, 'are more likely to experience significant barriers accessing health and social services which will have a negative impact on socioeconomic status, health and well-being' (Melville et al 2008:434). The primary health care system relies on self-referral and assumes that people are able to monitor their own health and access appropriate services if required. This can be difficult for people with learning disabilities and those who support them and might result in failure to see a health care practitioner until the problem was advanced (Turner and Moss 1996; Lennox and Kerr 1997). Difficulty accessing health services is compounded by health care practitioners who do not have the necessary communication skills or accessible information, are potentially unaware of the particular needs of this group, or might mistakenly assume problems arise from impairment (Turner and Moss 1996, Kappell et al 1998; Lennox and Kerr 1997; Emerson and Baines 2010). Further, health promotion initiatives aimed at reducing health inequalities in the general population are less likely to reach this group. For example, the life course of people with learning disabilities often differs from that of the general population and they often do not experience events commonly associated with weight gain such as marriage or child bearing (Melville et al 2006) and so targeted health promotion and screening might not reach them. Mainstream health promotion could even increase health inequalities as these measures will help to improve the health of the general population without addressing the needs of those with learning disabilities (Cooper et al 2004).

Health needs are found to differ according to level of intellectual impairment and type of living arrangements. For example, a higher rate of cardiovascular disease, something that is associated with obesity and poor fitness levels, was

found in people with mild to moderate learning disabilities who lived in the community (Turner and Moss 1996). It is suggested that 'living in the community may bring higher health risks... through increased levels of obesity and smoking, both established risk factors for cancer' (Turner and Moss 1996:440). However, smoking related health problems are reported to be less common, along with those associated with alcohol and illegal drugs (Robertson et al 2000; Cooper et al 2004) perhaps reflecting the limited opportunities adults with learning disabilities have to engage in such activities. Other research found high levels of previously undiagnosed or untreated conditions, the failure to review ongoing treatment, and unmanaged hearing or visual problems which led to communication problems (Turner and Moss 1996). The literature also indicates that people with learning disabilities face problems relating to obesity, diet, and physical activity (Robertson et al 2000) and it is the issue of obesity that is explored next.

3.1.2 Obesity and general health

The section begins by looking at obesity and outlining some of the health risks associated with it. Overweight and obesity are significant causes of ill health (Kopelman 2007). Obesity is known to increase the risk of serious diseases, including stroke, coronary heart disease and hypertension (Kopelman 2007; Scottish Government 2010b) as well as other chronic conditions such as osteoarthritis, type-2 diabetes and sleep apnoea (Wilding 2007). In the UK the risk of being obese is higher in lower socioeconomic groups, those with the least education and women (Law et al 2007; Cummins and Macintyre 2006). The nutritional quality of diet is also known to vary according to socioeconomic group, with lower socioeconomic groups showing the greatest dietary deficits (White 2007).

Due to the associated health problems and high numbers of people who are overweight, obesity has become a high profile public health issue in Scotland. In 2008, 26.8% of adults were estimated to be obese whilst 65.1% were obese or overweight and it is estimated that obesity levels could rise to 40% by 2030 (Scottish Government 2010a). This is a significant risk to the population's health and cardiovascular disease, of which obesity is known to be a risk factor, has been identified as Scotland's second biggest cause of death (Scottish

Government 2010b:5). Many of the Scottish population's health problems are attributed to poor diet, which has excess saturated fat, sugar and salt but lacks fruit and vegetables and has been shown to lead to weight gain (Scottish Government 2010b). There are also wider social and economic implications as 'obesity has been shown to adversely affect employment, production levels (via increased sickness absence from work or school and premature death) and mental wellbeing' (Scottish Government 2010a:8). Finally, whilst physical activity has been shown to be related to reduced incidences of obesity and cardiovascular disease, among other health issues, only 37% of people (43% of men and 32% of women) meet the recommended levels of physical activity (Scottish Government 2010b).

Obesity is commonly seen as being the 'fault' of the individual (Wilding 2007). However, treatment of obesity is not often straightforward and there is unlikely to be a single solution:

Although increasing activity and improving diet may appear straightforward, there is growing recognition that the ways in which wider societal influences shape people's opportunities to exercise and exert choices over their diet mean that strategies to prevent weight gain need to look beyond solutions targeted at individuals. (Scottish Government 2009:194)

Therefore, there needs to be some understanding of those influences before effective strategies can be implemented. Health care practitioners are often untrained in the management of obesity, reducing the likelihood of them being able to provide effective advice whilst 'treatment is often started in the absence of an appropriate support programme and is frequently unsuccessful' (Wilding 2007:137). Research has shown that for effective weight loss the environment, as well as diet, should be modified (Wardle 2007). This is particularly relevant when looking at how to tackle obesity in Scotland:

... the factors that contribute to gaining weight have been interwoven into the very fabric of our lifestyles to such an extent that weight gain is almost inevitable in today's society. The evidence... suggests that the

provision of health information, although important, is not sufficient and that to make the changes necessary we have to reshape our living environment from one that promotes weight gain to one that supports healthy choices. (Scottish Government 2010b:5)

It is therefore likely that successful weight loss will require the interaction of various factors including the support and assistance of others close to the individual, the opportunity to make lifestyle changes and the ability to take advantage of any support structures already in place. This is likely to be difficult for those unable to exert much control over their environment, something that is often the case for people with learning disabilities. It is the issue of obesity and people with learning disabilities that this chapter now turns to.

3.1.3 Obesity and adults with learning disabilities

Research has shown that people with learning disabilities are more likely to be obese than the general population (Emerson and Baines 2010; Emerson 2005; Yamaki 2005; Hamilton et al 2007). Melville et al (2006) reviewed a variety of studies that measured the levels of obesity in adult learning disability populations in a range of residential settings. Although the percentages of those found to be obese varied considerably, all studies showed that ‘the prevalence of obesity in adults with [learning] disabilities is greater than that found in the general population’ (Melville et al 2006:224), increasing the risk of a range of health problems and contributing to both the reduced life expectancy and the health inequalities of adults with intellectual disabilities (Hamilton et al 2007; Emerson 2005). Due to differences in study design the research is not always easily comparable. Further, there are several syndromes that are associated with a higher risk of weight gain, including Down syndrome and Prada-Willi (Robertson et al 2000; Golden and Hatcher 1999). However, when reviewed the studies contribute to a composite picture of issues of obesity and overweight in people with learning disabilities.

Research has looked at a range of variables to try and understand the determinants of this increased risk of obesity. Gender has been found to be a risk factor for obesity in people with learning disabilities and women are more likely to be obese (Melville et al 2006; Emerson 2005; Moran et al 2005; Yamaki

2005) and physically inactive (Emerson 2005). This is a finding similar to that seen in the general population. However, for reasons that are unclear, 'it appears that the gender effect is accentuated, placing women with [learning] disabilities at particular risk' (Melville et al 2006:225).

The level of intellectual impairment has also been found to be an independent risk factor for obesity, and adults with mild to moderate intellectual impairments are at greater risk than those with a severe impairment (Emerson 2005; Melville et al 2006). This is possibly due to increased autonomy over food choices and exposure to social and environmental influences. Some studies found that the risk of obesity increased with age (Emerson 2005; Yamaki 2005), a pattern similar to that seen in the general population. However this was not something that was seen across all the research (see, for example, Melville et al 2006) perhaps reflecting the effects of differences within the learning disability population on health, such as level of impairment or living arrangements.

Research has tended to focus on those in receipt of formal services. This has resulted in a gap in knowledge about those people who live independently and receive little or no formal support, despite this being the group who, it is suggested, are at greater risk of being overweight or obese (Yamaki 2005). A greater proportion of people with learning disabilities living in a less restrictive environment, such as a family home, have been found to be obese or overweight compared with the general population (Yamaki 2005) whilst adults living in more restrictive environments were less likely to be obese (Melville et al 2006; Moran et al 2005). Similarly, Robertson et al (2000) found that the most significant predictor of obesity in their sample population of adults in various types of supported accommodation was 'living in a setting with lower senior staff ratios' (Robertson et al 2000:481). Whilst the association of weight with staffing levels could be indicative of wider impairment issues it might also indicate staff control over the diets of residents or the impact of having greater choice over food. The influence of others, such as support workers and family members, is explored later in the chapter.

3.1.4 Physical activity and people with learning disabilities

Physical activity is increasingly recognised as being a way that people can help to maintain a healthy body weight as well as being important to general health. There is evidence that exercise assists with weight loss and the long term maintenance of the loss (Fox and Hillsdon 2007), yet research suggests that people who have a learning disability are more likely to be sedentary (Emerson 2005; Golden and Hatcher 1999; Robertson et al 2000; Janicki et al 2002; Melville et al 2006). The level of inactivity increased with the degree of impairment and was affected by living arrangements and age (Emerson 2005; Robertson et al 2000). Studies have identified external, as well as intrinsic, barriers to physical activity faced by people with learning disabilities. These include existing health conditions, resource shortages, including staff and transport constraints, limited opportunities to combine physical activity with leisure in the community, the impact of impairment, financial constraints, and unclear guidance for staff in residential and day services. In addition to these practical constraints there are attitudinal barriers to leisure facilities fuelled by the assumption that disabled people are not particularly interested in accessing the services (Messent et al 1999; Golden and Hatcher 1999; Rimmer et al 2004; Finlayson et al 2009).

Low levels of domestic, as well as recreational, activity, suggest that people are 'not effectively supported to take advantage of the everyday opportunities for activity which are routinely available' (Emerson 2005:141). Staffing levels of both supported accommodation and day-time services were found to influence the range of activities available (Messent et al 1999) whilst the diverse nature of the learning disability population can make it difficult to arrange group activities. Day-time services were found to provide options that were largely sedentary such as crafts or computer-based activities (Messent et al 1999). Many of these findings are echoed in research carried out with adults with learning disabilities in the Greater Glasgow area (Finlayson et al 2009). The study found that people with learning disabilities were less likely to participate in moderate or high intensity exercise than the general population and only 5% of the sample of people with learning disabilities met the recommended target of 30 minutes of at least moderate activity on at least 5 days a week (Finlayson et al 2009). Further, 'only 36 (8.3%) and 18 (4.2%) of the total sample were regularly

engaged in housework and gardening respectively... This suggests that an active support model is not being adopted by support staff in particular, to involve adults with intellectual disabilities in home-based activities and the day-to-day upkeep of their own home' (Finlayson et al 2009:244) removing opportunities for regular activity. Finally, the study found that the lack of daytime opportunities, such as attending college or a day centre, were identified as an independent predictive factor for low levels of regular physical activity, as was living in a residential home (Finlayson et al 2009), seemingly demonstrating the impact of support and living arrangements on the opportunity to undertake physical activity. It is therefore apparent that there are structural barriers to activity that would need to be removed before effective promotion of activity can take place, making it harder for people with learning disabilities to avoid weight gain or facilitate weight loss.

3.1.5 Obesity in people with learning disabilities in Greater Glasgow

Recent research measured the prevalence of obesity in the adult learning disability population in Greater Glasgow (Melville et al 2008), the geographical area from which the participants in this thesis were recruited. The study found that there was a significantly increased prevalence of obesity in the learning disability population compared to the general population; women were more likely to be obese than men and there was no correlation between BMI and age for either men or women (Melville et al 2008). Men and women with profound learning disabilities had a much lower risk of obesity compared with those with mild learning disabilities (52% lower risk for women and 71% lower risk for men). The likelihood of being obese did not increase with age, in contrast with the general population, putting people with learning disabilities at risk of obesity-related disease from earlier in life. Other factors were found to increase the risk of being obese for women only: those living independently in the community, rather than with a family member, or in the most deprived areas, were more like to be obese (Melville et al 2008).

When compared with the data from the Scottish population, a higher prevalence of obesity amongst people with learning disabilities in Greater Glasgow was noted. 39.3% of women and 27.8% of men with learning disabilities, compared to 25.1% of women and 22.7% of men in the general population data, were found to

be obese (Melville et al 2008:429). The gender difference is greater in the adult learning disability population compared to the general population and could not be explained by differing levels of learning disability, deprivation, or the prevalence of Down syndrome (Melville et al 2008). Whilst other genetic syndromes are associated with obesity these could not account for the gender difference in this study.

Social deprivation increased the likelihood of being obese for women, but not for men (Melville et al 2008). The reasons for this are unclear. A similar finding in the general population is thought to perhaps reflect the likelihood of men being engaged in manual work but both men and women with learning disabilities have low levels of employment. It is suggested that it might be explained by women having 'interests or skills that make it more likely for them to experience a positive energy balance' (Melville et al 2008: 433) and that these more sedentary activities might be encouraged by support workers. It might also reflect differences in the way that men and women manage the chronic psychosocial stress that is proposed as the link between socioeconomic deprivation and health but this is something that requires further investigation (Melville et al 2008).

Melville et al (2008) note that their study was limited by 'the absence of any data on health behaviours, such as diet and physical activity, which may explain the high rates of obesity' (Melville et al 2008:435). The study concludes that 'interventions and services designed for the general population are unlikely to be effective when working with adults with intellectual disabilities' (Melville et al 2008:435). In fact, it suggests that these might even increase the health inequalities as the risk factors associated with obesity for people with learning disabilities differ from those for the general population. Health promotion strategies are therefore less likely to be effective for this group. The influence of health promotion information on the behaviour of people with learning disabilities is something largely neglected by the literature and would benefit from further investigation. So 'to inform the development of effective interventions and accessible clinical services, there is a clear need to carry out further research on the reasons for the increased prevalence of obesity in adults with intellectual disabilities' (Melville et al 2008:435), including exploring

attitudes towards food and healthy eating. It is this gap in understanding that this thesis intends to address. The causes of obesity are often complex and contributing factors are recognised as being individual, environmental and social (Law et al 2007) and it is the various influences on eating behaviours that are looked at next.

3.2 Influences on food choice

As obesity is related to calorie intake it is clearly necessary to look at what people eat and, importantly, how they decide what to eat. There are multiple influences on the various food choices that people make each day. Although consumers often report taste is the primary criteria by which food is chosen (Nestle et al 1998) there are many other, complex factors including socio-demographic characteristics such as income or availability of food, attitudes towards health or social and cultural norms (De Irala-Estevez et al 2000; Wansink 2004; Wansink and Sobal 2007). These influences vary according to the individual and the environment and change as they interact with each other (Wansink and Sobal 2007; Nestle et al 1998). Social and environmental factors have received less attention than individual behaviour and should be investigated as ‘influences on obesity that are a function of the environment rather than of the individual are likely to be paramount in shaping behaviours’ (Law et al 2007:21). In particular, the living environment has been shown to have an effect and influences on diet at a household level include: disposable income, gender, the skills and knowledge of those shopping for and preparing food, practical constraints such as the facilities available for cooking, and advertising (White 2007:99). Further, there will be various factors that will have a greater impact on people with learning disabilities. The influence that these variables have on food choice will be explored next. The section first looks at general literature exploring food choice before turning to literature looking specifically at issues relating to people with learning disabilities. Although there are many similarities with the general population there are several differences, particularly in the control people with learning disabilities have over their lives, which can have a significant impact on opportunities to make choices about food and these will be considered in the next section.

3.2.1 Income

People from lower socio-economic groups are more likely to have poor diets, low in fruit and vegetable consumption and high in salt, sugar and fat, compared to those in higher socio-economic status groups (Wrigley 2002; Abel and McQueen 1994; Macintyre et al 2005) despite nutrition knowledge being comparable across the income groups (Shepherd et al 1996). They were also less likely to rate their diet as 'healthy' compared to those on a higher income although a healthier diet was viewed as beneficial and enjoyable by both groups (Shepherd et al 1996). The cost of healthy food has been cited as an influence on food choice (Lappalainen et al 1998). People on a low income reported that they needed more money to buy basic or healthy food items (Shepherd et al 1996) whilst a European study concluded that people with higher socio-economic status consumed more fruit and vegetable compared to those from lower socio-economic groups (De Irala-Estevez et al 2000). Whilst this might reflect a real inability to afford food, perceived value for money can be a barrier. Cox et al (1998) noted that 'fruit was not seen as filling and therefore poor value for money' (Cox et al 1998:66) and it is possible that those with lower incomes prioritise buying more energy dense food. However, while the individual's socio-economic status clearly affects what a person is able to buy it is not clear what informs the way the food budget is spent or what influences beliefs about food.

3.2.2 Gender

Studies have found a gender difference in eating habits and have shown that women are more likely to be 'healthy eaters' than men (Anderson and Hunt 1992), to comply with dietary recommendations when shopping, preparing and eating food and to believe that these are important to health (Turrell 1997). It has been suggested this is due to a combination of greater health and nutrition knowledge and pressure to conform to social norms regarding body shape and the domestic role:

At the broadest level of explanation, women's more healthy food behaviours, their higher levels of knowledge, and their more positive orientation to diet, are probably a consequence of their extensive and direct involvement with food throughout the life-course... Women's definition of self, and their perceptions about their adequacy as mothers

and partners are intimately bound-up in the provision of food and meals which accord with the preferences of other family members... women are the principal guardians of their family's health and welfare and the provision of nutritious food is seen by most women as being an important part of their carer role. (Turrell 1997:1115)

By linking nutrition to mothering, food itself is gendered and becomes associated with a caring role. Whilst women are ascribed a cultural role as the family's dietician, men are not assumed to have the same responsibility: 'their roles in society have not required them to know a great deal about health, food, nutrition and their interrelationships' (Turrell 1997:1115). Instead, they are assumed to not care about food and to see it as a source of fuel rather than nurture (Lupton 1996). Cultural expectations can also influence the perceived taste preferences according to gender, with foods being assigned either masculine or feminine qualities (Turrell 1997). For example, women are often assumed to prefer sweet or more 'delicate' food whilst men are associated with red meat, large portions and 'heavy' food (Lupton 1996:106-107). However, while it is likely that social and cultural values will influence habits and preferences these conclusions make certain assumptions about life-course and gender roles that might not be applicable to the whole population, and particularly people with learning disabilities, or take account of differing socio-economic circumstances. For example, it is not common for women with learning disabilities to marry and have children, something that might be reflected in the education, both formal and informal, that they receive about cooking and nutrition. Further, whilst this suggests that there are gender differences in the way food is perceived and the meaning it is given, it does not explain why a significant number of women are overweight or obese.

3.2.3 Taste

Taste is recognised as a dominant factor in food choice (Glanz et al 1998). It potentially contributes to weight gain, as energy-dense, palatable diets are more likely to be over-consumed (Jebb 2007; Wardle 2007) while 'concerns about reductions in the taste quality of the diet are the most often mentioned obstacles to adopting reduced-fat and healthful diets' (Glanz et al 1998:1125). In addition, the modern environment provides 'an increasingly attractive,

diverse and energy-dense food supply', often ready to be eaten immediately and heavily promoted through advertising (Wardle 2007:74). Some of those foods have been criticised for their poor nutritional value (White 2007) but the perceived convenience of these options causes some people to choose them over other, healthier, options (Glanz et al 1998).

Whilst personal preference for particular foods can prevent purely pragmatic choices there are other, complex issues that influence what people choose to eat. Individuals might hold both positive and negative feelings about food:

People have very mixed feelings and beliefs about healthy lifestyle options. They experience positive sensations from eating foods that provide excessive calorie and salt content, yet finding the time to exercise (which in itself they may find unpleasant) is difficult. People know that rich foods are bad for them but, on the other hand, they also know that moderate exercise is good for them. No one escapes the psychological conflict, or 'ambivalence' that ensues. (Maio et al 2007:123)

This ambivalence might make it harder to change behaviour as beliefs and attitudes are not clearly defined (Shepherd 1999). Choice, stress and habit have been found to exacerbate the 'temptation' to eat less healthy food (Maio et al 2007), thus making it hard to make 'rational' food decisions, based solely or primarily on health, even when fully informed. Further, people might attach particular meaning to certain foods with the result that the decision whether or not to eat something cannot be based only on nutritional value. Food can be used to mark a special occasion, as a form of self expression or as a gift (Lupton 1996). It can be used as a demonstration of feeling and 'the preparation and serving of food... may also be regarded as a potent sign of love and duty' (Lupton 1996:47). As these meanings are ascribed by the individual, this is a particularly difficult issue for public health measures to address. It seems, therefore, that a number of factors can override the 'healthiness' of food and that an individual's food choice results from the interaction between various factors including nutrition, convenience and taste. Although individual preferences and attitudes will influence choice, these will have been shaped by wider social and environmental factors and it is these that are explored next.

3.2.4 Environment/ food access and place

Living in a deprived or low income area has been shown to be related to the prevalence of obesity and poor diet, even when individual socio-demographic characteristics are taken into account (Cummins and Macintyre 2006; Macintyre et al 2005). This is thought to be linked to two factors: the availability of food to be purchased for consumption at home and local access to places to eat outside the home (Cummins and Macintyre 2006). It has been suggested that the availability of healthier food, such as fruit and vegetables, in a local area might influence the diets of residents. Research in the 1980s found that, due to the price and stock differences between the large supermarkets and local shops, 'consumers, especially those on a low income, who live in poor areas may be hit by a reduction of food choice, and a corresponding increase in food price' (Cummins and Macintyre 2002: 2116). The existence of deprived neighbourhoods where food was relatively expensive or unavailable was noted and such areas were termed 'food deserts' (Cummins and Macintyre 2002; Wrigley 2002). As a result it was feared that 'poor access to a healthy balanced diet may be a common feature of deprived urban neighbourhoods in British cities' (Cummins and Macintyre 2002: 2116) and that whilst 'mobile, car-owning affluent consumers' were able to benefit from the supermarkets, there was a second tier of 'disadvantaged consumers', unable to take advantage of the lower prices and greater choice of food (Cummins and Macintyre 2002: 2117).

Research considered the problem of 'food deserts' in the Greater Glasgow area, the location of the fieldwork for this thesis, and looked at the availability and cost of a basket of food recognised as making up a 'modest but adequate' diet (Cummins and Macintyre 2002). It found that, rather than area or level of deprivation, shop type was the best predictor of price and availability of the basket of food and that few shops varied their prices between more or less affluent areas but 'most of those which did were cheaper in more deprived areas' (Cummins and Macintyre 2002:2127) meaning that cost was not the barrier it was assumed to be. Further, 'foods which were cheaper in poorer areas included both energy-dense, high-fat, high-sugar foodstuffs... of which nutritionists currently recommend we eat less; and a smaller number of items which nutritionists recommend that we eat more' (Cummins and Macintyre 2002:2127). However, the price difference might reflect lower quality

ingredients of certain items; branded items did not significantly vary in price according to area. This would suggest that, although prices were lower for a variety of foods, 'poorer-quality, high-fat foods are available, at correspondingly cheaper prices, in poorer places' (Cummins and Macintyre 2002:2127).

These findings are in contrast to previous research which suggested that healthy food, such as fruit and vegetables, would be less available and more costly in more deprived areas (see Wrigley 2002 for a discussion on the development of this hypothesis). Cummins and Macintyre (2002) speculate on various reasons as to why this might be, including the effects of local planning which has encouraged development in deprived areas, bringing supermarkets into these areas and causing prices to fall locally (Cummins and Macintyre 2002). Similarly, a study of Glasgow found that 'out-of-home eating outlets', which it is commonly believed are more frequently found in deprived areas, were actually most prevalent in more affluent areas (Macintyre et al 2005). So, whilst it cannot be assumed that area will affect food availability, it might be that the cheaper food found in more deprived areas is of lower quality which will have consequences for the diet and health of the people who shop there. Indeed these findings perhaps highlight the need to be aware of the individual nature of diet as aspects such as access to food will vary according to environment, income and mobility as well as personal preference.

Other Glasgow-based research found that 'poorer neighbourhoods provide fewer opportunity structures for health promoting activities than more affluent areas', including adherence to dietary guidelines and participation in physical activity, whilst participants from the most deprived area were shorter, with higher BMI, and larger waist measurements with greater waist to hip ratios, all indicators of poorer health (Ellaway et al 1997:307), suggesting the existence of a neighbourhood effect. However, although opportunities to access affordable healthy food and be physically active will affect how easy it is for a person to pursue a healthy lifestyle, it does not fully explain why people make these choices. Health outcomes might be predicted according to area but it cannot necessarily explain them; indeed it is suggested that 'exclusive focus on food systems and landscapes outside the home may contribute to a deterministic or fatalistic view about how much influence individuals have over their own food

intakes' (Sobal and Wansink 2007:137). Factors within the home also influence how much and what is eaten, providing subtle 'environmental cues about appropriate consumption that influence food intake, often communicating intake norms to people who act on those influences in unconscious ways' (Sobal and Wansink 2007:135) making it difficult for people to acknowledge them or to make changes to their eating habits. Although area influences can act as a barrier to a healthier lifestyle they cannot fully explain the choices people make. However, they do have particular relevance for people who have little control over their living arrangements, such as those in supported housing, or who find it difficult to travel out of the local area.

3.2.5 Social norms

A variety of social pressures, or 'norms', will influence what and how much a person eats (Shepherd 1999; Wansink and Sobal 2007; Croker et al 2009). These norms can exist at a household as well as societal level and often incorporate cultural values, which form a framework for food choice as 'people use the categories and rules of their specific cultures, subcultures, and ethnic groups to frame what they consider to be acceptable and preferable foods, the amount and combination of foods they choose and the foods they consider ideal or improper' (Nestle et al 1998:51). These norms can influence the structure of a person's diet, potentially overriding internal signals indicating hunger and satiety: for example time of day, rather than hunger, frequently determines mealtimes (Mela 2001). Environmental and social cues, such as package size or a peer's meal, can implicitly shape food choice (Wansink and Sobal 2007; Wansink 2004). Social norms might also influence what is not eaten. Cox et al (1998) note that there did not seem to be social pressure to increase consumption of fruit and vegetables, which reinforced participants' views that their intake was standard and that, despite health guidelines, there was no need to eat more. Accepted beliefs about foods, particularly whether or not they are healthy, might prevent someone from eating something but it can also become something to rebel against, perhaps encouraging overconsumption of a food normally only approved of in small quantities.

Although the reasons for some 'norms' are unclear, research shows that we are influenced by a variety of factors, many out with our control. Further, 'the use

of consumption norms... may be relatively automatic and may often occur outside of conscious awareness' (Wansink 2004:458). However, research has found that people are unwilling to acknowledge the effect that social cues have on their decision-making, instead believing that they are acting freely (Wansink and Sobal 2007; Croker et al 2009). This confidence in their ability to make decisions without unwanted influence 'may lead to over-consumption and weight gain' (Wansink and Sobal 2007:119) and might reduce the efficacy of health promotion as it would not be seen as relevant. Further, it could be that these norms become internalised making it harder for people to question their belief structure.

3.2.6 Family and peer influences

As well as helping to establish norms around eating behaviours, families, peers and others in the household can influence food choice. Wansink (2006) refers to those who make many of the food decisions in the home as the 'nutritional gatekeeper': this person impacts on what is eaten within the home, as they are responsible for most of the shopping and cooking, as well as what is eaten outside the home as people are influenced by the example the gatekeeper sets. The role of these 'gatekeepers' could be particularly relevant when considering the diets of people with learning disabilities, who are often supported with tasks such as shopping and cooking, which possibly allows someone to take on this role. Clearly, the influence of others can be positive or negative. The support of the household has been reported to be an important factor for those making dietary changes (Sorensen et al 1998a) as has co-worker support (Sorensen et al 1998b), demonstrating the influence of personal networks. Further, social support has the potential to promote health and well being if it provides 'not only a sense of belonging and intimacy, but... also help[s] people to be more competent and self-efficacious' (Berkman 1995:251) which in turn increases confidence in their ability to affect change and adopt a healthier lifestyle.

3.2.7 Health knowledge and beliefs

Food and health are inextricably linked and there is 'an increasing focus upon prevention of chronic disease through adoption of healthy lifestyles. In the food arena, concerns with the prevention of chronic disease are most commonly associated with obesity' (Ward et al 2010:348). It could be expected that a lack

of knowledge would constitute a significant barrier to constructing a healthy diet but it has been found that people often do not feel that this is the case and knowledge levels have been found to be relatively high (Lappalainen et al 1998; Nestle et al 1998). It is possible, though, that people do not know how to apply it or are reluctant to change (Nestle et al 1998) or feel that they lack the time to adopt a healthier diet (Lappalainen et al 1998). Other research has found that some people have an 'optimistic bias'. This causes them to think that they are less at risk from health problems than others or to assume that health messages are intended for other, more vulnerable groups and are not applicable to them (Shepherd 1999; Lappalainen et al 1998), perhaps leading them to view their nutrition and health knowledge as irrelevant.

Messages about what constitutes a healthy diet can prove to be confusing, particularly as information is provided from a variety of sources, including official government bodies, media 'experts', and manufacturing companies. For example marketing some food as healthy or 'low-fat' can create a 'health halo' effect, and can actually lead to increased consumption, even though it is still a high calorie option, due to its apparent 'healthiness' (Wansink and Chandon 2006; Chandon and Wansink 2007). Official health messages can appear to be conflicting: a study found 'there was widespread agreement with the perception that the [dietary] experts can never agree' despite noting consistency in the information published (Margetts et al 1998:197). Perceptions such as this make it harder for people to adopt healthy eating strategies as they lack a trusted source of information.

Food can also be directly associated with health and is sometimes regarded as a form of medicine. The elevated status of these items meant that they 'should be eaten because of their nutrients or other components believed to be health-giving... rather than any gustatory pleasure they provide' (Lupton 1996:80). The combination of these beliefs with the variety of information put forward by a wide range of sources makes it hard to make a truly informed decision, particularly when added to the individual's circumstances which might make adherence to advice difficult.

3.2.8 Other inter-personal factors

There are various other factors that influence food choice both on a day-to-day basis and on a broader scale. Mood, for example, can influence choice as food might be eaten to ‘provide a dimension of psychological and physiological comfort’ (Wansink et al 2003). Although what is chosen as ‘comfort’ food will depend on the individual, it is often food associated with childhood and which evokes feelings of security and nostalgia (Lupton 1996). Stress has also been found to influence how much and what a person eats, causing them to over- or under-eat (Oliver and Wardle 1999; Wardle et al 2000).

Eating is often seen as a social act and it has been found that people consume more with others than they do when eating alone (Nestle et al 1998; de Castro 1997). This might be due to taking longer over a sociable meal, giving an opportunity to eat more, or it might be that people are less inhibited if they are relaxed in the company of others (de Castrol 1997). Eating as a social act removes it from its functional purpose, giving it social and emotional meaning, and it is this that makes the influences on food choice so complex. There are many other factors that might influence food choice but it is apparent from these examples that many decisions made are motivated by personal associations with what is eaten.

Although many of the factors associated with obesity and the general population are shared with people with learning disabilities, there are several issues of increased relevance to this group, in particular the prevalence of obesity and the opportunity people with learning disabilities have to make informed choices about food. It is the particular issue of obesity and people with learning disabilities that is explored next.

3.3 Influences on food choice for people with learning disabilities

Many of the influences and barriers discussed above will have relevance for people with learning disabilities: they are more likely to have low incomes (Lister 2004) so food cost will affect them, they will be influenced by social norms regarding consumption, and their decisions will be based on their beliefs about health and food. There are, though, various factors that are particularly

important when looking at the diets and lifestyles of people with learning disabilities. The following section explores the literature looking at factors that affect the choices people with learning disabilities make about food and the barriers that might prevent them having a healthy diet. The control that people have over what they eat is considered as this can influence attitudes towards food as well as the opportunity the individual has to implement a healthier lifestyle. The potential to be influenced by others, such as family members, flat mates or support workers, is also considered as there are often many areas of their lives in which they receive support. The notion of a ‘nutritional gatekeeper’ (Wansink 2006) might be relevant to some in this group if they live with others as adults or if they receive support with shopping and cooking. This section of the chapter will look at some of the factors that influence the decisions people with learning disabilities make about food and on their opportunities to have healthy lifestyles as well as considering broader issues concerning choice and control.

3.3.1 Knowledge and understanding

It has been suggested that people with learning disabilities might not be aware of the health risks associated with being overweight or have the opportunity to learn about them due to their impairment (Yamaki 2005). However, research has found they have a good knowledge of what should be included in a healthy diet (Rodgers 1998; Golden and Hatcher 1999). People with mild learning disabilities tended to have better nutrition knowledge than those with moderate learning disabilities whilst ‘increasing Body Mass Index was associated with increasing nutrition knowledge’ (Golden and Hatcher 1999:182). The reason for this is unclear but could be because obese people receive more reminders from staff, family and others on how they might modify their diet to lose weight (Golden and Hatcher 1999). It suggests that the current state of being obese is not related to a lack of nutrition knowledge although it is possible that people have learnt more since becoming obese. Little is known about adults with learning disabilities’ understanding or beliefs about food and its relationship with health (Golden and Hatcher 1999) and this is something that this thesis aims to explore.

Difficulty identifying sources of information has been noted (Rodgers 1998), something that could be a barrier to healthy eating. The format and method in

which information is provided is important: although a person might indicate that they ‘know’ or remember something this does not necessarily mean that they have the information required to make a real choice. Knowledge of nutrition does not automatically equate to an understanding, as people need to be taught, rather than just told, and might require ongoing support, particularly to understand long-term implications of decisions (Smyth and Bell 2006). If accessible information is not made available it could become a barrier to not just a healthy lifestyle but to a person’s opportunity to develop independence.

3.3.2 Impairment

Impairment can influence the extent to which people with learning disabilities are afforded choice, their ability to understand and use information about food and health and, ultimately, whether they are able to make decisions for themselves. People with learning disabilities are not a homogenous group and impairment effect cannot be generalised: whilst some people might be able to take full control of what they eat others might be restricted to making choices from options presented to them (Reid and Parsons 1991). However, some level of choice is likely to be possible with appropriate support (Reid and Parsons 1991). Impairment will affect how readily people are able to learn and understand new information and might also affect how easily individuals are able to communicate their decision. Further, those issues that complicate the provision of information for the general population, such as receiving conflicting messages from different sources, will also be relevant to those with learning disabilities (Rodgers 1998). Impairment is also likely to impact on practical opportunities to enact choice or to be involved with food; for example, physical impairment might affect an individual’s ability to prepare food. However the perception of impairment by others might have an even greater impact on the extent to which they are afforded choice, in turn affecting the way they perceive their own abilities and resulting in psycho-emotional disablism, discussed in the previous chapter.

3.3.3 Food and meaning

As discussed above, food choice reflects more than health or energy requirements. Food can take on extra meaning for people with learning disabilities and the meaning that others place upon it can also affect them. The

social role of food is likely to influence their eating habits and approach to food. For example, it is possible that young disabled people are given greater access to food ‘to ameliorate the effects of boredom, social isolation and problem behaviours’ (Melville et al 2006:227), something that is likely to have an effect on their attitudes towards food throughout life. Eating can be constructed as an ‘activity’, such as visiting a café or ‘watching television and eating doughnuts’ (Smyth and Bell 2006:229). For others, food can be a source of pleasure or something with ‘emotional significance... a gift of love’ (Rodgers 1998:15). Whilst this is not automatically problematic, if food takes the place of social interaction or eating becomes the main activity outside the home this could have a negative effect on health and weight.

3.3.4 The influence of others on the diets of people with learning disabilities

It is common for people with learning disabilities to have others closely involved in their lives, including paid support workers, family members and residential or day services, to provide support with daily tasks, including shopping and food preparation. Whilst they might not control food availability to the extent of the gatekeepers discussed in the previous section, they may be in a position to influence the behaviour, beliefs and knowledge of those they support and thus facilitate healthier lifestyles. However if their knowledge is limited this could have a negative impact on opportunities for healthy eating and might even overlook the potential problems associated with obesity, instead accepting it as normal in the learning disability population (Janicki et al 2002). Research looking at the knowledge and perceptions of healthy lifestyles of the support workers of people with learning disabilities found that most were only aware of the recommended fruit and vegetable intake and had limited knowledge of other recommendations regarding diet or physical exercise (Melville et al 2009). When benefits were recognised there was a tendency to focus on physical health benefits and not consider the impact on self image despite there being no evidence to suggest that people with learning disabilities would not value this effect (Melville et al 2009). This is important as support workers must acknowledge all the reasons for weight loss: ‘supporting change will be unsuccessful if paid carers are doing so based on perceived health benefits, and this is not in keeping with the motivations of the person with intellectual disabilities’ (Melville et al 2009:303).

Melville et al (2009) investigated the barriers to a healthy lifestyle identified by paid carers. The paid carers appeared to take an individual model approach to disability, rooting the cause of problems in the impairment, rather than looking outwards to identify any social barriers:

... paid carers... do not seem to recognize the significant interpersonal and external barriers to change, instead perceiving the main barriers (and perhaps responsibility for change) within the person with intellectual disabilities. It was particularly surprising that a significant proportion of the paid carers did not believe any of the barriers [presented by the researchers] were relevant to the person with intellectual disabilities. (Melville et al 2009:303)

Interpersonal factors were seen to be of some importance with regard to dietary change, perhaps reflecting the fact that many people with learning disabilities live or eat with others who will have considerable influence over what they eat. This focus on impairment-related barriers by people providing support potentially restricts opportunities to exercise choice and autonomy as if social barriers are not recognised they cannot be tackled (Melville et al 2009). Such attitudes could have a significant affect on the opportunities available to people with learning disabilities as paid carers appear to fail to recognise the existence of such barriers. Further, assuming the problem is inherent to the individual could cause psycho-emotional disablism (Thomas 1999) and, if internalised, may well impact on the individual's belief that they are able to achieve a healthy lifestyle even if the external barriers be removed.

A review of weight loss interventions with adults with learning disabilities also recognised the importance of involving others who are important in the life of the individual (Hamilton et al 2007). Decision-making power is often shared between people with learning disabilities and others, including family members and support staff, and changes made collaboratively. It is therefore likely that others' motivation will impact on interventions to aide weight loss and, in turn, interventions might be more successful if influential others are included from the beginning (Hamilton et al 2007). So, whilst people with learning disabilities

will be influenced by various external factors, including those discussed in the previous section, they are also likely to be affected by the knowledge and beliefs of those who support them and who, because of their relationship, are often in a position of some power and influence.

3.3.5 Opportunities to make choices about food

As discussed earlier in the chapter, people with learning disabilities often lack the opportunities to make choices that are available to people who are not disabled (Rodgers 1998; Treece et al 1999; Smyth and Bell 2006). This can include a limited choice regarding food (Rodgers 1998). Rodgers' (1998) study found that many participants do not get the opportunity to be involved in food shopping or cooking: various health and safety regulations and carers' concerns meant that they were reluctant to let the people they supported cook, even though several of them had been taught cooking skills at college or a day centre. Support workers restricted food they thought was unsuitable whilst participants' diets could be subject to the preferences of staff or family or the requirements of others in supported accommodation; opportunities to express a dietary preference were often limited to refusing the food offered or trying to help themselves (Rodgers 1998). However, two participants who planned their own meals actually had unhealthy diets, highlighting the potential risks of increased independence and the need for people living independently 'to practise planning their own diet, and making healthy choices for themselves' (Rodgers 1998:14).

Living in a less restricted environment and therefore having more responsibility for food choices might result in 'reduced supervision, and promotion of individual choices may result in greater access to fast foods and less emphasis on physical activity for those who live in the community' (Yamaki 2005:8) particularly if combined with insufficient knowledge. People with learning disabilities who had greater levels of freedom and less involvement from support staff were found to be more likely to have a 'fatty' or 'poor' diet compared to those living in a residential service (Robertson et al 2000). People living more independently were more physically active but other health behaviours, such as smoking or eating a healthy diet, were also more common. Thus 'It would seem that the greater choice afforded to people with intellectual disabilities which has resulted through the move toward community care, may have implications

for the prevalence of health risks in the lives of people with intellectual disabilities' (Robertson et al 2000:484) something perhaps demonstrated by the increased levels of obesity noted in people living independently. However, whilst it is possible that a good understanding by individuals, and those who support them, of the benefits of maintaining a healthy weight might prevent obesity or help weight loss (Moran et al 2005) it is not likely to be the sole solution. The availability of 'unhealthy' food choices combined with the encouragement of individuals to display independence by spending their own money might encourage people with learning disabilities to make unhealthy choices (Smyth and Bell 2006; Golden and Hatcher 1999). Advertising and availability provides considerable temptation and 'good nutrition knowledge is likely to be of little benefit in the face of powerful environmental factors' (Golden and Hatcher 1999:182). Further, the pursuit of independence might cause support workers to be unrealistic about the individual's ability to understand the health implications of choices (Smyth and Bell 2006) and particularly the long term consequences of their decisions, including those surrounding food.

As a result approaches to enabling people with learning disabilities to make choices vary. Smyth and Bell (2006) state a 'zealous concern for the protection of civil liberties could well result in the harm of vulnerable individuals' (Smyth and Bell 2006:232) and that a duty of care must be upheld. This sense of needing to protect people, combined with a notion of food as source of nourishment and care in excess of its nutritional components, could make people working with adults with learning disabilities feel that feeding them is an intrinsic part of the support they provide. In contrast Rodgers (1998) states we should 'encourage people to practice informed choice about eating, and accept that people will sometimes choose less than healthy options' (Rodgers 1998:15). These differing attitudes are likely to be seen in the support received and the attitude and approach of the person providing that support will also affect whether their sense of a duty of care will override the need to allow some choice and control. However, rather than exploring the appropriateness of 'allowing' choice this debate highlights the need to provide the necessary information and support to enable decision making where possible.

Issues around food choices and influences on what the individual views as a healthy diet are therefore particularly important for this group as health messages and interventions are frequently intercepted and interpreted by a third party, such as a parent or support worker. This not only affects the opportunities they have to make choices, and potentially influences their decisions, but might affect their sense of autonomy as well as making it harder for health policies to target them or for them to implement change in their own lives. The influence of others on decision making, as well as knowledge and beliefs, is something that will be explored in the data.

3.3.6 Attitudes towards choice and people with learning disabilities

Prior to the adoption of SRV and normalisation, people with learning disabilities, particularly those living in residential or supported accommodation, often had very little choice in many areas of their lives (Smyth and Bell 2006; Bannerman et al 1990). As discussed in the previous chapter, the move towards living in the community increased integration and opportunities for control: enabling choice was a way in which people with learning disabilities could be given control over their own lives. However, despite considerable changes in the way people live, 'people with learning disabilities still do not always have opportunities for choice on matters concerning them and they have much less opportunity for choice than people who do not have a learning disability' (Smyth and Bell 2006:229; Ferguson et al 2011).

Choice and control over aspects of an individual's life have been associated with improved quality of life (Reid and Parsons 1991; Smyth and Bell 2006; Treece et al 1999). Increased participation in decisions about healthcare is identified as part of the approach to addressing health inequalities faced by people with learning disabilities (Ferguson et al 2011) whilst powerlessness can be a risk factor for disease (Rodgers 1998). It might cause people to feel detached from their own health care. For example, a health education project found that participants with learning disabilities 'took more ownership for personal health issues at the end of the intervention than they did prior to it' (Lunsky et al 2003). The act of choosing might be enough to increase motivation (Jenkinson 1993) and individuals may therefore be more successful in adopting healthier lifestyles if they also feel involved in the overall management of their health. Indeed,

‘there appears to be little, if any, evidence that choice-making is detrimental to performance in activities’ (Stalker and Harris 1998:69). In contrast, people not involved in deciding upon activities, for example, might be less motivated to take part (Bannerman et al 1990), or might not feel able to take advantage of opportunities available to them (Treece et al 1999). Further, feeling out of control of the options available or the process can lead to reduced motivation and result in poor choices and can affect the way people approach other situations:

...if people fail to perceive any relationship between their actions and the things which happen in their lives, they may develop a generalised belief that they are powerless to affect outcomes in any situation. They are likely to become increasingly passive and unwilling to participate in making choices. Such situations occur when the environment is not structured to promote choice-making or when insufficient effort has been made to make people with learning disabilities aware that a choice is available. Options which are viewed as unacceptable, uncertainty and ambiguity among options, and choice situations where there may be adverse consequences, all deter people from making choices (Harris 2003:5).

This could have implications for the way a person views their general health: if they do not believe they have a real choice or if their previous experience suggests that they are able to exert little control they might feel that there is little point in trying to change. In contrast being involved in decision making and planning can improve outcomes and commitment (Bannerman et al 1990), presumably as the person’s preferences have been taken into account and they feel that they are involved and in control of the process.

Despite this, the extent to which people with learning disabilities should be involved in their healthcare ‘is evidently a source of difficulty and unease for those supporting them’ (Ferguson et al 2011). The most significant inhibitor of choice appears to be the attitudes and beliefs of those providing support and the structure of services (Stalker and Harris 1998). Choice-making can be stressful and those supporting people with learning disabilities might wish to spare them

from this (Stalker and Harris 1998). However, constraint might also reflect ingrained prejudices about the appropriateness of allowing choice and the ability of people with learning disabilities to choose. There is some debate regarding whether or not duty of care overrides a person's right to choose, particularly where there is concern that a person might make a 'bad' choice (Bannerman et al 1990; Smyth and Bell). Such concerns could result in significant restriction of the opportunities for choice available to the individual, particularly as those who provide support are often in a position to mediate the options available.

However, there is evidence to suggest that 'everyone can make choices at some level' (Stalker and Harris 1998:70). Rather than denying opportunities to make choice, or allowing people to do what ever they want, there is therefore a need to ensure that people are taught how to make choices and given the opportunity to do so (Bannerman et al 1990). Enabling choice need not mean putting someone in sole control: it can refer to small, individual choices or to making decisions about matters with long term consequences (Harris 2003) and giving a person the opportunity to choose does not mean withdrawing support or guidance. However it must then be accepted that, even when equipped with the skills to choose or make a decision, people might still make a 'bad' choice.

Much of the literature discussed in the previous sections has highlighted the need to explore the reasons for the increased prevalence of overweight and obesity in the learning disability population, with specific attention to attitudes towards food and healthy eating. Melville et al's (2006; 2008) Glasgow-based study, in particular, clearly outlines the relevance of this topic and the need for further investigation and has been influential in the development of this thesis, which is set in a similar geographical area. However, Melville et al's research used quantitative data and was primarily concerned with mapping the extent of overweight and obesity in people with learning disabilities. It was thus not able to explore the variables that might have influenced food choice and so offered little explanation about the reasons for the increased prevalence. Other research used qualitative methods to explore the motivations behind food choices. Qualitative approaches enabled the researchers to gain some understanding of the reasons behind food choices and the relationship between these influences. In particular, Rodgers' (1998) study provided insight into the way choices are made and the influences and barriers faced by people with

learning disabilities although it was limited by the sample size. This thesis uses qualitative methods to build on some of the findings of Rodgers (1998), and to answer some of the questions raised by the quantitative work of Melville et al (2006 and 2008) and others.

3.4 Conclusion

The literature shows that social, physical and environmental factors impact on health, obesity and the opportunity to have a healthy, active lifestyle or to make dietary changes. However, it is not clear how these affect people with learning disabilities. It is apparent that obesity is a problem in the learning disability population and this has the potential to have a significant impact on the health of people with learning disabilities. This thesis aims to look at the attitudes to, and influence on, food and health with people with learning disabilities. However the heterogeneity of this population makes generalisation hard. People with learning disabilities are influenced by a variety of factors, many of which are relevant to everyone, but the extent to which these influence food choices will depend on the interplay of differing support and living arrangements, impairment and the approach of the individual. There are, though, several influences of particular interest. Adults in this group often have little autonomy over what they eat (Rodgers 1998). The literature highlights the impact that others, including family members and paid support workers, can have on the lives of adults with learning disabilities. They are in a position to influence beliefs and knowledge about health whilst some directly influence or even control diet. Their approach to food coupled with their attitude towards the ability of those they support can have a significant impact on the opportunity people with learning disabilities have to make choices about what they eat. Policy designed to address the health needs of the population as a whole is thus unlikely to address the needs of those with learning disabilities and will not be able to do so until the factors that influence their eating patterns are understood. The research thus aims to examine the views of people with learning disabilities to establish the influences they identify, the role that food plays in their lives and the opportunities that they have to make choices about what they eat. The following chapter describes the research method designed to do this.

