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Sullivan, Charlotte (2011) A Qualitative Study Exploring the Perceptions and Experiences of Parents and Carers of People with Learning Disabilities When Accessing Healthcare. [Dissertation (University of Nottingham only)] (Unpublished)

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## **Abstract**

Historically people with learning disabilities (LD) have been subjected to discrimination, segregation, poor standards of care and even violence and abuse. Government policies have evolved with a changing society to incorporate people with LD into mainstream care with the most recent policies Valuing People (DoH, 2001) and Valuing People Now (DoH, 2009). Healthcare is of huge concern to people with LD and this has been accounted for in these policies.

The healthcare of people with LD still, however, faces challenges. There is also a lack of assessment of the current policies and procedures, taking into account the views of those involved in the care of people with LD. This is a qualitative study exploring the views of parents and carers of people with LDs when accessing healthcare.

A sample of seven participants, all carers or parents of people with LD, were interviewed. The transcripts of these interviews were analysed using the generic qualitative approach and three themes were identified: bad memories from the past, how things are now and hopes for the future. The results showed consistencies with the literature reviewed regarding this subject, however, inconsistencies were also noted. The need for better nursing education regarding LD, for all branches, was identified and recommendations have been made for future nursing education, practice and research. The limitations of this study have been acknowledged and, even in light of these, it is hoped that this study contributes positively to research into healthcare for people with LD.

## Chapter One: Introduction

### 1.1 Introduction

Research plays a vital role in society as it is the means by which discoveries are made, ideas are confirmed or refuted, events controlled or predicted and theory developed or refined (Dempsey and Dempsey, 2000; Morse and Field, 2002; Caelli, Ray and Mill, 2003). As nurses, we are expected to use evidence based practice to provide care and, by engaging in nursing research, nurses may identify practices that will help improve the quality of care they provide (Polit and Beck, 2004).

My experiences of working alongside people with a LD, both within the clinical area and as an agency care worker at a centre for people with LD, have influenced me to examine the policies underpinning healthcare for this group. I hope that through engaging with nursing research concerned with people with LD I may improve my own understanding of the research topic and contribute to the improved care of this population.

Having reviewed the literature concerning these policies it became clear that now is the ideal time to review these policies. It is ten years on from the release of “Valuing People: A New Strategy for People with Learning Difficulties for the 21<sup>st</sup> Century” (DoH, 2001) and three years on from its following paper “Valuing People Now: From Progress to Transformation” (DoH, 2009)<sup>1</sup>. Both of these documents placed huge importance on the health of people with LD and this is emphasised by other literature concerned with improving the quality of life for people with LD (Beadle-Brown, Murphy and DiTerlizzi, 2008).

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<sup>1</sup> From this point “Valuing People” will be referred to as VP and “Valuing People Now” will be referred to as VP Now.

The construction of these policies involved parent and carer input and so, in this research study, it was deemed appropriate that the success or failings of these policies should be explored using the experiences of parents and carers of people with LD.

## **1.2 Aims and Objectives**

The aim of this study is to explore the perceptions and experiences of parents and carers of people with LD when accessing healthcare.

The objectives of this study are:

- To explore the good and bad experiences of people with LD accessing healthcare
- To reflect upon the successes and failings of VP (2001) and VP Now (2009).
- To identify areas of improvement for care.
- To highlight areas for future research.

## **1.3 Framework of research study**

A literature review examining the theoretical, historical, ethical and political elements which underpin VP (DoH, 2001) and VP Now (DoH, 2009) will follow. The research methodology of this study will then be described in full to enhance the credibility of the research (Koch, 1994) and the research findings will be presented. The final chapter will discuss these findings and critically examine the methods used. The study will conclude with recommendations for the future of nursing education, practice and research.

## **Chapter Two: Literature Review**

### **2.1 Introduction**

This chapter will examine the policies regarding the healthcare of people LD. The historical and political influences effecting the development of VP (DoH, 2001) and VP Now (DoH, 2009) will be explored and the successes and failings of these policies, according to the literature concerned with this topic, will be reviewed. The limitations of the current research will be discussed and any areas of research not covered by current literature will be noted.

### **2.2 The Challenges Faced by People with Learning Disabilities**

People with LD have individual needs when accessing services compared to the general population (Mir, 2007). People with LD are more likely to experience mental health issues, develop chronic health problems, suffer conditions such as epilepsy, endure physical and sensory disability and generally be of worse health than people without LD (DoH, 2001; Emerson, 2004; Foster, et al, 2006; Cooper, et al, 2007; Emerson and Glover, 2010). Fewer people with LD are able to access screening for disease and are often unable to communicate their symptoms effectively. This means that they frequently fail to receive a proper diagnosis of ill health (Emerson, 2004; Mir, 2007; Emerson and Glover, 2010). Evidence also suggests that discriminatory judgements about the value of treating a person with LD are implicated in the higher mortality and morbidity rates of this population (Mir, 2007).

Much of the literature suggests that not only are people with LD often unable to communicate effectively but that members of the health service also lack the ability to communicate with people with LD (Emerson, 2004; Mir, 2007; Emerson and Glover, 2010; Mencap, 2010). The poor development of these professional skills in mainstream healthcare has been somewhat sustained by specialist LD services.

These services have sought to provide all necessary health care so that mainstream health services do not see people with LD as their responsibility (Mir, 2007). Some critics of the current policy suggest, however, that specialist services are more effective at treating people with LD (Manthorpe, et al 2003) and herein lies the debate of how best to address these health inequalities.

### **2.3 Historical Influences upon Current Policy**

The history of public and private attitudes towards people with LD have been that of violence, intolerance and lack of understanding (Young and Quibell, 2000; Gilbert, Cochrane and Greenwell, 2005; Mir, 2007; Mencap, 2010). Although government policies have gone some way towards improving attitudes towards people with LD (DHSS, 1971; Wolfensberger, 1972; The NHS and Community Care Act, 1990; Disability Discrimination Act, 1995) progress was slow and inconsistent (Stevens, 2004). The history of discriminatory attitudes towards people with LD have shaped the way in which they are provided for by the government now and in plans for the future. It can be assumed that the government policies not only aim to improve the lives of people with LD but that they also attempt to remedy mistakes of the past (Young and Quibell, 2000; Burton and Kagan, 2006).

The segregation of people with LD is believed to have started during the dawn of the industrial revolution when people with LD were considered a strain on society (Gilbert, Cochrane and Greenwell, 2005; Mencap, 2010). These attitudes towards people with LD lead to the introduction of asylums. Although these asylums had good intentions of providing good living conditions for those less able than the general population, the reality was that they institutionalised the residents and provided inhumane care (Mencap, 2010).

The idea that people with LD should be segregated from the general population continued into the 20<sup>th</sup> century (Burton and Kagan, 2006; Mencap, 2010). It was considered best practice to isolate people with LD in 'colonies', or what were later

called long stay hospitals (Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006; Mencap, 2010). Firstly it was intended for those with LD to be separated from the more able population but then later, with the introduction of the National Health Service (NHS) in 1948, to care for them (Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006; Mencap, 2010).

Although it can be argued that a more sympathetic stance on providing care to people with LD was established by the NHS, it may also be seen as patronising and restrictive of their actual ability (Burton and Kagan, 2006). This idea is reflected in the Mental Health Act (1959) which separated those with mental illness from those with a mental handicap and recognised for the first time that many people with either condition may be cared for outside of a hospital setting.

In the late 1960s scandalous reports appeared in the media, most notably the Ely Hospital Report (1969) and South Ockendon Hospital Enquiry (1974) in which staff shortages, overcrowding and the ill treatment of people living in long stay hospitals were highlighted (DHSS, 1969; Inskip, 1974). In an attempt to improve the quality of life and care for people with LD the government published "Better Services for the Mentally Handicapped" (DHSS, 1971). The intentions of this white paper were to close all long stay hospitals and improve community services.

Improvements to the lives of people with LD, with regards to integrating them further into society, was further encouraged by the concept of normalisation (Wolfensberger, 1972) and disability rights campaigns (Stevens, 2004). The Normalisation theory emphasises that individuals are unique and have a right to choice and opportunity as well as the right to any extra support they may need to fulfil their potential (Wolfensberger, 1972; Stevens, 2004; Gilbert, Cochrane and Greenwell, 2005; Mencap, 2010). It was then recognised that institutions were a major barrier to inclusion and the normalisation of all members of society (Mencap, 2010). The acceptance that people with LD are entitled to be part of society changed the way in

which services were planned from then on (Stevens, 2004; Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006; Mencap, 2010).

## **2.4 The Political Underpinning of Current Policy Regarding People with Learning Disabilities**

In times of economical and societal hardship UK government policies have reproved dependency on the state (Burton and Kagan, 2006). As people with LD are often dependant on the state the changing political attitudes towards entitlement and welfare indirectly affect public and private attitudes towards them (Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006; Emerson and Glover, 2010). In understanding the current policies regarding the welfare of people with LD, policies of previous governments must be discussed, considering the socio-economic influences of the time.

In Britain between the 1940s and 1970s there was a consensus that the government was responsible for managing the economy and providing social benefits such as: employment, free or affordable health and education services. This led to the consolidation and expansion of a social welfare model and the introduction of the NHS (Burton and Kagan, 2006). With regards to people with LD, the colonies were renamed long stay hospitals for the care rather than exclusion of people with LD. Although this was a more sympathetic attitude, people with LD were still considered somewhat of a strain on society (Wolfensberger, 1972; Stevens, 2004; Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006; Mencap, 2010).

The late 1970s may be considered a time of economic weakness for Britain (Atkinson, Hill and Le Grand, 1987) and in 1979 Margaret Thatcher became Prime Minister of a conservative government (Burton and Kagan, 2006). In an attempt to improve the situation Thatcher focused on the economy rather than the welfare of society (Burton and Kagan, 2006). It was believed that the problems of society would not be solved by state intervention and welfare benefits were considered undesirable

as they encouraged dependency on the state (Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006). It was only in the latter part of the Conservative government that improving the NHS and health of people with LD was considered (DoH, 1992; 1995). It has been argued that healthcare for people with LD remained static until Labour came to power in 1997 (Burton and Kagan, 2006) and developed VP (DoH, 2001).

Citizenship is an idea that was re-established during the Labour government as a way of conceptualising the relationship between the state and the individual, raising questions of inclusion and exclusion (Gilbert, Cochrane and Greenwell, 2005).

Citizenship promotes the idea of equality which is otherwise compromised by the persistence of inequalities centred on class, race, culture, age, gender and disability along with the duties of citizenship (Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006). People with LD often face exclusion from society due to the fact that they are often unable to exercise their duties as citizens by contributing to society through employment (Gilbert, Cochrane and Greenwell, 2005). Their reliance on welfare, without the ability to contribute economically, puts them in a subordinate position to the general population, putting them at risk of being accused or blamed as a strain on society and the economy (Gilbert, Cochrane and Greenwell, 2005).

The Labour government recognised this dilemma and understood that for people with LD to escape subordination, segregation had to end. Instead it was believed they should be integrated into the general population, not as the object of charity and sympathy but as part of a social contract. This belief led to the development of VP in 2001 (Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006). With a better understanding of the nature, rights and identity of people with LD and the political stance on the individual's responsibility to contribute to the state, the overall direction of any new policy regarding people with LD had to be that of social inclusion (Burton and Kagan, 2006).

By taking into account the changing attitudes towards people with LD over the last century; from defective and subordinate to finally accepted as citizens, it is possible to understand how policy has changed (Gilbert, Cochrane and Greenwell, 2005).