Chapter 4. Methodology

This research aimed to examine the attitudes of people with learning disabilities towards food, health and weight in the light of the increased prevalence of obesity in this group. It first aimed to explore how people with learning disabilities viewed food, focussing on the perceptions of a healthy diet and whether this was important to them. It was hoped that exploring the roles and meanings given to food would give a better understanding of what informed their choices and the barriers they faced to a healthy diet. Secondly, the research aimed to identify the opportunities available to the participants to make choices about food, to explore the significant others involved in these choices, and to establish whether or not participants felt it was important to have control over what they ate. Finally, it aimed to explore what participants believed being healthy meant and to examine the relationship, if any, they saw between health and weight and the extent to which they felt they could exert control over them. This chapter outlines the methods used to fulfil these aims and explores the reasons for the design of the research process. It then looks at the implementation of these methods in the field.

The research used a qualitative methodology. Qualitative methods can allow the researcher insight into the participant's private world and can offer the participant the opportunity to express their own views and interpretations of their experiences. This chapter seeks to account for how the research method was decided upon, how this was translated into the practical activity of fieldwork and how the data gathered was analysed.

The chapter starts by looking at the theoretical and ideological starting point for the research design before moving on to look at the methods decided upon for gathering data and the use of these methods with people with learning disabilities. It then focuses on the practical process of fieldwork of implementing these methods in the field. It considers the fact that research such as this involves unpredictable variables, including the researcher and the participants as well as those who controlled access to the field. The research process was constantly shifting and evolving as the initial understanding of the subject was challenged by new information and, indeed, new topics that emerged

throughout the period of data collection and analysis. The chapter will consider how this was accommodated both practically and intellectually. It will also consider how my own views and beliefs impacted on the research process and how practical and pragmatic decisions, as well as the theory, influenced the design and execution of the methodology. Finally, it will describe how the data was managed and analysed.

4.1 Beginning the process

The design of a research project is influenced by many factors. Whilst it might seem that these influences are predominantly practical in nature (time, geography and money, for example) the decisions made are not purely pragmatic but are informed by the theoretical underpinnings of the research question and the individual's personal approach to the subject. This section of the chapter explores those issues that influenced the choice of methodology.

The research design was informed through my readings of disability studies and the social model of disability as discussed in chapter two. Earlier research has been criticised for perpetuating the oppression of disabled people (Oliver 1992), being parasitic (Hunt 1981), and for excluding people with learning disabilities (Atkinson 2004). In an attempt to address these criticisms, research approaches have been proposed that actively involve disabled people in all aspects of the research process. These methods share a commitment to social change to create a fairer society (Walmsley and Johnson 2003) but differ in the extent to which they challenge traditional methods of research production. The following section outlines the theoretical starting point of my research before going on to look at issues relating to doing research with people with learning disabilities and researching potentially sensitive topics.

4.1.1 Research and the social model of disability

As discussed in chapter two, the social model of disability highlights the disabling effect that physical, cultural and attitudinal barriers can have. To avoid reproducing these barriers it is suggested that the medical model must be rejected and a social model framework adopted when conducting disability research (see, for example, Oliver 1992; Stone and Priestley 1996; Barnes 2004;

Mercer 2004). This idea was developed further and an emancipatory approach for conducting disability research was proposed. It questioned research production, including who controlled the research agenda, who carried out the research and which groups or individuals ultimately benefitted from it and has been seen as ‘having a key role in identifying those social structures and processes which create disabling barriers, and in eradicating those that exist’ (Walmsley and Johnson 2003:38) ⁴.

The key features of emancipatory disability research have been summarised by Stone and Priestley (1996). Firstly, research must be carried out within a social model framework and must involve a ‘commitment on the part of the researcher, both to a social analysis of disablement and to the development of the disabled people’s movement’ (Stone and Priestley 1996:702). The research should contribute to the identification and removal of social and physical barriers, and thus contribute to ending oppression. The social relations of research production must be reversed: the professional researcher’s skills should be made available to disabled people and disabled people should control the research. Personal experiences that form part of the data collected should be presented as part of a collective political experience and, finally, no single method of data collection should be presupposed to be best suited to emancipatory disability research (Stone and Priestley 1996).

The proposition that disability research ought to be carried out in this way has been contested (see, for example, Shakespeare 2006; Danieli and Woodhams 2005). Indeed Oliver (1997), whilst reflecting on his own research practice, acknowledged that ‘while our intentions have been honourable, we remain on the wrong side of the oppressive social and material relations of research production’ (Oliver 1997:26).

The very notion of determining whether or not research is emancipatory has proved particularly difficult. Mercer comments:

⁴ An extensive discussion of researching within a social model framework can be found in a special edition of *Disability, Handicap and Society* (1992).

‘... “emancipation” as a research outcome can be measured in very different ways, as the self-empowerment of disabled people might take several forms: documenting social barriers and oppression, re-evaluating perceptions of disability, and taking political action. Furthermore, empowerment rarely entails a sudden conversion on the road to Damascus, or even a simple progression to social inclusion or “liberation”. Typically, it is more diffuse, uncertain, and drawn out... In practice, separating out the impact of specific research projects from wider economic, political and social changes will be an extremely difficult and contentious exercise.’ (Mercer 2004:124).

Thus the emancipatory nature of a research project cannot be assessed until it has been completed and even then its true impact might not be immediately apparent. Further, Oliver (1997) argues that research itself cannot emancipate a person. This must come from the individual, making the goal of empowerment particularly hard to assess.

The implicit acceptance of the social model in the emancipatory disability research framework has led to criticism that researching in this way could cause researchers to overlook other pertinent issues (Danieli and Woodhams 2005; Shakespeare 2006). In particular it does not take into account the potential effects of impairment, something that is a key critique of the social model and discussed in chapter two (Shakespeare 2006). Indeed, full adoption of emancipatory disability research could lead to only research that supports the social model being produced, potentially excluding those who do not agree or whose experiences do not support the model (Danieli and Woodhams 2005; Shakespeare 2006). This in turn could further marginalise oppressed groups. As a result, power relationships are not changed as the researcher dictates the structure within which the research is conducted. Finally, it is suggested that adopting this approach does not necessarily strengthen or develop the social model as ‘replacing one theory with another does not reveal the ‘reality’ of phenomena’ (Danieli and Woodhams 2005:286).

There has been some debate regarding the role of the researcher in emancipatory disability research. It can be argued that research cannot be truly

emancipatory if the researcher stands to gain more from the project than the participants and it has even been argued that the presence of non-disabled people in disability research perpetuates the oppression of disabled people (Branfield 1998). However, this view is contested by others in disability studies: 'having a designated impairment does not automatically give someone an affinity with people with similar conditions or disabled people generally nor, indeed, an inclination to do disability research' (Barnes 2003:8; see also Duckett 1998; Shakespeare 2006). However the notion that the researcher must remain accountable to disabled people, either as individuals or as organisations, has been criticised. In particular there is concern that the commitment to accountability 'carries with it certain risks and difficulties including... the neutralization of a radical analysis' (Barton 2005:321). Further, it is rarely straightforward for a researcher to hand over a large amount of control to participants due to pressure from funders and institutions and it is questionable if participants can ever gain as much as a researcher who can see how the research can directly affect their careers (Stalker 1998).

The role of people with learning disabilities in emancipatory disability research is at times unclear. Articles by Zarb (1992) and Oliver (1992) do not speak specifically about learning disability research. Whilst this is understandably rooted in a desire to separate disability from impairment it effectively ignores any considerations that might ensure that people with learning disabilities are better able to contribute to, participate in, and benefit from research. It is possible to acknowledge the effects of impairment without assuming them to be the cause of disability (Thomas 1999) and not doing so might result in the further exclusion of disabled people from research production. The effects of impairment can make it intrinsically harder for a person with learning disabilities to access complex theory than at least some disabled people with physical impairments (Walmsley and Johnson 2003; Walmsley 2004). The issue of accessibility, therefore, requires more careful consideration when planning research. In contrast to those with physical impairments, the aides required by people with learning disabilities to participate in research production are 'not technological but human. For most research, people with learning disabilities need the assistance of non-disabled allies and they are less amenable to control than technology' (Walmsley and Johnson 2003:54). However, although people

with learning disabilities might not be researching or writing about the social model this does not mean they are not ‘doing’ it (Chappell et al 2001.)

Participatory research ‘can be an important way of enabling greater involvement for people with learning difficulties in the research process’ (Chappell et al 2001:47) whilst still focussing on the experiences of disabled people and engaging with the social model and it is this approach to research that is explored next.

4.1.2 Participatory research, inclusive research and people with learning disabilities

The following section focuses on issues concerning participatory research with people with learning disabilities and ways in which the ‘excluded voices’ (Booth 1996) of those who have not been represented in traditional academic discourse can be included in qualitative research.

Participatory research, which involves participants in, for example, research development or analysis, and aims to be accountable to them (Chappell et al 2001) is recognised as a step towards emancipatory research (Zarb 1992). Stalker outlines three main assumptions common to both emancipatory and participatory approaches to research:

‘first, that conventional research relationships, whereby the researcher is the ‘expert’ and the researched merely the object of investigation, are inequitable; secondly, that people have the right to be consulted about and involved in research which is concerned with issues affecting their lives; and thirdly, that the quality and relevance of research is improved when disabled people are closely involved in the process’ (Stalker 1998:6).

Previous research tended to treat people with learning disabilities as ‘objects’ or ‘sources of data’ rather than as credible participants who could actively contribute to the research process (Atkinson 2004). This was due, in part, to an assumption that they would not be articulate enough to make a meaningful contribution to the research or that their views and experiences were not valid. Instead, information could be gathered from observation or from others, such as

professionals involved in their care, who were assumed to be able to speak on behalf of the participants. This information was then used to test the researcher's hypothesis. However, people with learning disabilities are now recognised as credible research informants and participants and 'it is widely accepted that individuals are the best authority on their own lives, experiences, feelings and views' (Stalker 1998:5).

Participatory research offers opportunities for people with learning disabilities to become involved in research (Chappell 2000). It 'is based on the notion of the sympathetic and committed researcher striving to improve the lives of people with learning difficulties. However, in participatory research, this is undertaken in partnership with people with learning difficulties, rather than on their behalf' (Chappell 2000:41). Inclusive research encompasses both emancipatory and participatory research, advocating that people with learning disabilities actively participate in the research alongside a researcher who is 'on the side of disabled people' (Walmsley and Johnson 2003:63). In addition increased emphasis is placed on ensuring the accessibility of the research, including the research questions and the process as well as the final report (Walmsley and Johnson 2003).

Research that actively includes people with learning disabilities has been carried out successfully (see, for example, the work of the Norah Fry Research Centre). Some projects have used a 'professional' researcher as a 'research supporter' to work with the other researchers, who had learning disabilities (Williams 1999; Williams et al 2005). The researchers with learning disabilities were enabled to 'guide and lead' the research in conjunction with non-disabled researchers, leading the project to be described as 'inclusive' (Williams et al 2005:6). As in the debates around non-disabled people and emancipatory research, the role of the researcher without learning disabilities in inclusive research is complex. Walmsley argues that although the desire to include people with learning disabilities in the research process 'has led to some creative, even empowering projects' (Walmsley 2001:189) it has also restricted researchers from engaging in debate as they fear speaking on behalf of the participants and either removing their voice or misrepresenting them. Further, researchers feel a greater responsibility to the participants and so are less able to be objective or critical

about the ‘bigger picture’. This has been complicated at times by a lack of clarity regarding the role of the ‘supporter’, ‘helper’ or ‘research associate’ who assists those with learning disabilities with the research process (Walmsley 2004). The issue of control is central to all research that aims to actively involve its participants. Williams et al (2005) conclude that it is possible for a non-disabled researcher to be involved in the research process as ‘a professional with a trade to ply’ and that researchers with learning disabilities can be in control, provided they have the support to do so (Williams et al 2005:13). Ultimately, this can change the role of the ‘professional’ researcher as by handing over their control they may lose the opportunity to pursue their own research interests. Reflecting upon the researcher’s place within the process can help to overcome the issues of power and control:

Academic rigour should never be compromised in establishing the criteria for what constitutes ‘good research’. But, and this is the crux of the debate, where the researcher has expertise in research skills, this should not be taken as a green light to assume knowledge of the needs, feelings conceptualisations of other research participants. (Stone and Priestley 1996:713)

In the case of this research project, I did not relinquish control nor take on the role of supporter or co-researcher. This was due in part to time constraints, which would have made it difficult to work so intensively with others, and financial constraints, which meant it was not possible to compensate people for their time or other expenses incurred, other than occasional travel costs. However it was also due to the fact that from the outset the benefits of participation were inequitable: I believe I stand to gain more from the successful completion of the research. Whilst it is my hope and intention that the dissemination of the research furthers understanding of the lives of people with learning disabilities I must also meet the criteria set by both funding body and institution of study. To this end I maintained control of the overall research project. However, this has not meant that I independently directed the research. It was guided by adults with learning disabilities in the initial stages of the development of the research questions and indeed the research topic was suggested to me by a participant in a different project. The views of participants

informed the design of the semi-structured interviews, whilst the use of grounded theory, discussed later, allowed the ideas of the participants to remain central. Further, I approached the participants as the experts in their own lives. I hope that this starting point gave them the opportunity to give me a level of insight and information that they felt was appropriate to the topic and for them, and that this allowed them to retain control over their contribution to the project.

4.2 Qualitative methods

The decision to use qualitative methods for this study was based on several factors. As discussed above, a driving factor in the research design was the desire to avoid oppressive methods that might continue the exclusion of the views of people with learning disabilities from research. However these beliefs must be translated into practice and the suitability of methods for working with the participants and researching the chosen subject must also be considered. All research methods have both advantages and disadvantages and the researcher must strive to design a methodology that best suits the aim of the research and the ethos of the project. The following section explores the reasons why qualitative methods, and specifically interviews and focus groups, were chosen.

The term ‘qualitative’ covers a range of approaches to collecting data. These approaches can employ quite different methods, from fostering close relationships with participants through a series of in depth interviews to a more objective ethnographic approach. They do, though, have several shared features: a focus on words, rather than numbers; a preference for theory generated by data, rather than hypothesis testing; an interpretivist epistemology with emphasis on exploring the social world according to the views of the research participants; an understanding that the social world is a product of social interaction and a preference for data that occurs naturally rather than through experimentation (Bryman 2001:265; Silverman 2000: 8).⁵ Such methods ‘can provide a ‘deeper’ understanding of social phenomena that would be obtained from purely quantitative data’ (Silverman 2000:8). These qualities

⁵ As Silverman notes, such lists tend to generalise the features of qualitative research. Hypothesis testing, for example, is possible and ‘qualitative research would look a little odd, after a history of over 100 years, if it had no hypotheses to test!’ Silverman (2000:8)

make it a suitable approach for research when exploring new areas or with groups previously excluded as there is room for new ideas and voices to emerge.

Qualitative research allows the researcher insight into the participant's private world. It can offer the participant the opportunity to express their own views and interpretations of their experiences as an individual and can allow the researcher access to social groups and settings. Qualitative methods, and in particular those that encourage interaction with participants through interviews and discussions, allow people to tell their own story as the experts of their own experiences. Thus these methods appeal to researchers who wish to research with those who have previously been excluded: 'narrative methods provide access to the perspectives and experience of oppressed groups who lack the power to make their voices heard through traditional modes of academic discourse' (Booth and Booth 1996:55).

4.2.1 Qualitative methods and the research design

Focus groups

The research used both focus groups and semi structured interviews. The focus groups allowed the exploration of some of the broad issues of interest. The benefits of doing this were two-fold. First, the views of a several people were canvassed simultaneously. Second, they provided an opportunity for sensitisation and allowed the participants to further set the agenda. Although the project has been informed by research with other populations, focus groups provided an opportunity for 'local' concepts to be uncovered and the dismissal of other, less relevant topics (Glaser and Strauss 1967:46).

Focus groups can also provide a good method for discussing difficult topics. Grogan and Richards (2002) chose to use focus groups in their research on male body image as this method can 'result in increased disclosure. Focus group research has shown that participants are more likely to self-disclose and share personal experiences in a group rather than one-to-one settings, particularly when they are in the presence of others whom they perceive to be like themselves, because they can feel relatively empowered and supported in a group situation, surrounded by their peers' (Grogan and Richards 2002:221). It

can be hoped therefore that the participants will feel more comfortable discussing these issues with their peers. Further, if they feel empowered by the group situation they are more likely to challenge the researcher if they feel that the questions are inappropriate or that they do not address the key issues. This is perhaps particularly important when doing research with people with learning disabilities who are often not given the opportunity to express their opinions or to challenge others.

Interviews

The main bulk of the data was collected through in-depth interviews with 23 adults with learning disabilities. The research approached the participants as experts in their own lives; interviews were thus a particularly suitable method of data collection as they can ‘yield rich insights into people’s biographies, experiences, opinions, values, aspirations, attitudes and feelings’ (May 2001:120). Several semi-structured interviews were carried out with each participant. As well as allowing the various research questions to be explored, this approach allowed the participant and researcher to get to know each other and become accustomed to the way the other communicates. This could be particularly important if the participants have limited language skills or are from a group who are not often given the opportunity to express their views and thoughts.

A semi-structured approach allowed the interview to be guided, ensuring the key topics were explored, whilst still providing room for the participant to raise issues that they felt were important and to provide as much information on a subject as they wished. In turn, the researcher could probe responses further, turning the process into a dialogue (May 2001). If well balanced, the process should mean that the participant feels able to talk about the areas that they feel are particularly relevant and that have the most resonance for them whilst the researcher is both able to guide the interview to cover the necessary areas while maintaining the freedom to pursue other topics as they arise. Further, a semi-structured approach makes it easier to compare interviews across the group as the main issues will have been covered with each participant.

4.2.2 Research on 'sensitive' topics

There are various definitions of what constitutes a 'sensitive' research topic. Lee (1993) discusses various definitions, including specific areas deemed sensitive, for example sex or death, research that might have wide social consequences or research that potentially poses a threat to those taking part. As seen above, Grogan and Richards (2002) concluded that their investigation of male body image was a sensitive research topic. However what makes research sensitive is not categorically definable and it is possible that research that might initially seem to be intrusive and therefore sensitive is not necessarily so as 'topics and activities regarded as private vary cross-culturally and situationally' (Lee 1993:5). This could be a particularly pertinent issue when interviewing people with learning disabilities as their lives are more frequently regulated and they are therefore more accustomed to discussing their private habits. Further, it can be difficult for an individual to judge how much to disclose because they 'only know about their own behaviour [so] it is difficult for them to judge how 'normal' that behaviour is compared to other people. This may lead to an additional threat in research situations since the researcher may be presumed to know how one stands in relation to others' (Lee 1993:6).

Although anonymous methods of data collection have been favoured by those collecting potentially sensitive data, interviews and other qualitative methods often provide the best way of providing the in depth and exploratory information needed to investigate a topic. Interviewing raises various issues when approaching sensitive topics. Lee (1993) suggests that it can cause problems regarding informed consent as the researcher will normally spend time discussing the research and so developing a relationship, even if superficial, with the participant before asking the person to take part. However, even when consent is considered a continuous process, rather than something granted at the start, it is possible that once this relationship has been established the participant might feel obliged to continue taking part despite no longer being comfortable with the topic. Further, Lee points out that 'there is no guarantee that informants will realise before an interview begins what they might reveal, in what ways, or at what risk' (Lee 1993:103). From a practical perspective, therefore, the researcher must be aware of how the respondent feels throughout the interview process and must have sufficient frameworks in place to support a

participant who has become upset during the interview, who wishes to further discuss the issues raised or, indeed, who wishes to withdraw from the process.

4.2.3 Why use qualitative methods with people with learning disabilities?

As discussed above, participatory research has been recognised as a way in which some of the power imbalances that are present in research can be addressed. Adults with learning disabilities have often been excluded from the research process due to inaccessible approaches or an assumption they are not able to contribute but qualitative methods such as interviews, life histories or focus groups can provide a way for their thoughts and experiences to be heard.

It is argued that qualitative research methods can empower participants by acknowledging the validity of their views and experiences and enhancing their knowledge and understanding (Atkinson 2004), something that applies to adults with learning disabilities as much as to the rest of the population. For example, oral and life history research 'are seen as ways in which people can come to own and control the stories of their lives' (Atkinson 2004:691). Individuals are recognised as best placed to relay their views and experiences and interviewing people as 'experts in their own lives', rather than as research subjects, gives value to their stories and views (Stalker 1998). Thus, it is felt that the research relationship moves closer to being reciprocal as the participant is given an opportunity to share their experiences, and to become a valued contributor to the research, rather than a source of data to be mined for relevant information. Whilst taking part in research might not materially alter a person's life some feel that it enables participants 'to develop historical awareness and thus to view their lives differently- and this can be empowering for the people concerned' (Atkinson 2004:692).

Previously it was feared that qualitative methods might, even unintentionally, exclude those who are less articulate. However various researchers have demonstrated that this need not be the case (see for example Booth and Booth 1996; Goodley 1996) although some caution is needed to avoid misrepresenting the views of participants should the researcher find themselves in the role of interpreter or biographer (Goodley 1996). Innovative methods have been developed to better facilitate discussion,. For example, some researchers have

found that props, particularly visual aids, can help to trigger memories and provide talking points whilst grounding the research in the participants' experiences (Atkinson 2004; Scior 2003; Swain et al 1998; Stalker 1998; Danielsson et al 2006).

When doing qualitative research with people with learning disabilities, the researcher might need to be prepared to adapt their methods. More time might be required for fieldwork or participants might need support to take part (Atkinson 2004; Thomas and Woods 2003) and a flexible approach is required to allow the researcher to respond to the particular needs of a participant. Practical aspects of communication should also be considered: 'each method can be enhanced through knowing the person... and understanding individual needs and styles of communication' as well as factors that can inhibit communication, including 'power imbalance, lack of confidence, fear, anxiety, place and expectations of those involved' (Thomas and Woods 2003:81).

The role of the researcher can be complex and it is important to remain self aware, particularly when doing research with those have limited language or who might find it difficult to express their views: 'because the researcher has to do most of the pedalling, there is an ever-present risk of the interview becoming more like an interrogation. People with few words cannot easily defend themselves against unwelcome or intrusive questioning.' (Booth and Booth 1996:63) Further, the researcher must avoid focusing the interview on their own concerns despite potentially limited responses from the participant. Whilst open-ended questions allow the participant to lead the discussion they might not always be appropriate with people with learning disabilities who are less accustomed to being asked their opinions or who find it difficult to link several topics or arguments. In such cases, shorter, more direct questions can help the participant to explore the subject fully. Booth and Booth (1996) found that participants tended to be reactive rather than proactive when interviewed and gave short answers rather than long uninterrupted speech, again suggesting that targeted questions are more likely to gain responses and thus enable participation.

4.2.4 Some ethical issues

The methods advocated by Goodley (1996) and Booth and Booth (1996) are often in contradiction to those seen as best practice for qualitative research, both with people with learning disabilities and with others. For example, interviewers are cautioned against using closed questions to avoid problems of acquiescence. Further, the interviewer is advised to avoid commenting for fear of 'leading' the participant (Prosser and Bromley 1998). However, as discussed above, such techniques can provide a way of researching with those who might otherwise appear to lack sufficient language skills or who might be intimidated by the interview process. There are, though, potential ethical dilemmas here: employment of such techniques must avoid becoming an interrogation and the researcher must be very careful about filling in any 'gaps'. A participant's silence may stem not from difficulty in answering but the desire not to.

Common interview technique recommends putting the participant at ease at the start of the interview so that better data is obtained: if the participant is 'made to feel competent at the start of an interview their own views are likely to be elicited and the information is likely to be more valid' (Prosser and Bromley 1998:103). This too can present ethical issues for the researcher as it 'necessitates the manipulation of interviewees as objects of study/ sources of data, but this can only be achieved via a certain amount of humane treatment' (Oakley 1981:33) and therefore could amount to exploitative practice. Full disclosure as to the purpose of the research can help to overcome this, as the participant is fully informed and aware of their role within the project and the relationship between the interviewer and participant can then develop within these boundaries.

The issue of power between the respondent and the interviewer is important regardless of the research subject. However, if discussing a potentially sensitive topic it is perhaps more important to be aware of it and the effect it can have on the research. Power relations between interviewer and respondent have been closely examined by feminist researchers and Oakley writes that it has been assumed that 'the person who is interviewed has a passive role in adapting to the definition of the situation offered by the person doing the interviewing. The person doing the interviewing must actively and continually construct the

‘respondent’ (a telling name) as passive’ (Oakley 1981:35). To a certain extent this can be countered by using methods designed to ensure that the participant has some control over the interview. For example, semi-structured interview schedules and open ended questions give the respondent the opportunity to highlight the areas they feel are important. Emphasising the importance of informed consent and approaching the participant as the expert of his or her own ideas and experiences can also help to redress the power imbalance. However, the objective of the research must still be met and so the researcher must remain aware of the potential power imbalance and must work to ensure that the participant is fully informed and willingly consenting to take part throughout the research process. This should also include allowing the opportunity for the participant to withdraw their data even after the interviews have been completed.

To summarise, the move towards including people in the research process rather than just using them as research subjects has helped researchers to think more about how to involve those who have limited language skills. Whilst previously adults with learning disabilities might have been considered unsuitable participants in qualitative research, researchers are now aware that it is they who must adapt their methods to enable these people to participate and to contribute their ideas and experiences. By recognising people as the experts in their own lives, researchers acknowledge that they must find a way of communicating with participants so that their views can be included. Whilst it might be more time consuming and demanding for the researcher, approaching each participant as an individual and learning how to communicate with them will enable the inclusion of people who have previously been excluded from research. It was my intention to incorporate these principles into my field work and it is this that is turned to next.

4.3 Fieldwork

The aim of this section is to provide an account of how the data was gathered. The first part of the section describes the process of data collection: the ethical issues that arose, the recruitment of research participants and the methods used to gather the data. Qualitative research has been criticised for its lack of

transparency and the difficulties in its replication. The responses given during interviews reflect the thoughts and experiences of the participants at that particular time and are influenced by the dynamics between the researcher and participants, making a true repeat of the data collection impossible. However, whilst this section does not aim to provide a recipe for repeating the research it is intended to give an insight into the process and to expose both elements that worked and those that did not, allowing scrutiny of the fieldwork and engendering faith in the data. So, the next section of the chapter describes the process of data collection: the ethical issues that arose, the recruitment of research participants and the methods used to gather the data.

4.3.1 Data collection: an overview of the process

The bulk of the fieldwork was carried out between September 2007 and August 2008 although some consultation took place prior to this. An accessible information sheet was written for potential participants. Throughout the fieldwork an emphasis was placed on obtaining informed consent and on a participatory approach where possible as well as meeting broader ethical demands.

My previous experience as a research associate working on projects looking at the impact of supported employment on the mental health of people with learning disabilities (Jahoda et al 2007, 2009; Banks et al 2010⁶) and at the implementation of direct payments (Williams 2006⁷) gave me a good grounding for the fieldwork. I was familiar with the processes associated with interviewing research participants and negotiating access with professionals. Many of the interviews for the supported employment project had been done with people with learning disabilities so I was already aware of many adjustments that might be required to enable them to participate. The previous experience undoubtedly allowed me to approach the fieldwork in a more relaxed way than I would have felt had I been conducting interviews and focus groups for the first time, leaving

⁶ Jahoda, A. et al, 2005. *Does Transition to Supported Employment Impact on Mental Health, Social Networks & Perceived Well-being of People with Learning Difficulties?* Scottish Executive Health Department 2002-2005

⁷ Riddell, S. et al, 2006. *Disabled People and Direct Payments: A UK comparative study* Economic and Social Research Council 2004-2006 RES-000-23-0263

me free to concentrate on fulfilling the needs of the research and ensuring the participants were facilitated to contribute as they saw fit.

The data collection had two phases. The first phase consisted of three focus groups conducted with groups of adults with learning disabilities and was then followed by a second phase which involved individual, semi-structured interviews with adults with learning disabilities and, occasionally, support workers. A discussion with some members of a self advocacy group also took part during this phase as they, collectively, decided they would rather do this than individual interviews. Although not planned, this was a very useful focus group. As it took place towards the end of the data collection phase it allowed me to introduce some emerging themes with a group who already knew each other well and who engaged in a robust discussion that might not have occurred in an interview situation. The research was constructed in this way to allow me a broad introduction to the topic and to explore the research questions before narrowing the focus at the interview stage. There were practical and academic benefits to this approach. The focus groups sensitised me to the subject, bringing up issues I might not have been aware of, and giving me insight into the lives of the people taking part in the research. They also provided the opportunity to collect data from a larger number of people than I would have been able to interview in a similar time frame, allowing a breadth of understanding which could then be built upon through the semi-structured interviews.

It was my intention that all the field work be done with adults with learning disabilities. This was because the focus of the research was on the attitudes, beliefs and experiences of the participants as they expressed them so it was not necessary to try and corroborate their accounts with a third party or try and triangulate different data sources. An attempt to 'validate' the data in this way would have undermined the participatory approach of the research as it implies that the participants were not responsible for recounting their own thoughts. On several occasions support workers were present during the interviews. As they were there when I arrived it was not possible to determine whether or not the participants wanted them there: it can be difficult to ask another person to absent themselves, particularly if they feel it is their duty to be there. However,

participants seemed happy and, in several instances, the support workers did not stay in the room throughout. The contributions of the support workers have not been taken into account unless specifically agreed with by the participant during the interview.

The lifestyles of adults with learning disabilities were varied and it was intended that data be gathered from a wide range of participants to try and reflect this. Participants were recruited from day services, housing groups and advocacy groups. The focus group and interview participants were largely drawn from separate groups but some focus group contributors expressed an interest in taking part in the interviews and so were included at this stage as well. Tables 1 and 2 give key details about the interview participants.

The level of support participants reported they received varied from having one or two support workers with them 24 hours a day to having no formal support apart from contact with learning disability charities or self advocacy groups. All participants living independently, including those who lived with flatmates, received support.

Table 1: Participants divided by gender in semi-structured interviews

Total	Male	Female
23	13	10

Table 2: Details of interview participants

Pseudonym	Gender	Age	Recruited from	Living arrangements	Formal support hours/ week ⁸
Ruth	Female	Approx 45	Supported housing advisory group	Lives alone in supported accommodation for people with learning disabilities	<10
William	Male	40	Advocacy group	Lives alone	Full time
Annie	Female	39	Advocacy group	Lives alone	Approx 15
Thomas	Male	53	Advocacy group	Lives alone	30
Barbara	Female	56	Day centre	Lives alone	<10
Helen	Female	55	Day centre	Lives alone	<10
Ewan	Male	50	Advocacy group	Lives alone	24
Patricia	Female	55	Day centre	Lives in a residential home.	Full time
Alastair	Male	61	Day centre	Lives in hostel for people with learning disabilities	Full time
Gordon	Male	Approx 50	Supported housing advisory group	Lives with flatmate in supported accommodation for people with learning disabilities	Full time
Judith	Female	55	Key Housing TAG	Lives alone in supported accommodation for people with learning disabilities	Full time
Susie	Female	40	Day centre	Lives in own supported flat	45
Carol	Female	59	Day centre	Lives with her older sister	0
Richard	Male	47	Day centre	Lives with his sister	0
Claire	Female	45	Day centre	Lives with mother	0
Linda	Female	46	Day centre	Lives with mother and	0
Fraser	Male	55	Day centre	Lives with mother and niece	0
Steven	Male	47	Day centre	Lives with mother and sister	0
Rory	Male	27	Advocacy group	Lives with parents and brother	0
Andrew	Male	25	Advocacy group	Lives with parents	20
Ross	Male	25	Advocacy group	Lives with parents and brother	0
Douglas	Male	55	Advocacy group	Local authority housing, lives alone	12
Duncan	Male	28	Day centre	Shares flat with flatmate	12

⁸ 'Full time' refers to support from one or more support workers for 24 hours a day.

The fieldwork process will now be looked at in more detail to provide a more thorough account of what was done and the successes and limitations of each aspect.

4.3.2 Ethics

Addressing the issue of ethics is an important part of the research process. Whilst there are examples of researchers who have used covert methods or deception, or who have dismissed the need for informed consent (see Bryman 2001:477-486 for a discussion on this) this is now unacceptable and ethical approval from the Faculty of Law, Business and Social Science⁹ at the University of Glasgow was obtained before any recruitment began. In an attempt to conduct the research in an ethical manner it is necessary to consider what implications it might have, regarding both the immediate effects of participation and any wider effects the findings may have. This requires some critical thinking about the research and the processes involved which is not just confined to conduct in the field but must start with the research design and continue throughout the project.

There were several issues in particular that had to be considered in this research. First, the body and personal health are often considered to be 'sensitive' topics; second, the proposed participants were adults with learning disabilities, often considered 'vulnerable'. Body image and health issues can be difficult topics for some people to discuss and it is possible that the research would raise issues that I was not able to resolve. Participants might expect advice regarding health queries or might become distressed when talking about personal matters and such possibilities needed to be taken into consideration when designing the method and when conducting the fieldwork. Ensuring that participants were fully aware of the purpose of the research and of my credentials went some way to addressing this: I was always careful to point out that I was not an expert or able to provide information.

A number of issues were raised for special consideration by the University's ethics committee. Much of the concern centred on whether potential participants would be able to consent to taking part in the research and perhaps

⁹ Now the College of Social Sciences.

reflected some negative views about the value of people with learning disabilities as research participants. Although there should be no need to 'prove' the value of their contributions, this was addressed on a practical level by a commitment to gaining informed consent from all participants. Information, written to be easy to understand was provided to those interested and is included as appendix 1. I read the information sheet with potential participants, and invited questions at any point. I attempted to keep my intentions transparent throughout the recruitment and data collection period. The information sheet included my telephone number as well as that of my supervisor, and participants were made aware that they were welcome to call should they have any questions or concerns.

Consent was assumed to be an ongoing process. Participants signed consent forms (appendix 2) at the start of the first interview or focus group and also provided written consent to having the discussions recorded. All participants agreed to this. At the start of each focus group or interview participants were reminded of the purpose of the meeting and told that they need not answer any of my questions. They were also told that they could withdraw their consent to take part and were always given the opportunity to ask questions. Whilst the meetings were generally informal, often conducted over coffee, it was important participants remained aware of the research process and their role as active contributors to someone else's research and did not feel obliged to take part due to a desire to be accommodating or misled as to the purpose of the meeting.

It was made clear to participants that what they told me would be used in my thesis and other publications but that their names would be changed and they would not be identifiable. They were also told that recordings would only be heard by me and that full, unedited transcripts would be kept confidential. Many of these procedures do not differ from those used in other projects with a commitment to informed consent. However, particular emphasis was placed on ensuring that information was provided in a way that adults with learning disabilities would understand.

Interview and focus group recordings, and the resulting transcripts, were stored securely. When writing about participants, names were changed and key details obscured or changed to generic titles. This protected participants' identities without affecting the data. Research such as this is not possible without the considerable contribution of volunteer participants. In addition to being an essential requirement of participatory research process, a commitment to treating them and the resulting data in an ethical manner seems like a small offering in return for the information entrusted to me by the participants.

4.3.3 Participant recruitment

The decision to interview adults with learning disabilities, rather than their family members or support workers, for example, was integral to the research design, which aimed to explore the topics from the perspectives of adults with learning disabilities, as experts in their own lives. This intention was discussed with the Enable user group, ACE, in the early stages of the research and they agreed that this was an appropriate method, particularly as they believed the research subject was important to the lives of people with learning disabilities and therefore it was necessary to seek their views. Gaining access to this group can be difficult and negative perceptions about their ability to make a meaningful contribution can cause them to be withheld from the recruitment process or lead to negotiation with gatekeepers prior to meeting potential participants. However, I was pleased to find that people were often keen to take part and during the course of the recruitment I had more potential participants come forward than I was able to interview.

The initial access for recruitment of participants for both the focus groups and interviews was straightforward and was greatly aided by Enable Scotland who supported this research and referred me to several of their services and suggested organisations. Most groups contacted were helpful and endeavoured to find a way for me to meet their service users. Participants were recruited from the day services of several organisations, from advocacy groups and a supported housing residents' meeting. Where groups already existed I was invited to speak at a general meeting. This method worked well and required no extra effort for potential participants. Addressing them as a group meant that no one was singled out or, hopefully, felt under pressure to agree to take part. As the

groups already knew each other I took on the status of ‘outsider’, placing them in the position of power as I was there only with their permission. Bryman (2001) suggests that group discussions provide opportunities for participants to challenge each other in ways that are not normally possible for the interview-researcher. I would add that it is also easier for a participant, as a member of a group, to challenge the researcher. The meetings I attended were relatively formal, making it easier to objectify me and thus declining to take part was less of a personal rejection. In these instances the gatekeeper, usually the meeting coordinator, was a useful presence as they moderated the discussion whilst I was present and, hopefully, acted as a neutral ‘other’ with whom participation could be discussed once I had left, thus helping to ensure any decision to take part was properly informed.

In some cases staff within services spoke to service users to see if they were interested in finding out about the project and what their participation would entail prior to meeting me. This proved to be an efficient method of recruitment for me as I only met those who had expressed an initial interest. However there are several drawbacks to this type of recruitment. Firstly there is the possibility that staff members, consciously or not, were ‘cherry picking’ those service users who they thought would be most ‘useful’ to me or protecting those who they did not think able to participate thus imposing their interpretation of the research requirements onto the recruitment process and possibly excluding some who would like to take part. Secondly this type of recruitment gatekeeping by a staff member could make those chosen to meet with me feel under pressure to consent to take part as participation becomes linked to an authority figure thus contradicting the project’s requirement to allow participants to consent freely. However, it should be noted that these limitations are speculative and there was nothing to suggest that participants were coerced or pressured into taking part; indeed several declined after speaking to me.

One group that proved harder to recruit from were those adults with learning disabilities who were not involved with learning disability services. Recruiting participants through services specifically for this group provided a filter and meant that I did not have to determine whether or not a person met the criteria of having a learning disability. By recruiting from a range of organisations, such

as self-advocacy groups, as well as traditional day services I was able to recruit participants with various occupations, living arrangements and support as shown in Table 2.

4.3.4 Focus groups

As discussed earlier in the chapter, focus groups, a method of discussing a topic with a group of people (Bryman 2001) are a useful way of gathering data. In particular, this method provided an opportunity to explore some of the broad issues identified in the literature and to become more familiar with the key issues identified by the participants. Indeed, it is possible that interviews might not uncover some of the concepts raised in a dynamic focus group as the researcher would simply not be aware of the questions to ask.

Each group involved between four and eight adults with learning disabilities and participants were grouped with others from the organisation they were recruited from. The number of meetings varied according to the group. Two groups met twice whilst the third group, recruited from a self advocacy group, met only once. Holding several meetings allowed the first two groups to get to know each other, and the researcher, increasing participant confidence and allowing in depth discussion of the topics. Several meetings were also preferable from a practical point of view as it allowed adequate time to discuss each topic whilst fitting in with participants' other activities. This was particularly useful as, due to the participants' prior relationships with each other, the conversation often wandered and, at times, I found it hard to steer it back to the subject of the research. Ultimately, the number of meetings was decided in part by the groups, and the constraints on their time, and in part by the length of time it took to cover the topics.

The first three focus groups generated some very interesting data which informed the schedule for the semi-structured interviews as well as being useful and informative in its own right. The discussions sensitised me to the data and gave me some insight into the lives of my participants. I cannot be completely confident that this method prevented me imposing my own ideas on the group and stifling theirs as a result. Certainly I facilitated each discussion and asked the questions so it is inevitable that my approach to the topic was made obvious.

Further, it is possible that my commitment to my research agenda inhibited a more expansive discussion of relevant topics or possibly even stifled the introduction of new areas. However, the emergence of one area that I had not anticipated being so greatly discussed (personal weight) and the lack of discussion about another (notions of a general body ideal) suggest that the focus groups were at least successful in raising areas of interest.

4.3.5 Interviews

The main bulk of the data was gathered through in-depth interviews with 23 adults with learning disabilities. This method of data collection can 'yield rich insights into people's biographies, experiences, opinions, values, aspirations, attitudes and feelings' (May 2001:120). The aim was to approach the participants as experts in their own lives and to gain some insight into their personal experiences, their attitudes and beliefs, something that would have been hard to achieve without speaking to them directly.

Most participants took part in several semi-structured interviews although there were a few with whom I only met once. Again, this was due to a combination of the participants' available time and the speed with which the interviews were conducted and was largely dictated by the participants. I met participants in a range of settings, some more conducive to a good discussion than others. I met the majority of the participants outside their homes, in day centres, workplaces (theirs and mine), and, on one occasion, a pub. This meant I was often reliant on others to accommodate my needs as an interviewer and on a few occasions the space provided for meetings was not ideal. An example of this was in the canteen of a day centre I recruited from, where I conducted several interviews. It afforded little privacy for the research participant and interruptions disturbed the interviews. Further, the environment and the presence of staff, even if in the background, made me feel awkward about the topic at times and, whilst none complained, it may well have had a similar impact on participants. However, as interview locations were primarily determined by what was most convenient for the participant, we largely had to make the best of what was available.

I was able to develop a relationship with many of the participants, sharing information about myself, and resulting in a discussion, rather than an interview, on several occasions. The disclosure of personal information can raise ethical issues. During the interviews I was willing to answer questions about myself asked by the participants, following the principle that 'the researcher must be prepared to answer direct questions regarding the mutual exchange of personal information and, thus... introduce some vulnerability through self-exposure in the same way as we are asking the research participants' (Vernon 1997:169). However, I was predominantly asked questions about my own food preferences which caused me no ethical dilemma and when asked questions about nutrition or weight loss I stressed my status as a layperson.

A semi-structured approach, using a schedule developed using data from the earlier focus groups, was used to guide the interview and ensure key topics were explored, although participants were still given the opportunity to raise issues that they felt were important and to discuss the issues as much as they wished. This approach also meant that new ideas that emerged during the interview process could be explored within the interview and could be incorporated in future interviews with other participants, allowing the interviews to develop as the field work progressed. The interviews did not seek to find a single 'truth' or test a hypothesis but rather to gather accounts of people's experiences and it was therefore important that personal differences were allowed to emerge.

The interviews were a rewarding part of the research process. They generated rich and varied data, demonstrating different experiences and beliefs about food and health and revealed weight to be an important subject for many of the participants. The interview schedule was largely successful and most of the participants were happy to discuss the topics. Some were more forthcoming than others. When interviewing those who were less talkative I tried various methods, such as rephrasing questions or asking off-topic questions, to initiate conversation. However, although I was keen to hear as many views as possible I tried to remain sensitive to the participant and at times had to acknowledge that, despite agreeing to take part in the research, at least parts of it were not of interest to them.

There were times when I felt uncomfortable in the interviews. Although I always stressed my lay-person role and my interest in their thoughts and ideas, there were occasions when I felt participants looked to me for help with their weight or health queries. The following exchange occurred in the early stages of an initial interview:

- R Well, you talk about healthy eating. Like, oranges, tangerines, all that. Pears, eh, apples, bananas. That's more kind of that type cos I like to start what I'm supposed to do and what I'm going to do and I think, cos I think I will go along with you, cos I'm going stick to that, this here. I'm going to stick with it.*
- I I don't have a diet or anything to give you.*
- R No, I know that.*
- I I'm just interested in the sorts of things that you eat now.*
- R Yeah*

Then, later in the interview:

- I Right, ok. So if you were going to look for information, you were saying about healthy eating and about fruit and things, where would you go to get information?*
- R That's what I was looking for there!*
- (Richard, 47, lived with sister)

On these occasions I felt awkward that I was not able to help and concerned that these participants had agreed to take part on a false premise.

Participants might also share information that the researcher finds uncomfortable. One participant, perhaps in an attempt to impress to me, told me about his cousin's violent acts of revenge:

He seemed keen to talk about his family, in particular about his cousin beating up someone he thought had burgled Duncan's family's house and who had later come to Duncan's college to threaten some students Duncan thought were bullying him.

(From fieldnotes; Duncan, 28, lived in supported flat with flatmate)

I was somewhat shocked by his casual references to violence, particularly as they were not relevant to the interview. I did not challenge or encourage the discussion and was relieved when I managed to steer the interview back to the subject of the research.

Whilst I hoped not to influence the participants' responses it would be naïve to think that I did not. My age, gender, and non-disabled identity would all have influenced the way participants responded to me. My casual dress, combined with my student status, hopefully distinguished me from powerful professionals and might have helped to make participants feel more comfortable during out interviews. Prior to doing the research I had not considered how my own body might influence others' discussion of theirs but I was used as a point of comparison on several occasions, much to my discomfort:

R I see someone like you, I wish I could be like you, Victoria.

Laughter.

I I'm younger than you, I think that's part of it.

R It's not to do with your age. It's nothing to do with your age.

I No?

R People are different

(Annie, 39, lived alone with support)

It is likely that my physical presentation influenced the interviews in other ways that I remained ignorant to.

When interviewing participants who had limited language due to speech impairments I used a combination of closed questions and, where possible, time so that I could learn how they communicated. I also prioritised the transcription of these interviews so that they were completed while still fresh in my mind. However on at least one occasion a participant became frustrated that I could not easily understand her. These techniques proved useful with other participants. Whilst using closed questions raised concerns about potentially leading the participant's response, I felt that the benefits outweighed the possible risks as otherwise participants might have simply not answered at all. At times the participants struggled to understand my language, causing me to find

new ways to ask questions and to be more aware of the words and phrases I used. For example, the concept of a 'special occasion' might require more explanation or reference to a specific event, such as a birthday. Remaining responsive to participants' styles of communication hopefully helped to elicit full responses wherever possible.

As well as being a useful research tool the interviews largely proved to be an enjoyable part of the process as they were an opportunity to explore the topic in a 'real world' sense rather than approaching it from a purely theoretical perspective. I did not find I encountered many problems regarding communication, perhaps because I had done research with people with learning disabilities before and so was accustomed to adapting my approach according to the individual. Further, a familiarity with methods of support provision, day centre use, and day opportunities meant that I was able to contextualise participants' comments about these aspects of their lives with minimal clarification thus aiding the flow of conversation. In addition, the topics being discussed, food and health, were ones that I, too, was personally interested in and so some of the interviews felt more like conversation. Participants largely seemed to enjoy the interview process and no one refused to participate in further meetings and, when the interviews were complete several offered to arrange further meetings if necessary. Indeed, perhaps the most valuable part of the process was the way participants responded openly to my questions and allowed me some insight into their lives.

4.4 Analysing the Data

Research is not usually a neat, linear process in which analysis starts when data collection is complete. It is 'a pervasive activity throughout the life of a research project' (Coffey and Atkinson 1996:11), and is an ongoing, iterative process, informing and informed by field work and literature. The following section of the chapter looks at how I approached my data: the practical process of organising and managing it and the theoretical approach I took when examining it.

4.4.1 Practical data management

The fieldwork generated data that had to be processed before it was ready for analysis. Interviews and focus groups produced recordings that required transcription and this, and other tasks such as making field notes, took up a considerable proportion of my designated 'fieldwork' time. I aimed to transcribe each interview or focus group soon after it had taken place and, although a labour intensive task, this had several advantages. Transcribing the recordings soon after the interview or focus group had been conducted helped with accuracy as I remembered the conversation and was still familiar with the participants' speech, accents and phrasing, benefits that are lost by sending files to be transcribed elsewhere. As most participants took part in several interviews transcribing each interview prior to conducting the next one provided an opportunity to revisit what had been discussed. Any areas that seemed worth discussing further were recorded in the field notes to be brought up at subsequent interviews. Further, transcribing the interviews soon after I did them gave the sometimes uncomfortable opportunity to examine my interview technique and to identify what did and did not work, hopefully enabling me to improve my skills during the field work.

The focus groups and interviews took place over nine months, during which time I was immersed in the data. Although not involved in more formal aspects of data analysis during this time, such as coding, I was required to engage with the data and this undoubtedly fed back into the interviews as I became aware of emerging issues and began to identify themes.