## **2.5 What did Valuing People and Valuing People Now hope to Achieve?**

As previously discussed, the health of people with LD is of a particular concern to the government. These concerns are met by VP (DoH, 2001) in the chapter: 'Improving health for people with LD'. By focusing a chapter on healthcare for people with LD the government recognised the need to reduce inequalities in healthcare, make mainstream hospital services accessible to people with LD and to involve people with LD and their carers in the planning and implementation of a new health service (DoH, 2001; Burton and Kagan, 2006). Throughout VP the four key principals are proposed: rights, independence, choice and inclusion (DoH, 2001). As discussed previously, its development reflects the acceptance of people with LD as having the same rights as the general population, however, it also accords people with LD 'positive' rights (DoH, 2001). This means that people with LD have been given rights which attempt to provide special services and material needs to support them to access the same rights as the general population (Wolfensberger, 1972; Young and Quibell, 2000). The chapter on health acknowledges that people with LD have the right to access healthcare services and sets out the positive rights people with LD have in order to access greater health (Young and Quibell, 2000; Mir, 2007)

VP covered all aspects of care in its proposal to improve the health of people with LD (DoH, 2001; Mir, 2007). As primary healthcare is the first point of contact for meeting the health needs of patients, VP proposed that all people with LD should be registered with a GP by 2004 (DoH, 2001). Two of the more dynamic plans of VP, regarding primary healthcare, were the appointment of health facilitators by each local community LD team and plans for all people with LD to have a health action plan (DoH, 2001). These plans were to individualise the care of people with LD and make the

health service more amenable to them. With regards to secondary and tertiary healthcare, VP suggested that with improved primary health service for people with LD, hospital admissions would be reduced. In the instance of hospital admission, staff will be better trained in managing patients with LD especially with regards to communicating effectively with them (DoH, 2001).

VP Now discusses what has been achieved due to the change of policy in 2001, reflecting on the changing priorities across the government and what new improvements were to be made based upon examples of good practice (DoH, 2009). VP Now also set out a response “Health Care for All” (DoH, 2008). “Health Care for All” was released in response to “Death By Indifference” (Mencap, 2007), an independent paper in which the scandalous deaths of six people with LD, who were under the care of the NHS, were highlighted and deemed to be avoidable. “Health Care for All” had the aim of preventing such avoidable deaths in the future and questioned policies and practice held in place by the NHS, making suggestions for improvement (DoH, 2009).

One suggestion made by “Health Care for All” was the introduction of annual health checks for people with LD (DoH, 2008). This is one of the more praised aspects of the new policies for people with LD and the new coalition Conservative and Liberal Democratic government has stated its determination to enforce these health checks further (Romeo, et al, 2009; Emerson and Glover, 2010).

VP and VP Now clearly aimed to involve all relevant stakeholders in the planning and implementation of their proposals (Fyson and Simons, 2003), utilising the experiences of individuals who had had many years of experience of the available services (Manthorpe, et al, 2003; Forbat, 2006). VP Now includes case studies within the paper containing direct quotes from the carers’ of people with LD regarding the

care and support they have received, demonstrating their involvement in the formation of the new policies (DoH, 2009).

## **2.6 How Successful are Valuing People and Valuing People Now?**

Praise has been given to VP and VP Now in that they allow us to see beyond the impairment of people with LD (Burton and Kagan, 2006) by promoting their rights and independence (Fyson and Simons, 2003; Young and Quibell, 2005; Burton and Kagan, 2006; Forbat, 2006). The policies also appear to have a genuine desire to improve the lives of people with LD independent of reaction to scandal such as that of Health Care for all (2008) which was released after the Death By indifference (2007). The main concern highlighted by the literature, however, is that in hoping to achieve the ideal situation for people with LD, contradictions are detectable and, therefore, the policies are hard to read and unattainable (Fyson and Simons, 2003; Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006).

According to Fyson and Simons (2003) VP was based on ideology rather than practicalities and it is under debate as to whether this will result in the success or failure of the policy. Burton and Kagan (2006) and Fyson and Simons (2003) have described VP's vision of people with LD as romantic and unobtainable with "people [with LD] making choices about activities in pleasant neighbourhoods, with plenty of community resources. They are supported in this by their own staffs, which they employ and who work to their specification. They are likely to be in work and to have friendships and relationships, mostly with non-disabled people" (Burton & Kagan, 2006, p. 305). Although we, as a society, should strive for excellence and use an ideal image as a basis for making improvements, structuring policies around this ideal vision may deny people with more severe LD the right to benefit from the changing policies regarding their health as they do not and cannot fit into this perfect ideal (Fyson and Simons, 2003; Burton and Kagan, 2006).

Moving people from long stay hospitals into the community was seen as the first step of achieving inclusion for people with LD. It has been suggested, however, that the development of community support services has not necessarily led to increased opportunities for inclusion (Stevens, 2004). People with LD have achieved some degree of social inclusion through their physical presence in the community, however, they still experience exclusion due to their high dependence on the organisations intended to support their participation in communities (Gilbert, Cochrane and Greenwell, 2005). It has also been argued that the inclusion of people with LD in mainstream healthcare has limited the improvements to their specific healthcare needs, therefore, for effective change to happen, new policies should be tailored around the needs of people with LD (Burton & Kagan, 2006). Manthorpe, et al, (2003) praised the work of LD nurses, highlighting the increased satisfaction that was gained through their work compared to when people with LD access healthcare through general medical staff. It was, therefore argued that full integration of people with LD might not be as desirable as the development of specialist services (Manthorpe, et al, 2003). This is contradictory to the aim of inclusion of people with LD and the contradictions noted in VP (DoH, 2001) may be seen to make the paper less viable and, therefore, impossible to implement fully.

To ensure that people with LD do benefit from the VP it may be necessary for certain aspects of people with LD's immersion into communities to remain incomplete so that inclusion is achieved on some level but that the specialist needs of this patient group are still met (Gilbert, Cochrane and Greenwell, 2005). Burton and Kagan (2006) suggested that full independence of people with LD, as portrayed as the goal of VP, is unlikely to be achievable and that instead we should aim for interdependence due to people with LD continuing to need support from carers and service providers once integrated in communities (Burton and Kagan, 2006). Interdependence is a more humane term, reflecting the need of the entire population for external support and so

still fulfils VP whilst recognising the challenges faced by people with LD (Burton and Kagan, 2006).