All focus groups and interviews were transcribed verbatim into word documents that were later imported into NVivo, a qualitative analysis software package. NVivo offers a way to electronically store, manipulate and organise qualitative data. I mainly used it to manage my data. The programme allowed me to organise the data under a series of hierarchical headings and subheadings that could be easily retrieved, searched and compared, making the process more manageable.

4.4.2 Developing an analytical approach

Whilst NVivo provided a way to manage the data, it still needed to be examined and interrogated before it could be written about in a meaningful or useful way. Although the interviews in their raw form provided interesting insights into the lives of the participants, ‘data are there to think with and to think about’ (Coffey and Atkinson 1996:153), and critical analysis is an important part of this. The broadest level of analysis took place early in the research process when the main topics of interest were identified. These were included in the focus group schedule; the data these generated were reviewed and the categories refined before being taken forward in the interview schedule. Through this process of reviewing the data for the schedule development broad categories that might later become formal codes were identified whilst others were abandoned. An example of this process was the reduction in questions about body image in the interview schedule. How participants viewed and talked about their bodies had originally been intended to be a significant area of focus in the research. However it became apparent from the focus group data that this was not something participants were particularly interested in discussing; instead, they talked about their bodies in terms of weight and attempts at weight loss. The interview schedule was therefore designed to take into account this newly identified topic.

A broadly grounded theory approach was taken to data analysis with the aim of allowing topics to emerge from the data. Grounded theory can be viewed as ‘a set of principles and practices, not as prescriptions or packages’ (Charmaz 2006:9) to be used by the researcher throughout the research process. Originally outlined by Glaser and Strauss (1967), grounded theory marked a move away from positivist approaches, instead suggesting a method with which the researcher could construct theory from data (Glaser and Strauss 1967; Charmaz 2006). It allows for a flexible approach to data collection and analysis (Charmaz and Mitchell 2001) as, rather than data being collected to test a preconceived hypothesis, it is explored on its own terms (Dey 1999). An interplay between analysis and data collection is promoted, allowing theory to be developed from data as themes are identified and fed back into the data collection process (Glaser and Strauss 1967). During this project, transcription of each interview immediately after it was conducted not only informed subsequent interviews

with the participant but also interviews with others as each interview shaped my understanding of the topic and demonstrated the areas participants felt were most important.

Using this method, the data were visited and revisited during both collection and analysis and emergent categories were used to try and group the data in a meaningful way (Charmaz 2006). The aim of this was to encourage the development and identification of overarching themes, informed by the data, whilst remaining open to new ideas (Dey 1999). To this end, I approached the analysis with ‘theoretical sensitivity’ (Dey 1999:4) with the intention of exploring the transcripts under very broad categories, such as attitudes to health and attitudes to food, to look for common themes or marked differences in or across topics. Whilst the method originally implied a position of researcher objectivity, with theory emerging independently from the data, the biases brought by the researcher are now recognised (Charmaz 2006). It would be naïve to believe that I was only guided by my own interrogation of the data. The literature studied prior to starting the fieldwork undoubtedly influenced the development of the focus group and interview schedules as well as my own understanding of the topics whilst personal experience made it impossible to be truly objective. Drawing on grounded theory methods, an initial coding framework was developed by writing summaries of a sample of the interviews which were then examined for emerging themes. These were: the way in which participants’ categorised food and, in particular, ‘healthy’ food; the role of food, including opportunities for choice; their attitudes towards their health; and significant others who influenced their diet. Participants’ responses were initially grouped under these headings and similarities and differences noted to identify emergent categories.

There are several benefits of using grounded theory in research such as this. Any theory that is generated is firmly rooted in empirical evidence and encourages the researcher to engage in an iterative process, moving between their data and theory as themes emerge whilst collecting data as well as during its analysis. This fitted with my desire for the project to be driven by the participants where possible. Testing a hypothesis or theory identified at the project’s outset would not have left room for participants to raise issues important to them or for new

categories to emerge during data collection or analysis. Further, by allowing the analysis to be guided by the responses of participants I hoped to maintain the participatory approach of the research.

Various approaches can be taken to the analysis of participants' responses. For the purposes of this thesis a relatively factual approach was taken, rather than a more interpretive analysis, for example. This supported the stance taken throughout the research, in which participants were treated as experts in their lives and their experiences and views were assumed to be valid. It was intended that treating the data in this way would help to keep the voices of the participants at the centre of the analysis and the thesis as a whole. This approach worked well alongside the method of analysis used, which allowed themes to emerge from the data.

So, using a broadly grounded theory approach the data were explored and codes developed. The categories that initially emerged from the data were descriptive and unwieldy but as this process of examining the data progressed they became more precise and analytical and could be grouped into hierarchies. For example, I began analysing what participants thought about food by considering the labels it was given. From this I identified various categories that food was grouped into, including 'healthy', 'unhealthy', 'ordinary' and 'treats'. Further analysis revealed that foods labelled 'unhealthy' and 'ordinary' could, at times, be conflated whilst 'healthy' food was often separate to that considered 'ordinary', suggesting that a healthy diet was outside the norm of consumption for some participants.

This stage required repeated reading of the data and was laborious at times but was necessary to truly get to grips with the data. It was not my intention to impose an existing framework on the data. However, it would be disingenuous to suggest that, once acknowledged, links to existing research did not influence my analysis, as I began to look out for them, and ongoing reading made me consider earlier analysis in a new light. The lengthy break I took from the project for maternity leave also influenced my analysis as I found I returned to my data with fresh eyes, questioning my earlier conclusions and needing to remind myself why I categorised the data as I had. Through this process of revisiting the data I

eventually felt I reached a point where no new themes were emerging. However the intellectual process of analysis and of searching for the implications of these findings, continued throughout the writing process as ideas were refined. Writing about the data required me to do further analysis as I considered how the themes linked together; it was during the writing stage that it became apparent that the theme of choice and control was dominant throughout the findings. Indeed, it is probable that, without time constraints, analysis could continue indefinitely.

Conclusion

This chapter has intended to outline the methods used in this project and to provide some transparency on the research process. It has been informed by the social model and a participatory approach to research and by using a grounded theory approach for the development of the interviews and analysis the views of the participants have driven the research. The chapter has also discussed some of the concerns surrounding conducting research on sensitive topics and with people with learning disabilities. Although these areas can raise ethical concerns it seems that many of these issues can be overcome by adherence to good practice in qualitative research. Having a learning disability or limited speech need not prevent a person from contributing to research but it might require greater flexibility from the researcher; this is more than compensated for by the opportunity to include those who have frequently been excluded.

This chapter concludes this section of the thesis. The second section focuses on the analysed data and following findings present discussion on the findings. The chapters are arranged thematically. The first data chapter looks at the overarching theme to emerge from the analysis: the importance of choice and control, and its absence from the lives of many of the participants. This is explored in relation to food and those who did have control in the participants' lives are identified. The relationship between denial of choice and control and psycho-emotional disablism is considered.

The second data chapter explores the concepts of food identified by participants and the roles it was ascribed. It demonstrates that the meaning of food was

often complex and that food choice was affected by multiple and often competing influences. The notion of 'normal' food is discussed and the 'othering' of healthy food is identified. It explores some of the barriers participants faced when attempting to implement their knowledge about healthy eating.

The third chapter begins an exploration of attitudes to health. It begins by looking at participants' notions of control over their health and explores the reasons for these views. Drawing on the work of Blaxter (1990) the chapter looks at participants' concepts of health and considers how these might affect notions of control.

The final data chapter considers health promotion and the relationship between health and weight. Participants identified various actions that they believed could help to improve health and well being. The data revealed barriers to taking action to promote health and these are outlined along with what might motivate participants to take action. Finally, the chapter considers weight and its association with health. Reasons for wanting weight loss are considered, as well as those barriers that inhibit action. Analysis of these barriers, and the accounts of participants who had successfully lost weight, suggest that access to good support and accessible information, in addition to the opportunity to make changes, are required to adopt a healthier lifestyle.

Chapter 5. Food: control and choice

When analysing the interview data, control and autonomy emerged as overarching themes. This opening data chapter aims to show how the participants viewed control, the extent to which they thought it was important in terms of both their diet and health and the opportunities they had to exercise choice. Chapter three explored existing literature on the opportunities people with learning disabilities have to make choices. It was noted that people with learning disabilities have fewer opportunities to make major life decisions or choose routine activities (Jenkinson 1993; Rodgers 1998; Treece et al 1999; Smyth and Bell 2006). Further, concerns were identified surrounding the question of how much control people with learning disabilities should be allowed in their own lives including: the risk of making 'bad' choices (Bannerman et al 1990; Smyth and Bell 2006); that the individual's right to choose might contradict the aim of habilitation (Jenkinson 1993) and the service provider's duty of care (Smyth and Bell 2006); that decision-making can be difficult and stressful (Stalker and Harris 1998) and that people with learning disabilities lack the requisite experience to understand the potential consequences of a choice (Jenkinson 1993). However, there is often a clear intention for services to promote choice and control due to the positive impact they can have on quality of life.

This chapter aims to identify participants' opportunities to exercise choice and control over food and the barriers that prevented this. It is divided into two sections. The first section starts by briefly outlining the extent to which participants were autonomous in various aspects of their lives. The section then explores the opportunities participants had to be involved in choosing what they ate and its preparation, looking at the ways in which they were engaged or distanced from food. The role of gatekeepers in the lives of the participants emerged as a key limitation on opportunities for choice and control and the deliberate and unintentional ways in which they controlled what participants ate is also considered. The second section explores participants' attitudes towards food choice. Some participants did not want to become more engaged with what they ate and appeared to have internalised the views others had of their abilities. In some cases food choice had become a site of rebellion in reaction to

the control by others. The reasons for these reactions and the wider effects on the individual's sense of competence of having control and choice restricted are considered.

5.1 Choice and control in the lives of the participants

Choice and control were key themes to emerge from the data. They did not just relate to food choice but to many other areas of the participants' lives and are discussed throughout the data chapters. The extent to which participants had control over their own lives varied and was influenced by factors including their living arrangements, the type of support they had and how much support they received, the attitudes of those around them and their own feelings of competence. This section of the chapter explores some of the opportunities for choice and control available to the participants in their wider lives.

Participants lived in a range of settings, as demonstrated in Table two (chapter four). Most of the participants either lived on their own, with varying amounts of formal and informal support (n= 10) or with family members (n=9); within this group, two lived with their sisters and the remaining seven lived with one or both of their parents in the family home. The other participants lived in residential homes (n=2) or shared flats with other people with learning disabilities (n=2).

5.1.1 Control and living arrangements

All of those participants who lived on their own or who shared accommodation with other people with learning disabilities received some support, although the level of support ranged from those who had at least one support worker with them at all times (n=3) to those who had only a few hours each week. Those who lived with family members did not receive support outside the day services they accessed, apart from one person who was supported outside the home to pursue sporting and social activities.

The differences in living arrangements and frequency and type of support impacted on the opportunities participants had to exercise choice and control in their everyday lives. As will be discussed in this and later chapters, they

influenced the opportunities participants had to make choices about their food and their interactions with healthcare professionals. However, as highlighted above, people with learning disabilities often have limited control over many aspects of their lives or to participate in mainstream society. At the time of the interviews, only one of the interview participants was in full-time employment, three had part-time jobs and several others did voluntary work. Those participants not in work attended day centres, took college courses and took part in activities with support workers. The majority of their lives were spent outside of mainstream society. It was unclear to what extent participants had been involved in planning these activities; certainly, participants would be expected to be involved in determining those undertaken with a personal assistant or individual support worker. What was less clear was whether or not participants had been involved in the decision to use day services or if they had chosen their college courses.

5.1.2 Control and support

Support was provided in various ways. Some participants' families provided support, others received assistance from the local authority or other organisations and several employed personal assistants (PAs). The type and amount of support they received was perhaps one of the greatest barriers to or facilitators of control and choice in the participants' lives and will be discussed in this chapter in relation to food choice. The amount of support participants had would impact on what they were able to do each day whilst the personal approach of the support worker would affect the extent to which the participant was encouraged to make their own decisions. Only one participant living with his family received personal support for social and leisure activities. The lack of support for the majority of participants living with family is likely to have impacted on their opportunities to undertake activities other than those that were part of the day services. Whilst some of the younger, male participants spoke of meeting friends and generally directing their own social lives, others appeared to be more restricted. Several participants mentioned that they were not able to travel on their own:

[My brother] takes me on the bus, I can't travel myself, I can't travel myself on the bus but [my brother] takes me out on the bus on a Saturday... I can't travel independent, I can't travel independent.

(Linda, 46, lived with mother and brother)

I cannae go out myself... I cannae go on the bus myself. I used to, a long time ago, near my old house. I couldn't do it now.

(Carol, 59, lived with sister)

Such restrictions might have resulted from others' views of participants' capability to take control or from participants' own concerns about the risks associated with acting independently. As a result, these participants' opportunities to pursue personal interests outside the home were limited.

Those participants who lived independently with support did not necessarily feel they had sufficient hours to do the things they wished to do. One participant, Duncan, was particularly unhappy about his support arrangements, mentioning them frequently during the interviews. He shared a flat with a young man who received considerably more support than Duncan. The flatmate's support workers generally supported both of them with tasks in the house although there were occasions when Duncan did not have support, something he was not happy about. He did not feel he had sufficient hours for social support and as a result felt he missed out on various activities. He was understandably unhappy about the situation:

I need support with doing hoovering and things, but it is all domestic. But, in saying that, I should be able to get out on a Saturday, I don't see why I shouldn't, cos it shouldn't all just be domestic. Basically my support package really is domestic.

(Duncan, 28, lived in supported flat with flatmate)

The example of Duncan demonstrates how the structure of support could impact on the opportunities people with learning disabilities had to make choices in their lives. When combined with wider structural barriers and the effects of psycho-emotional disablism, the possibility of developing a sense of autonomy

can be constrained. Stalker suggests that psycho-emotional disablism is commonly experienced by people with learning disabilities:

... numerous studies have shown that people with learning difficulties face attitudinal barriers which range from being patronised or pitied to harassment and hate crime. As children and adults, they may be subject to high levels of abuse and neglect. (Stalker 2012 forthcoming:3).

Psycho-emotional disablism, discussed in chapter two, describes the impact such treatment has on aspects of the self such as a sense of worth or confidence to take on new tasks or even simply interact with others, causing barriers to 'being' and restricting who they can become (Thomas 1999). This could thus be considered one of the most significant barriers preventing the participants in this research from being able to exert some control of their own lives. These wider issues of control and opportunities to make choices will have impacted on the way they approached food choice and it is this that the chapter now examines.

5.2 Autonomy and food

As discussed above, it is not uncommon for people with learning disabilities to have limited opportunities to exercise control across all aspects of their lives. Similarly, the participants in this study had varied levels of involvement with food; some were detached from aspects such as planning and preparation altogether whilst participants' options outside the home were often restricted by circumstance and influenced by others. The lack of choice would not only have impacted on the opportunities to make decisions about what they ate but might also have influenced how they felt about food. These circumstances impacted on participants' ability to implement changes to what they ate as they had to be negotiated with the person responsible for providing the food. It might also make those participants with little control less likely to take notice of health promotion messages concerning healthy eating as they were unable to act on them. This section begins by looking at participants' involvement in shopping, cooking and meal planning. It then considers the role of others, including family members and support workers, as deliberate and incidental gatekeepers in

controlling access to food. Finally, it looks at the internal barriers that prevented participants from taking more control of their diets.

5.2.1 Participants' involvement with food

The extent to which participants were involved with shopping, cooking and choosing food varied. It was influenced by living arrangements, the attitudes of others and the expectations they had regarding the individual's impairment, and the participants themselves. Some participants had the opportunity to take responsibility for their diets and undertook much of their own shopping and cooking. Others were keen to become more involved or to use cookery skills that they had learnt at college. This section of the chapter looks at the ways in which participants were involved with food and how far this extended into their daily lives.

Food preparation and cookery skills

Very few participants were responsible for all their meals at home, although some prepared their own food on certain occasions, echoing findings in other research (Rodgers 1998). The following comments from Andrew were fairly typical:

I So at home, who does the cooking?

R Oh my mum, I cannae cook. My mum cooks. She cooks cos I make a mess of it if I cooked.

...

I Ok, and your mum and your granny do the cooking?

R Yeah

I And you don't really do much cooking?

R No. I used to, I usually cook in the microwave, that's all.

I What sort of things do you cook in the microwave?

R er, curries.

(Andrew 25, lived with parents)

Participants living with family members tended to prepare their own meals only under particular circumstances. For example, Claire's mother prepared most meals but Claire made her own breakfast at weekends; Rory cooked for himself

when his parents were away, but admitted he was likely to only make microwave meals or fry-ups. Participants who received support were more likely to make their own food, with their support worker. However, even those with regular support did not necessarily have sufficient time to cook and barriers such as these will be explored later in the chapter. Amongst those who cooked for themselves, either regularly or occasionally, there was a tendency to use pre-prepared meals that could be put straight into the oven or microwave. Whilst this does not involve skilled cookery, participants expressed pride that they were able to do it.

Some participants had taken cookery courses at college, which they had enjoyed, with several of them completing more than one course. Reasons for doing the courses varied. Steven enjoyed learning new skills that he thought might help him to have more independence whilst living with his sister and mother:

R one of the times it was in the service I'm getting... and had me in, they had me in making my lunch.

I Making your own lunch?

R Aye, making my own lunch. See they'll try and get yourself as independent as possible. I'll get the chance, cos more chances doing that the better.

I Sorry, more chances to do-

R More chances to help myself and my Mum at home.

(Steven, 47, lived with mother and sister)

Others simply enjoyed the opportunity to make things and one participant, Ross wanted to work in catering. Some participants were encouraged, by their support workers, to develop their cookery skills. As well as being a means of feeding themselves, cookery could also be a hobby for participants. It formed a productive leisure activity, undertaken with a support worker, and participants reported making things as varied as a jelly or a bulk batch of lasagne to be frozen in individual portions. For these participants, cooking was an enjoyable and productive pastime that enabled them to develop their skills.

Shopping for food

Participants' experiences of food shopping were similarly mixed. Those who lived independently generally shopped with a support worker whilst those who lived with family members or in group homes were unlikely to shop at all and, if they did, it was largely for 'extras', such as snack foods or, occasionally, for odd items that the household had run out of. These comments were fairly typical of this group:

I So do you ever do the shopping?

R The only time I ever do the shopping is, like, if I'm coming home I would normally text my mum, I would say do you want anything? And my mum would say, like, bring us in four cartons of milk or like a paper or bread. That's how just on my way home.

(Rory, 27, lived with parents and brother)

R Mum does the cooking, mum does the shopping.

I Does she?

R But a Saturday, if she wants anything, myself and Jim go up the shops on a Saturday.

(Linda, 46, lived with mother and brother)

Participants who shopped for themselves often made a shopping list with the help of a support worker but those who lived with family members were not likely to help compile a list, highlighting the differences between the types of support. Support workers might constrain some choices, often due to concerns about risk, discussed later in the chapter, they were more likely to involve participants in these activities while those who employed PAs were in theory able to control their involvement themselves. In contrast, family members were less likely to include participants in processes associated with food.

Despite participants' interest in food, opportunities to be involved with cooking and shopping were limited. Although it was apparent from their keenness to cook at college and at home, with support, this did not translate into control of, or even particularly close involvement with, what they ate at home. It was not always clear why the participants in this study were unable to cook. However, a

previous study showed that risk-related concerns, organisation constraints, household habits or low expectations about the abilities of the participants were all likely to be barriers (Rodgers 1998). The next section of the chapter will now explore the barriers to greater control and the roles played by support workers, family members and others in mediating the participants' involvement with food.

5.2.2 Gatekeepers, influential others and control over food

Choice can be inhibited by various factors. It is argued that most households will have a nutritional gatekeeper who determines what food is available and influences the food choices in the household (Wansink 2006). Although Wansink (2006) assumes that the gatekeeper is an individual living in the house it is possible that people who receive support with shopping and cooking might have several gatekeepers who live outside the home and potentially do not even eat the food they help to choose.

Several types of gatekeepers who moderated the choice and control participants had over what they ate were identified in the data, including support workers and family members. Their level of involvement varied and, as discussed above, in some instances stretched throughout participants' lives. Some gatekeepers took charge of the shopping, thus controlling what food came into the house, but not necessarily what participants then chose to eat; others took responsibility for all aspects of the participant's diet, choosing their meals and snacks. In several instances, family members acted as mediators in the relationship between the participant and their support worker, liaising with the support worker to suggest what the participant might eat. The gatekeeping role was not always welcomed by participants but often appeared inescapable. Participants had mixed feelings about others having, or trying to exert control over what they ate. Duncan was opposed to the idea that a support worker might try to influence his diet:

That's not their job. See if they did that they'd get into trouble... They cannae tell us what we can and cannae do. Staff are there to give us support, not to tell us what we can and cannae eat and can and cannae do.

(Duncan, 28, lived in supported flat with flatmate)

His idea of a support worker's role contrasted with the descriptions given by other participants of their family members' close involvement in their diets. However, despite Duncan's strong belief that he should be able to choose what he ate, his reluctance to develop his food skills and his subsequent reliance on support workers to prepare his meals meant that his opportunities to take control were limited. Others were more amenable to the notion that a support worker might openly influence what they ate, particularly those participants who were trying to improve their diet. In these circumstances, the support worker's involvement was seen as part of their role and was more likely to be interpreted as participant and support worker working in partnership for the benefit of the participant.

Gatekeeping could also take the form of advice or suggestion from support workers and family members and, in some cases, participants were deliberately prevented from having control over what they ate. Ewan was given unwelcome advice when shopping with support workers:

... there were definitely other staff telling me what to buy, get you this and get you that and I just said no, I just want my ordinary messages [shopping].

(Ewan, 53, lived alone with support)

He confided in his sister, who confirmed that they were being unreasonable and encouraged him to shop as he wished. Duncan also found that support workers were changing the shopping:

... one of the staff is all of a sudden saying about buying exotic organic juice or whatever you call it. I thought wait a minute, what's this all about? So there is something going to be said about that as well no doubt... Fair enough, I like that, but it's as if they are telling you what you can drink and what you cannae drink. That's what it feels like.

(Duncan, 28, lived in supported flat with flatmate)

Although he was clearly unhappy about the situation he did not feel confident enough to challenge it himself but was instead going to ask his parents to intervene.

These examples suggest that participants did not always feel confident about challenging support workers and indicate how easy it could be for support workers to take control. Further, they highlight the potentially difficult role of the support worker who must help their client to make 'good' choices whilst promoting their autonomy (Bannerman et al 1990). Both Duncan and Ewan had family members who could support them and their involvement demonstrated the role that some family members took in negotiating relationships for the participants. Whilst this might have provided welcome support, their involvement lessened the participants' autonomy as well as potentially complicating the support relationship.

Relationships with family members were perhaps more complicated and whilst support workers were often in a position to influence or control participants' diets through suggestion, family members were more likely to explicitly tell participants what they should or should not eat. Some participants reported that family members exerted considerable control over their diets. While support workers' roles were fairly clearly defined, family relationships were less straightforward and it therefore might have been easier for others to take on a gatekeeping role, particularly in those situations where participants lived with family members. Participants appeared to describe family members' assumptions that the caring role included making decisions on behalf of the person being cared for. In such scenarios it is likely that families would have maintained established norms, as discussed in chapter three, and so a lack of control or choice might be left unquestioned as it simply perpetuated the existing arrangement. For example, William lived in his own home with support but was regularly brought food by his mother. He did not question this, describing these actions as 'Things that any mother would do probably'. Similarly, the arrangement in Linda's home was that her mother cooked and Linda did not:

I So why doesn't she [mother] let you use the oven?

R Because! I don't know. She says, says.

I Does she say why not?

R [Silence]

(Linda, 46, lived with mother and brother)

Linda was not able to give an explanation for her mother's decision and, indeed, did not seem to question it but instead accepted it as normal for their household.

Some participants said that family members tried to control what they ate outside the home, too. This might be by providing packed lunches or restricting the amount of money they had to spend on snacks. Carol had recently been told by her sister that she should not be eating so much chocolate or crisps:

R See I bought so many bars of chocolate, I bought packet sweeties in college. I bought too much. I bought three cans of juice and a twix and a packet of sweeties, that's five. Four things a day. I took my pay pot and put it in my bag and never showed [my sister] or nothing. But that's it, I've stopped it again... [my sister] said get that stuff out of that bag right away, that's terrible buying them. You've got a packed lunch to take, you'll be sick. She said you'll get too fat, you'll get awful, you're going to lose that weight again. I say, I stopped it.

I How did you feel when [your sister] said that to you?

R [my sister] was very angry with me. I was just coming in and she said, what have you got in that bag? She looked in the bag, opened the zip: 'Oh my God, you've got three cans of juice, that's not good for you, I'm going to phone your doctor, I'm going to phone that doctor again and say about you.' Three cans of juice, a Twix, a packet of sweeties. And something else. Oh, and I bought it again, I bought it again. Oh, it was terrible.

Carol was treated like a naughty child: the little autonomy she had was taken away as she was no longer allowed to spend her money:

Oh, I cannae buy things, I cannae buy, I'm not allowed. My big sister says that I have to save up a lot of money. I'm to save up.

(Carol, 59, lived with sister)

Following this incident Carol's sister had taken greater control of her diet, substituting the biscuits in her packed lunch for fruit and instructing her to

‘share’ any biscuits or crisps she received whilst at respite. Although it is likely that her sister was motivated by concerns about Carol’s weight and health, her sister’s worry about potential risk exceeded her wish to encourage Carol to make her own choices. Carol did not know why she had been forbidden to eat sweets, and instead focussed on her behaviour as the source of her sister’s displeasure. The potential involvement of the doctor appeared to be used as a threat to impress upon Carol the seriousness of her actions rather than an indication of her sister’s concern about Carol’s health. Further, rather than being presented as a source of help, her GP became another possible source of dietary control.

Although family members often seemed to be trying to stop participants from eating foods thought to be unhealthy, it was sometimes the case that participants felt the food they were given was not healthy. Richard was, at the time of our interview, trying to persuade his sister, who had complete control of the household food, to give him a more healthy breakfast:

R I says to her, I says look, [sister], don’t give me a weekend [fried] breakfast at all cos it’s too greasy cos... I’m eating the wrong things and that doesn’t help and all the greasy help. And I don’t like greasy food, that’s fattening, I know that myself. And I says to [my sister] give me a bit of toast even, and that’ll be me. A bit of toast and a cup of tea. And I said that to her 17 times! [My sister] says you need something. I says give me a bit of toast and a cup of tea. So me and [my sister] had an argument over that’s what I want, a cup of tea and a bit of toast.

I And what did she give you?

R Sausage and potato scone and all that.

(Richard, 47, lived with sister)

It seems that it was hard for his sister to accept that her brother might want something different to the food that she normally prepared for him, and ate herself, and, as she did all the cooking and shopping, it was not possible for Richard to conceive of preparing his breakfast himself.

Positive intervention

Some participants welcomed the involvement of others in their food choice and meal planning, particularly if they felt that they needed to improve their health or lose weight. They gave examples of working in partnership with those supporting them and of feeling part of a 'team'. Susie was trying to lose weight and felt she was working with her support worker, with whom she attended dietician's appointments. Her support worker then helped present the information in an accessible way. As a result, when her support worker tried to restrict Susie's choices or influence her shopping, Susie did not feel undermined by this:

She tries to, she'll give me a couple of choices each day, what I want to eat, and she'll wait till I pick something. Then she'll tell me if that's a good choice or not.

Susie's support worker would look at labels on food packaging for her and try to help Susie make an informed choice:

R ... the way it works with biscuits and things, she doesn't tell me what ones I'm to have, she says it's nice to pick yourself, she says I can only advise you what's best for you.... [my support worker] would say to me, that's not good for you, Susie. She's quite good at advising me. And I take it as ok, I'll maybe buy one packet of Jaffa Cakes and I'll not buy 6 packets or whatever! You know.

I So you don't mind her sort of-

R Telling me. I don't mind. Sometimes I do mind but I know it's for the good of my health.

(Susie, 40, lived alone in supported flat)

Some participants, though, appeared ambivalent about the advice they received from their support workers, particularly if they were unclear as to the reasons for the advice.

The involvement of family members in deciding participants' diets also evoked mixed responses. Whilst most broadly welcomed the additional support they provided, participants sometimes disliked the close involvement of family

members. Ewan, who lived alone with support, was prompted to change his diet by family members, who drew up a meal plan for him to use with the help of his support workers. Although Ewan welcomed the support for his lifestyle changes he, at times, resented the intrusion of his family members into his daily life as he wanted to maintain a sense of control and to feel that he was responsible for the changes that were being implemented.

For a partnership approach to be successful, all partners needed to work together. Family members' involvement could pose problems for support workers whose aim was to promote independent living. Support workers must already balance their perceived duty of care with the right of the individual to make 'bad' decisions (Bannerman et al 1990; Stalker and Harris 1998) and managing the involvement of family members can further complicate this. Thomas's support worker, who sat in on our interviews spoke of how this role had, at times, made him feel uncomfortable:

See when you [Thomas] started, when [your sister] wrote the plan down and said this is what I want to happen, how did you cope? You coped well but maybe sometimes there was agency staff come in and Thomas would say, on a Friday night 'I eat in a Chinese restaurant on a Friday night. That's my care plan.' He told them porkies [lies]. Didn't you? Any temporary staff that come in, any staff not used to working with you, used to say, 'a night out, and a big bar of chocolate that size and I get 2 litres of Irn Bru.'

It does bother me, it still gets my conscience, that as Thomas's carer or support worker, am I taking away his independence to a certain degree? And it always will. But if it avoids Thomas being diabetic, and avoids Thomas having heart problems etc and living longer then that helps to cushion it.

(Support worker for Thomas, 50, lived alone with support)

Thomas's support worker was faced with a difficult task: whilst Thomas wanted to lose weight, and reported feeling happier and healthier for doing so, in the short term he wanted to eat those foods that were restricted, and his support worker had to prevent this from happening. Working to promote Thomas's future health required his support worker to temporarily curb Thomas's freedom and thus contradict the support worker's day to day role of assisting independent

living, a dilemma outlined by Bannerman et al (1990) in their exploration of the right to choose and the right to habilitation.

Participants who took more responsibility for food shopping, preparation and meal choice were mainly those living independently, with support. However, in some instances family members who lived outside the home were still involved in planning and shopping. This type of involvement elicited a mixed response. Annie lived in her own flat, supported by a personal assistant and also received support from her mother. Annie felt this worked well as her mother supported her commitment to a healthy diet and did not criticise her food choices. Several participants reported that family members had become involved in their diets in an attempt to facilitate weight loss. Their general support was largely welcomed but interference in every aspect of diet was not, in part because it appeared to undermine the participant's attempt to take responsibility for making the changes.

Several participants reported that their families maintained an ongoing involvement in participants' diets despite their independent living arrangements, by providing them with food, for example. The involvement of family members was likely to be due to a general wish to 'help'. However, it might also have reflected concerns that the participants or their support staff were not able to properly 'look after' their health. Family members' involvement meant they could monitor what was eaten and ultimately undermined participants' attempts to take control of what they ate.

Thus it seems that participants' food choices were often mediated by support workers and family members, in addition to other restrictions placed on food options by circumstances and food availability, something discussed in the next chapter. Choice can also be restricted by a lack of awareness of the potential options because of inadequate or inaccessible information (Harris 2003). Whilst those supporting the participants might have felt they were offering choice, in terms of allowing participants to pick from specified options, by not giving them more opportunities to take control of their diet they were impeding the development of their decision-making skills. These gatekeepers did not just influence food choice but also participants' opportunities to become involved in

tasks associated with food, such as shopping or cooking, thus inhibiting the development of skills required to create a healthy diet.

Incidental gatekeeping- access to food

It is clear from the examples given that some family members and support workers intended to deliberately control participants' access to food. However, support workers could inadvertently control the diets of those they worked with. Their knowledge and skills might restrict the support they were able to give. Several participants reported that they had been supported by people who were unable to cook their preferred food; William recalled some who were not really able to cook at all:

'for a while I was, no intentionally, some of the younger members of staff that you get, couldn't cook and all I was getting was kind of convenience foods...Ready meals. They are full of salt, fat and all that. I like the odd one but I don't buy them. Don't really have to. Luckily enough, people like [the other support workers] come in, they can cook. It is better that a way a bit, when they start and they come in, that was quite difficult.
(William, 40, lived alone with support)

He also found that support workers from different cultural backgrounds did not know how to cook meals he considered to be standard. Although such differences had the potential to expose participants to new foods and ways of cooking, such as grilling instead of frying, they were not always welcome. Problems such as support workers who could not cook either the participant's preferred meals or, in some cases, cook at all were sometimes hard for participants to tackle. This was partly attributable to the nature of the working relationship, which meant that participants were often very reliant on the person providing the support and did not want to offend them.

Staff who facilitated activities during the day could also inadvertently influence the diets of participants. Ewan recalled how one support worker introduced him to the pub lunch that became part of his weekly routine whilst Thomas recalled being taken for coffee and cake by a senior member of the support staff. Their close involvement in their client's life meant they were in a position from which

they could exert considerable influence whilst participants' limited experiences and knowledge of available options meant they were less likely to suggest alternatives.

Differences in approach could cause some problems. Annie believed that her support worker gave her large portions of food because she was a 'big eater' while Annie was not. Annie did not believe her support worker's large appetite was due to greed or hunger but to the fact that she smoked and could therefore eat more without putting on weight. The problems with portion size were seen to be a reflection of this rather than a failure in the support provided. At the time of the interview, Annie was having trouble persuading her support worker to give her smaller portions. Although they cooked together Annie felt she was expected to eat more than she wanted to:

Sometimes she almost half kills with food... I'm trying to get her to stop. This is what I want to do, she's not letting me.

(Annie, 39, lived alone with support)

She had told her parents about the problem and they intended to bring it up at the next support meeting. Such problems reflect the extent to which participants often lacked control over what they ate; even if they were able to choose their food, they might not be able to control how it was prepared or how much they were given. Working in such a close relationship with support staff or living with family members in adulthood meant that participants were subject to their influence. Disagreements about food and eating could challenge support workers' own belief structures if they were required to work in a way that contrasted with their own, personal approach.

The structure of support sometimes meant that participants had little control over what they ate. Both Helen and Susie found that there was often not enough support time to adequately prepare a meal. Susie's support arrangements had since improved but she recalled previous problems:

...because I had only the home helps I had to buy microwave meals. It was easier for me just to snack on junk.

The support for shopping also made it hard for her to control what she ate:

I don't even know if it exists now, it's a social work van that comes up and you give them money and a shopping bag and they go out and do your shopping for you. So I would write a list and they would maybe not always have what I wanted so they were trying to kind of guess what I would like. So, instead of buying meals I used to buy a whole lot of rubbish.

(Susie, 40, lived alone in supported flat)

There seemed to be little that participants could do about problems with the structure of support as physical impairment often prevented them from being able to perform such tasks independently and there was little else that could be achieved in the support time they were allocated. Those who shared homes and support with others were also unable to have full control over what they ate as they were required to fit in with the preferences of flatmates and family members. It is recognised that an important element of developing an individual's abilities to make choices is ensuring that they are aware of the opportunities available to them and that they practice decision-making (Harris 2003) but, in the case of many of the participants, it seems these opportunities were being overlooked due to the real or perceived limitations associated with their impairment. Indeed, it is suggested that reduced opportunities to make decisions might often result from the attitudes and practices of those closely involved in the lives of people with learning disabilities, rather than from limitations associated with impairment (Jenkinson 1993). The following section examines how participants felt about having control over what they ate and how this impacted on their involvement

5.3 Internal barriers to involvement with food

5.3.1 Participants' perceptions of their own ability

So far, this chapter has looked at the external restrictions placed on choice. However participants' own feelings and approaches affected how they felt about taking control of what they ate, as well as shopping and cooking. These internal factors influenced what the participant believed they were capable of doing or what they thought was appropriate for them to do as a result of their

impairment. In some cases, perceptions resulted from the internalisation of the opinions of others, and subsequent psycho-emotional disablism, as described by Thomas (1999). In other cases, though, these barriers might have been related to the effects of impairment: one participant, Susie, believed that it was harder for people with learning disabilities to make informed choices, particularly when faced with an array of unhealthy but tempting food:

Well, [the cook will] prepare like, pie and beans and chips and beans and chips and pies and things like that and I think when people are trying to lose weight, and certainly if they've got a learning disability, well that's there for them to see and they are going to pick pie and beans and things so Marie tends to make me a packed lunch so it's keeping me away from that.

(Susie, 40, lived alone with support)

She had recognised that she found this a problem and so had chosen to avoid such situations and to enlist the help of those she trusted. The extent to which this relates to impairment, rather than reflects the lack of accessible information or a simple bias towards preferred food at any given time, is hard to establish. In some cases, participants attributed their lack of involvement to impairment but seemed reluctant to try and develop skills that would allow them more opportunities for control over what they ate.

Some participants expressed the view that it was preferable to leave food preparation tasks to their support workers. William, for example, who lived independently with support, felt that it was easier to leave the cooking to the support staff and said 'if people want to help me, I'll let them do it'. This had also been the case when he lived with his parents: his mother had done the bulk of the cooking and he had not been expected to help. Although he was interested in what he ate and expressed clear preferences about food he was happy to defer to his support workers over how food was prepared. Many participants had limited experience of cooking so support workers and family members were quicker and more efficient at preparing meals, thus reducing the incentive for the participant to be involved in cooking. It is also possible that neither support workers nor family members wanted to pressure participants to do something the participant felt uncomfortable with and that they could easily

do themselves. However, whilst support workers might feel that they are acting in an individual's best interest by restricting choice, presenting limited options or influencing decisions can contribute to a belief that the individual is not able to decide or act for themselves (Williams et al 2009). Attitudes towards risk, food preparation and developing skills associated with food are explored next.

5.3.2 Risk

Perception of risk was an important factor both for those supporting choice for people with learning disabilities and for the participants themselves. There were concerns about physical risk as well as the risk of making bad choices.

Perceptions of risk were often underpinned by assumptions about the competency of people with learning disabilities and a belief that they were not able to make 'good' choices. These stemmed from the concerns of others as well as previous bad experiences. Whilst some fears appeared well grounded, others demonstrated that participants had internalised the views of those around them. This internalisation of the negative views of dominant groups impacts on the sense of self, 'affecting the self-esteem of the individual in addition to shaping their thoughts and actions' (Reeve 2004:90), and potentially limiting their notions of what they might achieve. The following section explores some of the risks identified by participants and the effect that these had on their willingness to become more involved with food.

Participants' views of their impairment could affect their inclination to learn food preparation skills. Duncan had been encouraged to get involved in preparing food by his support worker but did not feel it was appropriate:

But my support, tell me I'm supposed to be in the kitchen with my staff, but I never, not really. Cos I've never been able to cook anything.

He went on to say

R I've given it a go, like stirring soup and things. But as far as it goes with the oven, that's a no-no, that's never been allowed to happen... Well, it's

because I've never been able to cook anything. That's how my parents says 'no'. I normally try to do things myself but they say it shouldn't be happening.

...

I You were saying that your parents weren't happy with how things were with the cooking. Do they want you to do more cooking?

R No, I was saying, I've never been able to cook since I was brought up. So it's a definite no-no for that.

I Your parents don't want you to cook?

R Uh huh.

I Right. And why is that?

R Cos I've never been able to.

I And they don't want you to learn?

R No. Cos you need to be able to see what you're doing, and that's another reason behind it.

(Duncan, 28, lived in supported flat with flatmate)

As a result he was restricted in what he was able to eat and relied on microwave meals on the nights he had no support. He thought that it would not be safe for him to try to cook due to his poor vision, a view apparently shared by his parents, and felt that this should be done by a support worker. Despite limited support hours, leaving him largely reliant on those workers who supported his flatmate, he was reluctant to try and improve his skills at all and if faced with this level of unwillingness, coupled with family concern, support workers might well find it easier to cook for him. It seems that Duncan's perceptions of his abilities were influenced by what his parents thought that it was suitable for him to do. Rather than explore for himself what he was able to do, he appeared to have internalised his parents' view of his impairment and had based his views of what he might be able to try on this. Thus their views acted as a form of psycho-emotional disablism (Thomas 1999), as the dominant negative notions about his capabilities projected by others were incorporated into his sense of self, affecting his beliefs about his abilities and potential. This creates a particularly pervasive barrier to participation as the individual internalises these prejudices (Reeve 2002) which in turn impacts on their own expectations of their potential and inclusion.

Physical safety was a concern for several participants. Whilst this might stem from others' concerns, it could also be a response to participants' previous experiences. Ruth was nervous about cooking. Although she enjoyed it with her key worker, she tended to rely on meals that could be heated in the microwave or sandwiches when she was alone due to the perceived risks:

I've got to watch with the knives cos I've got bad coordination... and I've been cut a few times with knives, with sharp knives.

(Ruth, approx 45, lived alone with support)

Thomas's support worker also commented that Thomas was nervous about using the stove, although he still encouraged him to cook.

Even tasks that were relatively low risk were often still left to others. Packed lunches were often prepared by support workers or family members, although this might have been to control what foods were included rather than because of safety concerns. In addition, if participants required support or had little experience with such tasks, it would have been easier and faster for others to do them. This could reinforce beliefs that such jobs were beyond their capabilities, as suggested by this comment from Duncan:

I need support for that cos you need to be able to see how to spread butter on sandwiches and cut things like that. I need support while I'm cutting food and all that.

(Duncan, 28, lived in supported flat with flatmate)

Not all participants were reluctant to become involved in cooking and meal planning, although few were encouraged to do so; some were developing cookery and meal planning skills while others expressed an interest in doing so. As mentioned previously, many participants took cookery classes at college, had done previously or wanted to in the future, and it was something which they all said they enjoyed. Claire was particularly enthusiastic about her classes, listing the dishes she had made and describing her food as 'lovely'. She was proud of her achievement in the class:

...I've got hundreds and thousands of, what do you call them, when you look, you get a degree or a diploma, a certificate. I've got hundreds and hundreds of them. I've got that many of them!

(Claire, 45, lived with mother)

She hoped to make some of the meals she had made in class at home. Several expressed the wish to become more proficient at cooking to aide their independence:

It would be good for me if I got the chance to do it, it would be fine. I would be independent and then I wouldn't be dependent on people.

(Steven, 47, lived with mother and sister)

I've got to learn eventually. Cos if I'm going to be on my own eventually I've got to learn to do it.

(Andrew, 25, lived with parents)

Although cookery classes might be viewed as a hobby, at least some of the participants felt that they were developing skills that they could employ in their wider lives. However, whether or not they were able to use them to promote their control over what they ate was largely reliant on those around them.

Concern about making bad decisions could lead participants to restrict their food choices. The cost of buying unfamiliar food could be off putting, for example, as participants feared they might not like it, causing them to stick to known recipes:

I would say that looks good but at the end of the day buying the ingredients would be expensive.

(William, 40, lived alone with support)

They might also lack confidence that they or their support could cook new items properly. Support from a trusted formal or informal supporter could help to overcome these fears and make participants more willing to take risks:

Now that I've got the freedom to go out with [my PA] everyday, I think it's brilliant cos I go out and pick my own food, with a bit of assistance from [my PA], whatever advice she gives me, with [my PA]. And it's good that I can go out and choose my own food and see what I'm buying as well. So it's good.

(Susie, 40, lived alone in supported flat)

Working in partnership with her support worker helped Susie to feel confident and meant that she felt she was making real choices rather than just relying on a limited range of known foods. Perceived risks, both in relation to safety and decision making, could cause participants to limit their involvement in food but the experience gained through practising making choices and developing cooking skills could help to overcome this and subsequently enable them to become more confident of their abilities.

5.3.3 Control and rebellion

The opportunities that participants had to exert control over what they ate impacted on the role food took in their lives. As many of the participants had limited agency and access to food was often mediated by others, it became a site of rebellion for some. It was something that participants could use to show defiance and assert their identity: going against another's 'rules' was a way of undermining their authority and regaining some control. The various meanings ascribed to food by participants are explored in the next chapter; however, the following section of this chapter explores some aspects of the relationship between what participants ate and the control they had over this.

Some participants used food to rebel. Claire, whose mother restricted her access to certain food, described taking biscuits while her mother was elsewhere:

This morning I done something, I sneaked, see how my mum's got two biscuit tins, up on the thing, I took a wee cookie and then I took a wee plain digestive and I went, I was eating it outside the living room door!

(Claire, 45, lived with mother)

Claire used the forbidden food to rebel against her mother's attempt to control what she ate. Rebellion served two purposes: Claire undermined her mother's attempt at control whilst treating herself to something forbidden. She also

mentioned buying chocolate at college despite only being meant to have it at weekends, again using food to undermine her mother's rules. Snacks such as this were one of the few things she was able to spend her money on and so her actions offered her an opportunity to exert some independence as well a chance to rebel against her mother's attempt to control what she ate.

Susie spoke more explicitly of using food to rebel, describing how it represented her new freedom. She recalled a period where she ate a lot of 'junk food' and paid little attention to having a healthy diet:

I can think, maybe I was flying my wings, you know? Cos I'd been in my mum's house and then I was in residential care and they kept an eye on what I was eating, and then I went to sheltered housing. Now I'm in supported accommodation although I have my own support. And I think I was going through a stage where I just said, no, I'm going to eat what I want to eat.

Eating as she pleased, even those things she knew were less healthy, gave her an opportunity to rebel against the strictures of home and residential care. This control over what she ate remained important when she moved into different accommodation and she spoke of how she felt when others tried to moderate her eating habits:

I made sure, I asked where the shops were. I says, I'm used to going round to my own shops and getting it but it was a bad thing in a way though because I wasn't eating the food [in the home], I was buying crisps and all this again so staff were trying to tell me, but in saying that it was their manner that I didn't like.
(Susie, 40, lived alone in supported flat)

At the time of the interviews, Susie had more control over all aspects of her life, including food. She had made a conscious choice not to eat as she did previously whilst the good relationship she had with her PA meant that she was more open to advice. It appears that having control over food, even if it is just being able to choose to spend an allowance on crisps and sweets, can offer an opportunity to experience some independence. This can be particularly important for those who might otherwise feel that they have little control in their lives. When this was threatened, participants seemed upset. Already concerned that his support

worker was trying to introduce him to new foods, Duncan became agitated when describing how it was suggested that he might store fewer of his own cans of lager in the fridge to make room for new things:

And he's going out with my flatmate to Asda and buying cans of juice, organic juice and all that, organic orange and all that [participant clearly upset]. And he's telling me to store mine opposite saying there's too many cans in the fridge and all that.

(Duncan, 28, lived in supported flat with flatmate)

Duncan was upset because the support worker had bought juice for him and his flatmate to share that was not the type they normally bought. However, being asked to move the lager was particularly important because this was something that he bought separately from the household shopping and he felt it was his right to enjoy it (and store it) as he chose. Whilst small, this was a part of his life in his shared flat that he was able to control, and the lager was something specifically for him, in contrast to many of the communal aspects of a shared flat. Duncan felt dissatisfied with many aspects of the support he received in his shared flat, particularly as he felt he did not receive enough support hours to enable him to live as he wished. Comments such as this demonstrate how he felt that his autonomy in his own home was being undermined. Food could represent rebellion and control, both a way of demonstrating some self determination. Participants revealed that others, such as family members or support workers, might attempt to use food as a way of exerting some control over them, taking away some of the limited autonomy they had. However they showed they were sometimes able to undermine them and, when given more autonomy, might actually be more open to others' advice.

5.4 Conclusion

This chapter aimed to identify participants' opportunities for control and choice of what they ate and the restrictions that they encountered. A lack of choice or control emerged as a key theme in the data, preventing participants from taking responsibility for their diets. The chapter began by exploring barriers to choice and to greater involvement with food. It showed that gatekeepers, including

family members and support workers, both deliberately and incidentally restricted participants' access to food, despite some participants' wishes for greater involvement. Whilst gatekeepers are present in most households (Wansink 2006) those working with people with learning disabilities appear particularly powerful and pervasive. As a result, participants' chances to exercise real control by engaging with shopping or cooking were limited. This will have impacted on the factors that influenced food choice, which are explored in the next chapter. It should be noted that not all gatekeepers were negative forces. Participants reported working in partnership with others and it seems that some were happy to have their choices constrained provided they had been involved in determining the boundaries of their relationship with the gatekeeper.