A fundamental problem in implementing VP has been in knowing baseline information about the number of people with LD so that it may be assessed as to whether every person with LD has been included in the implementation of VP (Mir, 2007). A study by Charnock (2000) has also suggested that, for improvements to be made, services must be integrated further to allow for consistency. Ethical, cost and practical considerations have, however, hindered the construction of an accurate database of people with LD (Mir, 2007) meaning this baseline information is hard to obtain and share among practices. These difficulties are due to data protection legislation meaning information regarding patients cannot be easily shared. Adding to this, LD was not included in the Quality and Outcomes framework (QOF), through which GPs are monitored and paid, at the time VP was first introduced. This meant that there were no financial incentives for GPs to identify people with LD (Mir, 2007). VP stated that around 210, 000 people with LD live in the UK, however, it has since been suggested that the number is much larger (Emerson & Hatton, 2004; Emerson and Glovers, 2010). This estimation may have increased due to improved skills of health professionals and the fact that more people with LD are accessing specialised services due to these improvements. LD have also since been added to the 18 clinical areas included in the QOF (QOF, 2010). This means that GPs are more involved in providing health care to people with LD. It has, however, been suggested that GPs still need more training regarding communication when dealing with people with LD so that the care they provide is effective (Forbat, 2006). Without reliable information on the number of people with LD in the UK it is impossible to assess how far reaching VP is and how successful its policies are. The changes to the QOF and the increase in the identification of people with LD do prove some successes of VP.

Since the release of these policies it has been claimed that exclusions are still present and inconsistencies in care noted from area to area (Charnock, 2000; Fyson and Simons, 2003; Mir, 2007) with studies showing that people with LD still have a lower quality of life than the general population (Beedle-Brown, Murphy and DiTerlizzi, 2008). Improvements can, however, be seen in the longer life expectancies of people with LD showing that some improvements to health must have been made (Foster, et al, 2006; Walden, et al, 2007; Romeo, et al, 2009).

## **2.7 Suggestions for the Future**

Much of the literature surrounding VP (DoH, 2001) and VP Now (DoH, 2009) not only highlights successes and failing of the policies but offers suggestions for the future improvement of services for people with LD.

With regards to the policy's aims at social inclusion of people with LD much is to be done (Young and Quibell, 2000; Fyson and Simons, 2003; Manthorpe, et al, 2003; Burton and Kagan, 2006; Foster, et al, 2006). Burton and Kagan (2006) suggest that there needs to be assessment of the level and type of support required for people to successfully be included in communities alongside social transformation. This would allow discrimination against people with LD to be recognised and diffused whilst the people with LD are effectively supported. This suggestion is echoed in many other studies which have emphasised the need to ensure even development of services at every level so that care is consistent and covers all aspects of life as each individual aspect is dependent on all other aspects (Lindsey, 2002; Fyson and Simons, 2003; Emerson, 2004; Burton and Kagan, 2006). This implies that it is not simply enough to physically move people away from long stay hospitals into communities so that they are surrounded by the general public but that efforts must be made to integrate all services including housing and education so that healthcare may fully improve for people with LD (Fyson and Simons, 2003; Burton and Kagan, 2006)

Several papers emphasise the importance of including parents and carer's of those with LD not only in the planning and implementation of government policies but also in the training of staff involved in the healthcare of people with LD (Lindsey, 200; Fyson and Simons, 2003; Forbat, 2006; Mir 2007). As previously discussed, Manthorpe, et al, (2003) researched into the depth of participation of people with LD and those involved in their lives, in staff education. Due to the shortcomings found in this research, further recruitment of parents, carers and people with LD in the future of policy planning and education was suggested.

## **2.8 Gaps in the Literature and Research**

VP (DoH, 2001) has widely been received as a move forward for LD services, however, so far, relatively little research has been carried out to assess its progress (Forbat, 2006). The population of people with LD is an aging one (Foster, et al, 2006) and so the older population must be considered in the research concerning LD care provision. The majority of research found, however, was specific to children (Knox et al, 2000; Ramcharan and Grant, 2001; McCambie & Chilvers, 2005; McGill et al, 2006). Those studies found centring around adults with LD were generally more concerned with quality of life as a whole, not specifically healthcare (Walden et al, 2007; Grant & Ramcharan, 2001). The use of qualitative research around this topic is also scarce. Maintaining and improving the health of people with LD proves challenging for a variety of reasons, previously discussed in this chapter, and so should be of a huge concern when discussing the successes and failing of government policies concerning the lives of people with LD. As VP (DoH, 2001) and VP Now (2009) aimed to include all relevant stake holders in the lives of people with LD this study aims to explore the healthcare provided to people with LD through interviews with their parents and carers. Due to the gaps in the literature and research concerned with people with LD, this study has potential to expand upon the present knowledge and offer new opinions and suggestions to enhance health care delivery to people with LD.

## **2.9 Summary**

This chapter has examined the historical and political underpinning of current government policies concerning the lives of people with LD. Through greater understanding of these principles it is possible to understand how the current policies developed. The challenges faced by people with LD and the gaps found in the research have highlighted why this study may prove relevant to the improvement of healthcare provision for people with LD.

## **Chapter Three: Methodology**

### **3.1 Introduction**

This chapter will consider and justify the research methodology used in this study. The qualitative approach to research will be explored by discussing its differences and strengths compared to quantitative research approaches, the research design will be examined with relation to its trustworthiness, the ethical considerations and implications such a project may demand will be discussed and, finally, the data analysis and presentation of this study will be described. Understanding the methodology of a study is imperative to the understanding of its results and conclusions (Caelli, Ray and Mill, 2003).