The second section of the chapter explored attitudes towards choice and the 'barriers to being' which, at times, prevented them from taking control. Participants' views on being able to make choices about food were varied. Whilst some felt it was very important to be able to choose what they ate and wished to be involved in the accompanying tasks, others were mainly concerned with being given food that they enjoyed. Some participants were disengaged from the processes surrounding food and were disinterested in taking more responsibility for what they ate by, for example, developing cookery skills. In some cases this appeared to stem from psycho-emotional disablism (Thomas 1999) and the internalising of the negative views of people around them which lead them to believe that they were not capable of developing skills, nor was it appropriate that they should. However, in some instances, enabling the participant to have more independence helped them to have a healthier diet: a sense of control over everyday food choices seemed to help some participants take control of their diet in the long term. In contrast others, whose choices were very tightly constrained, took the limited opportunities they had to consume foods that they had been told they should not have. These acts of rebellion enabled them to assert some independence and gain a sense of autonomy even when they knew that what they chose to eat was not a healthy option in the longer term.

It is likely that some support workers felt conflicted about supporting people to make healthy food choices and in particular facilitating the long term aim of a healthy lifestyle whilst also allowing the individual control in their day to day life. Service providers at all levels are in a position to significantly influence the degree of choice afforded people with learning disabilities and choice needs to be engendered at all levels of provision if support staff are to feel able to encourage it in people's daily lives (Stalker and Harris 1998). However, the data suggested that many participants were being offered support to take control of their eating habits and were able to choose their meals and participate in cooking if they chose to. Participants' reluctance to become more involved perhaps stemmed from their beliefs, and those of others, that they were not capable of doing such things. The limitations on choice and control faced by participants will have influenced both food choice and attitudes towards health and weight, which are explored in the next three chapters.

Chapter 6. Food: influences and understanding

This chapter looks at the way participants talked about food and the themes that emerged from the discussions about diet and eating. Food has been found to fulfil many roles: it can form social rituals, be a potential medicine or pathogen or a means of expressing a sense of self (Lupton 1996). The interview data showed participants had similarly complex relationships with food and eating. Whilst maintaining a functional role, food often took on other characteristics and became a source of comfort, a means of rebellion and a form of celebration. The aim of this chapter is to explore the way participants defined food and the effect that this had on its place in their diets. The first section starts by exploring the way participants characterised food as good, bad or 'ordinary' and how this was reflected in their diets, particularly in the use of treats, and in views of the self. It then moves on to look at the role of food in participants' lives. Whilst eating was often mundane, other functions associated with food were identified by participants. These included eating as an activity, particularly if outside the home; a marker of a special occasion; and a source of comfort and these are explored in this section.

The second half of the chapter begins by looking at the influences on participants' diets. Participants identified a variety of dietary influences, including the availability of food; the influence of friends and peers, families and support workers, particularly in establishing eating norms; financial and time constraints; and self awareness of dietary requirements. Ways in which participants developed a sophisticated understanding of their own needs in order to negotiate these sometimes competing influences are explored. Finally, the chapter looks at how participants responded to health messages and explores their experiences of seeking out information about healthy eating. It concludes by looking at participants' responses to a long running, widespread healthy eating campaign and demonstrates that they reflected cultural norms.

6.1 Characteristics and meaning ascribed to food

The first section of this chapter examines the way participants talked about food, the meanings they attached to it and the roles it had in their lives. They

often demonstrated a good knowledge of the components of healthy eating but this was clearly not the only factor that influenced what they ate. Participants had a dynamic, sophisticated understanding of food and often held multiple constructions, categorising food according to the situation. Their awareness and insight into their own eating habits will also be explored.

6.1.1 Characterising food: Identifying the good, the bad and the ordinary

As discussed in the previous chapter, there are multiple influences on choices made about food. Discourses around food and health are complex and often contradictory, problematising diet and complicating choice (Madden and Chamberlain 2010). Assigning foods categories or values can help to simplify these choices by reducing the options available according to the circumstances (Connors et al 2001). So, for example, an individual might have decided that those foods classed as treats were only to be eaten at the weekend and thus need not be considered as an available choice during the week. Participants talked about food in different ways, ascribing labels and values, according to how it was viewed and the role it played in everyday diet. Distinctions were made between ‘good’, ‘bad’ and ‘ordinary’ food and these both informed the decision-making process while also reflecting the place these foods had in participants’ diets.

Food that was considered normal or ordinary did not generate much discussion and participants often struggled to remember what they had eaten recently, reflecting the extent to which these norms have been internalised (Wansink and Sobal 2007). Several participants expressed opinions about what constituted ‘proper’ meals although this was not necessarily what they would eat regularly. Ruth described ‘ordinary’ food as the type of meal her mother would make:

Just what mum made, loads of veg and that and stuff like that, mince and that. Proper dinners.

(Ruth, approx 45, lived alone with support)

However she did not tend to cook this for herself in her home, instead relying on food such as sandwiches or microwave meals, due to a combination of lack of

support, self-confessed laziness and the perceived risks of cooking such as those described in the previous chapter.

‘Normal’ might also be simply what was eaten regularly and thus notions of ‘ordinary’ reflected participants’ own preferences and circumstances. For example, Patricia considered meat and vegetables and a pudding to be a ‘normal’ meal as this was what was served in the group home where she lived while Rory thought that spaghetti or macaroni cheese, made either by his mother or from a packet, was a standard evening meal. Participants did not appear to question the relative healthiness of these meals, generally assuming them to be a good choice. This was perhaps because the food’s ‘ordinary’ status, conferred by its inclusion in the family diet whilst growing up or by the circumstances in which it is eaten, caused it to be consumed unquestioningly.

6.1.2 ‘Healthy’ food

It is perhaps unsurprising that participants talked about food in relation to health as much of the interview looked at the concept of healthy eating. The concept of healthy food can be complex, compounded by mixed messages from the media (Warde 1997). Participants applied the terms ‘healthy’ and ‘unhealthy’ to a variety of foods, largely in conjunction with the perceived effect on the body, rather than the mind. Food classed as ‘healthy’ varied according to the participant but generally reflected common recommendations regarding what should be included in a healthy diet. Some identified foods that they ate as a normal part of their diet, such as baked potatoes, or listed fruits and vegetables. Plain food or ingredients, rather than a finished dish, seemed more likely to be identified as ‘healthy’, as well as fruit, vegetables and yoghurt, rather than cooking styles or preparation methods. This is illustrated by Ruth’s description of healthy food:

Fish is good for you, or meat... Mince and that, all the meat and that, that’s giving you protein. And veg.

(Ruth, approx 45, lived alone with support)

Food did not tend to be talked about in relation to taste or enjoyment, perhaps indicating that healthy eating was not something that they expected to enjoy,

but rather to endure. When food was described as ‘good’, it tended to indicate that it was thought to be beneficial to health although occasionally it simply indicated a preference. Alastair separated certain food into a clear category:

Pears. Good...Cauliflower’s good, cauliflower, carrots.

(Alastair, 61, lived in a residential home)

Some participants suggested that they preferred food that they thought was a healthier option, linking their preferences with the wish to eat well. Linda commented:

I like yoghurts, they’re good for you. And I like fruit, I like fruit too.

(Linda, 46, lived with mother and brother)

The positive bias shown by some participants towards foods labelled as healthy could have been an attempt to provide information they thought was being sought, as it was explained that the research looked at attitudes towards health and food. A moral dimension to food is ascribed as part of its meaning and expressing a preference for food that is considered to be good for the body could be regarded by participants as a way of presenting themselves favourably (Lupton 1996; Madden and Chamberlain 2010).

Not all participants were positive about healthy food and the role that it had in their diet and for some it was something that was outside their normal diet. Despite knowing what foods were considered healthy they could not see how this could be incorporated into their own lives. Several identified fruit as something they thought was healthy and that they should eat more frequently but said that they could not eat it. Claire thought fruit was something that would be good for her, and that should be eaten often, but was she unable to do this because it caused her to have an upset stomach. Thus whilst she characterised this food as being healthy she was not able to include it in her own diet. William also saw fruit as a healthy option but it did not tend to form part of his normal diet:

I mean I like fruit but I am lazy. I forget to eat it... But it's just getting into the habit.

(William, 40, lived alone with support)

Although he thought he ought to eat more fruit he did not prioritise it or regard it as compatible with his current diet. He also thought that his limited budget meant that fruit, although healthy, did not represent good value as he found it went off very quickly in the house:

...so you tend to stop buying it because you think you're not eating it so you are wasting money.

(William, 40, lived alone with support)

Rather than identifying those elements within his diet that William thought were healthy, the healthy option was something other than what he ate, and was categorised as inconvenient, expensive and ultimately wasteful. This also highlights some of the financial risks associated with buying food that did not already form part of the regular diet, discussed in the previous chapter. Participants often did not have much flexibility in their budgets and so needed to buy those foods that they knew they liked and could eat.

6.1.3 Distinction between 'healthy' and 'ordinary'

While William and Claire indicated that they might have liked to include fruit in their diet but felt that there were barriers to doing so, others were less keen about incorporating those foods they thought were 'healthy', particularly if doing so was seen to be at the expense of other, preferred options. Duncan spoke at length in several interviews about an occasion when a support worker cooked him an apparently healthier alternative to his preferred fried breakfast. He was angry both because his choice had been undermined and because it had been given an inappropriate place in his daily diet:

Alright, fair enough, you're thinking about healthy eating but everybody likes a bit of a fry up now and again. I'm no saying you cannae have that, but a stir fry thing for breakfast in the morning? You can see the point in having something like that at lunch time or dinner time, right, so that's like a midday snack or a

nighttime one. But for a breakfast it's just not on. So when my parents found out they weren't very happy.

(Duncan, 28, lived with flatmate with support)

Whilst much of his complaint reflected the poor timing of the meal and the importance he placed on having control of his diet, as discussed in the previous chapter, his insistence that a traditional fry up was something 'everybody' liked reflected his indignation of having this substituted for a healthier alternative. This was emphasised by his final comment about his parents' reaction. Healthy food was generally recognised as being a positive addition to diet but not if it meant changing what was 'normal' and some found it hard to see how it might be incorporated. Further, this illustrates the difficult position of some support workers who risked encouraging healthy eating at the cost of individual autonomy, something that was clearly important to the participant, and reflects the issues of control discussed in the previous chapter.

Duncan was not the only participant to see food he labelled as healthy as different or separate from ordinary or everyday food. This did not necessarily mean that they did not feel that their diets were unhealthy but instead emphasised the 'otherness' of healthy food. Ewan regarded healthy options as distinct from his regular food choices. At the time of the interviews he was planning to make changes to his diet and spoke at length of the new foods he would be eating:

...well I tried the fish. The tuna was nice, so was the salmon. That's good for the healthy diet. And so is eggs, but you only get two. And ordinary tomatoes is good but fried ones aren't any good.

Adopting a healthy diet had involved a considerable change as he now regarded much of the food he had eaten before as unhealthy. Food was divided into categories according to whether it was healthy, ordinary or fattening:

...I think the ordinary one's made of the fattening cheese. You know the ordinary Edam and the ordinary Laughing Cow that's made of ordinary cheddar

cheese but, and ordinary milk, but the lighter cheese is made by the semi-skimmed milk. That's how I prefer it.

(Ewan, 53, lived alone with support)

Ewan expressed a preference for what he believed to be the less fattening option but he also separated it from what he regarded as 'everyday' food: 'healthy' food is distinct from a regular 'ordinary' diet. Other participants also talked about 'ordinary' everyday food, distinct from discussions about 'healthy' food, when discussing their preferences. Whilst it was not automatically assumed that 'ordinary' food was unhealthy, nor was it regarded as a 'healthy' choice, demonstrating the separation of healthy food from other options. The introductory chapter described some of the dietary deficiencies found in Scotland, and in Glasgow in particular, and it seems that participants views of an 'ordinary' diet reflected those of their wider community. Many participants had recognised the messages put across about food, such as fruit being a healthier snack, but either chose not to include them or did not see how they could put them into practice. Foods characterised as healthy were regarded as supplementary to a regular diet and their inclusion was not necessarily relevant to the individual.

6.1.4 'Unhealthy' food

Food labelled 'unhealthy' tended to include takeaways and fast food as well as other 'snack' food such as crisps or chocolate. These were generally thought to be unhealthy as they were believed to be fattening or to contain a lot of sugar. However, participants often identified food that they would include in their diet, despite its status as unhealthy. In some cases it was allowed as a 'treat' or on a special occasion; but in others it was eaten more frequently. This suggests that participants often thought of unhealthy food as an unavoidable or expected part of their diet, something most did not see as a problem, as well as something that was particularly enjoyable. Andrew normalised his food choices, commenting that, although he might not always pick healthy options, his behaviour was no different to that of others:

I So do you think you've got any bad habits with food, do you eat any things that you think you shouldn't eat?

R Maybe fast food places... McDonalds, well they're not very healthy... We all eat them, don't we? We all eat them.

(Andrew, 25, lived with parents)

Andrew's assumption that unhealthy food of this type formed part of a 'normal' diet has been found to be common in young people (Lupton 1996). However, it contrasts with the participants' views of healthy food as an extra, rather than core, part of their eating habits. Even those participants who said that they would rather avoid the unhealthy food admitted that it was hard to do so when others wanted to eat it. This was compounded by the feeling that unhealthy food was a standard component of a normal diet. Ewan took this further, acknowledging that some of those things that he felt were most 'bad' for him were also the most tempting:

R ... you know the fried Mars Bar? It can be very sweet and very fattening.

I I've never had one of those.

R Oh, try one, they're good! It was very sweet and fattening, can't have that again!

(Ewan, 53, lived alone with support)

This demonstrates Ewan's internal struggle: he simultaneously chastised himself whilst urging me to try the food he should not eat. Many participants demonstrated a complex understanding of food and such interpretations reflect those found in non-disabled people's understanding of food. Just as 'good' food has positive moral dimensions, 'bad' food can have negative associations, suggesting moral weakness and a difficulty in achieving balance (Lupton 1996; Madden and Chamberlain 2010). Although participants demonstrated an awareness that 'unhealthy' foods should be restricted or avoided, by reminding themselves that 'we all eat them' or encouraging others to do so they attempt to normalise their presence, revealing the negotiations that occur within the self when choosing food.

6.1.5 Treats

Participants characterised various types of food as being a 'treat' although the status was not necessarily static and food could become a treat under certain

circumstances. There were various reasons identified for having a treat, including feeling that a person has a right to please themselves (Warde 1997) and the notion that the individual deserves a treat, perhaps as a reward or response to something that has happened (Madden and Chamberlain 2010). Common items considered to be treats were often those also thought to be ‘bad’ or ‘unhealthy’ such as chocolate, ice cream or crisps. However, treats were also ‘good’ as they were foods that participants particularly enjoyed. Characterising them as treats gave a place to those foods that participants acknowledged should perhaps not be part of their general diet. This is illustrated by Duncan’s comments below:

I Are there any things that you think are bad for you? And that people shouldn’t really eat, or should only eat occasionally?

R Chocolate, crisps. Um, like any other sweets.

I And how often do you think people should eat them?

R Well, just as a treat now and again. Like, I like to do it, we all like to do it.

(Duncan, 28, lived with flatmate with support)

Like the comments about unhealthy food, treats were rationalised as something ‘everyone’ has and Duncan attempted to normalise his behaviour by aligning it with that of others. Unlike those participants who described this type of food as ‘junk’, participants who classed it as a ‘treat’ appeared to express less guilt about eating it. A treat often seemed to be a way of allowing participants something that they would not normally have and reflects the fact that it would normally be restricted in their general diet. By making it a ‘treat’ they acknowledged its unhealthy status but also that it was something that they enjoyed eating, again demonstrating their complex constructions of the meaning of food.

The reasons for having a treat were multiple. They were eaten on special occasions, when a person was feeling ‘down’ or as a reward, either for a specific achievement or simply because they felt they deserved ‘a wee treat’. Although on certain occasions food was used as a way of noting a special occasion, at other times classifying something a ‘treat’ relieved it of its negative status as

unhealthy, and excused the inclusion of it in the person's diet. However, it also emphasised the food's special place in the diet: it was not what would ordinarily be eaten and was consumed primarily for pleasure. The frequency with which people thought it was appropriate to have a 'treat' varied but several participants thought that once a week or at weekends was about right, although others ate them more frequently:

...occasionally at the weekends, once in a blue moon, some weekends you can have a treat.

(Ruth, approx 45, lived alone with support)

I have cereal bars and at the weekend I can have a treat

(Claire, 45, lived with mother)

A treat represented a break in the routine of the weekday diet and a lifting of restrictions imposed on what the person ate.

Treats played a part in the diets of most participants and the characterisation of treats was generally restricted to a limited range of food, such as chocolate, or meals such as a takeaway. However, one participant, Ewan, used the concept in a much broader way to encompass many of the foods he regarded as unhealthy or 'bad' and so felt he should not be eating. Characterising something as a treat enabled him to justify including it in his diet and although he spoke at length about his plans to adopt a new, healthier diet he still intended to include some of his favourite foods as 'treats':

Well, the thing is just my treat plans, that's the treat foods that I eat, like ordinary crisps... and ordinary coke and fatty foods and fries, like sausages and fries and sausage rolls and bridies and cakes and scones and doughnuts. Just for a treat.

(Ewan, 53, lived alone with support)

He used the word 'ordinary' to indicate that these are not the 'healthy' foods he intended to eat and demonstrating the separation of 'healthy' food from 'ordinary' food: he did not think that the two groups could be included in his

diet without special justification. By labelling these items as treats Ewan was able to reconcile their presence in his diet with his wish to eat more healthily.

This section has explored the ways participants characterised the food they ate and organised it into categories. These categories were not fixed but could be reassigned according to the situation and needs of the participant. It has also shown some of the ways participants normalised their choices, removing some of the personal responsibility for their diet and reflecting the influence of cultural norms. The chapter now explores the relationship between the participants' views of themselves and the food they ate, looking in particular at how views of the self impacted on dietary choices.

6.2 Characterisation of the self in relation to eating

The food people choose to eat can play an important part in the way they see themselves. It can connect the individual to a collective identity or can signify personal characteristics (Lupton 1996; Valentine 1999). What a person eats can work 'both to construct a notion of individual subjectivity through the individual taking in the qualities of that food, and also include that individual into a culinary system and therefore into a social group' (Lupton 1996:25). The way meaning is inferred can derive from the values ascribed to the food by marketing campaigns, social groups, the individual or others close to them. These values influence food choice and become part of the self. Indeed, a food can become more important in terms of what it represents than how it tastes (Lupton 1996).

Participants not only discussed the role food played in their lives but some also defined themselves, and others, in relation to food and eating. Choices were attributed to perceived lifestyle and they labelled themselves and others according to their food choices. Some descriptions were only applied to specific aspects of participants' eating habits. Claire described herself as having a 'sweet tooth', and William labelled himself a 'chocoholic', attributing their consumption of certain foods to these characteristics and providing explanations for their eating habits. Self-characterisation could also be used to explain why a participant did not eat certain foods; for example Ruth said that she was not a 'fruit person', which was why she did not eat fruit or believe that she should. By

classifying themselves in this way, eating habits were implied to be intrinsic to the self and not something the individual could control or change. Thus responsibility was removed from the individual and they were provided with an explanation for their eating habits.

Participants also defined themselves and what they ate in much broader ways. Annie described herself in a positive way, saying ‘I’m a healthy eating person!’ She was proud of this aspect of her character, reflecting the notions of morality associated with food mentioned earlier, and discussed the changes she had made to her diet to develop this part of herself. William and Ruth also categorised themselves in terms of their overall eating habits. William described himself as a ‘plain Jane’, saying that he was nervous about trying new things in case he did not like it and was left with nothing to eat as he relied on support staff to prepare his food. This description of himself excused both William and his support staff from cooking new meals or moving away from those foods he had always eaten. Ruth described herself as being ‘rough and ready’ with regard to food:

I’m not into all this fancy foods and that. Just plain, I’m just plain.

This was characterised by the way she ate:

[I’ll eat] Whatever’s handiest, so a sandwich or something I make. Or I just take something out the freezer like macaroni and cheese or something like that and just put it in the microwave.

(Ruth, approx 45, lived alone with support)

Both William and Ruth justified their eating habits as being part of their personality, again suggesting that their behaviour was not something they could control, even though they felt they should make changes to their diets.

Food was about far more than meeting bodily needs and could be part of the way identity was constructed. Eating habits were used to infer character traits of others and other people’s dietary choices were explained according to the type of eater they were thought to be. In contrast to Ruth’s own ‘rough and

ready' approach, she thought that her brother and his partner displayed different characteristics:

They're into healthy eating a lot. My brother and his partner, yes. They're into all that... Well they're into all that cooking and stuff, I'm not into all the fancy stuff that they make.

(Ruth, approx 45, lived alone with support)

Ruth's comments were not particularly judgemental although she did criticise some of her own eating habits; instead her observations were talked about as part of the individual's personality. However, the way other people approached food could be used as a way to judge them. Carol's comments on the eating habits of a colleague at the day centre implied criticism:

What about Karen? She gets her pay pot and buy, buy, buy, all the time. She loves chocolate. She never stops. She takes her dinner in here and takes a dinner when she goes home every night. She never stops eating. That's how she's, she'll never lose weight. She loves eating, she never stops. See I never eat cakes either. I've got a big birthday cake, I'll have to share it when my birthday comes.

(Carol, 59, lived with sister)

Carol used eating habits to infer negative characteristics of Karen while showing her own positive behaviour in contrast. She went on to further favourably compare her own eating habits with Karen's, saying 'I like anything that's healthy', later adding 'I like anything that's a diet food.' Carol's judgement of Karen highlights her own, more restrained behaviour and helps construct her idea of herself (Valentine 1999). In this way food is used as shorthand for aspects of the personalities of participants and others.

Having explored the way participants characterised both themselves and the food they ate, this chapter will now look at the various roles given to food and the activities surrounding it.

6.3 The role of food

Participant interviews revealed that food and eating took on many roles ranging from functional refuelling to denoting special occasions. Food and eating were put into categories according to their function, which in turn might depend on where or when they were eating. So, for example, food could become a symbol of celebration or a source of comfort and something that was acceptable in one context could be viewed as inappropriate in others (as demonstrated by Duncan's annoyance at being given a 'stir fry' for breakfast). It is the role played by food in the lives of the participants that will be considered next.

6.3.1 Function, favourites and rituals

Much of the time participants mentioned food in a functional way: whilst it took on greater significance in social settings or became a form of solace at other times, it was often just a part of the participant's day and not ascribed any particular meaning. Meals followed similar patterns each day and participants spoke of eating the same food on a regular basis, according to what they were doing; for example, Carol took a packed lunch to college but bought a meal at the day centre while Barbara ate macaroni cheese with her brother each week. Participants spoke of eating traditional meals, similar to those they had eaten as children, such as mince and potatoes or meat and vegetables, and convenience foods, including pizza and microwave meals. They felt that much of what they ate was unremarkable and indeed often could not recall what meals they had recently eaten.

Although much of what the participants ate was potentially mundane and something that fulfilled a basic need it could also convey pleasure and enjoyment. Participants were asked if they had a favourite food. Most named several foods, often having different preferences according to the occasion. Claire had different favourites according to whether she was out or at home while Alastair had a current favourite and one from the past. Gordon named his favourite foods as steak pie and cake with custard but said that both items were fattening and should not be eaten regularly, a factor that perhaps contributed to them becoming favourites rather than every day meals. Some participants did not have a favourite food or meal and could not think of anything that they

would choose to have on an occasion such as a birthday, perhaps reflecting their disengagement with food and the associated processes discussed in the previous chapter.

Some participants demonstrated habit or ritual in their eating habits. Andrew spoke of eating biscuits with a cup of tea at bedtime whilst several participants ate fried breakfasts at the weekend:

R ... sometimes an egg. Sausages, bacon. Have it once a week.

I What day do you get that on?

R Sausage and egg and bacon and mato.

I Do you know what day that is?

R Sunday breakfast.

(Alastair, 61, lived in a group home)

Most did not question their rituals although Ruth felt that eating crisps in the evening while watching the television was a bad habit and something that she did because she was bored. For most participants these rituals were part of the rhythm of their daily lives and were important because of what they represented, such as time with family members in the evening, comfort, or simply something to do, as well as the functional value of eating.

Food took on other, more specific roles for some participants. The previous chapter looked at food in relation to control, exploring the ways it was used as a tool for self-expression and how it became a site for rebellion and control. The following section explores other roles participants ascribed to food eaten both in- and outside the home as an activity, an event marker and, finally, as a source of comfort.

6.3.2 Eating out: food as social activity

Many of the participants spoke of trips to cafes and pubs and for some this was a regular activity. Eating outside the home fills a variety of functions and whilst the food is important, research has found that people rate their enjoyment of eating out according to sociability, service, value for money and the environment (Warde and Martens 1999). Eating out offered some participants an

opportunity to socialise. Andrew, for example, met friends for pizza. The food gave Andrew a purpose for the meeting and a forum for social activity which elevated eating from the simple physiological purpose of refuelling the body.

Eating out was not only about socialising or even eating. Some participants regarded it as an activity, interchangeable with something such as going to the cinema or shopping. For some participants, particularly those who used day services, a trip to a cafe was a common part of their weekly activities:

I What about the days when you're with [the day service]?

R Oh, see if you go out with [the day service} you need to tell them what you want. Well, you go to the pubs or something for a meal.

(Fraser, 55, lived with mother and niece)

In these instances, visiting a café for food and drink was about the opportunity to get out of the house or the day centre as much as the need to eat. Visiting different places to eat punctuated the other activities, offered participants the opportunity to eat something they would not normally have and added variety to their daily routine. It is suggested that eating creates a sense of 'community solidarity' as diners are in a contrived environment with clear expectations of appropriate behaviour (Martens and Warde 1997). Trips such as this offered the participants a relatively easy opportunity to take part in 'mainstream' society and were a popular activity.

Eating outside the home offered participants the opportunity to eat food they might not otherwise consume either due to its limited availability or because it would not normally form part of a 'healthy diet'. However such trips fall outside the normal eating conventions and as a result healthy eating rules are often suspended (Warde 1997). Patricia said that cafes were where she would go to eat unhealthy food, such as curry or a custard bun. She did not go to cafés frequently but visiting one was an accessible treat and offered the opportunity to indulge in food she would not normally have. Even if she did not do it regularly, it was important that Patricia had the opportunity to do this with her support worker if she chose to. Part of the enjoyment of eating out comes from

the anticipation of the opportunity to eat different food (Martens and Warde 1997) and this formed an important part of the activity for Patricia.

6.3.3 Special occasions

Food played an important role in marking special occasions and acting as a reward for most participants. The use of food to distinguish between festival and everyday and observing traditions with food is common in western societies (Lupton 1996) and was found in participants' accounts of how they made food choices. The foods eaten were often those characterised as a 'treat' and included food that was otherwise considered 'unhealthy' or 'bad'. Holidays and special occasions provide a 'mandate for pleasure' and the subsequent relaxation of normal restraints (Williams 1997). A special occasion might also involve food that was normally considered too complicated to prepare or too expensive or it might simply entail having a 'blow out' and eating more than usual.

Special occasions identified by participants ranged from Christmas and birthdays to the weekend, and different food was sometimes the only action that differentiated the occasion from a 'normal' day. However, marking an occasion with food was an accessible way for participants to connect to something they were not otherwise involved in. For example Ewan used food to observe a local holiday:

... that was the Glasgow Fair holiday... I just thought I can have extra treats. But this week I've decided to go back on the healthy diet again.

(Ewan, 53, lived alone with support)

Celebrating with food allowed him to feel part of an event while giving him an opportunity to enjoy foods that would normally be restricted.

Not all participants identified specific foods with special occasions; Patricia simply said that she would go 'overboard' on a birthday or similar occasion, allowing herself extra portions of foods that she would normally restrict. Others identified food to be eaten on specific occasions, such as a birthday cake or a takeaway. These meals were often shared with others, such as family members,

and demonstrated a common use of food to denote a celebration or unusual event. Food offered a way for participants who perhaps had limited opportunities to take part in activities, a way to enter into a celebration or to mark a day out as different. It should be noted that not all participants used food in this way and some could not think of anything that would be either a favourite food or something they might have on a special occasion, as illustrated by Ruth's comments:

I Ok. So, do you have any foods that you think of as treats or as special occasion foods?

R No.

I Is there anything that you would have if it was your birthday or anything?

R No.

I No favourites?

R No.

(Ruth, approx 45, lived alone with support)

There were also participants who identified special food but were not able to have it. Alastair named several things that he would choose to have on his birthday but, other than a birthday cake, the residential home he lived in did not offer him the opportunity to have them, demonstrating the lack of control he had over his diet.

6.3.4 Comfort

Treats or other special foods were not just for special occasions; they could also provide comfort and relieve anxiety or boredom. Several participants spoke of the way their appetite was affected by mood:

R I believe it depends on your mood, the way your eating habits go.

I Right. Do you have any sort of examples?

R If I feel a bit down and that I go for sweets, you know, like cakes and chocolate and fries. It's weird, it's like a craving. Then there's other times I can go off them.

(Helen, 55, lived alone with support)

[if] I'm stressed or worried or anything like that I'll go to the fridge as a way as, it's not the answer, but at the time it helps, you know.

(William, 40, lived alone with support)

Susie was, at the time of our interviews, trying to lose weight by following a healthy diet but she too found solace in food:

If I'm fed up or I've not had a good day... if I've had a not very nice day I would comfort eat.

She recalled that this had been a particular issue when she had been receiving inadequate support, and she had eaten a lot of 'junk food'. Although she said that at the time she 'loved it' she now felt it had been indicative of other problems:

I think at that time I was comfort eating as well because at that time I suffered from depression and I still do and I was very, very low and I thought, just have something to eat, and it was all the sweet things. I was like, that'll cheer me up, and I just kept eating, eating, eating.

(Susie, 40, lived alone with support)

Ross also linked his eating to depression saying that, although he normally avoided chocolate, he would allow himself a small bar when he was 'down'. Food eaten for comfort is often found to be something that the individual associates with security, enjoyment or nostalgia (Wood 2010) and commonly something that evokes childhood (Lupton 1996). Further, it has been suggested that young people with learning disabilities might be more likely to be given food as comfort or to alleviate boredom (Melville et al 2006). If this is the case, this may form eating associations that continue into adulthood. Participants largely named specific foods that they would turn to for comfort. These tended to be sweet foods, such as chocolate, or foods often identified as 'unhealthy' or 'bad', as well as tasty, rather than healthy foods or those commonly eaten at mealtimes, and so represented indulgence and reward.

Food did not only provide comfort in times of crisis, it also provided some respite for boredom:

I don't smoke and I don't drink so it's something to do with your hands basically.

(William, 40, lived alone with support)

As demonstrated by this comment, eating was also an acceptable and accessible 'vice'. Participants did not necessarily see this as a problem, unless they were specifically restricting their diet, as Ross was, so food became an accessible source of solace.

It is clear from the data presented thus far that participants had an often complex relationship with food. It fulfilled different roles and took on layers of meaning which then reflected the participants' sense of self. The previous chapter explored some of the restrictions on participants' control of what they ate and this chapter will now turn to look at the influences on participants' choices and how they approached information on food and healthy eating.

6.4 Influences

The second section of the chapter looks at what influenced the dietary choices of the participants. It considers the availability of food and the influence of health messages, and the role of peers, family members and support workers. It then looks at the sources of information about food that participants identified before exploring participants' responses to the campaign to encourage greater consumption of fruit and vegetables. The previous chapter showed that the level of involvement that participants had with food varied considerably and that few were actively engaged in all stages. All but one participant were able to feed themselves¹⁰ but, as outlined in the previous chapter, some had few opportunities to make choices about what or where they ate and so were very much disengaged from the processes around food. However as the earlier section of this chapter showed, participants were still interested in what they ate.

¹⁰ The participant was helped by a support worker. No participants were PEG fed and all were able to eat a 'normal' diet although in some instances it required some fine chopping to make it easier to chew and swallow.

Participants identified a range of sources from which they might obtain information about food and healthy eating and a broad set of influences on the food choices they were able to make. These are explored, as is the extent to which participants made use of the information sources they listed.

Participants named a variety of influences on how they chose what to eat. On many occasions they were simply governed by what they felt like eating. When asked how she chose what to have for breakfast, Patricia answered ‘Just, how they taste’ while Andrew chose a particular takeaway sandwich because ‘I like the taste of them’. Similarly he bought what he described as ‘junk food’ simply because ‘I like eating it sometimes.’ These sorts of comments were common amongst participants and most chose at least some of their food this way. However, as discussed in chapter three there are many complex and often interactive factors that influence food choice and these impacted on the decisions the participants made.

6.4.1 Availability of food

As the previous chapter showed, the level of control people had over what they ate at home varied considerably. The food choices of participants living in their own homes were often constrained by their cooking skills and the amount of support they received as well as their interest in food. Those living with family members generally had little control over what they ate at home as they tended not to shop or cook; several were provided with packed lunches when out of the house, removing almost all opportunity to exercise any autonomy over their diet.

Participants were involved in a range of activities during the week. They attended day centres, work places and voluntary placements as well as spending time out and at home. The food options available to them were therefore equally varied and they were not restricted to just eating in the home. Some participants, who used day services, reported regular food-based outings but the amount of choice they had over where they went depended on the group they were with. One participant was given food by the place she worked. Both of the day/ work centres I recruited participants from sold breakfast and lunch although service users could also bring their own food if they preferred. People

generally spoke favourably of the food on offer but a couple were more critical of the range and type of food available, suggesting that there was often no healthy option:

R In here, the diet in here [the day centre]? Pheeew. It's not a good diet, believe me.

I What sort of things do you get for lunches and things?

R They had sausage, potatoes, I can't remember what the other one was. Pizza, maybe. Or pies. Beans, chips. What else? Just your basic stuff really. But their salads are not that appetizing.

I Ok.

R Basic tomato, lettuce, cheese. Nothing, occasionally I can get them to make me a couple of boiled eggs in the morning, if he remembers.

I What sort of breakfast things do they have then?

R Oh, sausages, bacon, black pudding, potato scone. And sometimes he does a fried potato. And rolls.

(Helen, 55, lived alone with support)

It should be noted that the food available differed across the day centres, and participants did not have to eat the food sold there. However, participants did not necessarily have the option to choose whether or not to take a packed lunch, or what went in it, and those who relied on buying food at the centre clearly had their choices restricted.

Choices were also restricted by circumstances and the support available. William felt obliged to buy lunch from a burger van on the days he was at a voluntary placement:

They've got a kitchen and you can have tea or coffee or whatever, but as I say, you'll take in your own rolls or tins of soup and that but you can't ask staff to do that for you. I'm not saying they wouldn't do it but if they were doing it for one they would end up doing it for maybe about 5 or 6 and then by the time they get sitting down for themselves it's cold.

(William, 40, lived alone with support)

He felt it would be embarrassing to ask other staff members for help to heat soup or eat a sandwich, and no one had offered. He was aware that asking for help would require someone else to give up some of their lunch break and was unwilling to inconvenience anyone. Thus circumstances restricted the food choices available to him.

Although eating out might appear to offer plenty of choice this was not always the case for some participants. Support workers had to please the majority of the group and participants said that they would feel embarrassed if they asked for different food. Further, opting out might not be possible whilst taking a packed lunch would be difficult as it might not be acceptable to eat it in a pub or a café even if the participant was comfortable doing this.

6.4.2 Friends, peers and family members

Friends, family, support workers, and peers were all named as influencing participants' diets. The previous chapter explored the various ways they could act as gatekeepers to food. However, they could also act as influences in other ways. Some participants thought they imitated their friends' habits; for example Andrew felt it would be hard to turn down lager if a friend was having one. Others, though, reported that peers caused them to restrict their diets:

R I think it's the same all the time because it's finding it hard for different foods for my flatmate to eat. I mean, with, what happened was, my flatmate I had before, there was no problem with the food cos we didn't have to sit and do a menu.

I How did you used to do it then?

R Just did the shopping for foods and that was it.

I So just whatever you fancied?

R Aye.

(Duncan, 28, lived with flatmate with support)

His new flatmate ate a restricted diet. As Duncan relied on his flatmate's support worker to cook Duncan, too, ate a limited range of food. Food preferences can be very personal and Duncan found having his diet influenced by someone else's requirements, and the structure of his support very frustrating.

Although he was involved in meal planning he was very aware that ultimately he only had a small influence on what he ate at home and this affected his wider feelings about his living arrangements. This type of restriction echoed the lack of choice and control discussed in the previous chapter and Duncan's unhappiness with the situation was indicative of the role food played in constructions of identity.

Family members often had direct involvement in what participants ate and therefore had the opportunity to influence their food choices or to act as gatekeepers, as discussed in the previous data chapter. However family sometimes influenced participants in other ways, offering information and, in some cases, exerting pressure on the participant to change their diet. Ewan's cousin had encouraged him to make changes and had drawn up a diet plan; Thomas's sister had been instrumental in influencing him to alter his diet, working with his support worker to help him lose weight; and Andrew's mother had told him 'you're going on a healthy diet' as she thought he had put on weight. Andrew did not mind her comment but Ewan recalled that he had got tired of his cousin's comments as he intended to make changes anyway and felt that she was undermining his efforts. Whilst these attempts to influence participants' diets were presumed to be well-intentioned it did little to encourage participants to develop their own knowledge of themselves or food. These overt attempts to influence participants were reflective of the lack of control and autonomy they had in many aspects of their lives and could impact their sense of their own ability to make decisions for themselves.

6.4.3 Time and money

Other influences identified by participants included convenience and time. For example, Ross said that he would make a microwave meal when he was drunk to save having to use the oven. As outlined in the previous chapter, the structure of support influenced choice and time and convenience were important considerations for some participants who had support with cooking. Cost and perceived value for money were influential factors for several other participants; Andrew chose takeaway and Claire chose chocolate according to which provided the best value while William was tempted by offers in the supermarket. However he largely felt restricted by his budget which meant that

he would not try new recipes because the ingredients might be too expensive or, if it did not work, would be a waste of money, as referred to earlier.

A lack of skills required to cook also impacted on food choice. Ruth felt that she was not a very good or confident cook and so chose to eat 'junk' or snack food rather than prepare a meal which, if not good, would have been a waste of time and money. This perhaps stems from a wider lack of confidence around taking control of food, as discussed in the previous chapter. Participants did not identify advertising, other than special offers, as having an influence on the food they bought. This could be because they are not aware of the effect of advertising (Sobal and Wansink 2007) but might also reflect the limited financial autonomy many participants had and the lack of opportunities to make decisions about what to buy and eat, making the advertisements irrelevant to them.

6.4.4 Food and self awareness

Although participants often lacked opportunities to be involved in planning and choosing what they ate, or expressed little interest in becoming more involved, some of them did demonstrate considerable self awareness around eating and monitoring their food intake. Working within the limitations of their opportunities to make decisions about food, and using their knowledge of themselves, they were able to exert some control over their diet. Not all participants spoke about their insight into their eating habits but several demonstrated an awareness of their appetite and an interest in their health and talked of the ways they negotiated their diets and the health guidelines so that they worked for them.

It has been established that it was not uncommon for participants to have limited involvement in the food they were given. As discussed in chapter three, it is common to accept norms regarding portion size which will then influence how much is consumed (Wansink and Sobal 2007; Wansink 2004). Those who had their meals provided for them often had little control over portion size and were likely to have assumed that the amount served was the 'right' amount to eat. However some participants spoke of the ways they managed the meals they were given so that they could eat according to the fluctuations in their own

appetite. This involved monitoring their daily diet and responding to how they felt:

At lunchtime, I've ate at lunchtime and when I go home I'm eating again. Well I've ate here probably, I won't be eating as much when I go home.

(Steven, 47, lived with mother and sister)

See I never take a dinner when I go home after [being in the day centre]. See if I'm taking a dinner today, I'll no take it when I go home now... See they take dinners, see them there, they take dinners in here and when they get home.

(Carol, 59, lived with sister)

For Carol, eating habits were indicative of a person's identity. She believed it to be greedy to eat two large meals each day and felt there was a moral imperative to develop self awareness.

External influences could complicate this. Susie mentioned that it had been hard for her to develop an awareness of her own appetite when she had attended a different centre and lived in a residential home as she was presented with the food and found it hard to refuse:

I went to [the day centre]. And you would have a meal here, at [the day centre], then you would go back to the care home and then you would have another meal. So you were eating, like, two meals. Know how you would have, well I'm sure you would have, right, a meal, a snack at lunch time and maybe your bigger dinner at night? Well instead of that we were having breakfast, which consists of cereal, toast and sometimes they made sausage, sometimes it was eggs, I mean the cereal and toast was enough for me but because it was put down to me you just keep eating.

She was now aware that she did not need to eat three large meals a day and felt that it was important to pay attention to what she ate, particularly as she used a wheelchair:

..I think, sometimes I think in here [the day centre she currently attended]... [the cook] doesn't make the best choices for people in chairs. I'm not saying everybody needs to lose weight, obviously, everybody's got different dietary needs, but I do think, like today I just had a roll and turkey, that's all I had because that's all I wanted. I didn't want anything else on the menu. It was like, pasta, but it's not so much the pasta it's the sauce that's really, really fattening. So I was sitting watching that, right, and hot dogs. Hot dogs aren't very good for you either! The other choice was pies and they're not ideal for you! I just said, no, just give me a roll and thingmy.

(Susie, 40, lived alone with support)

Despite limited control over what was available to eat, Susie had developed considerable awareness of her eating habits and dietary requirements but it was not always possible for her to eat as she would ideally choose. Thus despite her self-awareness, she was still unable to meet her dietary needs. For other participants, their lack of control over what they ate made it hard for them develop an awareness of their own appetite as often other people decided what they should eat. This left them without the opportunity to establish what best suited them or to practise making decisions about food in the context of the overall diet.

One participant, Annie, spoke of a more sophisticated awareness of her self which she called her 'body knowledge'. This connected food with her health, impacting directly on what she ate, and she attributed her desire to lose weight and commitment to healthy eating to this knowledge. Annie had developed this understanding of her body herself and felt that it was very personal:

It's like different people like healthy eating. People are different, different knowledge of their body.

(Annie, 39, lived alone with support)

She intended to use and develop this knowledge so that her diet worked for her and to enable her to achieve a body weight with which she was comfortable.

Participants demonstrated that even with the constraints placed upon their diets they had been able to develop considerable in depth awareness of their eating habits. Some had then developed strategies to manage within these constraints and had tailored their diet to their requirements. This was perhaps particularly important for those who had very little opportunity to influence what food was available to them. However it was not easy to do, particularly as they would have had to manage the expectations of others and the temptation of simply eating what was available to them.

6.5 Using health information

Participants were asked to discuss sources of health information both that they had accessed and that they knew of. Whilst this was intended to be about healthy eating, they tended to focus on information about weight loss. This is perhaps because healthy eating is associated with the desire to lose weight, rather than any other health effect, or it might be because this was what they were most interested in. Participants often identified potential sources of information rather than those they had actually accessed, reflecting the fact that many of them had not really looked for information or tended to rely on the advice of those closest to them. This was perhaps linked to the limited opportunities many had to control their diet, as they were not able to easily implement advice.

During the interviews, several participants spoke of the ways they balanced indulging their food preferences with the desire to be healthy. Many were aware that their diets included elements that they did not think were 'healthy' and some spoke of their struggle to balance their wish to eat a 'healthy' diet with the temptation to eat preferred but less healthy food:

... as I say, it goes back to common sense. It goes back to less chocolate, less sweets and more fruit and stuff like that but again it's, it's getting that into your brain that you can have a banana instead of a bar of chocolate, something like that, you know.

(William, 40, lived alone with support)

Even though he thought he knew what was the ‘right’ thing to do, it was hard to make the ‘healthy’ choice when a less healthy, but more appetising option was available.

Ewan spoke of the internal struggle he had trying to change his diet. Despite being determined to improve his health he found it hard to reduce his intake of the less healthy foods he used to eat:

...head and heart used to tell me to take these foods, but I’m getting older now and heart and head is no, they say go for healthy foods. Take healthy instead of thinking of fat foods and greasy foods.

(Ewan, 53, lived alone with support)

Others spoke of how they negotiated the health messages so that they were manageable for them. Andrew was aware it was not advisable to drink a lot of alcohol but did not intend to give up lager. Instead he tried to keep below self-imposed limits.

I How much do you think is too much?

R 13. I drink about 8 or 9 pints sometimes.

(Andrew, 25, lived with parents)

He also had his own guidelines regarding how often he should drink, stating that it was alright to drink this much once a week but every night would be too much. Participants tried to balance their current eating behaviour with the health guidelines so that they could incorporate their own ideas of what was appropriate, something that they acknowledged was not always easy. Concerns about health and weight were also identified as influences on dietary choices. These were driven by a combination of external influences and internal motivations and will be explored in later chapters.

In addition to the range of influences identified as directly impacting on participants’ food choices, a wide variety of sources of information about food and, in particular, what they regarded to be healthy food were also discussed. Again, family and support staff were identified by many participants as potential

sources of information. Female family members were identified by both male and female participants as someone who they could ask for advice:

She'd, my sister would be, my sister would know.

(Steven, 47, lived with mother and sister)

[My mum's] interested as well. She's trying to lose weight. So she's just cutting down herself.

(Ruth, approx 45, lived alone with support)

My mum, on a good day.

(Ross, 25, lived with parents and brother)

As family members were often very involved in participants' lives it was not surprising that they would be seen as a source of information; indeed, it was not uncommon for them to have given unsolicited advice, perhaps as an extension to their role as gatekeepers to food. This level of involvement dissuaded some participants from speaking to family members as they wished to maintain some independence: Rory did not want to talk to his parents, with whom he lived, and preferred to find out about healthy eating and weight loss methods himself. Support workers, both those providing domestic and social support, were also identified by some as people they would be happy to ask for advice. For some participants they could be a trusted source of information, independent of the family. However others were clearly provided with the information whether or not they felt they needed it. Gordon, for example, said that several of his support workers had spoken to him about healthy eating but when questioned further said that he could remember very little of what they had said.

Participants were asked whether or not they would speak to a health professional, such as their general practitioner (GP), if they were looking for information about healthy eating and whether or not this was something they had done. Many thought their GP or practice nurse were potential sources of information but this did not mean they would see them if they wanted advice. Most who had spoken to a GP or practice nurses reported being given verbal instructions about what not to eat; few had come away with any written

guidelines. This was perhaps not the most useful way of conveying information as it could easily be misconstrued or forgotten:

I Have you ever talked to your GP about it or anything?

R Yes. Can't remember what they said.

I Can you remember if you thought it was helpful?

R I did.

I You thought it was helpful?

R Yes

I But you've forgotten what they said?

R Exactly.

(Patricia, 55, lived in a residential home)

Further it would be useful for those participants who were supported by more than one person to have written information that they could discuss with each support worker, rather than rely on their memory or that of another support worker, thus enabling them to begin to take some control of their diet.

Whilst GPs and practice nurses might be seen as 'experts' and be potentially well placed to provide accessible information about healthy eating, a lack of individualised information put some people off contacting them. Claire's GP had previously advised her to lose weight and had provided her with a list of recommended food. However it included things that Claire did not like, but felt the doctor expected her to eat, and as a result she was reluctant to initiate another conversation about diet for fear this would happen again. Such advice was likely, ultimately, to be ignored as it appeared irrelevant to their particular situation. In contrast several participants found information they had received from dieticians was helpful, particularly as it was tailored to the individual:

I would go to my GP if I was really stuck, but really Fiona, who was the dietician, had explained everything that I really needed to know. She explained everything to me.

(Susie, 40, lived alone with support)

However this is a specialist service and not available to most people.

Although there is some information specifically designed to be accessible to people with learning disabilities this was not widely discussed. However those who used it found it useful. One participant, Annie, had accessed information about healthy eating on an internet site aimed at people with Down's syndrome. It had been brought to her attention by a colleague from an advocacy group and she had printed out recipes and other information from the site, which she had found useful:

You can plan out your meals that way, with cards. They show you, at the back they show you how to do it...It's actually quite good, actually.

(Annie, 39, lived alone with support)

In contrast, Ross had received information from a dietician as part of a weight loss programme run by the local hospital. It was not specifically designed for people with learning disabilities and he found it hard to use and, ultimately, it put him off the programme. Annie had also used her local library, a source identified by others but which they had not used. Annie, however, was in a position to determine her own diet and so could make use of the information she gathered. Information, it seems, had to be easily accessible, straightforward and relevant to the participants. It also seems that, in general, they would be more likely to talk to a person they felt they knew well as the topic was potentially sensitive, particularly as for many, healthy eating was so closely linked to weight loss. Further, whilst some general information was helpful, it seems that participants were more responsive to advice when they had sought it.

6.5.1 Eating more fruit and vegetables: 5 a day?

In addition to being asked where they might look for information, participants were also asked what they knew about a particular health promotion message, the *5 a day: Just Eat More (fruit and veg)* campaign run by the Department of Health. It recommends that at least five portions of fruit and vegetables are eaten daily, in line with the WHO's guidelines (WHO 1990). Most participants knew of the campaign, and several brought it into the conversation themselves, but very few chose to try and eat five portions of fruit and vegetables a day, despite most thinking that it was a good idea in theory. Whilst they were aware

of the message that it might be beneficial to health, many responses indicated that they did not think it particularly relevant to them:

No, you don't have to eat 5 portions of fruit a day, you don't have to. Not really.

(Linda, 46, lived with mother and brother)

Well, maybe not. Some people might do it, some people maybe no do it. It depends basically.

(Duncan, 28, lived with flatmate with support)

Depends if you like to do things like that, eat 5 a day. Some of them don't bother and some of them do.

(Ruth, approx 45, lived alone with support)

These responses reflect the views of many of the participants: the advice was optional and not something to be taken seriously. Participants were not aware of the reasoning behind the guidelines and so could not see whether or not it would be applicable to them. Their responses need to be taken in the context of their wider environment: many said that they did not know of anyone who actually ate this much fruit and vegetables, making it seem like an arbitrary and unobtainable goal. Their comments reflect other findings that show fruit and vegetable consumption to be low in both Scotland as a whole (Scottish Government 2010b) and Glasgow in particular (Hanlon et al 2006), suggesting that their behaviour could actually be considered the 'norm' for their environment. So, although that campaign had clearly been successful in letting people know the recommended minimum amount that they should be eating it had failed to have an impact on the participants' diets as the majority did not know why they should do it whilst the wider cultural context of their dietary choices rendered it irrelevant to them. This echoes findings from other research which showed a range of barriers to the dietary inclusion of fruit and vegetables have been identified, including a perception that vegetables and fruit are expensive and represent poor value for money; that they are time consuming and difficult to prepare; that they are 'boring' and eaten only as part of a diet to aid weight loss; a lack of social 'norms' regarding consumption, perhaps

reflecting a lack of knowledge of the health benefits or that current consumption exceeds actual quantities and a general feeling that there was little real need to heed the guidance (Cox et al 1998; Herbert et al 2010; Fitzpatrick et al 2010).

6.6 Conclusion

Participants had a multi-layered relationship with food and characterised it in a number of ways. They had a good knowledge of the components of healthy eating but, due to a variety of factors, this did not always inform their food choices. The lack of control discussed in the previous chapter undoubtedly affected this as participants often lacked the opportunity to make use of their knowledge. However, constructs of food also affected the way participants viewed their diet. Food was divided into three categories: healthy, unhealthy, and ordinary or normal. Two categories, unhealthy and normal, were sometimes merged, particularly when the individual was trying to change to a more a healthy diet; in these circumstances, the old 'ordinary' diet was re-categorised as 'unhealthy'. Healthy food was often described as being separate to 'ordinary' food and as a result was eaten in addition to a normal diet rather than instead of other, less healthy options. Categorising food can make dietary changes harder as a 'healthy' diet is perceived as negative and assumed to consist of specific items, rather than being viewed as an approach that incorporates a range of food. Participants normalised their current food choices and, as a result, were often reluctant to change what they ate. This excused those choices that they acknowledged were not healthy and again made change harder as they were reluctant to be seen to deviate from normal behaviour.

The data revealed that some participants were particularly susceptible to the influences identified as they had little opportunity to change their environment. Thus a poor selection of food at a day centre, for example, could have a significant impact on their overall diet if they were unable to take their own food or opt to go elsewhere. However, some participants demonstrated that they were able to work within these constraints by developing an awareness of their dietary requirements and, more generally, their bodies.

In addition to these influences, a number of sources of information were identified. These were not always considered useful though. Several participants had received information from their GP but, unless they believed it to be relevant to their particular circumstances, participants found it hard to implement and were inclined to disregard it. In addition, at least one participant reported that she was reluctant to discuss her diet with her GP as a result. Information designed to be accessible to people with learning disabilities was reported to be more useful, as was advice tailored to the individual. General health promotion messages, and specifically the advice to eat five portions of fruit and vegetables each day, did not seem to have had much impact on participants' diets. The *5 a day* campaign was largely thought to be irrelevant and not something that needed to be taken seriously. Again, participants normalised their current fruit and vegetable consumption and concluded that, as it was not something those around them adhered to, they need not either, despite awareness of the recommendation and its connection to health. Given the cultural context within which they make the dietary choices, such attitudes will need to be changed on a broader level in order to challenge widely held norms.

Campaigns such as *5 a day* require people to take action for a potential benefit in the future. This calls into question how participants conceptualised health and whether it was indeed something they thought they could influence in the long term. The following chapter continues to discuss the theme of control and explores participants' attitudes towards their health in more depth. It identifies those people who mediated participants' involvement with healthcare before looking at the way they conceptualised health.

Chapter 7. Health: concepts and control

The previous two chapters have considered participants' relationship with food. They have explored the role of gatekeepers in mediating and controlling food choice, the way food was characterised and other factors that influenced participants' decisions about food. The following two data chapters look at perceptions of health, actions that can be taken to improve health and the connections between health and weight. This chapter looks at the extent to which participants felt they had control over their health and weight. The chapter is divided in two sections. The first part of the chapter looks at notions of health and control. It begins by examining participants' interactions with healthcare professionals and considers the extent to which these were mediated by others, including family members and support workers. It then looks at whether participants believed that they could have control over their own health. Beliefs are divided into three groups: that it is possible for an individual to have control over their health; that it can be controlled by others; and that it is largely due to fate. The final part of this section considers the way these beliefs impacted on the participants' views of their own health and on health-related behaviour.

The second section of the chapter explores the way participants conceptualised health. Health is a complex concept and its meaning differs between individuals, making it virtually impossible to find a collective definition (Saunders 2001). Individual concepts of health are heavily influenced by personal experiences and social context (Mullen 1993) and participants were encouraged to discuss their beliefs both in relation to their own lives and how they might be applied to friends and family and to the wider population. Participants defined health as a holistic positive feeling, an ability to complete self-identified functions, and a neutral state, noticed only when it was absent and the chapter draws on the work of Blaxter (1990, 2010) and others to define these ideas. The main themes identified in participants' discussions about health were: health as a feeling; health as the ability to function; health as appearance and weight; health as the absence of illness; health as a state affirmed by others; and health as behaviour.

7.1 Health: autonomy and control

The data chapters have so far explored the participants' involvement with food, the roles it played in their lives and the various meanings it had. In particular they have looked at barriers to healthy eating and at the gatekeepers who mediated participants' choice and consumption of food. It has considered the effect that this had on their ability to take control of what they ate, both in practical terms and with regard to the self belief required to do this. This section of the chapter looks at participants' involvement in their healthcare and the extent to which it was controlled by others. It is important to consider choice not just because it impacts on the quality of life of people with learning disabilities but because 'increased inclusion and participation in healthcare choice making have been identified as essential in addressing the health inequalities experienced by people with learning disabilities' (Ferguson et al 2011:74). It then explores participants' concepts of control over health and the extent to which this was affected by both physical and psycho-emotional barriers, drawing on ideas about the health locus of control (Allison 1991; Blaxter 1990; Stainton Rogers 1991). As discussed in chapter three, people with learning disabilities have greater, often unmet, health needs in comparison to the general population, and they face a variety of barriers to accessing healthcare. Despite attempts to increase the opportunities that people with learning disabilities have to become actively involved in making decisions about their lives, involvement in healthcare has remained limited due, at least in part, to attitudinal and organisational barriers (Ferguson et al 2011).

7.1.1 Gatekeepers to healthcare

This section starts by looking at others who were identified as having some influence over participants' healthcare. The research found that interactions with medical professionals were sometimes mediated by family members. Problems communicating complex issues and concerns about ability to consent have been put forward as reasons to explain why people with learning disabilities have not been included more in discussions about their healthcare (Ferguson et al 2011). Some participants reported doctors speaking to the person accompanying them and not to the participant. This has been found to be a cause of exclusion of people with learning disabilities from participating in

discussions about their healthcare (Ferguson et al 2011). It was common for appointments to be arranged by others on behalf of participants, sometimes for reasons that were unclear to the participant: one reported that a doctor would be visiting her at home, but did not know why. Whilst there might be practical reasons for others making appointments it was not clear whether this was initiated by the participants and suggests a lack of control and potential disengagement from their healthcare. The influence of participants' families could also discourage them from seeing a doctor. For example, Annie said that her mother told her not to see her GP for fear that he might suggest Annie use the gym, something her mother thought was a bad idea.

Although some participants seemed to accept their families' involvement in their healthcare, others were less comfortable about it. Richard was quite upset about the control his sister had. She had told Richard that he should lose weight but he felt that she did not listen to him regarding his food choices. He wanted to make decisions regarding his health himself:

I says, [to my sister] that's up to me cos that is my own body, I want to look after my body. To make myself healthy. And [my sister] says I know that, you need something [to eat]. And I says, look you're missing the point by the way cos that's up to me to decide that, it's me inside me.

(Richard, 47, lived with sister)

He did not discount the idea that his sister might be able to support him but he did not want her to dictate his actions to promote his health; he wanted to retain some control and to have this ownership of his body acknowledged. His statement 'it's me inside me' encapsulated the notion of control for many participants: they wanted to foster a sense of autonomy over their lives and their bodies.

Support workers could also be involved in participants' healthcare, not least because of the type of support they provided: they were often closely involved in the day to day lives of those they supported and so inevitably became involved in helping to manage participants' health. For the most part, this was recognised as being helpful although, as discussed in chapter five regarding food

consumption, it could sometimes be difficult for support workers if they felt they had to prevent participants from doing something they enjoyed in order to promote their long term health.

7.1.2 Health ‘experts’ and dietary advice

Those regarded as experts in health could use their status to influence food choice. These were normally people associated with formal healthcare although others might be elevated to ‘expert’ status if participants believed they had sufficient knowledge. For example, Susie was happy to take advice from her support worker as she had attended meetings with a dietician with Susie. Several participants intimated that they would be more accepting of dietary advice that came from health professionals compared to support workers, family members or peers. For example, Ewan demonstrated his commitment to improving his health via dietary change by recounting his promise to the practice nurse:

Promised [the nurse] that I’ve got to slim down. She said, remember Ewan, no pies! None of this and none of that!

(Ewan, 53, lived alone with support)

He accepted her advice and seemed to enjoy being accountable to her, despite not welcoming similar advice from family members. It seemed that participants believed that the advice from health care professionals was more likely to be tailored to their individual needs and given with the sole aim of benefitting the participant, unlike information from family members or support workers which might be part of a separate agenda. This was reflected in William’s comment that medical advice would cause him to change his behaviour:

Oh, if I was told on medical grounds it wouldn’t be up for debate... That would just happen, cos I’m not going to waste my time and I’m not going to waste his time... You don’t argue, if you are going to disobey there’s no point in going. He’s telling you for a reason so you don’t argue with it. Anybody who argues with it is silly.

(William, 40, lived alone with support)

Participants viewed the involvement of medical practitioners as confirmation

that weight or diet were problematic and this legitimised action to rectify it. The individual could be cast in a 'sick role' (Nettleton 1995) with the accompanying responsibility to respond to the concerns and to comply with treatment. William revealed that, despite believing he was overweight, he had not actually discussed his weight with his GP, perhaps to avoid the subsequent obligation to make unwelcome changes to his diet and lifestyle should weight loss be recommended. The notion that the GP or other health professional might give advice that the participant did not want to hear could make them fearful of the appointment or deter them from going at all. Andrew recalled how he felt when his mother made a doctor's appointment because she thought he should lose weight:

R Bit sad.

I Do you know why you felt sad?

R I don't know. I thought they might tell me to give up a lot of stuff. I was a bit sad as well.

(Andrew, 25, lived with parents)

The doctor was seen as an authority figure whose advice should be adhered to; as it was 'expert' advice specifically for the participant they felt it could not be ignored. Participants were also aware that the advice given might be hard to follow and so, in some instances, felt it was preferable not to get the advice at all rather than try and find ways of fitting it into their lifestyles. Further, when unpalatable advice was received it was often dismissed as being unsuitable for the individual, something that was explored in relation to food in the second data chapter. A lack of reliable, accessible sources of information will make such concerns more likely and might discourage people with learning disabilities from seeing a health practitioner (Ferguson et al 2011).

7.2 Control over health

Chapter five identified choice and control as a key theme to emerge from the interview data. This has been explored in relation to food but it is necessary to also consider control in relation to health. Adopting a healthy diet requires the individual to take action now, for a potential future benefit. This assumes that

the individual believes that they are able to influence their health and that their actions will have an effect, something that is difficult for those who have little control elsewhere in their lives (Allison 1991). Notions of control over health were explored with participants and they revealed a range of views about the possibility of being able to influence their health. Whilst they were aware of some measures that could be taken to identify problems, such as getting check-ups, they were unsure of their efficacy, particularly as the individual nature of health meant that people might benefit from differing approaches. Beliefs about the amount of control that the average person could have over their health varied and even if control was possible in principle it did not automatically follow that it was possible in practice. Views such as these are likely to have impacted on whether or not they chose to follow health advice.

The extent to which participants felt health was something they could control or influence is particularly important when considering how it was conceptualised. Notions of control will affect whether proactive steps are taken to look after health or combat illness. In turn, this might influence dietary choices and the extent to which participants believed what they ate could affect their health in both the immediate and long term. Related to this are ideas about whether or not health is a personal responsibility. Participants held a range of views regarding what could be done to promote health, which are explored in the next chapter. Attitudes towards control over and responsibility for health will influence the extent to which they felt it was worth attempting to implement any of these ideas about health promotion and illness prevention, in addition to attempting weight loss to improve their health and wellbeing.

Health actions are influenced by a variety of factors, including perceived costs and benefits, values, beliefs, external circumstances and individual personality (Blaxter 1990). The notion of self-efficacy and the individual's belief about how much control they have of their life is thought to be an important influence on the way they think about their health:

Readiness to take a health action, it is suggested, is determined by the individual's perception of his [sic] own susceptibility and of the severity of the consequences of not taking the action, together forming the

perceived threat... Particular ‘triggers’ to action are also necessary, and personality factors or external circumstances may be modifying factors. (Blaxter 1990:149)

It has been hypothesised that an individual’s locus of control will indicate whether or not they are likely to take steps to improve their health: those with an external locus of control believe that they are not able to determine what happens to them, instead seeing it as a result of outside forces such as chance or influential others. It is suggested this group will therefore be less likely to believe in their own self-efficacy and so will not take action. Those who do believe that they affect outcomes or bring about change are described as having an internal locus of control and are assumed to be more likely to act (Blaxter 1990). This model has been criticised for being too simplistic and, critically, for not being a useful predictor of health behaviours. Stainton Rogers (1991) presents a robust critique of the model and highlights its key failing:

The problem about that was that quite often it was *externality* which proved to be linked to ‘healthy’ behaviour (e.g. compliance with drug regimes). In other words, at least as often as not, it was the self-motivated ‘internals’ who were *least* likely, and the ‘fatalistic’ externals who were *most* likely to do what health professionals wanted them to do! (Stainton Rogers 1991:173).

Whilst this might not have been the pattern the model intended to explain it is perhaps not surprising: those who do not believe in their own self-efficacy may be the most likely to follow advice from health professionals as they have little faith in their own ability to manipulate their health. Further, it has been pointed out that ‘the *expectancy* that one’s actions can control health outcomes is not the same as the *motivation* to control health’ (Allison 1991:147). It requires more than a particular way of viewing health to cause an individual to take action. Thus the notion of an internal or external locus of control can be a useful illustration of the way a person thinks about their health but should not automatically be assumed to be a strong predictor of behaviour. However, it can be combined with other factors to present a more useful predictor of behaviour.

It has been proposed that the impact of social structural factors should be considered, as a lack of control in areas of life such as employment may have a ‘spillover’ effect into other areas of life (Allison 1991; Pill and Stott 1982). Rather than encourage people to believe that they are solely responsible for their health it should be acknowledged that there are many aspects of health that cannot be personally controlled and so ‘individuals who have little opportunity to exhibit control in their lives in general should not be expected to believe they have control over health or disease, or to take preventative action’ (Allison 1991:150). This could be particularly pertinent to the lives of people with learning disabilities when it is considered that there are often numerous individuals and agencies able to exert influence, leading to ‘a considerable risk that such negative beliefs relating to self-efficacy will be commonplace’ (Dunn 2001:221). The concept of psycho-emotional disablism (Thomas 1999), outlined in chapter two, is also of significance here as it helps to explain the circumstances that can prevent a disabled person from developing a belief in their own self-efficacy or ability to have some control over their lives. It is of particular relevance to people with learning disabilities for whom this type of disablism is common as a result of attitudinal barriers (Stalker, forthcoming 2012), including negative assumptions about their abilities and the subsequent denial of choice. If internalised, this inhibits the development of a sense of personal responsibility or feeling of control over health, as well as other aspects of life, whilst preventing the individual from developing the skills required to exercise choice and control and acting as a barrier to who the person can become (Thomas 2004a).

So, whilst the simple notion of whether or not an individual can be described as having an internal or external locus of control as a predictor of behaviour might be mitigated by the presence, or lack, of motivating factors it can give an idea of how a person viewed their health in abstract. Other factors will influence whether or not they respond to motivating factors, including previous experiences of attempting to take action and the views of those around them.

The following section explores participants’ notions of control over health. In an attempt to explore concepts of personal responsibility for health, participants were asked whether or not they thought health was something they

could control. Their answers were varied; some thought they could personally influence their health; others thought that it could perhaps be controlled by a health professional, or other expert, but not by them; finally, some thought that, ultimately, there was little that anyone could do. Participants' sometimes held several beliefs at once, for example believing that some health issues were a matter of personal responsibility but that others, such as catching a cold, were just a matter of luck, and these views then impacted on their attitudes towards health promotion.

7.2.1 Taking control

The interviews explored the extent to which participants felt they had control over their own health and whether or not they believed that they were able to do anything to prevent both minor illnesses and more serious problems. Research has found that individuals can believe themselves to be morally accountable for illness if they do not look after their health in either the short- or long- term (Pill and Stott 1982). Many participants initially stated that they felt they did have control over their health and saw a correlation between their actions and their wellbeing. For example Ruth attributed some of her apparent resilience to colds and coughs to her habit of taking garlic supplements and vitamins. Participants, however, often said that they felt they ought to have more control, or should be able to manage their health better. This was frequently related to their behaviour, which they felt they should be able to modify to benefit their health but found difficult to do in practice. This was found to be due to either a lack of opportunity to implement changes or because they were unsure what would actually make a difference, findings similar to those suggested by Allison (1991).

Some participants suggested it was hard to know what sources of information about health were reliable whilst dietary information was often thought to give conflicting messages. Further, information was sometimes misinterpreted:

I don't like roast pork, cos apparently I don't normally take it at home, cos it puts me off cos you know that mad cows disease? And that's what I don't like.
(Richard, 47, lived with sister)

This would make it very difficult for an individual to actually change their behaviour or lifestyle. When asked if he felt his health was something he could influence, Andrew commented:

I do but I don't use it a wee bit... I don't take control, yeah.

(Andrew, 25, lived with parents)

Whilst he thought that he should theoretically be able to control his health, in practice he found it hard to take action, or change his behaviour, a feeling echoed by other participants who were unsure about what they could actually do. Further complicating ideas about control over health were views that each person was fundamentally different. Thus, what was effective for one person might not work for another. Annie illustrated this with her reference to weight:

I Do you think some people aren't in control [of their health] or do you think everyone can take control?

R It's too different. I think people are trying, some people who are overweight, kind of thing. Just the way you are.

(Annie, 39, lived alone with support)

She emphasised this by saying 'People are different'. Further, as discussed in the following chapter, concepts of health varied and thus the notion of what control meant would also vary: whilst some might feel in control if they successfully managed a chronic condition another might feel that they were not in control unless they improved their general health.

Thus, some participants found it difficult to make changes despite believing that they would benefit their health. Actions that participants identified as those that could improve their health included changing their eating habits. Patricia, for example, who lived in residential accommodation, said that she thought she would be able to have some control over her health if she had the willpower to stop herself from eating whatever she wanted. Another participant cited the widespread advice to eat a balanced diet, with plenty of fruit and vegetables, as a method of preventing health problems. These beliefs placed participants in a frustrating position: they understood that health maintenance required ongoing

action but, as discussed in the previous two data chapters, they often lacked the resources to do this. Thus their health was a moral responsibility that they were unable to fulfil. Further, it is perhaps unrealistic to expect them to take action to promote their health, or to believe that this was a realistic option. The participants in this research had little control in many areas of their life and so were often unaccustomed to taking responsibility or seeing their decisions realised. Therefore to be able to assume control for something as abstract as 'health' and to take action or implement changes whose effects will not be seen for some time may well require a change in outlook that the individual cannot achieve without support from others or changes elsewhere in their life.

When participants did take action, it offered a way for them to feel more in control of their health. Ewan was in the process of changing his diet:

I've got a feeling that I have controlled my body a wee bit. So, I was telling [my support worker] there, if I cut down on chocolate biscuits and just eat one on Saturday, and not during the week, I would think I would lose a wee bit more if I do that.

(Ewan, 53, lived alone with support)

At the time of the interviews he had taken steps to improve his health and felt that, with support, he was able to exert some control over it. His main concern was dying prematurely and so he was taking action to try and avoid this, including changing his diet, losing weight and exercising. However his belief that he could have some control over his health, and his confidence that he could take the action required, was not common amongst the participants.

7.2.2 Beyond personal control

Some participants, whilst saying that they thought they should be able to personally influence their health, demonstrated that actually they felt their health was determined by factors they could not influence. William felt that there were various factors beyond his control that prevented him from taking steps to look after his health. For example, he thought that exercise would be beneficial but the combination of his physical impairment and need for support meant that this was not, in his opinion, a feasible prospect: even if he was able

to get the help he required to take exercise it would largely be pointless as he could not do enough cardiovascular work. The restrictions placed upon him by his physical impairment were seen in the same way as the potential complication of trying to arrange support to exercise and were regarded as outside his control and insurmountable. So, although he felt he should take steps to positively influence his health he believed that he was prevented from doing so.

The view that it might be possible for the individual to influence their health if other, external criteria were met meant that, in practice, participants did not believe that they could actually exert control. Others, who did not feel that they were able to control their health personally, felt they were able to manage it by, for example, taking prescribed medication. Thus a form of control that would normally be viewed as external to the individual was internalised as they took on at least partial responsibility for their health. For example, Susie bracketed making choices about what she ate with taking her prescribed medication when talking about ways in which she felt she had control over her health. By agreeing to take the medication she had entered into a contract to take some responsibility for her health although her notion of 'control' was still dependent on the intervention of others.

For some participants, managing health and illness was very much external to the individual and was usually seen as part of a health professional's remit. When asked about whether he felt he could influence aspects of health, such as blood pressure, Ross thought it was unlikely that he could:

I think my doctor's got control over it. He checks my heart out, my blood pressure out, so, he does that bit.

(Ross, 25, lived with parents and brother)

Similarly, Andrew thought the best thing he could do was 'Listen to my doctor.' For some participants this directly reflected earlier experiences of ill health. Duncan had been born with heart problems and remembered having surgery to correct them. He felt that he could do nothing to benefit his heart as that was 'just the way it was when I was born basically' and this attitude affected the

way he saw his health in general. As a result, he felt that his health was almost entirely out of his control and commented:

Well, that's the hospital that deals with that. I cannae do that, I cannae take any control over that.

(Duncan, 28, lived in supported flat with flatmate)

However, as mentioned above, it was not uncommon for participants to avoid talking to their doctor about those issues that they thought might provoke instruction to change their behaviour. By doing this they were avoiding taking responsibility, as the 'problem' had not been confirmed by a doctor and so need not be acted upon.

Previous experiences of ill health that required treatment are unlikely to be the only factors that led people to feel they lacked control over their health or that there was little they could do to influence it. Limited opportunities to make decisions in their day to day lives or to affect what happened to them might have led them to doubt that they had any real influence over their health. Further, as discussed in the first part of the section, many of the things that participants believed could promote health or protect against illness, such as modifying their diet or taking exercise, were often not in their control, whilst some participants were not able to access healthcare themselves but instead relied on others to ensure they saw a medical practitioner. Acknowledging that others have influence over health, and other aspects of a person's life, has been associated with an external locus of control and, to a certain extent, an abdication of responsibility. However their involvement is perhaps better viewed as part of the environment in which the person makes decisions or takes action (Stainton Rodgers 1991). Thus, while those who believe they have little control over their health might view the intervention of others as another factor they cannot influence, those who feel that they are able to exert control will see it as another aspect that they must take into consideration when making decisions.

7.2.3 Health: fate or luck

Some participants expressed the opinion that they had little or no control over their health. They instead believed that good health or illness were largely due

to luck, thus preventing themselves from being held responsible for their health, echoing findings in other research with non-disabled populations (see, for example, Pill and Stott 1982; Blaxter 1990; Mullen 1993). Several participants commented on the unpredictable nature of illness:

One week you could be, you could be quite healthy and still have a heart attack. Cos, there's no things around the heart, right active and that, you could still just drop.

(Rory, 27, lives with parents and brother)

I've seen folk who are, who have been ill. I've seen them healthy one minute and then ill the next one. I've seen them in here, healthy in the morning then by lunchtime he's not.

(Steven, 47, lived with mother and sister)

Like I said before, when you're going to go, you're going to go. And if there's going to be something wrong, ill, it'll happen.

(William, 40, lived alone with support)

Due to the apparent unpredictability of health and illness, even regular check-ups might not help to avoid problems:

I think maybe we could all have [health checks], cos cholesterol and that's a big thing for your heart. Make sure that there's enough for the heart there to beat. I mean you could have an active person who just walks constantly but the heart could be, because it goes that fast it could just, when you're walking, it could just stop.

(Rory, 27, lives with parents and brother)

As a result, routine healthcare such as check-ups might come to be regarded as pointless and so be declined by the individual. Similarly, if health and illness were believed to be due to luck, and long-term health was pre-determined, tackling the barriers that prevent an individual from taking action to promote health might not be felt to be worthwhile unless there was also short-term benefit. The belief that actions to improve health or wellbeing could not

influence future health, or a lack of confidence that an individual's actions could be effective could leave participants feeling helpless. At the time of our interviews William had discovered an infection had reoccurred. He did not know why, or what he could do either to heal it or to prevent it in the future, other than seek treatment for the immediate problem. As a result he felt he was preoccupied with his health whilst not actually able to take action:

Obviously... when you're not well you think about your health... I mean like this morning I was thinking, why me? For about ten minutes I was thinking, why me? Why's this coming back?

(William, 40, lived alone with support)

He felt unable to influence the situation and was concerned about the possibility that it might happen again. Some participants who stated that they did have control over their health still attributed their lack of illness, at least in part, to luck. Steven spoke of how he worked to maintain his health, particularly his strength, saying that it was important for him to maintain control of his physical self, of which health was a key component:

R To me that's more important, keep myself mobile. That is important to me because I don't want to lose move-ability. That's one thing I don't want to lose because that's what I'm saying, I'll end up losing move-ability, I'll end up having to get, I mean, I want to keep the move-ability I've got. I don't want to end up losing it. It's important to have it.

I And do you feel you're in control of whether or not you get to keep it?

R I've always been mobile so I don't want to lose it.

I And do you feel you're in control of keeping it?

R I'm in control the now [currently] so I want to keep it as long as possible.

(Steven, 47, lived with mother and sister)

He added that his health was 'A1, I've not had any illness or whatever'. However despite his comments about his attempts to maintain control of his physical self and the ways in which he did this, he could not see any reason why he had avoided illness despite the rest of his family being unwell, demonstrating the way participants could hold several, contradictory views at once. Steven

appeared to separate his physical health from his wellbeing and did not connect his efforts to maintain his mobility with any potential benefit to his general health, enabling him to hold separate notions of control.

Several other participants gave examples of others who had appeared fit but had not found that this protected their health. Whilst acknowledging that health can be unpredictable could be indicative of a balanced view, with health neither entirely controllable nor uncontrollable, these participants' views reflected a fatalistic attitude. William explained how the premature death of several footballers impacted on his approach to his own health:

I mean, I don't mean to sound nasty or cruel, but you look at people like David Cooper and Phil O'Donnell who were physically fit football players, who train everyday, and basically they died. And he was only 35. So the way I look at it, is, when your time's up, your time's up. Sounds a bit nasty, but at the end of the day I'm going to enjoy my life while I've got it.

(William, 40, lived alone with support)

These views led him to feel that he should enjoy himself rather than make sacrifices for the potential benefit to his health. Beliefs such as this stopped health from being the responsibility of the individual and thus they absolved themselves of the expectation that they should take actions to try to improve their health. Unless the costs of inaction were intolerably high or the proposed changes had attractive immediate benefits, it is unlikely that participants holding such beliefs would modify their behaviour for possible future health advantages.

The way participants conceptualised health will have played a part in the extent to which they felt they could exert any control. If health was predominantly defined in terms of illness, the idea of having control might seem remote as sickness and disease often appear to be random and unavoidable. However, health as a sense of wellbeing might seem like something that the individual can influence. Thus it is important to consider how participants thought about health and it is this that the chapter will now explore.

7.3 Participants' concepts of health

Various models of lay concepts of health have been put forward. These have included positive definitions of health that go beyond the dichotomy of 'well' and 'ill' to encompass a broad holistic view, including physical and mental wellbeing, as well as negative definitions that focus on health as the absence of illness or loss of function (Calnan 1987; Hughner and Kleine 2004; Blaxter 1990, 2010). Concepts are not, usually, unitary but multidimensional and it is quite possible for health to be viewed simultaneously as "good" in one respect, but "bad" in another (Blaxter 1990). These views are influenced by a wide range of features. They do not just stem from scientific understanding but 'are complex interweavings of information drawn from different sources including lay knowledge, folk beliefs, experiences, religious and spiritual practices and philosophy... consumers have no choice but to construct their own worldviews from the confusing array of information available' (Hughner and Kleine 2004:397). Each person's concept of health will affect how they behave and experience their environment and this, in turn, will further inform their notion of health (Saunders 2001). Thus it can be expected that previous experiences of ill health and medical intervention will influence an individual's concept of health. The difficulties associated with defining health can be further compounded by disability as it is generally assumed in Western society that a disabled person cannot be truly 'healthy' (Saunders 2001).

During the interviews participants were encouraged to talk about ideas of health in terms they felt could be applied to the general population before exploring these concepts in relation to themselves. These ideas reflected their own experiences of health and how they had experienced health or illness and it is likely that they also reflected the views of the people around them as well as popular health messages. Fewer topics emerged from the wider discussion, perhaps indicating that participants found it easier to talk in terms of their personal experiences rather than about more abstract ideas. Views became more nuanced when applied to people they knew and this increased when they spoke of how their beliefs applied to their own lives, something demonstrated by the discussion about weight as an indicator of health later in this chapter.

A number of ways in which health was conceptualised emerged. Concepts of health were not fixed and no dominant themes emerged; participants could hold several different and sometimes competing ideas about what it meant to be healthy. Levels of interest in personal health varied. Whilst some participants appeared to view it as a personal responsibility others appeared to regard thinking about health as self indulgent. However when asked to describe what it meant to be healthy most participants put forward one or more concepts. Health was described as a feeling; as something noted in its absence; in relation to the individual's ability to perform certain functions; as being reflected in appearance and weight; as a state conferred by others; and as something implied by behaviour. These concepts echo many of those identified by Blaxter (1990), demonstrating the considerable similarities between the participants in the study and the non-disabled respondents in Blaxter's research. There were several noticeable absences, however. These included concepts of health in relation to work and social relationships, perhaps indicating the limited involvement this study's participants had in employment and the restricted opportunities they had to form social networks. These reflect the proscribed nature of the lives of many people with learning disabilities and the lack of control many participants had over much of their lives, as discussed in the first data chapter.

7.3.1 Awareness of health

The extent to which participants prioritised their health varied. The value and priority people ascribe to their health is an important consideration when looking at the way it is conceptualised (Hughner and Kleine 2004). Whilst some participants were aware of their health and took steps to maintain or improve it, health as a general concept was not something that every participant thought about and was often something noted only when it was absent and they became unwell, something that is explored later in the section. Those participants who were, or wanted to be, actively involved in looking after their health tended to regard it as a personal responsibility and demonstrated a level of internal monitoring, a concept outlined by Hughner and Kleine (2004). For them, being aware of their health was a positive thing as they could take steps to maintain or improve it. Their health was seen as being a part of who they were, and monitoring it was a form of self awareness, and therefore something they did

not necessarily want to delegate to others. Helen had ongoing health problems and felt that she had an important role in managing them. She commented:

I just need to get a grip of what's went wrong somewhere, go, ok if I've got to deal with, I'll deal with that.

(Helen, 55, lived alone with support)

In order for her to be able to play an active part in looking after her health she felt she needed to have an understanding of what affected it so that she could then act. This internal monitoring was similar to some participants' awareness of their dietary requirements, discussed in the second data chapter. Focussing on health could be seen as a form of self awareness as well as something that was necessary if the participant was to be able to play an active part in looking after their health.

Whilst some participants saw an awareness of their own health as a positive part of taking responsibility for oneself or an aspect of self awareness, thinking about your own health could be seen as self-absorbed. One participant, when asked if he felt he often considered his health commented:

I think of other people before myself, always have, always will. I'll think of folk before myself.

(Steven, 47, lived with mother and sister)

In this case appearing to think excessively about personal health had a moral component and, rather than being regarded as part of taking responsibility, was seen as a potentially selfish or vain act. This echoes findings that illness is associated with 'personality and a lack of moral fibre' (Blaxter 2010:53) and that dwelling on health could be regarded as self-indulgent or a sign of neurosis (Calnan 1987). This view appears to contrast with the belief that the individual has a moral obligation to look after their health (Hughner and Kleine 2004). However, the participant later spoke of his efforts to maintain his fitness so that he might avoid becoming a 'burden' to his mother and sister. This demonstrates that thinking about his health was acceptable when it had consequences for

others and illustrates how several, competing ideas of health could be held simultaneously.

Several participants spoke of previous experiences of ill health; these were likely to have coloured their interest and expectations regarding their own health. Duncan, for example, reported he was generally well, but the ongoing monitoring of his health due to previous problems meant he viewed himself as potentially unwell:

Well, fine, aye. I'm just, cos of the problems I'm having with my health and stuff, cos I used to go to the hospital a lot, and I'm getting another blood test again tomorrow morning at half nine.

(Duncan, 28, lived with flatmate with support).

However, rather than taking an active interest in what might be wrong he appeared to be quite passive: he did not know what the tests were for and did not seem concerned about finding out. Whilst this apparent lack of interest or understanding of what was happening to his own health might have resulted from his impairment, it might also have reflected his and others' assumptions that he would not be interested but would instead take on the sick role and devolve responsibility to medical professionals, a notion that is explored by Calnan (1987).

It was not uncommon for participants to be given limited opportunities to take any responsibility for their health. This could cause participants to not expect to be involved, or take an active interest, in their health in the future as they have been distanced from their healthcare and face barriers to accessing health services (Emerson and Baines 2010; Cooper et al 2004). Further, those participants who had experienced serious health problems might find it hard to imagine they could take any meaningful role in their healthcare as they had previously been reliant on medical practitioners and others. As explored in the first data chapter, 'socio-cultural processes' can generate negative attitudes towards disability and impact on disabled people, potentially restricting activity (Thomas 1999:48). This apparent passivity could stem from disablement and the assumption, overt or not, that the participant was not able to take an active

part in their health care. Further, it might reflect a wider denial of autonomy leading to the acceptance that decisions were made by others. So, whilst some participants showed considerable awareness of their health, others were more passive in their approach, relying on both informal and formal monitoring by others and only becoming aware of it when they encountered problems. The section now explores the ways participants talked about health, looking first at the broad concept of how they thought it felt to be healthy.

7.3.2 How it feels to be healthy

Participants were asked what it meant to be healthy. Some were not able to offer an answer, or focussed on what it meant to be unhealthy, but others gave their definitions of how it felt to have good health. Participants often spoke of health as it was experienced emotionally rather than describing physical sensations or the effect it might have on the body. A healthy person was described as:

... happy... Grateful. They know they're healthy.

(Ross, 25, lived with parents and brother)

Comments describing what it meant to be healthy included that it felt 'nice' and made a person 'quite happy', suggesting a holistic concept of good health. The focus was on the positive impact good health had on a person's sense of wellbeing and how this felt, rather than how this might be reflected in physical health or bodily feelings.

In contrast, other participants spoke of the way ill health affected their feelings about the physical self, rather than the effect it had on their sense of wellbeing:

I think, maybe being healthy could make you more confident in yourself. And unhealthy can make you be depressed with the way you look.

(Andrew, 25, lived with parents)

Andrew felt that good health encouraged positive feelings whereas poor health, whilst not necessarily impacting on appearance, was likely to make a person feel negatively about their physical self. Ill health was spoken of by some

participants as being felt in the whole body and experienced both emotionally and physically. This was demonstrated by Claire, who thought that being unhealthy would make a person feel ‘yuck!’

Participants were asked how they would tell if they were in good health. Some were not sure how to answer this. Those who did not describe how it felt to be healthy in any detail perhaps regarded it as a ‘normal’ state, and not something that they thought about, and so found it hard to describe further. People who regard health as ‘ordinary’, or the norm, have been found to not rate it highly as a value, to think their own health is poor and to express little interest in ‘healthy’ behaviour (Blaxter 1990) perhaps because it is taken for granted. Such attitudes might also reflect a general sense that health is largely outwith individual control and therefore not worth thinking about as action was futile. Others did offer descriptions. As was seen when participants discussed broad concepts of health, personal health was often conceptualised holistically, encompassing emotions as well as physical sensations:

I feel better, mentally. More energy. Which hasn't happened for a long time. I go to bed tired, wake up tired. Your skin's better, your hair's better. Your overall appearance is better if you're healthier. And you feel different.
(Helen, 55, lived alone with support)

Health impacted on multiple aspects of Helen's sense of self, as well as her physical appearance. Her comment conveyed a sense of vitality that included the whole being and implied an enhanced state of wellbeing rather than simply a state of neutrality.

Other responses focussed on one or two aspects of what it meant to be healthy. Judith simply said that she knew if she was healthy because she felt ‘good’. This suggests good health was a positive feature, rather than there just being nothing wrong. Duncan also associated health with positive feelings which he felt both affected the way he behaved and were demonstrated by his actions. He described being healthy as

... the way I feel inside and I might feel great and I'm chatting away with people
(Duncan, 28, lived with flatmate with support)

His description suggests a connection between his health and psycho-social wellbeing (Blaxter 1990): good health enabled him to enjoy life. These positive concepts of health indicate its relationship with a general sense of wellbeing as well feeling healthy.

7.3.3 Health is defined by its absence

Some participants focussed on illness and disease or a lack of good health when talking about what it meant to be healthy, only becoming aware of their health when it was deemed to be absent. When health is conceptualised this way it is defined by a lack of symptoms that might suggest illness or the need for medical intervention (Calnan 1987; Blaxter 2010): health is 'not being ill' (Blaxter 1990:22). This has been described as a negative way of viewing health as it focuses on potential problems rather than achieving more positive outcomes (Calnan 1987; Blaxter 1990; Hughner and Kleine 2004). Unlike those participants, discussed above, who connected health with a range of positive feelings, some participants associated health with the presence of negative feelings. They demonstrated less awareness of good health and were more likely to describe how it felt when they were not well or what would cause them to think they were not healthy:

I How can you tell in yourself if you're healthy?

R Mood.

I How your mood is then?

R Uh huh. If you are a moody person and that's how you know something is wrong.

I So it's about how you're feeling.

R Yes. I'm not a moody person?

I So if you're being moody-

R Something's wrong!

(Patricia, 55, lived in a residential home)

Although the positive impact of good health on how a person feels was not recognised by Patricia, its absence was acknowledged as a negative feeling when something was wrong. So, health as a positive state was overlooked or assumed to be the normal state and was not considered until it was lost.

Participants used experiences of ill health to determine whether or not they were healthy:

Well, I tend to know when I'm not healthy... And that's because I sleep more, tiredness all the time. Listless and don't want to do anything. And sure enough I end up next week in a hospital bed.

(William, 40, lived alone with support)

Well, haven't had any illnesses, so haven't been near the hospital, haven't been near the doctor.

(Steven, 47, lived with mother and sister)

Good health was what was assumed to exist in the absence of illness and was indicated by the absence of factors associated with ill health, such as the involvement of health services, rather than an acknowledgement of any positive features of good health. Both William and Steven felt their health status was in part demonstrated by the involvement of health professionals. Health professionals, and others, can play an important role in defining an individual's health status, something that is explored later in this section.

7.3.4 Health and functionality

Some participants measured health in terms of functionality. It was conceptualised in terms of physical ability and was connected to what they were or were not able to do. Central to this definition is the individual's own expectation of what they ought to be able to do (Hughner and Kleine 2004) and it has been found to be used by those who might find health to be a restricting factor rather than those who take their ability to undertake tasks for granted (Blaxter 1990). Low expectations might therefore lead a person in relatively poor health to actually feel quite positive about their health (Hughner and

Kleine 2004) perhaps causing them to delay taking action to improve their health as they meet their basic requirements of functionality (Zola 1973).

Participants discussed functionality in a variety of ways. Some spoke of it as being able to maintain a general level of activity. Ruth said that she could tell she was healthy by her activity:

... cos you're moving around more, you're not getting restless and that, later adding I'm not always sitting down, if I'm on the go.

(Ruth, approx 45, lived alone with support)

Participants did not always refer to an enhanced sense of wellbeing, such as extra energy, but talked about being healthy as meaning that they could maintain what they considered a normal level of activity.

Some participants stated that they did not think about their health unless it impacted on their ability to function normally:

I Do you think that you think about your health much?

R No, I don't. Only when I'm walking, cos I get heavy on my feet so I can't walk too far, too heavy for my feet.

(Patricia, 55, lived in a residential home)

Health only became an issue when it limited what Patricia was able to do. As mentioned above, it was not uncommon for participants to think about their health when confronted with a specific problem. Indeed, several thought that they would probably only consider their health when it restricted their behaviour, rather than acting in a way to protect or promote their health. Threats to functionality were identified as potential triggers for seeking medical intervention, something that is explored in the next chapter.

7.3.5 Health, appearance and weight

Participants were asked how they might determine whether or not a person was healthy. Health was assumed to be visible in a person's appearance and might be reflected in a person's skin, eyes or body. Some participants felt they might be

able to tell whether or not someone was healthy by the way they looked and described how they thought this would be reflected in a person's physical appearance. When describing a healthy person, participants usually chose positive attributes and suggested that they would look 'good', referring to both the person's physical characteristics and their overall presentation, including dress; this again suggested a holistic interpretation of good health. However many respondents could not think of ways that good health might be reflected in a person's appearance and were more likely to suggest visible characteristics of ill health. This could be specific features, such as pale cheeks, or a general displeasure with your appearance:

...if you're unhealthy you could be looking at yourself in the mirror, but once you look at yourself in the mirror, turn it over because you don't want to see yourself. Whereas a healthy person, you don't smoke, you don't drink, you're just keeping on top of things.

(Rory, 27, lived with parents)

This comment demonstrates a multi-layered concept of health and links feelings about appearance with perceived causes of ill health. In this example appearance reflected negative behaviours and caused the individual to feel unhappy about their actions as well as how they look. In contrast, a healthy person does not just feel more attractive but is reminded of their positive actions when they see their reflection which, in turn, makes them feel better about themselves. Health was connected to the idea of keeping the self in balance through your actions, thus avoiding illness and achieving a state of equilibrium. Unhappiness with appearance was linked to the person's failure to maintain this balance and their subsequent unhappiness with themselves.

Weight was the most common physical attribute identified as a visible indicator of health. However, beliefs about the connections between health and weight were more complex than those associated with general appearance. It was identified as both an indicator of health status as well something that might actually contribute to a person's health.

Participants frequently said that being thin or skinny was the best visible indicator of good health:

Healthy, you should be slim, do plenty of exercise, you'll be into fitter, neater clothes, eat the right, correct food.

(Ross, 25, lived with parents and brother)

... it'll look empty and healthy... It means there'll be no fatty foods in it. It'll be all nice and slim body, nice, slim healthy body.

(Ewan, 53, lived alone with support)

Well they're eating a lot healthier foods, aye, if they're nice and slim.

(Ruth, approx 45, lived alone with support)

However, as these comments show, weight not only suggested the state of a person's health but it also implied certain behaviour, represented by the body. The comments demonstrated the belief that health was not just connected to weight and the body but to a person's overall appearance and general behaviour. They reflect not just what participants believed it meant to be healthy but the actions that are required to become healthy, echoing Rory's comments about a healthy person 'keeping on top of things', and suggesting a more holistic approach to health.

Determining an 'ideal' weight could be difficult. Several participants cautioned that being thin did not automatically mean that a person was healthy. One commented that 'You don't want to be too thin,' whilst another warned that this could make you 'lose your colour'. These comments demonstrated an understanding that weight was not just a way of judging health, but could also impact upon it. Although some participants stated that they would like to be 'skinny', others thought that it was better to be an 'average' weight and that this would be healthier than being very thin. This reflected a far more attainable ideal, in contrast to the belief that it was necessary to be thin to be healthy, for the many participants who spoke of their own desire to lose weight.

Weight and body shape were not assumed to be exact indicators of health status. Participants' views regarding weight were complex and individuals often held several, conflicting opinions at the same time. Whilst it was acknowledged that being over- or under-weight could be detrimental to health it was not assumed that it would always be unhealthy, or even that a 'normal' weight indicated health:

Not too fat, not too thin. Just stay where you are. It's different because people are so different... Don't have to be all the same.

(Annie, 39, lived alone with support)

You can be underweight and be very, very ill, I know that. Cos I didn't feel well at all when I was only 6 stone. But you can also be overweight and be unwell and all, so there's a balance. People have got to know what that weight is.

(Susie, 40, lived alone with support)

The conflict some participants felt was evident as they recognised that weight could be an important factor in health but that it also had to be appropriate for the individual, making it much harder to declare that there was a 'right' way to be. Arguing that an 'ideal' weight should be determined on an individual basis might have been a way of normalising being overweight. However both participants spoke of their commitment to healthy eating and it seems that their comments reflected their understanding that health and weight depended on a range of factors and had to be applied on an individual basis. Personal experiences fed into participants' concepts of health both as they were applied individually and as they were applied to others. However, whilst it was acknowledged that a healthy weight might differ according to the individual, most did not want to be an above average weight themselves.