### **3.2 Qualitative versus Quantitative Approaches to Research**

The two main approaches to research can be identified as quantitative and qualitative research. Quantitative research aims to confirm or refute theory in which the researcher remains detached from the subject and its participants, using structured and formal methods of gathering data such as questionnaires or inventories (Duffy, 1987; LoBiondo-Wood and Haber, 1998; Dempsey and Dempsey, 2000; Morse and Field, 2002; Parahoo, 2006). In contrast, qualitative research is concerned with the creation of theory through the development of description of an observed phenomenon (Morse and Field, 2002). The methodology of qualitative research is defined by its in depth data collection and analysis, in which, the researcher becomes immersed in the subject (Polit, Beck and Hungler, 2001; Morse and Field, 2002; Parahoo, 2006).

Qualitative data does not allow the researcher to predict the future or allow for an understanding of the cause of a phenomenon (MacNee and McCabe, 2008).

Instead the purpose is to understand the experiences of people, discussing the elements of the phenomena which are personal to them (Duffy, 1987; Sandelowski,

2000; Burns and Grove, 2007; MacNee and McCabe, 2008). Depending on the aim of the study, this may be seen as a limitation or an advantage of qualitative research.

It has been argued that quantitative research is an inappropriate research approach when the subject matter is related to the actions and experiences of human beings (Cormack, 2000). By using data collected through quantitative research, analysed statistically, it is difficult to interpret any personal perceptions and experiences of participants. In contrast qualitative research embraces the wholeness of humans, focusing on human behaviour in naturalistic settings to enhance the understanding of the human experience (LoBiondo-Wood and Haber, 1998; Sandelowski, 2000). Qualitative research may, therefore, be used more effectively than quantitative research when the purpose of research is to understand the meaning of, and interpret, complex social phenomena (Duffy, 1987; Sandelowski, 2000; Crooks and Davis, 2004).

When considering the differences between quantitative and qualitative research, the benefits and limitations these approaches may offer to the validity and reliability of a study must be discussed (LoBiondo-Wood and Haber, 1998; Morse and Field 2002). These terms are used to describe how well a study measures a phenomenon and to what degree the findings of a study can be seen to relate to other populations or environments without being affected by random variation (LoBiondo-Wood and Haber, 1998; Morse and Field 2002). Terms such as trustworthiness and rigor are more common in the use of critiquing the quality of qualitative research (Sandelowski, 1986; Caelli, Ray and Mill, 2003; Shenton, 2004), however, all terms relate to how credible the conclusions drawn from a study are. Establishing trustworthiness and rigor in qualitative research is considered to be more complex than in quantitative research due to the nature of the data gathered and how it may be interpreted. This can, therefore, be an argument for the use of quantitative research as opposed to qualitative research. Several factors can affect the trustworthiness of a qualitative study including the relationship between the researcher and participant and

their individual character traits may leading to variances in the data collected and the analysis of it (Sandelowski, 1986; Morse and Field, 2002; Shenton, 2004). It has been argued that although validity and reliability may be more evident in quantitative research it cannot be considered to be the foundation of all knowledge (Avis, 2003). As qualitative research has the potential to offer greater insight into certain phenomena, efforts must be made to ensure data collected by qualitative methods is trustworthy so that it may effectively contribute to knowledge in the same way quantitative data is supposed to (Sandelowski, 1986; Avis, 2003).

Due to the vast differences in qualitative and quantitative research, the choice of approach should logically be decided upon by examination of the aims of the study, after completion of the literature review (LoBiondo-Wood and Haber, 1998). This study proposes to investigate the experiences of the carers of people with LD when accessing health care. In researching this subject, in-depth understanding of experience and opinion must be sought. In light of the discussion of qualitative versus quantitative research approaches and considering the aims and objectives of this study, it seems logical that a qualitative research method should be adopted for the collection and analysis of data. In order to determine the quality and trustworthiness of this research, it is important to fully discuss the research design and the methods by which the trustworthiness of the data were established. These are described throughout this chapter.

### **3.3 Research Design and Data Collection**

Having decided on the qualitative research approach in carrying out this study, the research design and data collection method has to be carefully considered in order to gather the most appropriate data to support the subject under discussion. The literature studied in relation to research instruments used in qualitative research has highlighted two possible approaches that may be suitable for this study: questionnaires or interviews (LoBiondo-Wood and Haber, 1998; Dempsey and Dempsey, 2000; Polit,

Beck and Hungler, 2001). These techniques are deemed as appropriate for this study as the types of questions that are to be asked are known in advance and so can be framed appropriately to gain the best result (LoBiondo-Wood and Haber, 1998).

Questionnaires and interviews have the purpose of asking participants to report data for themselves, however, each has its own advantages and disadvantages (LoBiondo-Wood and Haber, 1998). Questionnaires offer several advantages over interviews regarding the cost, time and effort required to gather data (LoBiondo-Wood and Haber, 1998). Questionnaires also offer the advantage of complete anonymity and the reduction of bias affecting the participant's answers due to the participant completing the questionnaire on their own (Polit, Beck and Hungler, 2001). The advantages of interviews, however, far outweigh those of questionnaires (LoBiondo-Wood and Haber, 1998; Polit, Beck and Hungler, 2001). The response rate of participants tends to be higher in face-to-face interviews as the participant is less likely to refuse to speak during an interview than they are to ignore a questionnaire.

Interviews also offer advantages in the understanding of the participant owing to the face-to-face nature of an interview meaning non-verbal cues such as body language may provide additional information, adding to interpretation of the data (LoBiondo-Wood and Haber, 1998; Polit, Beck and Hungler, 2001). People who would otherwise not be able to take part in questionnaire studies due to their age, literary skills or disabilities such as blindness may be more comfortable or able to take part in an interview (Polit, Beck and Hungler, 2001). Questions are less likely to be misinterpreted in an interview than in a questionnaire as the researcher is on hand to offer explanation or clarification of what is required in the answer (Polit, Beck and Hungler, 2001).