Critically assessing their bodies both in terms of appearance and apparent health was a personal measure of health mentioned by both male and female participants and interest in appearance and weight seemed to be of equal interest to both genders. Observations were generally related to aspects of their bodies that participants were unhappy with, as this comment illustrates:

Well if, I do feel a lot healthier once I get rid of this big tyre, you know? But, I feel a lot better when I'm not going to the [pub] because I'm saving a lot of calories. That's about 1200 calories I'm saving which is very good.

(Ewan, 53, lived alone with support)

Ewan connected the part of his body with which he was dissatisfied to feelings about his health, a feeling which was, at least in part, ameliorated in the short term by his actions to correct the problem. Bodies provided a visible, tangible measure of health for some participants and a way of monitoring it over time. Rory, when asked if he often thought about his health, spoke of how he monitored it, and his weight, by checking his stomach:

... sometimes I look at myself in the mirror, which everyone else does, and they look at themselves, and then look at the side, and sometimes I wonder if I'm going to be like that one day [uses hands to demonstrate a big stomach].

(Rory, 27, lived with parents)

His concept of health was bound up with his appearance and weight, and future health concerns were represented by the possibility of weight gain. Others also closely connected ideas about their personal health with their bodies and weight. Annie linked her weight to her health and monitored it by gauging changes in her body according to how her clothes fitted. She felt she had a good awareness of her body, as discussed in the previous chapter, and could apply this to weight as well as her diet.

7.3.6 Health as a status affirmed by others

The views of other people were often important to participants when they were considering their health. Whilst in most cases participants would value the opinion of someone regarded as an 'expert', such as a doctor or nurse, they also gave credence to the views of others. The comments or observations of other people, including friends, family members or support workers, might be used to form participants' concept of what it meant to be healthy and to determine whether or not they were personally in good health. There was no clear hierarchy of advice amongst participants and even 'expert' medical opinions might be ignored if they were felt to be unreasonable or irrelevant, particularly

in relation to food and alcohol consumption, as discussed in the previous chapter. The responses reflected the personal nature of health and individual concepts of health were likely to be negotiated according to their circumstances.

The opinions and comments of others were used by participants to help assess their health. Annie used the views of others to help judge her health status:

Someone says, you look so well, really healthy. They can tell by looking at your face and the colour of your skin.

(Annie, 39, lived alone with support)

Comments like these were used as a positive affirmation of health. They were not the only gauge with which Annie measured her health but were used to confirm her own views. For other participants, affirmation from others formed part of a range of factors that informed them about their health. As well as acknowledging good health, comments from others might have made participants aware of problems, or confirm what they already thought. Rory demonstrated how he would use both his own observations and those of others to monitor his health:

R Probably I would look at myself to see if there's any difference in my weight and see if there's been any, just like, maybe people saying last time I saw you, you were like that, it's a lot of difference in you.

I Do people say that?

R Sometimes people say oh, Rory you're putting the weight on. And I'm ah, don't say that!

(Rory, 27, lived with parents)

He looked for visible changes in himself and others and expected others to do the same, trusting them to use the same standards to assess health that he did. However, their observations were not always welcomed, as demonstrated by his reaction to the suggestion that he had gained weight.

It was not just comments or diagnoses that influenced the way a participant might feel about their health. The simple involvement of a health professional, for example, could have significance when it came to determining what it meant to be healthy. Needing to see a health care practitioner was often taken as confirmation that a person was ill and, conversely, if their attention was not required the person could assume that they were healthy:

My doctor said I keep in good health. I don't go to the doctor very often.

(Linda, 46, lived with mother and brother)

The doctor's comment conferred a general health status which was then confirmed by Linda's behaviour. Although this provided a fairly straightforward definition of health and illness it left little room for nuance; rather, 'it implies no one can be ill until recognised as such, and leaves the concept at the mercy of idiosyncratic individual medical decisions' (Blaxter 2010:13). Comments such as Linda's suggest that some participants relied on the judgement of others, rather than their own, to determine their view of their personal health. As established at the start of the chapter, participants' interactions with healthcare professionals were often mediated by others. In such cases, even the decision whether or not to see a medical practitioner took on extra meaning as it became a comment on the individual's health from the person making the appointment, rather than a decision made by the participant.

7.3.7 Health status is conferred by actions

Several participants mentioned actions that they felt helped to define whether or not they were a healthy person, as well as impacting on their health. For example, Steven concentrated on activities that would increase his strength, so that he could maintain his mobility and thus his independence. Exercise was very much a proactive attempt to maintain his health:

R I go to the gym to get myself mobile, that's what I'm saying, if I didn't go to the gym I'd end up with my legs all, with stiff legs.

I To keep your legs strong?

R To keep my legs strong and to keep my body fit... To go from the floor to a normal chair, no bother. So that means I can go from the floor, cos I go to the gym, can pull myself up... If I didn't do that, it'd be hard doing that.

(Steven, 47, lived with mother and sister)

Part of Steven's wider concept of what it meant to be healthy was that he remained strong and mobile. In order to achieve this he needed to be able to undertake exercise so attending the gym became part of his conceptualisation of health. He focussed on maintaining, rather than improving, his strength and thus his mobility and independence. This echoed his wider concept of health as the absence of illness rather than positive associations and an enhanced sense of wellbeing.

Other participants mentioned things they did that they felt were possibly detrimental to their health, such as eating food they felt was unhealthy. Very few participants mentioned smoking regularly, but those who did admitted that they felt they should stop:

See I smoke too. I shouldn't have started smoking at all. So I went to the chemist for the patches to stop smoking to stop it going through my system. Get the cravings out of my system. But I think they wasn't strong enough.

(Douglas, 55, lived alone with support)

Still smoke, shouldn't be smoking cos I have a lung disease. But, I don't drink anymore. Gave it up years ago, just made me ill.

(Helen, 55, lived alone with support)

Both participants appeared to be trying to deflect potential criticism of their behaviour, the former by mentioning attempts to quit and the latter by the absence of other 'unhealthy' behaviour. These comments perhaps reflected participants' awareness of general messages about health which normally condemn smoking as particularly damaging to health and assert the individual's responsibility to quit.

There were also activities or actions that were seen as being indicative of health and these behaviours formed part of the concept of what it meant to be healthy. Such responses implied that appearing to live a healthy life was synonymous with health, without offering any real explanation for this (Blaxter 1990). Some participants spoke of activities that they believed demonstrated that they were healthy. These included eating certain foods, taking exercise or perhaps having a particular attitude. For example Richard felt that he was healthy when he ate brown bread or lost weight whilst Fraser felt that the action of reducing his consumption of fatty food signified being healthy. Eating or restricting certain foods were the most common actions associated with health but other actions assumed to indicate good health included accepting medical treatment or having good personal hygiene. Participants associated health with the action, rather than the outcome, and the reason for undertaking the action was often not mentioned. Instead, it appeared that the action itself had been elevated to the status of conferring health.

This section has shown that participants' definitions of health were multi-layered and was often difficult to measure health, particularly in others. Health was often a negative concept, noted in absence or in a loss of functionality, rather than viewed as a collection of positive attributes. The relationship between health and weight was particularly complex as weight was seen as something that could be both a physical indication of an individual's health and as something that could affect health in the immediate and long term. Some participants were primarily concerned with the immediate effects of their actions rather than the long term consequences of their behaviour. Finally, some responses suggested that health was not necessarily viewed as something a person has control over as it is confirmed by the opinions of others and health is demonstrated by submitting to medical care if it is deemed appropriate.

7.4 Conclusion

The chapter began by exploring the gatekeepers to health and identifying those people and organisations that might have influence or control over participants' health and access to healthcare before looking at participants' sense of control over their health. Participants' discussion of their access to healthcare

demonstrated that it was not uncommon for them to be reliant on others to facilitate access and, in some cases, mediate these interactions. This might have been because the individual's impairment required third party involvement to ensure that the individual was able to make best use of the appointment and any resulting advice or treatment. However, this intervention may have contributed to participants' feelings that they were not able to influence their health. The environmental control that some participants thought they required to be able to influence their health was not available to them while the general lack of opportunities to exercise autonomy in daily life is likely to have influenced those who felt health and illness were primarily attributable to fate. Further, this situation is likely to have contributed to some participants' belief that they lacked the self-efficacy required to change either their health or their situation.

The chapter then discussed the concepts of health identified by the participants. It demonstrated that participants created complex, multi-layered concepts of health. These concepts could be fluid and behaviour could be adapted according to the situation. Some participants held negative ideas about health and viewed it only in relation to illness: if there was no illness then the individual must be healthy. Health was often associated with functionality and the ability to perform certain tasks. This concept again focussed on what was lost. Health was also conceptualised in more positive ways and some participants discussed holistic views of health, concentrating on the positive attributes of wellbeing and good health. These concepts focussed on health as something that made daily life better, improving not just physical health but also aspects of mental health including confidence and self esteem.

Health was associated with various actions and, similarly, the body was thought to reflect an individual's behaviour. However, views about weight and appearance were complicated. Whilst some participants regarded being 'slim' or 'thin' as desirable others had a more nuanced view of weight, acknowledging that an 'ideal' weight varied according to the individual. Further, whilst being overweight was thought to have a negative impact on health, participants were often reluctant to conclude that this meant the individual was, in fact, unhealthy. These complex views of health could make it difficult to foster healthy behaviour. For those who thought that health was largely not something

they could control, or who thought of health as an absence of illness or loss of functionality, taking action to improve health could be hard, not least because it was not seen as something that needed improving until there was a problem. Even for those who wished to increase their sense of wellbeing, the restrictions they faced in many areas of their life, and in particular regarding food and access to healthcare, actually taking action could be difficult. Actions identified as possibly improving health and what might motivate participants to take action are explored in the next chapter. The data section of this thesis then concludes by looking at how this impacted on participants' attitudes towards being overweight and weight loss, something many of them said they would like to achieve.

Chapter 8. Improving health, losing weight

The final data chapter aims to identify actions and behaviours associated with health, identifying both those that participants believed could promote good health and help avoid illness, and those that they actually undertook. Actions identified centred on diet and exercise. Participants' motivation for these actions is then explored, drawing on Zola's (1973) work identifying triggers for seeking medical attention. They gave a number of reasons that might prompt them to take action and these included prompting from others; concerns and self awareness stemming from previous health problems; and the desire to maintain functionality and avoid becoming 'more disabled'. Reasons for not taking those actions identified are also explored.

The chapter will then explore participants' views and experiences of being overweight and the way these views were connected to their concepts of health. It looks at the way participants connected weight to health, their motivations for attempting to lose weight and the actions they took to achieve this; the relationship between weight and health is also explored. In addition to associated health risks, weight takes on a moral component whereby 'failing to maintain an (appropriately) slim body can be read as evidence of unsuccessful personhood: of somebody who has either wilfully chosen 'unhealthy' behaviours or who does not have sufficient self-control to conform to norms of appropriate size and shape' (Markula et al 2008:14). The language used to discuss weight reinforces the idea of an abstract ideal, with the terms 'overweight' and 'underweight' implying that there is a correct middle weight to be attained (Wiggins 2008). Weight, and by extension other areas of health, are regarded as the responsibility of the individual who, if not within a socially acceptable weight range, 'is constructed as not only unhealthy but also failing as a (responsible) person' (Markula et al 2008:15). This section aims to establish what effect participants thought being overweight had on their lives, whether they planned to try and lose weight and the barriers they identified as preventing them from doing this. Finally, it considers the effect attitudes towards control over health had on participants' approaches to weight loss and their diet.

8.1 Actions identified that promote health

Participants were asked about some of the more practical aspects of health including actions associated with protecting health or avoiding illness. While health was thought to be implied or demonstrated by some actions, there were also those that were deliberately taken with the aim of maintaining or improving participants' health. Participants were asked what they thought they could do to be healthy and about any action that they took. It must be noted that participants were likely to be thinking about food and its relationship with health already as it was explained at the beginning of the interview that one of the main areas being researched was attitudes to healthy eating. However participants were also asked what other factors they thought contributed to health and what they thought was important, encouraging them to think of what was relevant to them rather than just what they thought was of interest to the interviewer. The notion of whether or not they could have control over their health underpinned their responses and their commitment to any changes made.

This section first explores the two main actions participants felt they could undertake to influence their health: food and exercise. It then looks at motivations for taking action, considering why some participants did not feel able to do the things they identified, despite identifying it as potentially beneficial.

8.1.1 Food for health

Food was frequently associated with health and many participants spoke of ways they thought food could be used to promote health both in terms of what they actually ate and what they felt they would do in an 'ideal world' scenario. Context often influenced how participants chose to act. The second data chapter explored participants' beliefs that there were appropriate times to eat healthy food. Others reported that thinking about food actually prompted them to think about their health:

Think about my health, like, what can I eat today? Look in my cupboards and my freezer, pull everything out, right, I'm going to have that today.

(Annie, 39, lived alone with support)

I What sort of things make you think about your health then?

R Cut down my eating. Cut down the fat foods. On a Sunday I used to eat egg and bacon and that on a Sunday. No more, I don't.

(Fraser, 55, lived with mother and niece)

Both Fraser and Annie associated food with their health and thought about the potential impact of what they ate. Annie approached this in a proactive way, attempting to plan meals that she thought would benefit her health. In contrast Fraser spoke of deciding what not to eat when he was thinking about his health. Their interest in food was a reflection of their interest in their general health and their diet was one of the ways they addressed their health.

A considerable number were interested in or were trying to lose weight at the time of their interviews and so were keen to discuss what they were doing to try to achieve this. Health was often connected to weight although participants did not necessarily have any specific health-related reasons for weight loss and instead tended to make loose connections with generally improved wellbeing. Much of the discussion around food and health focussed on including 'healthy' items, such as fruit and vegetables, to their existing diet, rather than using them to replace less healthy elements, reflecting the concept of 'healthy' food as separate to that found in an 'ordinary' diet discussed in the previous chapter.

The connection between weight and health also included ideas about specific foodstuffs that would make a person healthier and slimmer:

Support worker What makes a person healthy Ewan? What makes, what helps them to be healthy?

R Uh, well, eating is lettuce, and green peppers and yellow peppers and there's also in a salad you can also get syboes, that's very healthy for you.

(Ewan, 53, lived alone with support)

Ewan linked health to the consumption of individual items, rather than general eating habits. Although the subject of the research perhaps meant that participants were more likely to discuss food choices and eating habits, it should

also be noted that this was one of the areas, alongside exercise, in which some participants felt they were actually able to do something for their health.

Some participants connected eating with specific health issues, such as diabetes, particularly when they affected family members or themselves. Several had previously had health problems and, as well as being more aware of potential symptoms, some participants spoke of changes they had made to try and protect against future illness. These actions largely focussed on preventing the original problem, rather than promoting their wellbeing, suggesting that illness was seen in isolation rather than as part of the wider spectrum of general health. For some, there was a clear correlation between past behaviours and the subsequent problems which made it easy to take an active interest in prevention, particularly if there was something specific a participant could do. For example, William had been treated for a double hernia, which had involved a lengthy hospital stay during which he contracted MRSA. He attributed the hernia to taking medication on an empty stomach, something that had been possible for him to remedy:

I Is there anything that you think is the most important thing in terms of being healthy, the most important thing that you should do?

R Eh, possibly eat a breakfast.

I Right. Is that for you or for people in general?

R Well, for me cos I never used to eat one, I was terrible. I used to be on a lot of medication but I never ate one just because I was too tired. But the tablets burnt a hole in the lining of my stomach and em, as a result caused a double hernia. So that's why now I take the medication and I eat something and I drink these Muller (yoghurt) drinks, these healthy drinks.

(William, 40, lived alone with support)

Food took on a medicinal quality and William was able to take manageable action to hopefully prevent a recurrence of the problem. However, although participants frequently identified eating healthily as something that was important for their health, it was not something they necessarily did. It was acknowledged that it was hard to change eating habits:

Aye, trying to be healthy but it's hard to cut down when you like your food
(Gordon, approx 50, lived with flatmate with support)

I What do you think would make it easier to be healthy?

R To go off food and drinks.

(Patricia, 55, lived in a residential home)

Although this was an area over which participants were more likely to have opportunities to exercise some choice, and was something they thought was important to their health, they found it hard to adhere to their own beliefs. These conflicting feelings could be for various reasons. Some participants found it hard to maintain changes to their behaviour, even though they knew or had been told that it was in their interest to do so. It is likely that a complex set of reasons affected participants' struggle to make changes. Circumstances that made it harder to implement changes, such as limited opportunity to make choices about food, outlined in the first data chapter would act as a barrier to change whilst the extent to which participants' eating habits were incorporated in their notions of self, as demonstrated by the discussion of the characterisation and roles of food in their lives would also have contributed. Further, it is likely that participants' wider views on health and the extent to which they felt it was something they were able to control were reflected in their difficulty to make and maintain changes.

8.1.2 Exercise and health

Exercise was also frequently mentioned as something that was important for health. Various types of exercise were mentioned, with walking being one of the most popular, perhaps as it was fairly easy for most participants to do. The concept of exercise for health varied amongst participants and is likely to have reflected their wider concepts of health. For some participants, exercise, such as walking, was an incidental part of their daily routine, rather than a formal attempt to be more active:

The only time I do [exercise] is when I'm walking about with my staff, basically. Or when I'm walking round here, when I go up for my tea break, or going for, if

I'm going outside for a bit of air, walk about.

(Duncan, 27, lived with flatmate with support)

Duncan felt that this was sufficient and saw no need to take any exercise other than that which occurred in his daily routine, reflecting his feeling that health was something best managed by others. Others took a more formal approach to exercise, and, for example, used equipment in the gym or took a dance class in addition to their normal activities. Participants spoke of enjoying the exercise but specific health benefits were not generally mentioned and instead there tended to be a general belief that it was beneficial. Of those benefits that were expressed, weight management was most commonly mentioned.

Participants did not just take part in activities for the potential health benefits and indeed this could sometimes be secondary to other positive aspects of exercise. It could have social benefits, particularly if the person was a member of a sports club or did a group activity. For some participants, exercise had benefits beyond health and was simply enjoyable in the short term, regardless of possible long term effects. This led one participant to comment that he was active because of the way it made him feel:

Alright. Good. Goody good.

(Gordon, lived with flatmate with support)

Exercise was not accessible to everyone, though, and a number of participants spoke of factors that limited their physical activity. As discussed in chapter three, people with learning disabilities have been found to face a variety of barriers to physical activity (Messent et al 1999; Heller et al 2011). The discussed barriers often related to perceptions of impairment and the need for extra support to undertake an activity, either due to a physical impairment or because the participant or those around them felt it was not possible for them to exercise on their own. Some participants reported being unable to travel independently or walk alone, making it very difficult for them to exercise alone, and lack of appropriate support to go to the gym or to sports clubs, or even take a walk, was a common restraint cited by participants. Even those who received one to one support during the day could find it hard to organise formal exercise,

particularly if they felt that their support worker did not share their interest in exercise:

Instead of being in the gym he was sitting down in the cafeteria of the gym. He was like that. Well, if he's doing his job, he's not doing it. So, I made a complaint. He didn't like it.

(Steven, 47, lived with mother and sister)

Although he addressed the problem, the support worker's apparent reluctance to support him in the gym might have discouraged Steven from continuing his exercise regime and could compromise their working relationship. This example demonstrates that support workers could act as gatekeepers to exercise as participants were often reliant on them to access activities. The practicalities associated with using sports facilities could also be a barrier to exercise. William would have liked to go swimming but needed two support workers to help him get in and out of the pool whilst Susie was not sure whether her support worker would be required to pay to attend the gym with her once their introductory period was over despite only being there to assist her.

Some participants, whilst stating that exercise could generally be beneficial to health, felt that it might not actually be good for them personally:

... it's not good for your muscles, it tires them out, wastes them.

(Ewan, 53, lived alone with support)

I feel like I do enough, I don't want to overdo it. Cos again, you don't want to kind of threaten your body or anything cos you overdo and you might just, in case something goes wrong, so you don't want to overdo it.

(Duncan, 27, lived with flatmate with support)

Duncan did not want to introduce anymore exercise into his daily activity as he felt it might be detrimental to his health. This was in part related to previous health problems, which he felt might be threatened by exercise:

I Would you want to do more exercise or are you happy with what you do?

R Happy with what I do because I've got to watch with my heart condition as well. I've got to be careful.

(Duncan, 27, lived with flatmate with support)

His fear did not seem to be based on any medical advice but reflected his own interpretation of what was required to maintain his health. Similarly, Claire was reluctant to use the gym or attend exercise classes as she had previously had a hernia and was concerned this might reoccur:

See I don't want to really hurt, really hurt myself. Cos if I went back I might hurt myself again.

(Claire, 45, lived with mother)

Even opportunities for walking could be limited as several participants believed, or had been told, that they should not go out on their own and so could not take exercise this way unless they had someone willing to walk with them.

Participants' responses suggested that these social and attitudinal barriers were one of the main reasons they were not able to undertake exercise as they might be discouraged from being active or might not have appropriate support, which in turn would restrict their options. Further, a lack of understanding about the benefits of exercise, or fear of potential injury, clearly dissuaded some participants from being active; these are issues that could be addressed with appropriate information or education.

8.1.3 Motivations for actions

Participants' actions varied according to the participant and so their motivations differed according to their circumstances and their objective. Some participants were motivated by specific health concerns whilst others took action because they had been advised to do so. The decision to seek medical advice has been found to result from a combination of factors. Zola argues that it is not just the personal acknowledgment of sub-optimal health that prompts an individual to see a healthcare practitioner:

One could hypothesize that there is an accommodation both physical, personal, and social to the symptoms and it is when this accommodation

breaks down that the person seeks, or is forced to seek medical aid' (Zola 1973:679)

Zola (1973) identified five triggers that might each cause the individual to seek medical attention: the occurrence of an interpersonal crisis; perceived interference with social or personal relations; sanctioning, or the recommendation by another person that medical help is sought; perceived interference with physical or vocational activity; and the temporalizing of symptomatology, in which action is taken if the problem is not resolved within a certain timeframe (see also Nettleton 1995). Several of these triggers seemed particularly relevant to participants: the interference of physical activity, or loss of function; the decision being sanctioned or even taken by another person; and a change in interpersonal relations, when the participant's lifestyle was no longer supported. These triggers are also seen in the participants' reasons for trying to lose weight, discussed later in this chapter. This section explores participants' decisions to take action in more depth.

Ewan took an active interest in his health, which was mainly demonstrated by his interest in his diet. His interest was in his general wellbeing but his primary concern was longevity and he connected premature death with being overweight and eating the 'wrong' foods. This concern was in large part fuelled by a cousin who had told him he needed to change otherwise he would die, thus withdrawing the 'social accommodation' identified by Zola (1973) and sanctioning his own wish to change. His cousin had suggested he might die due to sleep, a poor diet and being overweight. As a result of her input, and subsequent discussions with a nurse, he came to a conclusion:

I had to make a choice: lose weight or die. So I just said, no, lose weight, definitely.

(Ewan, 53, lived alone with support)

Ewan's concern was for his general health, although he had focussed on a specific issue which provided both problem and solution: his weight. As a result, thinking about his health led him to think about his eating habits and his weight. Whilst it might appear initially that his cousin's involvement compromised his

ability to make his own decisions about his health, her actions had prompted him to look at those aspects of his life he could control and subsequently to consciously take responsibility for what he ate.

William was also concerned about his health although he focussed more on particular problems than his overall wellbeing. During our interviews he spoke of some bladder problems which he had seen his doctor about. Although he felt the problem was significant and that the advice given to him was reasonable, he did not think it would be possible to stick to it in the long term:

You start out with good intentions and it just falls by the wayside.

(William, 40, lived alone with support)

In contrast to Ewan and despite his awareness of his own health and concern regarding a specific health issue, William did not anticipate taking a more active role in managing it. This reaction is not uncommon: research has found that, despite being fully aware of health messages, those who were at risk often continued their 'unhealthy' behaviour (Blaxter 2010). It is possible that his behaviour in part resulted from his earlier experiences of health problems which, whilst making him aware of potential problems, strengthened his belief that modern medicine could resolve them. Further, his experiences perpetuated his view that health, and illness, were states best managed by health professionals, removing control from the individual. This reflected his wider feelings about the futility of trying to control his general health, as discussed in the previous chapter.

Several participants spoke of previous health problems and felt that this impacted on the way they thought about health now. In some cases this made them more alert to illness and their earlier experiences made them keener to take an active role in looking after their health. Some participants demonstrated considerable insight into their previous conditions and recognised what they could do to make problems less likely in the future. For example Susie had previously lost a lot of weight, which had made her unwell. At the time of the interviews she felt she was overweight but, based on her previous experience, she felt able to identify a 'healthy' target weight.

However for some participants' past experiences of illness made them anxious about their health both as it was at present and how it might be in the future. This was partly attributable to a poor understanding of what might have caused the problems initially, making it hard for them to distinguish whether or not they were suffering from a recurrence of the same problem. Richard seemed very muddled about the state of his health and believed that becoming ill, being taken into hospital and dying, were realistic possibilities, although he did not know if he had any specific health problems. His previous experience of seeing specialists in hospital had left him with a fear of serious illness but he did not fully understand what he had been treated for, leaving him unable to take action to prevent it recurring. In such circumstances it is unsurprising that some participants felt their health was beyond their control. Offering Richard the opportunity to learn about his condition, and his general health, could have allowed him to take more constructive action to look after his health whilst alleviating his fears.

Participants' responses suggested that previous illness might lead to an increased self awareness and interest in personal health and could potentially give them insight into what they needed to do to maintain good health. However whilst this encouraged some participants to take a more proactive approach to their wellbeing it seems that, for those participants who did not understand the nature of their original problem, it could lead to enhanced anxiety and concern about problems if they were not given accessible information relating to their health. Further, although participants often spoke of actions they believed could positively impact on their health this did not necessarily mean that they would make use of this knowledge. There were various reasons for this. Whilst a lack of willpower was acknowledged as a barrier by some, the feeling that changes were too hard to make often reflected the wider nature of participants' lives. For some, their circumstances made it harder to change what they ate, whilst for others assumptions about their impairments or their abilities restricted their activities. These factors might have had a direct impact on whether or not a participant could do something or might have had a more insidious effect, leading them to believe that there was little that they could do and making it easier to delegate responsibility.

Some participants identified internal motivations. Several participants identified good personal hygiene as being an important part of looking after their health. Whilst this had a clear relevance for one participant it was less clear why others should feel it was a priority for their health. It seems most likely that it was a way that people could look after their physical self themselves and was something that they had control over and could monitor: they were able to influence how they presented themselves and so wanted to make the best attempt they could. Patricia summed this up:

R I take care of myself though. I do this myself if I can.

I Ok. Is that important to you then?

R I think it is, yes. If not, you become more disabled.

(Patricia, 55, lived in a residential home)

By taking care of herself, Patricia was able to demonstrate to herself and others that she was still able to function to the level she had determined was acceptable to her. It seems that she associated disability, rather than impairment, with her ability to function and thus to not be able to perform such tasks would have wider implications on the way she saw herself. However, it also suggests Patricia was responding to some of the negative views held about disabled people, which might in turn impact on opportunities offered to her by other people.

The chapter will now explore participants' attitude towards their weight and considers the influence these views had on their views about maintaining a healthy weight.

8.2 Health and weight

8.2.1 Connections between health and weight

The final data section explores participants' views about weight. As discussed in the previous chapter, weight was seen as an indicator of, and influence on, health. Whilst participants sometimes thought that being overweight need not mean that a person was unhealthy, it was common for them to report that they wanted to lose weight. This was for various reasons, explored below. Weight can

be a complex issue, associated with appearance and morality (Kennedy and Kennedy 2010:130) as well as health. As outlined in the previous chapter, participants thought their appearance affected their confidence and how they felt about themselves as well as their physical wellbeing. This section explores how participants felt about their weight before going on to examine the reasons given for attempting weight loss. Although health was given as a motivating factor, others were also put forward, including appearance and the influence of others. The section then considers the effects of weight loss, which were mainly viewed as positive, before discussing the various barriers identified as inhibiting weight loss, focussing on the limited opportunities that participants had to influence their environments and thus making it harder to modify their diets.

Many participants thought that they were overweight although not all were concerned. Ruth's comments were representative of this group. Although she said that she thought she was overweight, overall she felt 'Fine, I've just got to plod on.' She accepted her weight as part of who she was and thus saw no urgent reason to try and change it.

However, not all participants were as accepting of their bodies and several who acknowledged that they were overweight spoke of the negative feelings they associated with it. Being overweight was described as feeling 'terrible' or 'awful'. The comments seemed to reflect both participants' feelings and the bodily effect of being overweight. Ross had taken part in several weight loss programmes, and at the time of the interviews was doing a weight loss course with his GP. He spoke of how his weight and appearance affected the way he felt:

I And how do you feel about your body?

R Hmmm... not great. Could be down. I'd be happy, I'd be more confident and more happier when my body is down, when it's slim.

(Ross, 25, lived with parents and brother)

As well as the potential problems associated with being overweight on his physical health, how he felt about his body had a negative impact on the way he felt about himself in his day to day life. Others took a more pragmatic view and

viewed being overweight as a predominantly practical issue:

R I feel I'm overweight.

I And how does that make you feel?

R Makes me feel, doesn't make me feel sad or anything, just cut down....

Healthy eating because I like healthy foods.

(Annie, 39, lived alone with support)

At the time of the interviews, Annie was taking practical steps to address her weight and this perhaps helped her to feel more positive about it. She felt she had some control over her weight and her diet and did not feel as negative as some of the other participants who did not know what to do to create change.

The following section explores the reasons why people wanted to lose weight. Some participants had already made attempts to lose weight whilst others thought of reasons that might prompt them to take action. Various factors were identified. These include health, the ability to function, appearance, the influence of others and the way that participants viewed themselves. The section starts by looking at those motivations associated with health.

8.2.2 Reasons for wanting to lose weight

Health

Health concerns were often cited as a reason for wanting to lose weight. These ranged from a general wish to improve health to more specific concerns that often related to previous problems. Some participants were motivated by the wish to improve their overall wellbeing:

I would rather lose weight than take a medicine all the time, all my life. And then, oh, no way. No. See in 6 years time I would rather be a healthy 60 year old than an unhealthy one.

(Ewan, 53, lived alone with support)

I think your health should really come first.

(Annie, 39, lived alone with support)

Monitoring their weight, and trying to lose weight if necessary, was a way for these participants to look after their health. Some participants were prompted to think about their weight by specific health concerns, such as joint problems or blood pressure, or anxieties that related to previous problems. Other participants, though, were not clear about the health benefits of weight loss, although being 'thin' or of an average weight was often assumed to indicate general good health and associated eating 'healthy' food. These views might result from exposure to health promotion messages that state that being overweight is bad or even dangerous for health without receiving corresponding information that explained why this was, or why it might be preferable to be thinner. It was also possibly a reaction to media messages that it was socially desirable to be thin.

The effect of being overweight was more likely to be discussed in conjunction with health or linked to potential health problems, but participants were unsure whether or not this feature alone meant that a person was unhealthy. Several participants suggested certain medical problems that they thought might be an effect of being overweight. In particular, it was thought to be bad for the heart although other, less specific, health concerns, such as breathlessness, were also voiced. So, as well as potentially being an indicator of poor health, some thought being overweight might also contribute to poor health.

However, participants were not always willing to associate bodyweight with poor health:

R ... you could meet someone who you've not seen in a while and you're like that, wow, you're looking great and you see them on the street 6 months down the line and they're breathing awfully bad because of their weight they're holding.

I Right, so if they've put weight on, do you mean?

R Uh hmmm. Plus their breathing.

I Do you think you can be big and heavy and still be healthy?

R I don't know. I mean I've got a friend that's quite heavy and he just gets on with it.

I Do you think that he's healthy?

R I don't know. I don't know. He could be eating healthily, but he likes his beers and that.

(Rory, 27, lived with parents)

Another participant was similarly reluctant to conclude that his friend's weight was a sign or cause of poor health despite describing his breathing difficulties and trouble walking. It was perhaps because participants often had friends or relations who they thought were overweight, or were aware that they were overweight themselves, that they did not want to associate this with poor health: whilst they might pathologise excess weight when it concerned an anonymous other, to do so in relation to people they knew would have been to reach a negative conclusion about others', and their own, wellbeing. Further, participants' beliefs were complicated by their own experiences and the knowledge that behaviour was often complex and contradictory so it was not necessarily possible to deduce a person's health or actions simply from their appearance.

Where weight was linked to other behaviours it was normally associated with what people ate and was much less likely to be connected to exercise. Whilst this is likely to be in part a reflection of the bias of the research, which focussed on food, it might also reflect the fact that all the participants were directly involved with food, even if only through eating, and so this was uppermost in their minds when thinking about the factors that could influence health. In contrast, opportunities for exercise were far more restricted and so this might be something they were less likely to think of when talking about the factors that could influence someone's health.

Weight and the body were linked to functionality, which could both signify, and contribute to, health. For example, Ross wanted to lose weight so that he could become more active which he felt, in turn, would have a positive impact on his health. Weight and weight loss were clearly very important issues for some participants both because of their links to health but also because of their effect on appearance and feelings about the self. Whilst participants often said that a thin body indicated a person was healthy when talking about general indicators

of health, it seemed it was harder for participants to identify a healthy weight for themselves. The extent to which participants were able to exert control over their weight was a complex issue for many participants, both male and female, and will be discussed further in this chapter.

Participants also discussed the negative effect of overweight on their mental health and several mentioned that they thought they would be happier or more confident if they lost weight. Being overweight was associated with negative feelings about the self. Several participants thought that they would feel better about themselves if they lost weight:

[I want to lose weight] To be slim, to look attractive, be happier, be confident. When I've lost my weight and I'll be able to do things what I haven't done before, like go swimming, go cycling again, all that... It would make a big difference to my life.

(Ross, 25, lived with parents and brother)

Being overweight had affected many areas of Ross's life and he envisaged that losing weight would not just impact on his health or his body shape but on his mental health, his sense of well being and his wider life. Another participant echoed this feeling and stated that losing weight would help him 'to come back to myself and give myself a life as well'. Weight affected not just the bodies of the participants but their sense of self and the way they experienced their wider lives. The positive effects of weight loss were not just associated with achieving a goal weight: participants who had lost weight also reported feeling happy during the process as they saw changes in their bodies and when they received confirmation that they had lost weight.

Wanting to lose weight did not always mean that a participant was actually going to try and do so. One participant thought that he would lose weight if instructed to do so by a healthcare professional, in part because he believed he would receive help to do so:

... you would have support. You would have nurses coming in and doctors giving you medication.

(William, 40, lived alone with support)

However, he had no immediate plans to make any changes himself. Thus both the decision to lose weight and, to a certain extent, the responsibility for doing it, were left to other people. Further, comments such as this suggested a belief that modern medicine and the healthcare profession would be able to resolve any problems that might occur (Saunders 2001). So, although participants appeared to be aware of their own health status, and health promotion messages, they did not feel it necessary to act on them.

As mentioned in the previous section, various triggers that prompt an individual to seek healthcare have been identified (Zola 1973) and these can be applied to the decision to attempt weight loss. In addition to being motivated by acute physical need, Zola (1973) also identifies the sanctioning of the 'problem' by another person, as something that can prompt the individual to seek help or take action. In some cases it seemed participants' weight loss attempts were driven by others' concern for their health, in addition to their own wish to lose weight. Although Ewan, for example, expressed considerable self-motivation to improve his health and lose weight, his first visit to the doctor had been initiated by his sister. In some instances it was hard to tell how much of a problem participants considered their weight to be, prior to intervention from family members. However, at the time of the interviews they appeared keen to lose weight and agreed that there had been a problem. Making the decision to get medical advice on behalf of the participants could, though, reduce any feelings of control over their health or their weight that participants felt and the impact this had on their motivation is explored in later in this section.

Functionality

Just as health was sometimes related to a person's ability to perform certain tasks, so weight could also be linked to a loss of functionality and this could provide motivation for weight loss. Participants each had their own notion of an acceptable level of functionality which, if lost, would prompt them to take action, echoing Zola's (1973) finding that perceived interference with social relations or physical activity was a trigger for seeking medical help. William identified several criteria that might prompt him to try and lose weight:

Well I'm quite happy at the moment but I wouldn't like to get much bigger. So, I mean I've seen able bodied folk on tv and they cannae fit through doors. That must be hard, it's hard for anybody, but.

...

I When you say that you think you should think more about what you eat, why would that be?

R Because the more weight I put on, the limited movement I have... In my upper body. And if it gets to the stage where I need a bigger chair I'm going to have a problem with transport and taxis and that... Like how are you going to get in and things like that.

(William, 40, lived alone with support)

Despite having gained weight, the situation was not yet serious enough to act as trigger to prompt weight loss. Rather than take action to prevent his weight becoming a problem, William did not intend to attempt to lose weight unless it had a tangible negative impact on his everyday life. This reflects some of the attitudes to health expressed by participants in the previous chapter, who did not tend to take an interest in their health unless they became unwell or were unable to perform normal activities.

For others, though, the consequences had been significant enough to trigger action:

I was finding it hard to transfer in my chair, and I knew I needed to lose weight or I'm going to end up needing hoisted and I don't like getting hoisted. And I don't like getting put to bed. Because I don't have the support at [her supported flat], and the home helps come in and put my pyjamas on at quarter to 7 at night, if I couldn't transfer myself I would be put to bed at quarter to 7 every night. So I thought, no, I'm not having this. I need to stop doing what I'm doing and I need to concentrate on trying to eat healthily. And I know that, I know that it's either I eat all the junk food in the day and get put to my bed at quarter to 7 or I can do something about it and stay up till I want to go to my bed. And that's the bottom line, really.

(Susie, 40, lived alone with support)

For both William and Susie it seemed that it was not unless the threat of lost mobility, and the associated independence, was imminent that they would take action. In William's case, despite knowing the potential risks of gaining more weight he was not prepared to try and lose weight as the problems were still only possibilities. Immediate consequences of behaviour were less likely to be ignored but the prospect of potential problems in the future was not enough to motivate behaviour changes.

Other people's influence

It was common for participants who were trying to lose weight to report that they had been encouraged to do so by others, including family members and health professionals. It seemed that weight loss attempts could be bound up with approval from family and authority figures and several participants spoke of others' pride in them when they lost weight. Carol wanted to lose weight, and thought that she 'would feel better' if she did, but she also reported that her sister wanted her to lose weight and had taken her to the doctor to discuss it. Both her sister and the doctor had been angry about her diet and weight gain but had been very pleased with her dietary changes and subsequent weight loss. Some participants found the comments of others to be upsetting. Claire reported that previous conversations with her doctor about her weight had left her upset and was very pleased that it had not been mentioned at a more recent appointment, despite wanting to lose weight. However, as a consequence, Claire no longer saw her doctor as a source of support.

Others told of family members encouraging them to go to see their GP and, in some cases, creating meal plans designed to aid weight loss and passing them to their support workers. Whilst some participants welcomed this support, others found it intrusive and said that comments intended to encourage them to lose weight made them feel 'sad' or 'terrible'. This reflects issues around autonomy and control over diet as well as the extent to which participants were encouraged, and enabled, to engage with and take responsibility for their own health and shows that what might be intended as helpful could be interpreted as undermining their autonomy.

Appearance

Appearance and, in particular, fitting into clothes were amongst the reasons why participants attempted weight loss, or that they thought might motivate them to try. Although not concerned about losing weight at the time of our interviews, Ruth mentioned both clothes and appearance as factors that might prompt her to think about her weight. Similarly, William thought about his weight in conjunction with his appearance:

Well, obviously if you feel rotten you don't care anyway but I mean, I can look at photographs up there and wish I could get back into those clothes. I mean I seen clothes in town today that were very nice, good for the winter. But they've only got XL and I need, like, XXL, which is the really big.

(William, 40, lived alone with support)

His comment highlighted the way that negative feelings about one area of life could lead to loss of interest in other areas. Positive changes were thus harder to achieve, perpetuating the negative feelings.

Some participants were motivated to lose weight due to their feelings about particular aspects of their appearance:

Look. (Pinches her stomach) That's why I want to get thinner and thinner.

(Carol, 59, lived with sister)

I've been trying for one, to go on [a diet] for years and years and I cannae get it off my legs.

(Claire, 45, lived with mother)

I Is there anything that you would change?

R Well, I've actually got a belly just now.

(Rory, 27, lived with parents)

The participants isolated and partly externalised the troublesome areas, distancing themselves from their 'problem' by associating it with a specific part of the body and not the person as a whole. Pinching at flesh on the stomach or

referring to a spare tyre was a common response by participants when weight was being discussed, even amongst those who did not express a serious wish to lose weight. This was perhaps a way of deflecting any potential criticism as by acknowledging that they were overweight pre-empted comments from others.

8.2.3 Weight loss methods

Most participants had attempted to lose weight in the past or were considering doing so in the future; several were actively trying to lose weight at the time of our interviews. Losing weight could be very difficult and frustrating for participants, particularly those who were very keen but did not seem to know what to do. It was an emotive topic and occasionally a break or subject change was required during an interview as the participant did not want to talk about it further.

Participants had largely tried to lose weight by modifying their diet, although a couple thought that they might increase the amount of exercise they took. The decision to change their diet was often done with advice from others. These included professionals, such as a GP, practice nurse or dietician, as well as family members and support workers. In addition, one participant had successfully lost weight by attending Weight Watchers and following their diet plan, with the help of one his support workers.

The dietary changes involved reducing or changing the amount eaten, or a combination of these. Changes such as making a lower calorie version of a meal or substituting commonly consumed items were thought to be easier to implement than introducing entirely new foods. William recalled changes he had made in the past:

... you buy butter or marg, I'll buy the low fat stuff. Simple things that are nice but still less fattening for you.

...

The biggest help I think was grilling my food instead of frying. Cos it's amazing the amount of grease comes out of food that you don't realise it's there.

(William, 40, lived alone with support)

These changes had required the cooperation of William's support workers as they cooked for him and there had been occasions when he felt that they had not made him healthy meals. Several participants who had successfully lost weight reported that support from others, such as support workers or family members, had been very helpful. The assistance they had received included accompanying them to weight loss groups, helping to plan meals and general encouragement when they were implementing lifestyle changes.

Some participants thought that if they needed to lose weight they would increase the amount of exercise they took but this was not a common response. As discussed earlier in the chapter, people with learning disabilities face a number of barriers to exercise (Messent et al 1999; Heller et al 2011). Even walking could be difficult for some participants as they were strongly discouraged to go out on their own and so could only go if they had someone to accompany them. This type of attitude compounded the feeling that exercise was not appropriate for many of them. Those who were supported to exercise found this both useful and enjoyable and appreciated having the company.

8.2.4 Effects of weight loss

Both the physical and psychological effects of weight loss reported were largely positive. The physical benefits mentioned by participants included reduced joint pain and better-fitting clothes as well as improvements in appearance. Weight loss was largely associated with feeling 'good', perhaps in part due to the knowledge that it was desired by others as well as themselves. Losing weight also had immediate psychological effects for some participants:

I felt good when I heard that, you've lost weight, two pounds. I felt a wee bit lighter in my posture and my legs when I heard that.

(Ewan, 53, lived alone with support)

Further, several said that seeing a fall in their weight encouraged them to continue with their weight loss diet.

Several participants had lost weight as a result of being ill. However they welcomed this outcome and thought that they had looked 'good'. Despite having

been very unwell and in hospital for some time, William felt the change in his body had made a positive impact on the way he saw himself:

You feel a difference, a big achievement, you know. But it's, again, you can put your best clothes on and feel comfortable in it. And you're not worrying about people looking at you, or self-conscious, you know.

(William, 40, lived alone with support)

Despite the positive feelings associated with weight loss it was not always enough to motivate participants to make changes to their diet. Although they anticipated feeling better the other factors involved, such as having to give up preferred foods or move from an 'ordinary' diet, meant that many were not planning to try to lose weight. Whilst there was a high level of interest in weight loss, few participants had successfully lost weight. A number of barriers were identified and these are explored next.

8.2.5 Barriers to weight loss

Many of the barriers to weight loss identified by participants were similar to those that they felt prevented them from eating a healthy diet. They centred on a strong sense of what was 'normal' to eat which made the dietary changes that were required to lose weight hard. As discussed in the previous chapter, notions of dietary norms made it harder to change eating habits as the inclusion of foods consumed regularly, including those classes as unhealthy, had been normalised. Thus, deviating from this meant they had to change the way they thought about food. It might also require them to eat foods that were different to those commonly eaten by friends or family, again challenging perceptions of what was normal and this proved difficult for participants. Andrew's comment reflects the unfairness he felt when it was suggested that he might cut back on a particular food he enjoyed and ate regularly:

... everybody eats Subways [takeaway sandwiches] and that, don't they? Probably doctors and then the doctor tells me to lose it.

Further, he thought he would feel uncomfortable if he had to eat different food to that which his friends and family ate:

Embarrassing. When everybody else is eating the wrong food, I'll be eating the healthy food.

(Andrew, 25, lived with parents)

Although he called the food others would be eating 'wrong', as it was not 'healthy', he felt he would be the one who would stand out. To avoid this he said he would just eat the same food as the others around him, even if went against the doctor's advice.

Changes that moved the participant too far from their normal diet were less likely to be maintained. Claire thought it would too difficult to cut chocolate from her diet completely as she would 'probably get fed up after a while and then you'd probably go back to it again' whilst William mentioned that it was hard to get into the habit of eating different things. Dietary changes could be difficult to maintain, as William described:

I'll drink water [instead of soft drink] but it's got to be really cold. I used to buy the Volvic, started that but then it just fell by the wayside. It's just, it's like everything else. You start out with good intentions and it just, falls by the wayside.

(William, 40, lived alone with support)

William did not fully incorporate these changes into his lifestyle, perhaps because he did not see the need to lose weight imminently. Instead they remained as 'extras' to his normal diet and were eventually dropped.

The notion that new diets must be maintained could be hard to accept even when participants saw that they were effective. Susie described the process of replacing her old eating habits with new, healthier ones:

... see I've lost weight before, I lose the weight and I feel great and then I start eating all the rubbish again so what I need to do, rather than saying I'm on a diet, [my support worker] says, you should say I'm on a healthy eating plan and you stick to the healthy eating plan whether you lose weight or not... she said if you lose the weight you know you're going in the right direction. Then to save

you putting all the weight back on, stick to what you're eating. So what I was doing was, I was losing the weight and going, oh brilliant, I've lost weight, I can eat what I want now. And that's defeating the purpose! But I couldn't understand that at the time. I was, I've lost this weight I can eat a bit more, and then it just creeps up on you and you pile it all back on again.

(Susie, 40, lived alone with support)

The discussion of 'normal' food in the second data chapter highlighted how ingrained the eating habits of some participants were. Although seeing positive results from dietary changes encouraged participants to continue with their new regime, advice on changing diets to aid weight loss might be more helpful if this was taken into consideration.

Sometimes the information available to participants was felt to be too complicated. This not only meant that participants could not follow the instructions they were being given but could also have discouraged them from continuing to try to lose weight or from seeking advice in the future. Ross dropped out of a weight loss programme run by the hospital as he felt he could not keep up with the amount of written material that was involved. It seems that impairment was an issue that was not always adequately addressed. However, as the comment above from Susie demonstrates, when participants were supported, and provided with information in a way that was relevant to them, they could make use of it successfully.

Several participants thought that it was necessary to be committed to making changes if they were to be successful. William thought that you needed to have the right mindset before trying to lose weight and Ewan commented that considerable willpower was often required to resist the temptation to return to old habits. Temptation was something that many participants recognised as being a threat to their weight loss attempts. The availability of convenience food, such as chocolate or fast food, even in places such as the gym meant that some participants felt they were frequently reminded of those items that they were meant to be avoiding. This was compounded by advertising (Wansink 2004). Although some participants might have recognised that they were being

influenced by external factors this did not always mean that they were able to ignore them:

I think if people walk into shops and they see there's chocolate it's quite difficult as well. Doesn't help you to lose weight, helps you to put on the weight! And also all the advertisements.

(Ross, 25, lived with parents and brother)

Sometimes it was easier to change activities and thus avoid temptation altogether:

[my support worker] said, why don't we go for a wee pint in the [pub] and I just said no, cos it's very hard having a pint at the [pub], then they'll tell you to have a meal with the pint of beer. I just said no. Definitely not. Cos I don't want to put my weight on again.