Furthering from these advantages, the aim of this study is to explore the different experiences of carers of people with LD when accessing healthcare. This requires obtaining personal and in-depth understanding that only the flexibility and penetrating nature of an interview can obtain (LoBiondo-Wood and Haber, 1998). Using a

qualitative approach in the form of individual, in-depth, semi-structured interviews allowed carefully selected participants to reflect on their experiences of healthcare for people with LD. Allowing participants to speak relatively freely about their experiences, with minimal cues from myself, avoided the participant being influenced by others increasing the trustworthiness of the study.

### **3.4 Interview schedule**

Through studying the literature on the principles of interview techniques, semi-structured interviews as opposed to structured or unstructured interviews are deemed to be most suitable for this study.

Using a structured interview technique is administering a questionnaire and does not allow for the development of certain topics highlighted by participants (Polit, Beck and Hungler, 2001). In contrast, non-structured interviews have the benefit of allowing the participant to talk about the matters important to themselves and their individual experiences and perceptions (Polit, Beck and Hungler, 2001; Morse and Field, 2002). The nature of unstructured interviews do, however, mean that all control of the interviewer is lost and the interview may develop away from the subject and not be relevant to the study at all (Morse and Field, 2002).

Semi-structured interviews have the benefit of allowing some structure to the interview so that data collection remains relevant to the study's subject, whilst still allowing for development of topics highlighted by participants (Barriball and While, 1994). As an inexperienced researcher, this approach is most suitable so that the benefits of unstructured interviews are incorporated whilst the disadvantages of structured interviews are not.

The interview schedule (Appendix 1) was developed following the completion of the literature review so that I had a firm understanding of the subject on an academic level. The topics chosen for discussion reflected areas of the literature in which there was debate or confusion and gaps of understanding.

The interview began with gathering information about the basic demographics of the interviewee and the adult with LD under their care. This allowed for any influencing characteristics of the participant that may impact on the results of the interview to be revealed and possibly discussed with the participant. Following this, the main body of the interview was left fairly unplanned, drawing on the topics highlighted by the literature review but gauging which areas to discuss based on the responses of the participant. At the end of the interview the interviewee was invited to raise any other issues they considered important or felt may be relevant to the study.

### **3.5 Subjects and Sampling**

A sample is the proportion of the defined population who are selected to participate in a study (Cormack, 2000). It is intended that this sample reflects all the characteristics of that population so that it can be inferred that what is learnt can be generalised to include most, if not all cases in that population (Cormack, 2000).

The two main approaches to sampling may be distinguished as probability and non-probability sampling. Due to the qualitative research method used in this study and the fact that findings do not need to be generalised to include the whole population, non-probability sampling is preferable over probability sampling as it involves the use of subjects who are both accessible and available allowing the researcher to be more selective as to who they include. Probability sampling would be inappropriate for this study as the sample is selected completely at random with neither the investigator nor the population having any influence over the sample chosen (Dempsey and Dempsey, 2000; Gerrish and Lacey, 2010).

The most common qualitative and non-probability based approaches to selecting a population sample are: convenience sampling in which the sample is selected based on their availability and willingness to take part in the study, quota sampling uses the basis of convenience sampling, however, participants are selected for certain criteria as well as their availability and willingness to partake in the study,

theoretical sampling in which the criteria for selected participants may be adjusted during the course of the study to incorporate the changing themes and categories highlighted by previous participants and purposive sampling in which participants are selected for their knowledge of the subject in question (Dempsey and Dempsey, 2000; Polit, Beck and Hungler, 2001). The benefits of convenience sampling are the saving of time, money and effort which, for this study, outweigh the disadvantages of the possibility of bias participants introduced to the study (Polit, Beck and Hungler, 2001). This is a small scale study in which the researcher is inexperienced and working against a strict time limit, therefore, convenience sampling, although it is possibly not as efficient at gathering trustworthy data as other non-probability approaches to sampling, is the most realistic approach to research and will suffice for this study. Having decided on the sampling technique ethical approval from the Medical School Ethics Committee was required to gain access to the target population: the carers of adults with LD. Once this had been obtained emails were sent to several charitable organisations and support groups working with members of the target population requesting that they advertise the study to prospective participants, providing contact details should they be willing to be involved (Appendix 2). Initial contact was then made via telephone or email to answer any questions they had about the study and to arrange an interview date. This initial contact was beneficial to both the participant and the researcher as any questions were answered putting the participant at ease and a rapport was built increasing the trustworthiness and reliability of the study (Dempsey and Dempsey, 2000; Polit, Beck and Hungler, 2001).

The sample acquired through this technique was made up of seven parents and carers of adults with learning. I was initially concerned with the small sample size of this study. As the sample size is quite small the trustworthiness of the study may be decreased when attempting to generalise results as the sample size is small in comparison to the population of people who care for others with LD. In qualitative research, however, the size of a sample in relation to the rigour of a study is of less

concern than in quantitative research, when a much larger number of participants is required to produce credible results (LoBiondo-Wood and Haber, 1998). Qualitative researchers are more concerned with gaining in depth understanding of the experiences of particular individuals (Dempsey and Dempsey, 2000), therefore, small sample sizes may still produce acceptable results. Qualitative approaches to research, such as Phenomenology, recommend the data is saturated meaning interviews are conducted until no new information is revealed (Cooper and Endacott, 2007; Gerrish and Lacey, 2010). Due to the semi-structured interview schedule saturation will be easier to achieve as participants may be guided to discuss topics of relevance to the study. The interview technique coupled with the short time in which the study was conducted and the number of participants available and willing to take part means that the number of participants is justifiable.

### **3.6 Ethical Considerations and Implications**

As with any study, there is the potential for a conflict of interests between developing the knowledge and understanding of a subject whilst maintaining the honesty and integrity of the study (Sandelowski, 1986; Morse and Field, 2002; Shenton, 2004). In qualitative research the ethical considerations and implications are especially important as there is the potential for findings of the study to be unintentionally misrepresented and the conclusions, therefore, to give a distorted account of actuality (Rosenthal, 1994). It is ultimately the responsibility of the researcher to conduct the study in an ethical manner (Dempsey and Dempsey, 2000) by maintaining the honesty and integrity of the study at every level (Cormack, 2000; Caelli, Ray and Mill, 2003) and reporting the findings of the research in an absolutely accurate manner (Dempsey and Dempsey, 2000).

The research planned for any study must be deemed to be appropriate and contribute to further knowledge of the subject (Cormack, 2000). Institutional review boards are responsible for protecting participants from undue risk and loss of personal

rights and dignity (Cormack 2000; LoBiondo-Wood and Haber, 2002). Therefore, before embarking on this study, a research proposal was presented to the School of Nursing, at the institution this study is based, and ethical approval was sought from the Medical School Ethics Committee in which every detail of the study was scrutinised to ensure that it was ethically viable.

Once this study was given ethical approval by the institutional review board I was able to recruit participants. The approval for the study was granted on the basis that only healthy volunteers would be recruited through charitable organisations. By emphasising the voluntary role of the participant, the participant's right to self determination was ensured. Humans should be treated as autonomous individuals, capable of controlling their own activities and their right to self determination means that they decide voluntarily whether to participate in a study without the risk of incurring a penalty (Polit, Beck and Hungler, 2001).

In recruiting the volunteers I made them completely aware of the aims and objectives of the study, what their involvement would entail and how the findings would be presented. At the first point of contact an information sheet (Appendix 2) was given to those showing interest in the study. The potential participants were made aware that they were more than welcome to contact the researchers regarding any queries they had about the study before they agreed to take part. Informed consent is the legal principle that, at least in theory, governs an individual's ability to accept or reject participation in research (LoBiondo-Wood and Haber, 2002) through their full understanding of what the study will involve (Dempsey and Dempsey, 2000; Cormack, 2000) . By providing detailed information in the recruitment of participants for this study the volunteers were able to give their informed consent to participate and were reminded that at every stage of the study they were welcome to ask questions and be reassured of their participation. The information sheets and consent forms were designed in such a way that they were understandable to all people involved in the study to aid the volunteer's informed consent (LoBiondo-wood and Haber, 2002).

So that participants were able to talk freely and express their views effectively during the interview process, they must be ensured of their anonymity and the confidentiality of the study. Transcription of the recorded interviews took place as soon as possible after the interviews were conducted, omitting any information that compromised the anonymity and confidentiality of the study, the transcripts were then kept in private folders. Throughout the findings and discussion of this study the participants will be kept anonymous so they will be in no way identifiable so that this study will not impact on their lives in the future. Through this reassurance, participants may have felt more able to talk truthfully of their experiences, again increasing the trustworthiness and rigor of the study.

### **3.7 Data Analysis and Presentation**

The purpose of data analysis is to organise and provide structure to data so that it may become meaningful (Burnard, 1991; Boyatzis, 1998; Polit, Beck and Hungler, 2001; MacNee and McCabe, 2008). Due to the interpretive nature of qualitative data analysis, several challenges exist in presenting data so that results reflect the true nature of a phenomenon, enhancing the trustworthiness of the research so that it is clear to the reader (Cormack, 2000; Polit, Beck and Hungler, 2001; MacNee and McCabe, 2008). The framework for data analysis must be decided on before data collection, however, there are no systematic rules that can be applied for the display and analysis of all qualitative data (MacNee and McCabe, 2008).

There are a number of traditional frameworks for qualitative research, the most common being; phenomenology, ethnography and grounded theory (Cooper and Endacott, 2007). Each framework has its own distinctive features and so is chosen according to the focus of the research (Cooper and Endacott, 2007). This purposefully limits a framework's applicability. Some research intends to develop theory based on description, in which case, the use of the grounded theory framework for data analysis is applicable (LoBiondo-Wood and Haber, 2002; Caelli, Ray and Mill, 2003; Cooper

and Endacott, 2007). An ethnography framework, however, will draw on the personal histories of participants and cultural rules to examine the results of qualitative data (LoBiondo-Wood and Haber, 2002; Cooper and Endacott, 2007). It has been suggested that by using methodical theory to analyse qualitative data, the original nature of the data may be obscured in order to fulfil the framework's specification (Avis, 2003). Some research studies simply aim to explore the perspectives of those involved in a particular phenomenon (Cooper and Endacott, 2007) it is, therefore, possible to focus on the results of such a study without over preoccupation with the method of analysis (Avis, 2003).

This study aims to gain insight into the experiences of carers of people with LD when accessing healthcare. The focus of the research into this topic is on individual perspective and this is reflected in the research approach and design. Having studied the literature surrounding different qualitative frameworks for analysing the data collected during this study, I have chosen not to align with one specific approach, instead I believe a generic qualitative approach is most suitable.

Generic qualitative approaches to data analysis have been criticised for their failure to follow particular protocol set by traditional frameworks, resulting in, what some consider, conclusions of inferior credibility (Caelli, Ray and Mill, 2003; Cooper and Endacott, 2007). Avis (2003), however, argued that qualitative research should not have to be justified by traditional and structured methods of analysis. Instead he suggested that although frameworks such as phenomenology are useful in developing and justifying qualitative methods, they are not necessary in confirming that said by participants to be true (Avis, 2003). As an alternative to focusing the study on one particular framework, several may be drawn upon so that the study is structured in a way that the analysis represents the data as a whole (Boyatzis, 1998; Caelli, Ray and Mill, 2003).

Previous studies which have used generic qualitative approaches have received criticism for their apparent lack of structure and rigour (Caelli, Ray and Mill,

2003; Cooper and Endacott, 2007). To avoid such criticism in this study I have attempted to explain the methods by which I will avoid gathering untrustworthy results during data collection throughout this chapter. To gain more structure in my generic approach to data analysis I will draw on methods used in the phenomenological approach, explaining those aspects I have chosen to adopt and those I have not.