(Ewan, 53, lived alone with support)

For others this was less easy, particularly if their opportunities to make choices were restricted. The meal plans in the residential home where Patricia lived routinely included cakes and puddings and Andrew found it hard to give up eating crisps as his mother always bought them, reinforcing his belief that such foods are the 'norm', and further influencing consumption (Sobal and Wansink 2007). In addition, the extent to which participants were able to influence their environment was often very limited and so they were unable to remove many of the everyday temptations, making it harder to eat a healthy diet.

Thus, while participants were clearly interested in weight loss it was often difficult for them to do so. A number of barriers made it hard for them to implement changes. In particular, it was hard to make and maintain dietary changes, in part because of strong views of what constituted a 'normal' diet, and further complicated by the limited opportunities they had to influence their environment. In addition, there were other practical barriers such as access to accessible information that made weight loss harder. It seems that it was hard for participants to envisage making successful, long term changes to their diets despite reporting positive effects when they did lose weight, perhaps reflecting

the level of control participants had over other aspects of their lives. The way in which many participants conceptualised health, as an absence of illness or a loss of functionality, meant that they were perhaps less likely to consider weight loss as a way of increasing wellbeing as health was seen as a neutral state. Thus they might only decide to lose weight if they could see it had a negative impact on their daily lives. Further, a limited sense of control over health would make such an outcome hard to envisage, meaning that the possibility of improved health was not likely to be a realistic or strong motivating factor for weight loss.

8.3 Conclusion

This chapter aimed to identify the actions participants associated with health promotion and what would motivate them to change their behaviour before exploring participants' views about weight, and barriers to weight loss. Two main actions thought to impact on health emerged from the data: modifying the diet and taking exercise. However barriers to both were noted. Participants' lack of control over their diet, coupled with the strong meanings attached to food meant that it could be difficult to make changes whilst they often faced a range of barriers to activity. Participants' motivations for taking action were mixed and several triggers were identified. Although those who were addressing health issues at the time of the interviews reported that they were doing so willingly, their actions often seemed to be the result of a push from a family member, reflecting the role that they had in managing the health and healthcare of the participants.

Weight was a complex issue. It was thought to be a visible characteristic of health and was recognised as being both a potential indicator of health and a contributor. However, it was not a clear signifier, and although many participants objectively recognised that being overweight could be detrimental to health they were often reluctant to acknowledge the effects it could have on their health or that of people they knew. Many described themselves as overweight but did not necessarily feel that they were unhealthy, as it did not impinge on their experience of illness or ability to function, further clouding the links between weight and health.

Although weight might not have been clearly linked to poor health, participants largely expressed negative feelings about being overweight and even those who did not intend to try and change their behaviour said that they would rather weigh less. Weight, like health, was associated with function although it was discussed in terms of what would need to be lost before behaviour was changed. Making long term changes to lifestyle to promote both better health and weight loss were identified as being difficult to do, particularly without support. This suggests that it was hard for some participants to make changes to their behaviour for potential benefits to their health or weight in the long term when they could see no immediate reason to do so. Those participants who did report that they had made changes had largely taken action to try and lose weight in order to improve their health. The change was often triggered by immediate health concerns and influenced by others, such as family members or medical professionals. Thus there was an obvious reason for making a change and the support to carry it out. Participants who did not believe that their actions could truly influence their health were likely to lack the motivation to implement positive changes and might also doubt that their behaviour could have long term negative consequences. Thus health promotion strategies aimed at encouraging personal responsibility will seem irrelevant or impractical (Pill and Stott 1982) regardless of the desire to change.

Chapter 9. Discussion and Conclusion

This study has set out to explore the attitudes of people with learning disabilities to food, health and obesity. The prevalence of obesity has been shown to be higher in people with learning disabilities when compared with the general population (Emerson and Baines 2010; Hamilton et al 2007; Melville et al 2006; Emerson 2005; Yamaki 2005). This research aimed to examine how people with learning disabilities made choices about food and the extent to which this was influenced by their thoughts and feelings about healthy eating, health and weight. However, during the course of data collection and analysis it became apparent that, whilst these were important influences, wider issues concerning restricted opportunities for choice and control in many aspects of participants' lives affected the way they thought about food. Food is a key part of expressing the self and food choice provided a way to tap into a broader exploration of the lives of people with learning disabilities. Within the broad theme of choice and control, other themes became apparent from the discussions around food choice: the role of gatekeepers, who both deliberately and incidentally moderated choice and actions; and the importance of the social relational model of disability (Thomas 1999) and the effects and experiences of psycho-emotional disablism. In addition, the extent of cultural influence on eating habits and attitudes towards health and healthy eating became clear and this, combined with participants' lack of control to bring about change in their own lives, made taking action to promote health without the support of others a near impracticable task.

The findings demonstrated that people with learning disabilities were not stopped from following a healthy diet, or taking other actions to promote their health, by problems inherent in their impairment. Whilst the existence of a learning disability might have meant they required additional support in some or all areas of their life, participants were able to demonstrate that they had at least a basic understanding of the principles of healthy eating; in some instances, participants demonstrated sophisticated ways of managing their diet within the constrained options available to them. However, much of the restriction placed on participants' opportunities to exercise control over their own lives stemmed from assumptions about the effects of impairment and the

associated risks. The social model of disability has done much to move emphasis away from the effect of impairments and to highlight instead the structural and material barriers that prevent disabled people from participating in society. However, as discussed in chapter two, the model has been criticised for failing to adequately allow for the experiences of people with learning disabilities. Work such as that by Thomas (1999; 2007) and Reeve (2004; 2012 forthcoming) on a social relational model of disability and the effects of psycho-emotional disablism, although not specifically focussed on the experiences of learning disability, can inform our understanding of the impact these expectations and assumptions have on the lives of people with learning disability.

Goodley (2001) describes social constructions of learning disability that are based on assumptions about what an individual cannot do. Assumptions based on a view of learning disability as an 'organic impairment' (Goodley 2001) may result in structural barriers as the difficulties they encounter are assumed to stem from the effects of their impairment. However, these assumptions also result in barriers to being (Thomas 1999) as they are conveyed by the negative reactions of those around people with learning disabilities and, sometimes, reflected in the individual's own sense of self, and potentially result in the actions and personalities of people with learning disabilities being pathologised. Stalker and Connors (2010; see also Connors and Stalker 2007) found that children with learning disabilities experienced such barriers and concluded that further exploration of their experiences of psycho-emotional disablism, and the resultant barriers to being, could help to develop a better comprehension of their lived experiences and the ways in which they understand disability. This research has found that experiences of psycho-emotional disablism were particularly relevant when looking at the lives of people with learning disabilities and the way they have developed a sense of self and that, in the context of healthy eating, barriers to being proved to be the most significant obstacle.

This chapter aims to bring together the key findings from the data and to link the emergent themes with wider literature. It is divided into four sections. It starts with a synopsis of the data chapters before presenting the key themes to come out of the data. The overarching theme identified by the research is

choice and control but three further themes are examined within this: the role of gatekeepers; the effects of psycho-emotional disablism; and the construction of healthy choices as separate to 'normal' choices. There then follows an exploration of the findings in relation to current policy that focuses on the provision of individualised support. The final section identifies the limitations of the project and suggests future directions for research.

9.1 Overview of thesis

The first section presents a brief overview of the findings discussed in the preceding four chapters and outlines the main themes to be discussed next. Analysis of the data had revealed choice and control to be the key theme when looking at the diets of people with learning disabilities. The extent to which they were able to control what they ate influenced their ability to implement their knowledge of healthy eating and, importantly, affected whether or not they felt it was possible to make changes either in their diet or to their health. As it was central to understanding the analysis, the first data chapter explored this overarching theme of choice and control in the lives of the participants. Within this, three key themes were identified: limited opportunities for control of what they ate, the presence of gatekeepers who moderated food choice, and the impact of psycho-emotional disablism on their beliefs about their capabilities to exert choice and control. The data demonstrated that participants often had very little control over the pattern of their daily lives. This was influenced by the type and amount of support they had, with more personalised support generally facilitating greater autonomy. The chapter then focussed on choice and control in relation to three key areas associated with food: shopping, cooking and choosing what and when to eat. It established that gatekeepers were important agents in the participants' diets. Whilst research has found that it is common for gatekeepers to manage access to some food and nutrition (Wansink 2006), the participants experienced an increased level of gatekeeping and their food choices were moderated at multiple stages. Thus, it was not unusual for them to have little or no involvement in shopping, cooking or choosing food at mealtimes. Participants who lived with family members reported having the least involvement in the processes associated with food and made fewer decisions about what to eat. Those participants who lived outside

the family home tended to make more decisions about food; however they were also likely to have several gatekeepers and it was reported that family members, as well as support workers, influenced their diets. This control was not always unwelcome: when participants worked in partnership with those who supported them, their involvement was felt to be helpful and was welcomed.

A key theme to emerge in the first data chapter was the effects of psycho-emotional disablism, brought about by others' assumptions about what they were, and were not, capable of doing. These views created 'barriers to being' (Thomas 1999) and prevented some participants from developing a sense of competence and self-efficacy in relation to food choice. Concepts of risk, held by both participants and those around them, had a significant impact on their involvement with food. Some participants spoke of their reluctance to take more responsibility for what they ate or to develop their skills, particularly in relation to cooking. Their responses revealed that they had internalised the negative views of others and believed that such activities were too risky or complicated.

The second data chapter explored the way participants conceptualised food. It revealed that they often held complex, nuanced views of food that reflected the situation in which it was eaten. Food was not just a source of sustenance but filled many varied roles in addition to being a source of pleasure and enjoyment. Participants demonstrated a good knowledge of the principles of healthy eating but, for various reasons, were unable to put it into practice. As outlined in the first data chapter, they often lacked the autonomy to take control of what they ate and so could not apply their knowledge. In addition, they faced cultural barriers which influenced the way they viewed food. The construction of food as healthy, unhealthy or ordinary was explored and it was found that 'healthy' food was often regarded as separate to that which participants would expect to eat as part of a 'normal' diet. This made it hard to include healthier items in the place of 'ordinary', less healthy options. The concept of unhealthy food was often associated with items that were particularly enjoyable to eat, making 'healthy' substitutions seem particularly unpalatable. Finally, participants ate a diet similar to those around them and changing to a healthier diet would involve an awkward rejection of conventional food choices. This was demonstrated by their reaction to the recommendation of eating five portions of fruit and

vegetables a day which, although known about, was largely regarded as irrelevant and unnecessary. Thus, being 'healthy' required a conscious effort to change in the face of considerable resistance from both individuals and the wider environment. It is unsurprising, therefore that some participants felt the effort needed to change their notion of 'normal' was not justified by possibility of unquantifiable gains in the future.

The third and fourth data chapters (chapters seven and eight) were concerned with participants' concepts of health and weight and, in particular, whether it was something they believed they could influence. Chapter seven looked at the control participants had over their health. It began by identifying various groups that moderated participants' relationships with healthcare professionals, showing that often these interactions were initiated by others. It then explored participants' notions of control over their own health, showing that they often believed that their health was not in their control but was determined either by fate or by the interventions of others, or a combination of these influences. These beliefs were connected to the way participants conceptualised health. Health was viewed in a number of ways and participants' concepts were similar to those identified by research with non-disabled groups (Blaxter 1990). Some concepts were positive, reflecting holistic notions of enhanced wellbeing but others saw health as a neutral state that exists when one is not ill or characterised it according to functionality or the absence of illness. Negative views of health are likely to compound the belief that health cannot be influenced by the individual. Unlike positive views of health, which include a sense of enhanced wellbeing, negative concepts do not suggest that health can be improved, only that illness can hopefully be avoided or treated.

The final data chapter examined the actions that participants associated with health improvement. The focus was largely on food and exercise but, as with healthy eating knowledge, there was often a gap between knowledge and action and barriers to implementing change were apparent. Further, perceptions of impairment and associated limitations prevented some participants from taking actions they identified as potentially beneficial, particularly becoming more active. Some participants had made changes for purposes of improving their health. Motivations for doing so were largely a combination of the need to

address a specific issue and encouragement from others. Other participants identified triggers, often related to the ability to perform certain actions, that had not yet occurred but which they felt would encourage them to take action.

The final section of the fourth data chapter concerned participants' attitudes and approaches to weight loss. Obesity and the desire to manage their weight were important issues for many of the participants. Weight was identified as both a signifier and contributor to health status and many participants reported that they wanted to lose weight. This was commonly because it was thought that it would have a positive effect on health but it was also associated with improvements in appearance and the way participants felt about themselves. However, as with other potential actions to improve health, a number of barriers were identified and the limited opportunities participants had to implement changes again emerged as a significant influence. Further, a number of participants felt that they were simply not yet at a stage where it was necessary for them to make the dietary sacrifices required to lose weight and so, until they reached their own tipping point, such as a specific loss of functionality, or were instructed to do so by a health professional they intended to maintain their current lifestyle. Finally, several participants had lost weight and cited good support from those around them as being an important contributing factor. Access to appropriate information and personalised support from healthcare professionals, as well as family and those working with them, appeared to be crucial to successfully changing to a healthier lifestyle.

Having looked at the substantive themes that emerged from the data chapters, this chapter now moves on to discuss these issues to locate them in current understandings of learning disability. It starts with an exploration of choice and control, the overarching theme to emerge from the data, touching on the place of 'control' within learning disability policy and in practice. It then moves on to look at three themes within this: the mediation of choice by others who acted as gatekeepers both to material items and to opportunities for control; experiences and effects of psycho-emotional disablism that were revealed through the exploration of food in the lives of people with learning disabilities; and finally the 'othering' of healthy choices and the impact that this had on the choices people made.

9.2 Discussion of key findings: Choice and control

The following section sets out the key conclusions to emerge from the research. Whilst the original aim of the project was to explore how participants interpreted healthy eating messages in their food choices it became clear through the data analysis that this topic gave an insight into the opportunities of people with learning disabilities to experience independence. Thus, the overarching theme to emerge from this thesis is the importance of choice and control. People with learning disabilities have been found to have fewer opportunities to exercise choice and control in all aspects of decision-making (Jenkinson 1993; Rodgers 1998; Treece et al 1999; Smyth and Bell 2006) and participants in this research reported that their options were restricted in many areas. Lack of control has been found to affect wellbeing whilst a sense of autonomy coupled with the option to make choices has been associated with improved confidence, independence, self-esteem and satisfaction with life (Stalker and Harris 1998; Treece et al 1999) as well as being a way in which the individual can assert their identity (Jenkinson 1993). The opportunity to make decisions about food is central to many of these issues about an individual's right to choice and control.

Facilitating individual control has been at the heart of disability policy for some time and, since the 1960s, policy has moved towards the provision of care and support in a community setting with an increasing emphasis on the promotion of independent living (Welshman 2006). Current Scottish learning disability policy, The Same as You? (Scottish Executive 2000) states the need for people to have more control over their lives, in addition to the necessary support and information, in order that they are able to be meaningfully involved in making decisions about their lives to enable them to live a 'full life'. Independent living is central to the UK disability policy document Improving the Life Chances of Disabled People (Prime Minister's Strategy Unit 2005). Again, this puts choice and control at the centre of the policy in addition to the provision of any required support and it states that 'Independence comes from having choice and being empowered regarding the assistance needed' (Prime Minister's Strategy Unit 2005:58). These policy documents, combined with Direct Payments legislation and the Scottish policy of self-directed support (discussed below),

demonstrate that there is a clear discourse concerning the rights of disabled people to have the opportunity to exercise choice and control within their lives and ensuring that they are provided with adequate support to achieve this. However, despite substantial improvements to the lives of people with learning disabilities, choice is clearly still a contested issue and the data presented in this thesis suggests that this right is not always being upheld by those directly providing the support in either a formal or informal capacity.

Food can form an intrinsic part of an individual's identity and thus the right to choose what is eaten should be supported wherever possible: the removal of the chance to decide when to make a cup of tea is described as encapsulating 'the disruption to a sense of autonomous adult self' (Mennell et al 1992:113) and a signifier of dependency. By exploring the way participants made choices about food, the data chapters have revealed the restrictions placed upon the participants, some of which impacted on their opportunities to take part in 'normal' activities. Participants reported having limited control in a number of areas, including lack of choice about their living arrangements, daytime activities, food shopping, cooking, meal choice, arranging to see a doctor, taking exercise, support arrangements, and using public transport. However, participants reported that they felt it was important that they were allowed choice in many of these matters, particularly those regarding food.

Stalker and Harris (1998) note that choice requires three elements: available options, an understanding of these options, and power to take action, to which can be added the right to make the 'wrong' decision or to take risks. The data has shown that, whilst participants often demonstrated good knowledge of healthy eating, they frequently lacked the availability of choices or the opportunity to implement changes. Concern about the risk of making 'bad' choices can result in the individual being discouraged to choose for themselves (Stalker and Harris 1998). Indeed the risk of making 'bad' choices, particularly those with the potential for negative consequences in the long term, such as repeatedly choosing unhealthy food, is cited as the strongest reason to constrain choice (Bannerman et al 1990; Smyth and Bell 2006). This can cause the perpetuation of the denial of choice as the lack of previous experience or

learned skills and behaviours (Jenkinson 1993) inhibits the ability to evaluate the potential consequences.

The data shows that there was often a struggle to balance the right to express the self through choice and the risks that upholding this might pose. Concerns about the individual's capacity can cause the opportunity to make choices to be withheld and the risks associated with not controlling the diets of people with learning disabilities have been considered significant enough to advocate denying them the right to choose (Smyth and Bell 2006). This was apparent in the data in relation to both choices about food and accessing healthcare, where appointments were made on behalf of participants for reasons sometimes unknown to them. There is, though, considerable evidence to show that, with the appropriate support, 'people with profound intellectual disabilities can make meaningful choices even though these may be restricted to concrete objects or activities in the immediate environment' (Stalker and Harris 1998:65). The temporality of choice is perhaps particularly important here as being unable to articulate an understanding of long-term consequences does not necessarily negate the possibility of being able to make decisions in the immediate term. Further, supporting the individual to make choices about the short-term allows the process of choosing to be 'practiced', helping to develop the skills needed to make more complex decisions in the future. However, as a result of assumptions about competency, people with learning disabilities are often asked to demonstrate higher levels of understanding than those expected of non-disabled people before being allowed to exercise choice (Jenkinson 1993). If such expectations are maintained, it is possible that 'we may never reach a point of allowing people with a disability to exert self-determination and thus gain the experience necessary for more adequate decision-making' (Jenkinson 1993:364) as they will be denied both the opportunity to practice choosing or to discover the consequences of their choices (Stalker and Harris 1998). Further, restricting choice and control prevents the individual from becoming an active participant in their own life and thus developing the sense of self-efficacy required to bring about lifestyle changes.

Participants who had been given the opportunity to make decisions and to take control of various aspects of their lives reported feeling more motivated to

maintain changes and were more likely to believe that they could influence their health. This, in turn, encouraged them to think about behaviours that might have a positive affect on their health and wellbeing. These findings are reflected in the literature, which shows that choice and decision-making skills, combined with other characteristics, including internal locus of control and positive associations of efficacy and outcome, are essential aspects of self-determination which, in turn impact on quality of life (Wehmeyer and Schwartz 1998). This has led to the conclusion that a good quality of life is possible ‘if we have control over our own lives and if we have the help we need to keep that control and independence in our own lives’ (Wehmeyer and Schwartz 1998:11).

The research found that participants often lacked the opportunity to make choices or implement changes to the way they lived. This was for several reasons: the influence of those around them who acted as gatekeepers to food, healthcare, and information, amongst other things; a lack of belief in their own abilities, both to take part and to effect change, brought about by the internalisation of the views of others, known as psycho-emotional disablism (Thomas 1999); and the way meanings of food and health were constructed, resulting in an ‘othering’ of healthy behaviour and its apparent irrelevance to their lives. These three themes are part of the overarching subject of choice and control but are distinct areas and so will be discussed individually below.

9.2.1 Gatekeepers: mediators of choice

This section discusses the notion of gatekeepers and their influence in the participants’ lives, both as controllers of nutrition and mediators of access to healthcare. The data revealed that participants often had several layers of gatekeepers and that they were found in a range of aspects of daily life. The gatekeepers identified were mainly parents and support workers. Their influence was very evident in relation to the food available to participants, as described in chapter five, but they were also noted in participants’ descriptions of their access to healthcare. They were found to exert control in a number of ways, in some cases deciding whether the participant should see a medical professional. They were also in a position to facilitate choice by enabling participants to take control and helping them to make use of information or implement change. It is their role that is discussed below.

Gatekeepers have been found to have a significant influence on what is eaten both in- and outside the home. Wansink's (2006) American study found that gatekeepers directly and indirectly controlled an average of 72% of what was eaten by a family. Gatekeepers are often identified as mothers (Wansink 2006) and, indeed, women have been described as 'guardians of the family health' (Mennell et al 1992:108). Whilst one or more gatekeeper(s) might be present in the average family, participants in this research encountered a greater number and had fewer opportunities to take responsibility themselves. This was clearly seen in relation to food. Wansink's (2006) research largely relates to families with children still living at home; once a person reaches adulthood and moves into their own home it can be expected that they will no longer experience gatekeeping to this extent, if at all. However, family members had significant influence on most participants' diets, even when they no longer lived together, whilst support workers often indirectly affected what participants ate. This involvement could have both positive and negative effects on participants' relationship with food. In some instances, particularly when participants lived with family members, they reported being disengaged from most processes associated with food and either left shopping, cooking and meal choice to others in the household or were not allowed any involvement. In some instances family members also controlled food consumption outside the house by providing packed lunches and restricting participants' access to money. This resulted in few occasions to practice making choices about food or to take responsibility for this aspect of their health. Further, in some instances it was seen to have a negative impact on their confidence with food and the accompanying activities such as shopping and cooking. The effects that this had on the participants' perceptions of their own abilities are discussed below in the section examining participants' experiences of psycho-emotional disablism.

Family members also sometimes acted as gatekeepers to health services, taking control of making appointments and attending them with the participant. It seems that they did not just act as advocates or supporters but, in some cases, managed their healthcare; one participant, for example, reported a forthcoming appointment with a GP for which she did not know the reason, demonstrating the absence of responsibility for her health that was afforded to her. If it is

assumed that adults with learning disabilities cannot make decisions themselves, those supporting them will continue to position themselves between the individual and the medical professional. Research into the inclusion of adults with learning disabilities in health services found that ‘carers justified the exclusion of the individuals they supported on the basis that they were unable to make them aware of their role in the choice-making process and the options available’ (Ferguson et al 2011). It was found that they prioritised the choices they presented to those they supported (Ferguson et al 2011), thus consciously, or subconsciously, acting as gatekeepers to their healthcare. Such behaviour is likely to further distance the individual from their own care, making it harder for them to develop a sense of self-responsibility or to take control of their lives.

Support workers were more likely to be involved in incidental gatekeeping. Whilst some people who work with people with learning disabilities are in a position to make many choices for them, the participants in this study reported that they were generally involved in the decision making process, if not always in charge. However, aspects of the support system, such as the amount of time a support worker had, as well as features specific to the individual worker, such as their cookery skills, constrained the dietary choices available. Further, whilst some restrictions stemmed from the need to accommodate impairment, ‘the reduced opportunities which people with an intellectual disability have for decision-making may be a function of the attitudes and practices of care-givers and administrators rather than of the limitations and impairments associated with disability’ (Jenkinson 1993:370). Enabling people with learning disabilities to take control requires work from those who support them in addition to a long-term view of what it is hoped can be achieved. Whilst it might be easier and apparently more efficient for tasks to be done on behalf of the person supported this inhibits people from developing the skills required to make choices or take control. As discussed in the previous chapter, good personal support and accessible information can reconcile enabling the individual to take control and develop skills with maintaining a duty of care.

The data revealed some positive examples of gatekeeping. When participants had opted into this sort of relationship a collaborative approach to managing

choice developed. Some control was rescinded by the participant in the short term to enable them to take control of their health in the long term. Several participants reported working in partnership with family members or support workers to make changes to their lifestyles. Ultimately, this enabled them to take more control even though some day to day tasks were devolved to others. For example, one participant allowed her day to day food choices to be moderated by her personal assistant to help her achieve her long term goal of weight loss. This relationship worked because the participant trusted her PA to make good choices for her, according to both her preferences and her health. Most importantly, she was consciously and willingly allowing her PA to have this control. The way support is delivered can have a significant impact on the individual's notion of control over their lives: 'for social support to be health promoting, it must provide not only a sense of belonging and intimacy, but it must also help people to be more competent and self-efficacious' (Berkman 1995:251). Encouraging those they support to develop the skills to make choices, and the confidence to do this and the belief that they can, should be a central part of the support relationship. When this is done well, it can have positive consequences for people with learning disabilities by fostering a sense of autonomy and self-efficacy.

The gatekeeping role can be complex for support workers, as demonstrated by Thomas's support worker's comments in chapter five. The role was built around the gatekeeper's idea of what learning disability meant and so within it were assumptions about the individual capabilities. Balancing the person's right to choice with a duty of care and commitment to developing the skills required for increasing independence is likely to be a difficult task for those working with people with learning disabilities (Bannerman et al 1990) even when it has been negotiated with the participant. Gatekeeping is an understandable response to risk and, indeed, could be interpreted as part of the support role (Smyth and Bell 2006). Indeed, disallowing the consumption of unhealthy food could be seen as desirable in the context of the high levels of obesity in the learning disability population, with such interventions perhaps being viewed in a similar way to long-term medical management of other conditions. Such gatekeeping, though, would not be tolerated by non-disabled people, despite their risk of making poor choices and the general problems of overweight and obesity, outlined in the

introduction. It is thus important to discuss whether or not it is acceptable for those who have a learning disability. As discussed in the previous section, choice is an important part of self-expression and self-determination. Such an approach perhaps indicates a training issue to ensure that support staff are able to provide appropriate individual support to encourage the development of the necessary skills to make choices. Further, structural aspects of support should be addressed to ensure that individuals are given sufficient time to make decisions and to become more involved in practical aspects of their lives as this is likely to take longer whilst skills are being developed. Service providers at all levels are in a position to significantly influence the degree of choice afforded people with learning disabilities and choice needs to be engendered at all levels of provision if support staff are to feel able to encourage it in people's daily lives (Stalker and Harris 1998).

There are several consequences of denying individuals the opportunity for choice. Firstly, some participants became disengaged from the processes involved and did not have any desire for greater involvement. Secondly, some appeared to have internalised others' views that they are not capable of choosing or taking responsibility and so believe that they are not capable of doing so. It is this that is discussed next.

9.2.2 Restricted expectations: the effects of psycho-emotional disablism

The data presented for this thesis showed both examples and effects of psycho-emotional disablism. As outlined in chapter two, the negative perceptions of others can impact on the disabled person and can 'place limits on our psycho-emotional well-being' (Thomas 1999:47) and sense of self. Over time, this has a cumulative negative effect on self-confidence and self-esteem (Reeve 2012 forthcoming), potentially leading to restrictions on individual's own beliefs about what they can do. Reeve (2002; 2004) describes a particularly pervasive form of oppression that occurs when the oppressed group internalise the negative assumptions of those around them (Reeve 2002). This idea has largely been developed in relation to the experiences of people with physical impairments. However, this form of oppression is commonly experienced by people with learning disabilities and 'can lead to "barriers to being" meaning restrictions on who an individual feels they can become, their inner worlds,

sense of self and social behaviours being negatively shaped by these experiences' (Stalker 2012:3, forthcoming). It is important to consider the effects of psycho-emotional disablism when looking at the experiences of people with learning disabilities and this thesis has attempted to do this by looking at encounters with food.

Reeve (2012 forthcoming) identifies several forms of psycho-emotional disablism: direct psycho-emotional disablism which 'arises from relationships that the disabled person has with other people or themselves' and indirect psycho-emotional disablism which comes from 'the experience of structural disablism' and is caused by the hurt associated with exclusion (Reeve 2012:2 forthcoming). People with learning disabilities experience direct psycho-emotional disablism as a result of the attitudinal barriers they face (Stalker 2012 forthcoming); the impact this had on participants is discussed below. The data also showed experiences of indirect psycho-emotional disablism. For example, several participants described being given inaccessible materials when seeking weight loss information. This left them feeling de-motivated and led some to conclude that the information was simply not relevant to them. Others reported that activities such as physical exercise were 'not for them', a feeling that, for some, was compounded by physical impairments that required a greater level of support than other pursuits.

A more direct form of psycho-emotional disablism was found in some participants' descriptions of their involvement with food, particularly in relation to the development of cookery skills and perceptions of risk in the kitchen. Reeve states that 'being forced to define oneself in terms of what one is *unable* to do impacts on psycho-emotional well-being' (Reeve 2012:10 forthcoming). It is thus possible that support, if not provided in a way that engenders a sense of autonomy in the individual, could appear to confirm the feeling that the individual is not capable of taking part in the task and requires it to be done for them: the presence of a support worker or helpful family member acts as a reminder of their incompetence. Several participants expressed the belief that it was not worth them attempting to increase their involvement with food as their support workers were much quicker at preparation. They seemed to feel that this was unlikely to change and so did not see the point of changing the support

relationship to enable them to take more control in the kitchen. One participant, Duncan, was particularly resistant to the idea that he might become more engaged in the processes associated with food and believed that the support workers were there to perform the tasks for him, rather than help him to participate. This led to enforced dependency on their support as he did not gain new skills. He felt strongly that it was not appropriate for him to do so, due to both his learning disability and his visual impairment, citing his parents' similar views as a way of validating his own. It appeared that he had internalised his parents' belief that he was not capable of cooking or preparing food and thought it pointless to try and change this situation, despite encouragement from his support workers. Indeed, at times he seemed offended by the suggestion that he might want to improve his skills or take more responsibility, describing the possibility as 'a definite no-no'. This example demonstrates the effects of both direct and indirect psycho-emotional disablism, as the structural barriers associated with his visual impairment combined with his parents' views of his capacity to develop skills as an adult with learning disabilities, caused him to believe that he could not take more responsibility despite encouragement from those working with him and dissatisfaction with his support arrangements.

As discussed above, participants were often denied the opportunity to make choices and were thus also denied the chance to express themselves through their choices, and to develop decision-making skills and a sense of autonomy. A lack of opportunities to exercise choice can lead to learned helplessness and 'a generalised belief that he or she is powerless to affect outcomes in all situations' (Jenkinson 1993:366). This, ultimately, can result in passivity as the individual feels that they are unable to create change. Further, not allowing people to exercise choice influences the way they are viewed by others: 'it is hard to come over as competent, or to be treated as an autonomous human being, if one's identity is premised on sustained incompetence' (Williams et al 2009). Thus, the assumption that the individual is not capable of making choices is maintained.

Participants' views on their ability to influence their health demonstrated some of the consequences of psycho-emotional disablism. Chapter seven explored the extent to which participants felt able to control their health and showed that

some felt it was not something they could influence, believing it either to be the subject of fate or luck or the intervention of qualified others. Some participants did express the desire to bring about change, and in particular to lose weight. However, many had not yet taken any action. Allison (1991) suggests that such views are linked to the control an individual has in other areas of their lives: if they have little hope of affecting outcomes in other areas of their life, they are unlikely to believe that they are able to positively influence their health in either the short- or long-term. Given the limited chances the participants had to influence their daily lives, it is perhaps not surprising that participants were not always confident that they could make changes or that their actions might improve their health and wellbeing.

9.2.3 Constructing 'healthy' as 'other'

An important factor in the behaviour of the participants in this study was the way they conceptualised food and health. The meaning they gave to food was indicative of the role it had in their lives. Although most participants were aware of the main health messages related to eating, they often did not incorporate these into their diet, characterising healthy food as 'other'. In contrast, foods identified as unhealthy were assumed to be part of a 'normal' or 'ordinary' diet and something that everybody ate at some point. Attitudes such as this made dietary change harder as it was difficult to see how 'healthy' foods could be incorporated into an 'ordinary' diet. Where participants had included them, these foods tended to be regarded as supplementary to what was already eaten rather than replacements for other items. Participants' constructions of an 'ordinary' diet will have been influenced by what those around them ate and their responses must therefore be taken in context with what is known about the general diet in Greater Glasgow, where the study took place. When this is taken into account, participants' responses do not appear to be out of line with other residents in the city. For example, the percentage of people in Greater Glasgow who do not eat fruit and vegetables daily has been found to be 25% and 13.5% respectively, rising to 31% and 17.6% in the most deprived areas (Hanlon et al 2006:205). Fruit and vegetables are not a culturally normal part of the diet. Thus, it is not surprising that for many of the participants the notion of eating at least five portions of fruit and vegetables every day did not seem like a realistic target, despite being aware of the recommended levels of consumption, as it

was not reflected in the behaviour of those around them. This dismissal of public health advice perhaps also reflects the idea that ‘food is felt to remain within a personal and social domain, not a medical one (Cohn, 1997:198) and so such messages are thought to be open for review even issued by authoritative sources.

The cultural connotations of what makes up a ‘normal’ diet does not just affect the way specific health promotion messages are interpreted. As discussed in chapter three, environmental and social norms have a significant influence on food consumption (Wansink and Sobal 2007; Nestle et al 1998). People with learning disabilities are more likely to be at risk of poverty and to live in deprived areas (Emerson and Baines 2010) and this is likely to be reflected in their construction of dietary norms. Area deprivation, as well as individual socio-economic factors have been found to impact on what is eaten:

...quality of diet is socially patterned, with consumption of nutrient-rich diets high in whole grains, lean meats, fish, low-fat dairy products and fresh fruit and vegetables associated with higher socio-economic status and lower-quality, energy-dense diets- including elements such as refined grains and added fats- associated with deprivation (Gray and Leyland 2008:1351).

In addition, people living in the Greater Glasgow area were found to have ‘an unfavourable dietary profile compared with the rest of Scotland’ (Gray and Leyland 2008:1355), including higher consumption of non-diet soft drinks and salt. It is important to note, therefore, that this provided the background for the participants to establish their dietary norms. Such cultural norms will make change harder for the individual. This is for several reasons. Firstly, the dominance of these norms makes it harder to recognise that change might be required: participants reported discounting advice from their GP, and others, as it was counter to the behaviour of those around them, and therefore did not correspond with their idea of an acceptable diet. Secondly, those individuals who do decide to implement new eating habits will not just have to change their behaviour but will also have to negotiate the contrasting views of those around them. Finally, they might face challenges from those around them who operate

within the original construction of 'normal' and thus struggle to accommodate the individual's new behaviour; such resistance was seen in the data, most notably from one participant's PA who continued to serve large portions and from another's sister who seemed to simply disregard his new food choices.

It is apparent from the data that participants faced multiple barriers to healthy eating. Not only did they face the barriers to being associated with psycho-emotional disablism, but there were material, structural barriers due to the cost of food, its availability, and cultural expectations related to a 'normal' diet. Therefore the effort required to make dietary changes could appear difficult and it might well appear to be beyond the individual's ability to achieve this without considerable help from others and belief in their own self-efficacy.

It was not just healthy food that was constructed as 'other'. Some participants also saw health promoting behaviour, in particular taking exercise, as something that was outside their idea of normal. Indeed, some of the concepts of health put forward focussed on absence and a loss of health, suggesting that a notion of enhanced wellbeing was also seen as something other than their daily experience. The way participants conceptualised health affected how they interpreted health information and perhaps whether they sought it out at all. This seemed to be the case for several participants who reported that, despite being unhappy about their weight, they would not seek information about weight loss until they experienced a significant loss of function, suggesting that they did not think about health in terms of wellbeing, or as something they might be able to improve, instead hoping only to avoid a decline. In contrast, some participants who associated health with positive feelings, both physically and mentally, reported working to try and improve their health. Further, concepts of health affected whether or not participants felt they were able to take control of their health: if health is characterised by an absence of illness that is only treatable with intervention from a health professional it is likely that an individual will not feel able to exert much personal influence.

The amount of control a person has over various aspects of their life impacts on their health. Social vulnerability and poor social relationships are known to have negative affects on aspects of both mental and physical health (Wilkinson 2006;

Stansfield 2006) whilst a sense of belonging can help foster a sense of agency that, in turn, enables the individual to develop an identity as competent (Berkman 1995). Autonomy in other areas of life can have a significant impact on both perceptions and of health and health outcomes. Research exploring the relationship between control in the workplace and health shows that limited autonomy causes stress which correlates with a poorer health status (Wilkinson 2006:342). Allison (1991) suggests that individuals who are faced with few opportunities to exercise control and self-determination, in both the short- and long-term, can conclude that, just as they have little hope of bringing change in other aspects of their lives, neither do they have a realistic prospect of exerting control over their health. These findings are particularly relevant to people with learning disabilities who are more likely to experience ‘social disconnectedness’ (Emerson and Baines 2010) and to have little control over some of the major part of their lives, including where they live and with whom, and what they do on a daily basis. Indeed, the participants in this study were not always able to decide what they ate for their next meal. In such circumstances it is perhaps unrealistic to expect them to have the agency and sense of self-efficacy to believe that they are either able to exert a positive influence over their health or weight in the long-term or that they will have the opportunity to bring about the changes necessary.

9.3 Policy Implications

This section of the chapter looks at how policy might currently be used to support people with learning disabilities to feel more in control of their health and to eat healthier diets.

Diet and healthy eating have been of keen interest to successive governments, both in Scotland and the UK, in recent years and are the subject of much health promotion material from a range of sources. Information can be found in print, online, on podcasts, and DVDs, produced by the NHS (www.nhs.uk/livewell/healthy-eating), government bodies (for example, the Department of Health’s Eatwell Plate resources), food producers (for example, www.ryvita.co.uk/healthyeating, www.florahearts.co.uk) and charities (for example, the British Heart Foundation at www.bhf.org.uk/heart-health/prevention/healthy-eating). Accessible

information has been produced for people with learning disabilities and the Scottish Government has recently completed a pilot project, 'Healthy Eating, Healthy Living', now under evaluation, which aimed to use practical exercises to help people with learning disabilities develop healthy behaviours regarding shopping, cooking and eating. It is clear that promoting healthy eating is high on the agenda and that a wealth of information is available for those who wish to use it. However, this thesis has shown that one of the main problems faced by people with learning disabilities who wish to change their diet is that they find it hard to make use of their knowledge as they have little control over their everyday lives, and that, in part due to this denial of autonomy, do not believe they have the agency to bring positive changes to their health. This section will look at policy aimed at individualising the support available to people with learning disabilities to examine whether this might help them to develop a sense of self-efficacy and greater engagement with the food they eat.

Policy documents including Improving the Life Chances of Disabled People (Prime Minister's Strategy Unit 2005) and The Same as You? (Scottish Executive 2000) have a clear discourse of choice and control, espousing independent living, enabled by appropriate and adequate support, as a primary aim. However, the extent to which disabled people are afforded opportunities for choice and control often depends on the interpretation of the policy at ground-level. Thus the way support is provided can have a big impact on the promotion of independence. The concept of personalised services, known as self-directed support, has been at the heart of policies for providing support for people with learning disabilities. Current government strategy intends for it to become the mainstream approach for delivering support in Scotland (Scottish Government 2010). The fundamental principles of self-directed support are choice and control:

Choice is evident where people are able to choose how they live their life, where they live and what they do. People have control of their support by determining and executing the who, what, when and how of the provision.

(Scottish Government 2010:7)

It aims to create individual solutions to people's social care, education and health needs by placing the service user at the centre of the planning process and creating an individualised plan that best meets their needs and delivers a better quality of life. This philosophy has emerged from other existing methods of services provision, in particular direct payments, and the drive from the disability movement towards types of welfare provision that promote independent living (Leadbeater et al 2008). Service users have reported increased satisfaction with personalised services; for example, direct payments have been shown to be an effective way of increasing the control the service user has, both in the way support is delivered and what it allows them to do (Priestley et al 2010; Pearson 2006).

An individualised approach to delivering services could have particular relevance to food choice and healthy eating for adults with learning disabilities. Personalised support methods, such as direct payments, offer people with learning disabilities the opportunity to move away from group-based support, which generalises need, to a system that can enable real choices (Williams and Holman 2006). Promoting greater choice and control is central to personalisation and self-directed support could offer service users the opportunity to exercise autonomy and should result in services that are more flexible and responsive to the needs of the individual (Leadbeater et al 2008). This could have positive benefits for those adults with learning disabilities who are interested in food either with regard to their health or because they are keen to develop their cookery skills due to personal interest or as part of the skills for independent living. Further, the promotion of choice might lead more people to become interested in food and cookery as they will provide more opportunities to decide what they eat. However, this type of support could have more far reaching effects. If it successfully enables people with learning disabilities to have more control in the daily lives it could lead to a greater sense of autonomy in their wider lives. Allison (1991) describes the impact limited control in the workplace can have on health behaviours due to the passivity and lack of self-direction it implies. This effect is likely to be experienced to an even greater degree by people with learning disabilities who often have very few opportunities to express choice. In contrast, involvement in structural planning for the longer term, might have a 'spillover' effect into other areas of life, making planning

and implementing positive action for long term health promotion seem more realisable.

However, although self-directed support can provide the structure for a more individualised service, much will still depend on the ethos of the service provider and of the support workers themselves. The data suggests that the principle of choice as a key component to independent living was often overlooked by those working at ground level. As highlighted in both the literature review and the data, risk, coupled with a sense of duty of care, can be a significant issue for parents and support workers, making them reluctant to encourage those they support to take more control, particularly if it seemed that they might make poor food choices. The potentially limiting consequences of risk averse practice are recognised in the strategy for self-directed support (Scottish Government 2010) and it is recommended that risk is managed and shared by the person, support workers, family and friends and the providers. The need for training for staff across health and social care is stated both in the strategy and the draft Social Care (Self-directed support) (Scotland) Bill (Scottish Government 2010c). Mencap (Mencap 2006) guidelines for supporting healthy eating also emphasise the need for those who are being supported to be allowed to make their own choices about food whilst aiming to equip those providing the support with knowledge so that they can help their clients to make informed choices. With choice identified as a key principle of enabling people with learning disabilities to lead full lives (Scottish Executive 2000), and a theme of personal responsibility running through public health strategies, the question of how best to support people to have control and, importantly, to be able to make informed decisions will continue to be of relevance. The relationship with the person providing support, and with those providing the services, appears to be critical to ensuring this is facilitated. Leaving a person to make choices without adequate support could have the effect of making them feel less in control as they would not necessarily have the resources or skills to inform decision making. The participants in this project who had successfully made changes to their diets or who were trying to improve their health often described working *with* their support worker or personal assistant. A relationship akin to partnership emerged which enabled them to feel confident about make choices, implement changes, and to take more control.

9.4 Study limitations and future directions for research

The following section is a critical appraisal of this thesis, highlighting those aspects of the research that could be improved upon and identifying topics that would benefit from further research.

The section first considers the limitations associated with the research design. The purpose of the research design was to gather rich, in-depth data, and to explore the key issues with the participants. It would therefore have been useful to have contributions from a larger number of participants to add greater breadth for the purposes of comparison across the group. If resources had been available, a larger sample could have allowed comparison within the group by gender, socio-economic background, ethnicity, and occupation, and with existing research on non-disabled populations, thus further identifying points of convergence and divergence and potentially gaining greater understanding into what informed attitudes towards health and food. However the time-intensive nature of the processes involved in interviewing, transcription and data analysis meant that this was not possible and, as discussed in the methods chapter, a less involved method of interviewing would not have provided the required depth of data. The use of focus groups at the start of the fieldwork period was in part an attempt to address this limitation as it enabled the researcher to gather data relatively quickly, and enabled some sensitisation to the key topics prior to starting the main phase of data collection.

In addition to a larger sample, a more diverse range of participants might have enriched the research. The participants all consented to take part in the research, thus implying that no one deemed not to have the capacity to do this took part in the project. Those who cannot consent are potentially some of the most vulnerable people with learning disabilities and issues surrounding choice and control are particularly relevant to them as their opportunities are likely to be constrained. Future research should ensure that their voices are included. All participants interviewed were of the same ethnic background: white Scottish. This was entirely reflective of the people that were put forward as potential contributors but it does mean that cultural or religious differences are potentially absent from the data. Future research might want to endeavour to

include participants from minority ethnic backgrounds for the purposes of better representation and to allow for potential points of similarity and difference.

The research design involved interviewing participants several times, over the course of two or three weeks. Whilst this allowed some time to get to know each participant to gain an understanding of their lives and routines, the research might have benefitted from also including some participant observation. This would have given the researcher an opportunity to observe interactions between the participant and others, potentially providing some insight into their relationships with the family, friends, and support workers who were often identified in the data as gatekeepers, sources of information, and important influences. This approach would also have enabled the researcher to explore the structural barriers faced by the participants, including food access both within the home and the community, cooking facilities, and the effects of economic deprivation. These observations could have been discussed with the participant at subsequent interviews and would have allowed the researcher to contextualise the data.

The issue of food cost is one that is absent in the data. Financial circumstances will influence food choice but the issue of cost was not mentioned by most participants, and only in passing by those who did. People with learning disabilities are more likely to suffer economic disadvantage (Emerson and Baines 2010) and it could therefore be expected that cost would be an influence on their food choice. Although ‘money’ and ‘supermarket offers’ were included in the interview schedule as potential influences they did not generate much discussion. With hindsight, it might have been beneficial to question participants further to discover why cost was not thought to be an issue. Future research might want to consider this important topic and find ways of exploring it more comprehensively with people with learning disabilities. It is possible that the subject of cost of food was of little interest to the participants because it was not something that they had to manage: one participant reported that her sister encouraged her to ‘save’ any money she received, but did not know why, whilst participants who were not involved in purchasing food or who received support to do so may not have had to deal with the financial management of their shopping budget. Finally, the often routine nature of food shopping, whereby

items are repeat purchased and the overall cost of the shopping basket only changes gradually over time, might have meant that participants generally did not consider the cost of what they bought. Although these issues did not seem to be of particular interest to the participants in this study, the impact of the cost of food on choice, and whether or not people with learning disabilities wish to have greater control of their finances, merits future exploration.

A further issue that is absent from the data is the role of gender in food choice and perceptions of health. As discussed in chapter three, gender differences in eating habits have been noted in the general population; in particular, women have been found to be more interested in 'healthy eating' and more likely to consider the links between food and health to be important. However, no clear patterns of gender difference were noted in the data. This might result from a failure to draw out differences in the interviews or might reflect the wider desexualisation of adults with learning disabilities, resulting in them not displaying traditional gender bias. Gender differences would be a valuable area of further research, particularly as women with learning disabilities are known to be at greater risk of being overweight or obese (Melville et al 2006).

Finally, a flaw in the participatory approach of the research is that the findings are yet to be presented to the participants and other interested parties. An important part of the participatory approach is ensuring that the research findings are accessible to those who contributed (Walmsley and Johnson 2003). However, the strictures associated with the PhD process, in particular the tight deadlines imposed by the Economic and Social Research Council, did not allow time to adequately disseminate the findings and then incorporate the views of interested parties. To address this, the findings will be prepared as an accessible document and distributed to all participants who expressed an interest in the outcome at the time of their interviews. If possible, the findings will also be presented to those advocacy groups and day centres from whom participants were recruited to ensure that as many participants as possible are able to find out the results of the research and to express their opinions on it. Their thoughts on the conclusions will be included in future articles prepared for publication.

Several areas of research have come to light as a result of this project. The previous section emphasised the need to explore whether or not cost acts as a barrier to healthy eating for people with learning disabilities. In addition, the concept of psycho-emotional disablism in relation to the experiences of people with learning disabilities would benefit from further development. As discussed in this thesis, experiences of psycho-emotional disablism can have a significant impact on the lives of people with learning disabilities yet their accounts are largely absent from the literature. Stalker highlights the relevance of this concept when looking at the lives of people with learning disabilities:

the concept of psycho-emotional disablism appears to speak to the experiences of people with learning difficulties although it has been little explored in relation to them. Importantly, Thomas's model allows the impact of specific impairments to be acknowledged without detracting from the central role and significance of disablism. (Stalker, 2012:13-14, forthcoming).

Indeed, psycho-emotional disablism and the concept of internalised oppression (Reeve 2002) seem key to understanding the barriers to inclusion faced by people with learning disabilities. Future research applying the social relational model of disability (Thomas 1999) and exploring the types of psycho-emotional disablism encountered, and the effects it has on perceptions of self, would help to enrich our understanding of the lives of people with learning disabilities.

9.5 Conclusion

This thesis aimed to explore the attitudes towards healthy eating of adults with learning disabilities by exploring influences on their food choices and the way they conceptualised food and health. Previous research, discussed in chapter three, has focussed on the epidemiology of obesity in the learning disability population (Melville et al 2006; 2008; 2009). This research looks at why the prevalence is higher and focuses not on impairment related issues but on the social factors that influence food choice and attitudes towards health and health promotion. However, in addition to exploring the participants' relationship with food, it became apparent that there were other emergent themes, more

complex than simply the way individuals negotiated personal preference and healthy eating messages. Food is a highly visible part of the majority of people's lives and a means of self-expression that is subject to a huge range of competing messages. It is a shared experience and so discussion of food and eating allows the researcher to access themes broader than the original subject matter.

The research reveals that an absence of choice was central to the lives of many of the participants, and opportunities for control were routinely moderated by formal and informal gatekeepers. Given the emphasis in policy on facilitating choice and control, and enabling independent living, this is a troubling finding. The research shows that, although participants often had a strong interest in what they ate, their opportunities to determine what they ate were restricted and various gatekeepers moderated their diet and their involvement with food. Subsequently some participants appeared to be disengaged from the processes associated with food, retaining an interest in what they ate but preferring to leave tasks such as shopping and cooking to others. The effects of psycho-emotional disablism are also clear in this research: denying participants the chance to exercise control had caused some of them to internalise the view that they were not capable of developing their skills and left them unable to implement dietary changes, despite displaying a good knowledge of the principles of healthy eating. This lack of control was also reflected in participants' views of health, which was commonly seen to be subject to luck or the intervention of others, rather than the participants' own actions. When health is regarded to be out-with the individual's control it is unlikely that they will be motivated to take actions reputed to promote wellbeing, instead only responding to breakdowns in normal levels of function.

Support emerged as an important element in the facilitation of control. It could act as a barrier, particularly when those around the participants took on the role of gatekeepers in response to the potential risks associated with allowing choice. However, good support that encouraged the individual to take on as much responsibility as they were able to and allowed them a 'safe' environment in which to practice making choices led participants to feel more confident in their decisions and more in control of their lives. Policy that espouses a more individualised approach to support can therefore have a significant role in

promoting a sense of control and autonomy in people with learning disabilities. This, in turn, could encourage individuals to take actions to promote their health and wellbeing as they have evidence that they are able to bring change elsewhere in their lives. It does, though, rely on implementation of the policy at ground level upholding the principles of choice and independent living so that people with learning disabilities are provided with the support that they require to have control of their lives and the ability to make informed decisions. Given that these have been promoted by policy for some years, yet choice is still routinely moderated and even obstructed, it appears that this is something that needs addressing both by the services that provide support and in families and the wider community.

There is a need for people with learning disabilities and those who support them to have access to accurate information about healthy eating and health promotion. The participants in this study were aware of health promotion messages concerning healthy eating and obesity but were prevented from making use of their knowledge by internal and external barriers that reflected the attitudinal and structural constraints they faced in their wider lives. Some of these can be addressed by material changes. Concerns about the risks that accompany choice reflect fears that people with learning disabilities are not able to make informed decisions. Accessible information can help people to understand the consequences of their choices, enabling them to make a real choice, even if they decide not to make a 'good' one; practicing making immediate choices will help to build the skills required to make more complex decisions in the future. However, even with the necessary information, the cultural context within which decisions are made should not be ignored. The choices made by people with learning disabilities will be influenced by those made by others around them and will reflect the cultural and social norms they encounter. Their concepts of health will often be similar to those identified in the non-disabled population and will similarly be informed by what is around them. It is therefore likely that many of the reasons for weight gain in people with learning disabilities will reflect those associated with weight gain in the general population. They will thus benefit from broader campaigns to promote healthy behaviour if they manage to challenge the notion of healthy eating as something separate to an ordinary diet and shows health messages are, indeed,

relevant to their lives and those of the people around them. Changing the cultural landscape of diet will result in changes in the way people with learning disabilities conceptualise food. Ultimately, though, they need the opportunity to make use of their food knowledge in order for health promotion messages to successfully change behaviour.

This research has shown that there are complex, interlinked influences on the way people with learning disabilities view food and health, and that there is no single solution that will cause people with learning disabilities to eat a healthier diet and attain a healthy weight. However, a sense of self-efficacy and the opportunities to make choices, even bad ones, need to be promoted if people with learning disabilities are to find the motivation to make changes that could positively influence their health.

Appendix 1



A Study into Healthy Eating, Body Image and Obesity with Adults with Learning Disabilities

You are being invited to take part in a study about healthy eating and what it means to have a healthy body. We want to understand more about what people eat and why they choose this food. I will be talking to about 20 people about what they eat, how they choose what they eat and what they know about healthy eating. I will also be talking to them about how they feel about their bodies and what they think makes a person healthy. This is part of a study that I am doing to try and understand why some people become overweight.

If you would like to take part in the study I will meet up with you 2 or 3 times. You will always be able to ask me questions about the project. You will not have to answer any of my questions if you do not want to. It is not a test! I am interested in what you say and your ideas. If you agree to take part now but change your mind later that is fine. You can drop out at any time.

I would like to tape record the meetings. This is to make sure I know exactly what we talked about. All the recordings are private and I am the only person who will listen to them. When I write my report all the names will be changed so that no one will know that you took part in the study. If you do not want the meetings to be recorded I will write notes instead.

The information I collect will be used in a report. You will be able to find out more about this from *insert organisation*.

Please think about whether you would like to take part. If you would like to ask me any questions please contact me on the number below.

Victoria Williams
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University of Glasgow

0141 330 2390
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You can also contact Professor Nick Watson,
Strathclyde Centre for Disability Research
University of Glasgow
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0141 330 3916
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Appendix 2



A Study into Healthy Eating, Body Image and Obesity with Adults with Learning Disabilities

Consent Form

This project has been explained to me and I have a copy of the information sheet.

I know that I do not have to take part and that I can drop out at any time.

I know that what I say will be kept private and that my name will not be in the report.

I would like to take part in the project Yes No

I am happy to have the meeting recorded Yes No

Signed

Name

Date

Researcher.....

Researcher's contact details

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Bibliography

Abberley, P., 1987. The concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society*, 2(1), pp.5-19.

Abel, T. and McQueen, D.V., 1994. Determinants of selected unhealthy eating behaviours among male and female adults. *European Journal of Public Health*, 4, pp.27-32.

Allison, K., 1991. Theoretical issues concerning the relationship between perceived control and preventive health behaviour. *Health Education Research*, 6(2), pp.141-151.

Anderson, A.S. and Hunt, K., 1992. Who are the 'healthy eaters'? Eating patterns and health promotion in the west of Scotland. *Health Education Journal*, 5(1), pp.3-10.

Apsis, S., 1997. Self-advocacy for people with learning difficulties: does it have a future?. *Disability and Society*, 12(4), pp.647-654.

Atkinson, D., 2004. Research and empowerment: involving people with learning difficulties in oral and life history research. *Disability and Society*, 19, pp.691-702.

Banks, P., Jahoda, A., Dagnan, D., Kemp, J. and Williams, V., 2010. Supported employment for people with intellectual disability: the effects of job breakdown on psychological well-being. *Journal of Applied Research in Intellectual Disabilities*, 23(4), pp. 344-354.

Bannerman, D.J., Sheldon, J.B., Sherman, J.A. and Harchik A.E., 1990. Balancing the right to habilitation with the right to personal liberties: the rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behaviour Analysis*, 23(1), pp.79-89.

Barnes, C., 1996. Theories of disability. In L. Barton, ed. *Disability and Society: Emerging Issues and Insights*, Essex: Longman, pp.48-64.

Barnes, C., 2003. What a difference a decade makes: reflections on doing 'emancipatory' disability research. *Disability and Society*, 18(1), pp.3-17.

Barnes, C., 2004. Reflections on doing emancipatory disability research. In J. Swain, S. French, C. Barnes and C. Thomas, eds. *Disabling Barriers- Enabling Environments*. London: Sage Publications, pp.47-53.

Barnes, C., Mercer, G. and Shakespeare, T., 2000. *Exploring Disability: A Sociological Introduction*, Cambridge: Polity Press.

Barnes, C. and Mercer, G., 2003. *Disability*, Cambridge: Policy Press.

Barnes, C. and Mercer, G., 2010. *Exploring Disability*, 2nd ed. Cambridge: Polity Press.

- Barton, L., 2005. Emancipatory research and disabled people: some observations and questions. *Educational Review*. 57(3), pp.317-327.
- Berkman, L.F., 1995. The role of social relations in health promotion. *Psychosomatic Medicine*, 57, pp.245-254.
- Blaxter, M., 1990. *Health and Lifestyles*, London: Routledge.
- Blaxter, M., 2010. *Health*, 2nd ed. Cambridge: Polity Press.
- Booth, T., 1996. Sounds of still voices: issues in the use of narrative methods with people who have learning difficulties. In L. Barton, ed. *Disability and Society: Emerging Issues and Insights*. Harlow: Addison Wesley Longman, pp.237-255.
- Booth, T. and Booth, W., 1996. Sounds of silence: Narrative research with inarticulate subjects. *Disability and Society*, 11, pp.55-69.
- Branfield, F., 1998. What are you doing here? 'Non-disabled' people and the disability movement: a response to Robert F. Drake' *Disability and Society*, 13(1), pp.143-144.
- Brechin, A. and Walmsley, J., eds., 1989. *Making Connections: Reflecting on the Lives and Experiences of People with Learning Difficulties*. London: Hodder and Staughton.
- Brown, H. and Walmsley, J., 1997. When 'ordinary' isn't enough: a review of the concept of normalisation. In J. Bornat, J. Johnson, C. Pereira, D. Pilgrim and F. Williams, eds. *Community Care: A Reader*. 2nd ed., London: Macmillan Press, pp.227-236.
- Bryman A., 2001. *Social Research Methods*. Oxford: Oxford University Press.
- Burchardt, T., 2004. Capabilities and disability: the capabilities framework and the social model of disability. *Disability and Society*, 19(7), pp.735-751.
- Calnan, M., 1987. *Health and Illness: The Lay Perspective*. London: Tavistock Publications Ltd.
- Chandon, P. and Wansink, B., 2007. The biasing health halos of fast-food restaurant health claims: lower calorie estimates and higher side-dish consumption intentions. *Journal of Consumer Research*, 34, pp.301-314.
- Chappell, A.L., 1992. Towards a sociological critique of the normalisation principle. *Disability, Handicap and Society*. 7(1), pp.35-51.
- Chappell, A.L., 1997. From normalisation a to where?. In L. Barton and M. Oliver, eds. *Disability Studies: Past, Present and Future*. Leeds: The Disability Press, pp.45-62.
- Chappell, A.L., 1998. Still out in the cold: people with learning disabilities and the social model of disability. In T. Shakespeare, ed. *The Disability Reader: Social Science Perspectives*. London: Continuum, pp.211-220.

- Chappell, A.L., 2000. Emergence of participatory research methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities*, 28, pp.38-43.
- Chappell, A.L., Goodley, D. and Lawthorn, R., 2001. Making connections: the relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities*, 29(1), pp.45-50.
- Charmaz, K., 2006. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage Publications.
- Charmaz, K. and Mitchell, R.G., 2001. Grounded theory in ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland and L. Lofland, eds. *Handbook of Ethnography*. London: Sage Publications, pp.160-174.
- Coffey, A. and Atkinson, P., 1996. *Making Sense of Qualitative Data*. London: Sage Publications.
- Cohn, S., 1997. Being told what to eat: Conversations in a diabetes day centre. In P. Caplan, ed. *Food, Health and Identity*. London: Routledge, pp.193-212.
- Cole, J., 2001. The social model in practice? Reflections in research evidence. *Disability and Society*, 16(4), pp.501-510.
- Connors, C., and Stalker, K., 2007. Children's experiences of disability: pointers to a social model of childhood disability. *Disability and Society*, 22(1), pp.19-33.
- Connors, M., Bisgoni, C.A., Sobal, J. and Devine, C.M., 2001. Managing values in personal food systems. *Appetite*, 36, pp.189-200.
- Cooper, S., Melville, C., and Morrison, J., 2004. People with intellectual disabilities: their health needs differ and need to be recognised and met. *British Medical Journal*, 329, pp.414-415.
- Corker, M. and Shakespeare, T., 2002. Mapping the terrain. In M. Corker and T. Shakespeare, eds. *Disability/Postmodernity*, London: Continuum, pp.1-17.
- Cox, D.N., Anderson, A.S., Lean, M.E.J. and Mela, D.J., 1998. UK consumer attitudes, beliefs and barriers to increasing fruit and vegetable consumption. *Public Health Nutrition*, 1(1), pp.61-68.
- Crocker, H., Whitaker, K.L., Cooke, L. and Wardle, J., 2009. Do social norms affect intended food choice?. *Preventive Medicine*, 49, pp.190-193.
- Crow, L., 1996. Including all of our lives: Renewing the social model of disability. In J. Morris, ed. *Encounters with Strangers: Feminism and Disability*, London: The Women's Press Ltd, pp.55-72.
- Culham, A. and Nind, M., 2003. Deconstructing normalisation: clearing the way for inclusion. *Journal of Intellectual and Developmental Disability*, 28(1), pp.65-78.

- Cummins, S. and Macintyre, S., 2002. A systematic study of an urban foodscape: the price and availability of food in Greater Glasgow. *Urban Studies*, 39(11), pp.2115-2130.
- Cummins, S. and Macintyre, S., 2006. Food environments and obesity-neighbourhood or nation?. *International Journal of Epidemiology*, 35, pp.100-104.
- Dalley, G., 1989. Community care: the ideal and the reality. In A. Brechin and J. Walmsley, eds. *Making Connections: Reflecting On the Lives and Experiences of People with Learning Difficulties*. London: Hodder and Stoughton, pp.199-208.
- Danieli, A. and Woodhams, C., 2005. Emancipatory research methodology and disability: a critique. *International Journal of Social Research Methodology*, 8(4), pp.281-296.
- Danielsson, H., Ronnberg, J. and Andersson, J., 2006. What am I doing in Timbuktu: Person-environment picture recognition for persons with intellectual disability. *Journal of Intellectual Disability Research*, 50, pp.127-138.
- Davies, C. A. and Jenkins, R., 1997. "She has different fits to me": how people with learning difficulties see themselves. *Disability and Society*, 12(1), pp.95-109.
- De Castro, J., 1997. Socio-cultural determinants of meal size and frequency. *British Journal of Nutrition*, 77(Suppl.1), S.39-55.
- De Irala-Estevez, J., Groth, M., Johansson, L., Oltersdorf, U., Prattala, R. and Martinez-Gonzalez, M.A., 2000. A systematic review of socio-economic differences in food habits in Europe: consumption of fruit and vegetables. *European Journal of Clinical Nutrition*, 54, pp.706-714.
- Dey, I., 1999. *Grounding Grounded Theory: Guidelines for Qualitative Enquiry*. London: Academic Press.
- Dowse, L., 2001. Contesting practices, challenging codes: self advocacy, disability politics and the social model. *Disability and Society*, 16(1), pp.123-141.
- Duckett, P., 1998. What are you doing here? "Non-disabled" people and the disability movement: a response to Fran Branfield. *Disability and Society*, 13(4), pp.625-628.
- Dunn, D., 2001. Sexual health. In J. Thompson and S. Pickering, eds. *Meeting the Health Needs of People with Learning Disabilities*. London: Harcourt, pp.211-234.
- Durvasula, S., Beange, H. and Baker, W., 2002. Mortality of people with intellectual disability in northern Sydney. *Journal of Intellectual and Developmental Disability*, 27(4), pp.225-264.
- Ellaway, A., Anderson, A. and Macintyre, S., 1997. Does area of residence affect body size and shape?. *International Journal of Obesity*, 21, pp.304-308.

Emerson, E., 2005. Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Intellectual Disability Research*, 49(2), pp.134-143.

Emerson, E. and Baines, S., 2010. *Health Inequalities and People with Learning Disabilities in the UK: 2010*. [online] Available at: <http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf> [Accessed 10 June 2011].

Ferguson, M., Jarrett, D. and Terras, M., 2011. Inclusion and healthcare choices: the experiences of adults with learning disabilities. *British Journal of Learning Disabilities*, 39(1), pp.73-83.

Finkelstein, V., 1980. *Attitudes and Disabled People*. New York: World Rehabilitation Monograph No5.

Finlay, M. and Lyons, E., 1998. Social identity and people with learning difficulties: implications for self-advocacy groups. *Disability and Society*, 13(1), pp.37-51.

Finlayson, J., Jackson, A., Cooper, S., Morrison, J., Melville, C., Smiley, E., Allan, L. and Mantry, D., 2009. Understanding predictors of low physical activity in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22, pp.236-247.

Fitzpatrick, I., MacMillan, T., Hawkes, C., Anderson, A. and Dowler, E., 2010. *Understanding Food Culture In Scotland and its Comparison in an International Context: Implications for Policy Development*. Edinburgh: NHS Health Scotland.

Fox, K.R. and Hillsdon, M., 2007. Physical activity and obesity. *Obesity Reviews*, 8(Suppl. 1), pp.115-121.

French, S., 1993. Disability, impairment or something in between?. In J. Swain, V. Finklestein, S. French, and M. Oliver, eds. *Disabling Barriers- Enabling Environments*. London: Sage Publications, pp.17-25.

Glanz, K., Basil, M., Maibach, E., Goldberg, J. and Snyder, D., 1998. Why Americans eat what they do: taste, nutrition, cost, convenience, and weight control concerns as influences on food consumption. *Journal of the American Dietetic Association*, 98(10), pp.118-1126.

Glaser, B.G. and Strauss, A.L., 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. London: Widenfeld and Nicolson.

Gleeson, B.J., 1997. Disability studies: a historical materialist view. *Disability and Society*, 12(2), pp.179-202.

Golden, E. and Hatcher, J., 1999. Nutrition knowledge and obesity of adults in community residences. *Mental Retardation*, 35(3), pp.177-184.

Goodley, D., 1996. Tales of hidden lives: A critical examination of life history research with people who have learning difficulties. *Disability and Society*, 11(3), pp.333-348.

Goodley, D., 2000. *Self-Advocacy in the Lives of People with Learning Difficulties: The Politics of Resilience*. Buckingham: Open University Press.

Goodley, D., 2001. "Learning difficulties", the social model of disability and impairment: challenging epistemologies. *Disability and Society*, 16(2), pp.207-231.

Goodley, D. and Rapley, M., 2002. Changing the subject: postmodernity and people with "learning difficulties". In M. Corker and T. Shakespeare, eds. *Disability/Postmodernity*. London: Continuum, pp.127-142.

Gray, L. and Leyland, A.H., 2008. A multilevel analysis of diet and socio-economic status in Scotland: investigating the 'Glasgow effect'. *Public Health Nutrition*, 13(9), pp.1351-1358.

Grogan, S. and Richards, H., 2002. Body image: focus groups with boys and men. *Men and Masculinities*, 4, pp.219-232.

Hamilton, S., Hankey, C.R., Miller, S., Boyle, S. and Melville, C.A., 2007. A review of weight loss interventions for adults with intellectual disabilities. *Obesity Reviews*, 8, pp.339-345.

Hanlon, P., Walsh, D. and Whyte, B., 2006. *Let Glasgow Flourish: A comprehensive report on health and its determinants in Glasgow and West Central Scotland*. Glasgow: Glasgow Centre for Population Health.

Harris, J., 2003. Time to make up your mind: why choosing is difficult. *British Journal of Learning Disabilities*, 31, pp.3-8.

Heller, T., McCubbin, J.A., Drum, C. and Peterson, J., 2011. Physical activity and nutrition health promotion interventions: what is working for people with intellectual disabilities?. *Intellectual and Developmental Disabilities*, 49(1), pp.26-36.

Herbert, G., Butler, L., Kennedy, O. and Lobb, A., 2010. Young UK adults and the 5 A DAY campaign: perceived benefits and barriers of eating more fruits and vegetables. *International Journal of Consumer Studies*, 34, pp.657-664.

Hughner, R.S. and Kleine, S.S., 2004. Views of health in the lay sector: a compilation and review of how individuals think about health. *Health*, 8, pp.395-422.

Hunt, P., 1981. Settling accounts with the parasite people: A critique of "A Life Apart" by E.J. Miller and G.V. Gwynne. *Disability Challenge*, 1(May), pp.37-50.

Jahoda, A., Banks, P., Kerr, W., Williams, V. and Kemp, J., 2005. *Does Transition to Supported Employment Impact on Mental Health, Social Networks & Perceived Well-being of People with Learning Difficulties?* Final Report for Scottish Executive Health Department.

Jahoda, A., Kemp, J., Banks, P. and Williams, V., 2007. Feelings about work: a review of the socio-emotional impact of supported employment on people with

- intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21(1), pp.1-18.
- Jahoda, A., Banks, P., Dagnan, D., Kemp, J., Kerr, W. and Williams, V., 2009. Starting a new job: the social and emotional experience of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22(5), pp.421-425.
- Janicki, M.P., Davidson P.W., Henderson C.M., McCallion P., Taets J.D., Force L.T., Sulkes S.B., Frangenber E. and Ladrigan P.M., 2002. *Journal of Intellectual Disability Research*, 46(4), pp.287-298.
- Jebb, S.A., 2007. Dietary determinants of obesity. *Obesity Reviews*, 8(supp. 1), pp.93-97.
- Jenkins, C.M. and McKenzie, K., 2010. The application of the theory of planned behaviour to diet in carers of people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, [Advance publication online] Available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2010.00594.x/full> (accepted for publication 15 July 2010) [Accessed 10 Oct 2010].
- Jenkinson, J.C., 1993. Who shall decide? The relevance of theory and research to decision-making by people with an intellectual disability. *Disability, Handicap and Society*, 8(4), pp.361-375.
- Kappell, D., Nightingale, B., Rodriguez, A., Lee, J.H., Zigman, W.B. and Schupf, N., 1998. Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation*, 36(4), pp.269-279.
- Kennedy, P. and Kennedy, C.A., 2010. *Using Theory to Explore Health, Medicine and Society*. Bristol: The Policy Press.
- Kopelman, P., 2007. Health risks associated with overweight and obesity. *Obesity Reviews*, 8(supp.1), pp.13-17.
- Lappalainen, R., Kearney, J. and Gibney, M., 1998. A pan EU survey of consumer attitudes to food, nutrition and health: an overview. *Food Quality and Preference*, 9(6), pp.467-478.
- Law, C., Power, C., Graham, H. and Merrick, D., 2007. Obesity and health inequalities. *Obesity Reviews*, 8(supp.1), pp.19-22.
- Leadbeater C., Bartlett J. and Gallagher N., 2008. *Making It Personal*. London: Demos.
- Lee R.M., 1993. *Doing Research on Sensitive Topics*. London: Sage Publications.
- Lennox, N.G. and Kerr, M.P., 1997. Primary health care and people with an intellectual disability: the evidence base. *Journal of Intellectual Disability Research*, 41(5), pp.365-372.

- Lerpiniere, J. and Stalker, K., 2009. Taking service providers to court: people with learning disabilities and Part III of the Disability Discrimination Act 1996. *British Journal of Learning Disabilities*, 38(4), pp.245-251.
- Lister, R., 2004. *Poverty*. Cambridge: Polity Press.
- Lloyd, M., Preston-Shoot, M., Temple, B. and Wu, R., 1996. Whose project is it anyway? Sharing and shaping the research and development agenda. *Disability and Society*, 11, pp.301-315.
- Lunsky, Y., Straiko, A. and Armstrong, S., 2003. Women be healthy: evaluation of a women's health curriculum for women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, pp.247-253.
- Lupton, D., 1996. *Food, the Body and the Self*. London: Sage.
- Macintyre, S., McKay, L., Cummins, S. and Burns, C., 2005. Out-of-home food outlets and area deprivation: case study in Glasgow, UK. *International Journal of Behavioural Nutrition and Physical Activity*, 2(16), pp.1-7.
- Madden, H. and Chamberlain, K., 2010. Nutritional health, subjectivity and resistance: women's accounts of dietary practices. *Health*, 14(3), pp.292-309.
- Maio, G.R., Haddock, G.G. and Jarman, H.L., 2007. Social psychological factors in tackling obesity. *Obesity Reviews*, 8(supp.1), pp.123-125.
- Manion, M.L. and Bersani, H.A., 1987. Mental retardation as a western sociological construct: a cross-cultural analysis. *Disability, Handicap and Society*, 2(3), pp.231-245.
- Margetts, B.M., Thompson, R.L., Speller, V. and McVey, D., 1998. Factors which influence 'healthy' eating patterns: results from the 1993 Health Education Authority Health and Lifestyle Survey in England. *Public Health Nutrition*, 1(3), pp.193-198.
- Markula, P., Burns, M. and Riley, S., 2008. Representations, identities and practices of weight and body management. In S. Riley, M. Burns, H. Frith, S. Wiggins and P. Markula, eds. *Critical Bodies: Representations, identities and practices of weight and body management*. Basingstoke: Palgrave Macmillan, pp.1-22.
- Martens, L. and Warde, A., 1997. Urban pleasure? On the meaning of eating out in a northern city. In P. Caplan, ed. *Food, Health and Identity*. London: Routledge, pp.131-150.
- May, T., 2001. *Social Research: Issues, Methods and Process*. Buckingham: Open University.
- Mela, D.J., 2001. Determinants of food choice: relationships with obesity and weight control. *Obesity Research*, 9(Supp. 4), pp.249-255.

Melville, C.A., Cooper, S., Morrison, J., Allan, L., Smiley, E. and Williamson, A., 2008. The prevalence and determinants of obesity in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, pp.425-437.

Melville, C.A., Hamilton, S., Hankey, C.R., Miller, S. and Boyle, S., 2006. The prevalence and determinants of obesity in adults with intellectual disabilities. *Obesity Reviews*, 8, pp.223-230.

Melville, C., Hamilton, S., Miller, S., Boyle, S., Robinson, N., Pert, C. and Hankey, C.R., 2009. Carer knowledge and perceptions of healthy lifestyles for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22, pp.298-306.

Mencap, 2006. *Support Healthy Eating: What You Need to Know*. London: Mencap.

Mennell, S., Murcott, A. and van Otterloo, A.H., 1992. *The Sociology of Food: Eating, Diet and Culture*. London: Sage.

Mercer, G., 2004. From critique to practice: emancipatory disability research. In C. Barnes and G. Mercer, eds. *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press, pp.118-137.

Messent, P.R., Cooke, C.B. and Long, J., 1999. Primary and secondary barriers to physically active healthy lifestyles for adults with learning disabilities. *Disability and Rehabilitation*, 21(9), pp.409-419.

Moran, R., Drane, W., McDermott, S., Dasari, S., Scurry, J.B. and Platt, T., 2005. Obesity among people with and without mental retardation across adulthood. *Obesity Research*, 13(2), pp.342-349.

Morris, J., 1991. *Pride Against Prejudice*. London: The Women's Press Ltd.

Morris, J., 1993. Gender and disability. In J. Swain, V. Finklestein, S. French and M. Oliver, eds. *Disabling Barriers-Enabling Environments*. London: Sage Publications, pp.85-92.

Mullen, K., 1993. *A Health Balance: Glaswegian Men Talking About Health, Tobacco and Alcohol*, Aldershot: Avebury.

Nestle, M., Wing, R., Birch, L., Drewnowski, A., Middleton, S., Sigman-Grant, M., Sobal, J., Winston, M. and Economos, C., 1998. Behavioral and social influences on food choice. *Nutrition Reviews*, 56(5), pp.50-74.

Nettleton, S., 1995. *The Sociology of Health and Illness*. Cambridge: Polity Press.

NHS Scotland, 2004. *Health Needs Assessment Report: People With Learning Disabilities in Scotland*. Glasgow: NHS Health Scotland.

- Nirje, B., 1999. How I came to formulate the Normalization principle. In R.J. Flynn and R.A. Lemay, eds. *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*. Ottawa: University of Ottawa Press, pp.17-50.
- O'Brien, J., (1981). *The Principle of Normalisation: A Foundation for Effective Services*. London: Values Into Action.
- Oakley, A., 1981. Interviewing women: a contradiction in terms. In H. Roberts, ed. *Doing Feminist Research*. London: Routledge and Kegan Paul, pp.30-61.
- Oliver, G. and Wardle, J., 1999. Perceived effects of stress on food choice. *Psychology and Behavior*, 66(3) pp.511-515.
- Oliver, M., 1990. *The Politics of Disablement*. London: Macmillan Press.
- Oliver M., 1992. Changing the social relations of research production?. *Disability, Handicap and Society*, 7(2), pp.101-114.
- Oliver, M., 1996. *Understanding Disability: From Theory to Practice*. London: Macmillan Press.
- Oliver, M., 1996b. A sociology of disability or a disablist sociology?. In L. Barton, ed. *Disability and Society: Emerging Issues and Insights*. London: Longman, pp.18-42.
- Oliver, M., 1996c. Defining impairment and disability: issues at stake. In C. Barnes and G. Mercer, G., eds. *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press, pp.29-54.
- Oliver, M., 1997. Emancipatory research: realistic goal or impossible dream? In C. Barnes and G. Mercer, eds. *Doing Disability Research*, Leeds: The Disability Press, pp.15-31.
- Oliver, M., 1999. Capitalism, disability and ideology: A materialist critique of the Normalization principle. In R.J. Flynn and R.A. Lemay, eds. *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*. Ottawa: University of Ottawa Press, pp.163-174.
- Oliver, M. and Barnes, C., 1998. *Disabled People and Social Policy: From Exclusion to Inclusion*. Harlow: Longman.
- Patja, K., Iivanainen, M., Vesala, H., Oksanen, H. and Roppila, I., 2000. Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research*, 44(5), pp.591-599.
- Pearson, C., ed. 2006. *Direct Payments and Personalisation of Care*. Edinburgh: Dunedin Academic Press.
- Perrin, B. and Nirje, B., 1985. Setting the record straight: a critique of some frequent misconceptions of the normalization principle. *Australia and New Zealand Journal of Developmental Disabilities*, 11, pp.69-74.
(Quoted in Culham and Nind 2003)

Pill, R. and Stott, N.C.H., 1982. Concepts of illness causation and responsibility: some preliminary data from a sample of working class mothers. *Social Science and Medicine*, 16, pp.43-52.

Priestley, M., 1998. Constructions and creations: idealism, materialism and disability theory. *Disability and Society*, 13(1), pp.75-94.

Priestley, M., Riddell, S., Jolly, D., Pearson, C., Williams, V., Barnes, C and Mercer G., 2010. Cultures of welfare at the front line: implementing direct payments for disabled people in the UK. *Policy and Politics*, 38(2), pp.307-324.

Prime Minister's Strategy Unit, 2005. *Improving the Life Chances of Disabled People*. London: Cabinet Office Strategy Unit.

Prosser, H. and Bromley, J., 1998. Interviewing people with intellectual disabilities. In C. Hatton, E. Emerson, J. Bromley and A. Caine, eds. *Clinical Psychology and People with Intellectual Disabilities*, Oxford: John Wiley and Sons Ltd, pp.99-113.

Reeve, D., 2002. Negotiating psycho-emotional dimensions of disability and their influence on identity constructions. *Disability and Society*, 17(5), pp.493-508.

Reeve, D., 2004. Psycho-emotional dimensions of disability and the social model. In C. Barnes and G. Mercer, eds. *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press, pp.83-100.

Reeve, D., 2012 forthcoming. Psycho-emotional disablism: the missing link?. In N. Watson, A. Roulston and C. Thomas, eds. *Routledge Companion to Disability Studies*. London: Routledge.

Reid, D.H. and Parsons, M.B., 1991. Making choice a routine part of mealtimes for persons with profound mental retardation. *Behavioral Residential Treatment*, 6(4), pp.249-261.

Riddell, S., Priestley, M., Pearson, C., Mercer, G., Barnes, C., Jolly, D. and Williams, V., 2006. *Disabled People and Direct Payments: A UK comparative study*. Final Report for Economic and Social Research Council RES-000-23-0263.

Rimmer, J.H., Riley, B., Wang, E., Rauworth, A., and Jurkowski, J., 2004. Physical activity participation among persons with disabilities: barriers and facilitators. *American Journal of Preventative Medicine*, 26(5), pp.419-425.

Robertson, J., Emerson, E., Gregory, N., Happton, C., Turner, S., Kessissoglou, S. and Hallam, A., 2000. Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities*, 21, pp.469-486.

Rodgers, J., 1998. Whatever's on her plate: food in the lives of people with learning disabilities. *British Journal of Learning Disabilities*, 26, pp.13-16.

Saunders, M., 2001. Concepts of health and disability. In J. Thompson and S. Pickering, eds. *Meeting the Health Needs of People who have a Learning Disability*. London: Harcourt Publishers Ltd, pp.24-40.

- Scior, K., 2003. Using discourse analysis to study the experiences of women with learning disabilities. *Disability and Society*, 18, pp.779-795.
- Scottish Consortium for Learning Disability, 2010. *eSay Statistical Release: adults with learning disabilities (2009)*. Glasgow: Scottish Consortium for Learning Disability. [online] Available at <<http://www.sclld.org.uk/sclld-projects/esay>> [Accessed May 2011].
- Scottish Executive, 2000. *The Same As You? A Review of Services for People with Learning Disabilities*. Edinburgh: HMSO.
- Scottish Government, 2008. *Healthy Eating, Active Living: An Action Plan to Improve Diet, Increase Physical Activity and Tackle Obesity (2008-2011)*. Edinburgh: The Scottish Government.
- Scottish Government, 2009. *Scottish Health Survey 2008 Volume 1: Main Report*. Edinburgh: The Scottish Government.
- Scottish Government, 2010. *Self Directed Support: A National Strategy for Scotland*. The Scottish Government [online] Available at: <www.scotland.gov.uk/Resource/Doc/329971/0106962.pdf> [Accessed 14th July 2011]
- Scottish Government, 2010a. *Preventing Overweight and Obesity in Scotland: A Route Map Towards Healthy Weight*. The Scottish Government: Edinburgh.
- Scottish Government, 2010b. *Scottish Health Survey 2009 Volume 1: Main Report*. The Scottish Government: Edinburgh.
- Scottish Government, 2010c. *Social Care (Self Directed Support) (Scotland) Bill*. The Scottish Government [online] Available at: <www.scotland.gov.uk/Resource/Doc/335168/0109638.pdf> [Accessed 14th July 2011].
- Seale, C., 2000. *The Quality of Qualitative Research*, London: Sage Publications.
- Shakespeare, T., 2006. *Disability Rights and Wrongs*, London: Routledge.
- Shakespeare, T. and Watson, N., 2001. Making the difference: disability, politics and recognition. In G.L. Albrecht, K.D. Seelman, and M. Bury, eds. *Handbook of Disability Studies*. London: Sage Publications, pp.546-564.
- Shakespeare, T. and Watson, N., 2002. The social model of disability: an outdated ideology?. *Research in Social Science and Disability*, 2, pp.9-28.
- Shepherd, R., 1999. Social determinants of food choice. *Proceedings of the Nutrition Society*, 58, pp.807-812.
- Shepherd, R., Paisley, C.M., Sparks, P., Anderson, A.S., Eley, S. and Lean, M.E.J., 1996. Constraints on dietary choice: the role of income. *Nutrition and Food Science*, 5, pp.19-21.

- Silverman, D., 2000. *Doing Qualitative Research: A Practical Handbook*, London: Sage Publications.
- Smyth, C.M. and Bell, D., 2006. From biscuits to boyfriends: the ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*, 34(4), pp.227-236.
- Sobal, J. and Wansink, B., 2007. Kitchenscapes, tablescape, platescapes, and foodscapes: influences of microscale built environments on food intake. *Environment and Behavior*, 39, pp.124-142.
- Sorensen, G., Hunt, M.K., Cohen, N., Stoddard, A., Stein, E., Phillips, J., Baker, F., Combe, C., Hebert, J. and Palombo, R., 1998a. Worksite and family education for dietary change: the Treatwell 5-a-Day program. *Health Education Research: Theory and Practice*, 13(4), pp.577-591.
- Sorensen, G., Stoddard, A. and Macario, E., 1998b. Social support and readiness to make dietary changes. *Health Education Behaviour*, 25, pp.586-598.
- Stainton Rogers, W., 1991. *Explaining Health and Illness: An Exploration of Diversity*, Hertfordshire: Harvester Wheatsheaf.
- Stalker, K., 1998. Some ethical and methodological issues in research with people with learning difficulties. *Disability and Society*, 13, pp.5-19.
- Stalker, K., 2012 forthcoming. Theorising the position of people with learning difficulties within disability studies. In N. Watson, A. Roulston and C. Thomas, eds. *Routledge Companion to Disability Studies*. London: Routledge.
- Stalker, K. and Connors, C., 2010. Children with learning disabilities talking about their everyday lives. In G. Grant, P. Ramcharan, M. Flynn and M. Richardson, eds. *Learning Disability: A Life Cycle Approach*, second edition, Maidenhead: Open University Press, pp.105-118.
- Stalker, K. and Harris, P., 1998. The exercise of choice by adults with intellectual disabilities: a literature review. *Journal of Applied Research in Intellectual Disabilities*, 11(1), pp.60-76.
- Stalker, K. and Lerpiniere, J., 2009. "It's against our law, never mind anyone else's": the Disability Discrimination Act 1995 and adults with learning disabilities. *Disability and Society*, 24(7), pp.829-843.
- Stansfield, S.A., 2006. Social support and social cohesion. In M. Marmot and R.G. Wilkinson, eds. *Social Determinants of Health*, second edition, Oxford: Oxford University Press, pp.148-171.
- Stone, E. and Priestley, M., 1996. Parasites, pawns and partners: disability research and the role of the non-disabled researcher. *British Journal of Sociology*, 47(4), pp.699-716.
- Strauss, A. and Corbin, J., 1994. Grounded theory methodology: an overview. In N.K. Denzin and Y.S. Lincoln, eds. *Handbook of Qualitative Research*, London: Sage Publications, pp.273-285.

- Stuart, O.W., 1992. Race and disability: just a double oppression?. *Disability, Handicap and Society*, 7(2), pp.177-188.
- Stuart, O.W., 1993. Double oppression - an appropriate starting point?. In J. Swain, V. Finklestein, S. French and M. Oliver, eds. *Disabling Barriers- Enabling Environments*, London: Sage Publications, pp.93-101.
- Swain, J., Heyman, B. and Gillman, M., 1998. Public research, private concerns: ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability and Society*, 13, pp.21-36.
- Thomas, C., 1999. *Female Forms: Experiencing and Understanding Disability*, Buckingham: Open University Press.
- Thomas, C., 2001. Feminism and disability: the theoretical and political significance of the personal and the experiential. In L. Barton, ed. *Disability Politics and the Struggle for Change*, London: David Fulton Publishers, pp.48-58.
- Thomas, C., 2002. Disability theory: key ideas and thinkers. In C. Barnes, M. Oliver and L. Barton, ed. *Disability Studies Today*, Cambridge: Policy Press, pp.38-57.
- Thomas, C., 2004. How is disability understood? An examination of sociological approaches. *Disability and Society* 19(6), pp.569-583.
- Thomas, C., 2004a. Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research*, 6(1), pp.22-36.
- Thomas, C., 2007. *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*, Basingstoke: Palgrave Macmillan.
- Thomas, D. and Woods, H., 2003. *Working with People with Learning Disabilities: Theory and Practice*, London: Jessica Kingsley Publishers.
- Treece, A., Gregory, S., Ayres, B. and Mendis, K., 1999. "I always do what they tell me to do": choice making opportunities in the lives of two older persons with severe learning difficulties living in a community setting. *Disability and Society*, 14(6), pp.791-804.
- Tremblay M., 1957. The key informant technique: a non-ethnographic application. *American Anthropologist*, 59, pp.688-698.
- Turner, S. and Moss, S., 1996. The health needs of adults with learning disabilities and the *Health of the Nation* strategy. *Journal of Intellectual Disability Research*, 40(5), pp.438-450.
- Turrell, G., 1997. Determinants of gender differences in dietary behaviour. *Nutrition Research*, 17(7), pp.1105-1120.
- Valentine, G., 1999. Eating in: home, consumption and identity. *The Sociological Review*, 47(3), pp.491-524.

- Vernon, A., 1997. Reflexivity: the dilemmas of researching from the inside. In C. Barnes and G. Mercer, eds. *Doing Disability Research*, Leeds: The Disability Press, pp.158-176.
- Walmsley, J., 1994. Learning disability: overcoming the barriers?. In S. French, ed. *On Equal Terms: Working with Disabled People*, Oxford: Butterworth-Heinemann Ltd, pp.148-160.
- Walmsley, J., 1997. Including people with learning difficulties: theory and practice. In L. Barton and M. Oliver, eds. *Disability Studies: Past, Present and Future*, Leeds: The Disability Press, pp.62-77.
- Walmsley, J., 2001. Normalisation, emancipatory research and inclusive research in learning disability. *Disability and Society*, 16, pp.187-205.
- Walmsley, J., 2004. Inclusive learning disability research: the (nondisabled) researcher's role. *British Journal of Learning Disabilities*, 32, pp.65-71.
- Walmsley, J., 2006. Ideology, ideas and care in the community, 1971-2001. In J. Welshman and J. Walmsley, eds. *Community Care in Perspective: Care, Control and Citizenship*, Basingstoke: Palgrave, pp.38-58.
- Walmsley, J. and Johnson, K., 2003. *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*, London: Jessica Kingsley Publishers.
- Wansink, B., 2004. Environmental factors that increase the food intake and consumption volume of unknowing consumers. *Annual Review of Nutrition*, 24, pp.455-479.
- Wansink, B., 2006. Nutritional gatekeepers and the 72% solution. *Journal of the American Dietetic Association*, 106(9), pp.1324-1327.
- Wansink, B. and Chandon, P., 2006. Can "low-fat" nutrition labels lead to obesity?. *Journal of Marketing Research*, 43, pp.605-617.
- Wansink, B., Cheney, M.M. and Chan, N., 2003. Exploring comfort food preferences across age and gender. *Physiology and Behavior*, 79, pp.739-747.
- Wansink, B. and Sobal, J., 2007. Mindless eating: the 200 daily food decisions we overlook. *Environment and Behaviour*, 39, pp.106-123.
- Ward, P., Coveney, J. and Henderson, J., 2010. Editorial: a sociology of food and eating. *Journal of Sociology*, 46, pp.347-351.
- Warde, A., 1997. *Consumption, Food and Taste*, London: Sage Publications Ltd.
- Warde, A. and Martens, L., 1999. Eating out: reflections on the experience of consumers in England. In J. Germov and L. Williams, eds. *A Sociology of Food and Nutrition: The Social Appetite*, Oxford: Oxford University Press, pp.116-134.
- Wardle, J., 2007. Eating behaviour and obesity. *Obesity Reviews*, 8(supp.1), pp.73-75.

- Wardle, J., Steptoe, A., Oliver, G. and Lipsey, Z., 2000. Stress, dietary restraint and food intake. *Journal of Psychosomatic Research*, 48, pp.195-202.
- Wareham, N., 2007. Physical activity and obesity prevention. *Obesity Reviews*, 9(supp. 1), pp.109-114.
- Watson, N., 2004. The dialectics of disability: a social model for the 21st century?. In C. Barnes and G. Mercer, eds. *Implementing the Social Model of Disability: Theory and Research*, Leeds: The Disability Press, pp.101-117.
- Wehmeyer, M. and Schwartz, M., 1998. The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 33(1), pp.3-12.
- Welshman, J., 2006. Ideology, ideas and care in the community, 1948-71. In J. Welshman and J. Walmsley, eds. *Community Care in Perspective: Care, Control and Citizenship*, Basingstoke: Palgrave, pp.17-37.
- Wendell, S., 2001. Unhealthy disabled: treating chronic illnesses as disabilities. *Hypatia*, 16(4), pp.17-33.
- White, M., 2007. Food access and obesity. *Obesity Reviews*, 8(supp. 1), pp.99-107.
- Wiggins, S., 2008. Representations and constructions of body weight and body management. In S. Riley, M. Burns, H. Frith, S. Wiggins and P. Markula, eds. *Critical Bodies: Representations, Identities and Practices of Weight and Body Management*, Basingstoke: Palgrave Macmillan, pp.23-26.
- Wilding, J.P.H., 2007. Treatment strategies for obesity. *Obesity Reviews*, 8(supp.1), pp.137-144.
- Wilkinson, R.G., 2006. Ourselves and others - for better or worse: social vulnerability and inequality. In M. Marmot and R.G. Wilkinson, eds. *Social Determinants of Health*, second edition, Oxford: Oxford University Press, pp.341-358.
- Williams, J., 1997. "We never eat like this at home": Food on holiday. In P. Caplan, ed. *Food, Health and Identity*, London: Routledge, pp.151-171.
- Williams, V., 1999. Researching together. *British Journal of Learning Disabilities*, 27, pp.48-51.
- Williams, V. and Holman, A., 2006. Direct payments and autonomy: issues for people with learning difficulties. In J. Leece and J. Bornat, eds. *Developments in Direct Payments*, Bristol: Policy Press, pp.65-78.
- Williams, V., Simons, K. and Swindon People First Research Team, 2005. More researching together: the role of nondisabled researchers in working with people first members. *British Journal of Learning Disabilities*, 33, pp.6-14.

Williams, V., Ponting, L., Ford, K. and Rudge, P., 2009. "A bit of common ground": personalisation and the use of shared knowledge in interactions between people with learning disabilities and their personal assistants. *Discourse Studies*, 11(5), pp.607-624.

Williams, V.A., 2006. The views and experiences of direct payments. In C. Pearson, ed. *Direct Payments and Personalisation of Care*, Edinburgh: Dunedin Academic Press, pp.46-58.

Wolfensberger, W., 1972. *Normalization: The Principle of Normalization in Human Services*, Toronto: National Institute on Mental Retardation.

Wolfensberger, W., 1983. Social role valorization: a proposed new term for the principle of normalisation. *Mental Retardation*, 21, pp.234-239. (Quoted in Culham and Nind 2003)

Wolfensberger, W. and Tullman, S., 1982. A brief outline of the principle of normalisation. *Rehabilitation Psychology*, 27(3), pp.131-145.

Wolfensberger, W., 1999. A contribution to the history of Normalization, with primary emphasis on the establishment of Normalization in North America between 1967-1975. In R.J. Flynn and R.A. Lemay, eds. *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*, Ottawa: University of Ottawa Press, pp.51-116.

Wood, P., 1980. *The International Classification of Impairment, Disability and Handicap*, Geneva: World Health Organisation.

Wood, S., 2010. The comfort food fallacy: avoiding old favourites in times of change. *Journal of Consumer Research*, 36, pp.950-963.

World Health Organization, 1990. *Diet, nutrition and the prevention of chronic diseases*. Technical Report Series, 797: World Health Organization.

Wrigley, N., 2002. "Food Deserts" in British cities: policy context and research priorities. *Urban Studies*, 39(11), pp.2029-2040.

Yamaki, K. 2005. Body weight status among adults with intellectual disability in the community. *Mental Retardation*, 43(1), pp.1-10.

Yates, S., Dyson, S. and Hiles, D., 2008. Beyond normalization and impairment: theorizing subjectivity in learning difficulties - theory and practice. *Disability and Society*, 23(3), pp.247-258.

Zarb, G., 1992. On the road to Damascus: first steps towards changing the relations of disability research production. *Disability, Handicap and Society*, 7, pp.125-138.

Zola, I.K., 1973. Pathways to the doctor- from person to patient. *Social Science and Medicine*, 7(9), pp.677-689.