Phenomenology is the process of learning and constructing meaning of human experience through intense, unstructured dialogue with individuals who have lived that experience (LoBiondo-Wood and Haber, 1998). Although the outcome of using a phenomenology framework is similar to what this study aims to achieve, a semi-structured research design is deemed as most appropriate for this study, as specified earlier in this chapter. Prior to conducting phenomenological research the researcher must identify their own preconceptions so that their bias does not influence the findings (LoBiondo-Wood and Haber, 1998). Several authors dispute this and argue that interpreting the behaviour of others depends on attributing to others many of our own beliefs so that new beliefs may be identified (Avis, 2003; Caelli, Ray and Mill, 2003; MacNee and McCabe, 2008). Phenomenology also requires data to be saturated to the point where no new information is gathered (LoBiondo-Wood and Haber, 1998; MacNee and McCabe, 2008). As discussed previously, this is only a small scale study and, as a novice researcher, this has not been possible. Enough data has, however, been gathered so that recurrent themes are identifiable. For these reasons this study does not wholly adopt the phenomenological approach. Parts of a phenomenological framework have, however, been adopted in the analysis of the data produced during this study.

Qualitative research and analysis requires full immersion and complete familiarity with data so that patterns may be recognised and key themes interpreted (Burnard, 1991; Boyatzis, 1998; Morse and Field, 2002; Cooper and Endacott, 2007; MacNee and McCabe, 2008). Transcripts from the interviews were written up in full with brief notes on initial thoughts and perceptions of the data written in the margins.

The transcripts were then read and re-read to achieve full understanding of the data as a whole. Initial conclusions on the data were then drawn by identifying recurring themes, encoding them (Burnard, 1991; Boyatzis, 1998; Burns and Grove, 2007; Cooper and Endacott, 2007). Coding is the breaking down of data into meaningful sentences (Burnard, 1991; Boyatzis, 1998; MacNee and McCabe, 2008) and examples of the codes identified within the data will be used to lead the reader through steps of the analysis to arrive at the final synthesis of the experiences and thoughts of the participants regarding people with LD accessing healthcare (LoBiondo-Wood and Haber, 1998). To support the rigour of the work the label given to each code is as broad as possible so that interpretation and bias are not evident at the development stage (Boyatzis, 1998). Complete copies of the transcripts were also kept as reference to the original meaning of what was said and consideration was given to any underlying influences and bias that may have occurred so that the trustworthiness of the study is maintained.

### **3.8 Summary**

This chapter has thoroughly described the methodology used in this study. The approach to research, the design of study used and the framework for analysis of data were deliberated to justify choices made. The ethical considerations and possible implications of this study have been discussed and throughout this chapter all attempts to maintain the trustworthiness of this study have been considered and reviewed so that the results may show a true interpretation of the perspectives and experiences of carers of people with LD when accessing healthcare. The next chapter will display the results and analysis of the data collected using the methods described here.

## Chapter Four: Results

### 4.1 Introduction

This chapter aims to present the research findings of parent and carer perceptions and experiences of people with LD accessing healthcare. The study involved interviewing parents and carers and the results have been generated from the transcripts of those interviews which were coded and analysed, as described in the previous chapter. The data produced during this study may have been interpreted differently by different people, due to the nature of qualitative research (Boyatzis, 1998; Dempsey and Dempsey, 2000), however, the themes I have chosen to divide to data into are as shown in box 1.

<u>Theme</u>	<u>Sub-Theme</u>
Bad Memories of the Past	Diagnosis Lack of understanding
How Things are Now	How things have changed Discrimination Labels Holistic Care Involvement Communication and Time Continuity and Quality of Care
Hopes for the Future	When parents and carers are gone Training Lowering the bar to a level accessible to people with LD

Box 1.

These themes will be explored using direct quotes from the transcripts which will illustrate and emphasise those points raised by participants. All names of people have been changed and all names of places have been left blank. Complete copies of the transcripts have been kept and each quote is referenced to the page number of the transcripts from which it has been referenced from.

#### **4.2 Bad Memories from the past**

In describing their experiences of people with LD accessing health care many participants began by talking about the diagnosis of LD in the person for which they care for.

*I went back to GP he said, "You know this is ridiculous there's nothing wrong with him," and he struck me off the register. So I went to the clinic told the nurse and she said, "come to my GP," which was actually in the same practice. But I thought this is going to be difficult, are they going to let me through the door? But it was alright and I went to her GP he said, "I don't know what's wrong with you woman, surely you can see he's in a world of his own," and I really didn't know what that meant, yes it wasn't very helpful. (P. 10)*

*The nurse who was in preschool , nursery, and he was going at age 2 and the woman, the nurse said she had been observing Ben over a few days and she was pretty much convinced that he had some sort of LD 'cause he wasn't mixing right. And he couldn't talk, as such, even at two, which was already worrying for us, as parents. Anyway the only advice we got from this teacher, who did the best she could, was that there was a school somewhere with a 7 year waiting list and that was it, total, all the information we had. (P. 18)*

These first experiences of accessing healthcare for people with LD are lasting memories for the participants and the lack of understanding appears to have continued when accessing healthcare once diagnosis was made.

*It was dreadful and it was all this discharge, all infected. So they took him to the burns unit but the nurse said, "it's alright really, not as if he's normal," so that just destroyed me, even today does make you feel like crying. (P. 12)*

This experience of discrimination and lack of understanding still affects the participant and is likely to still influence her opinion and perception of healthcare for people with LD.

One participant describes a particularly distressing time in which she was so unhappy with the care her son was receiving in hospital that she discharged him.

*I mean it was totally insane to take two people out in wheel chairs, I never thought about anything. I just wanted to get them out of that hospital...When you hear in paper that someone's killed themselves and their son or daughter I can empathise. I came so close that day and I was so horrible. I thought we'll drive in the river and die. I just thought we couldn't face the world with him suffering, it's terrible. (P. 15)*

These experiences all happened before the release of VP (DoH, 2001) and the next theme describes experiences after its release.

#### **4.3 How Things are Now**

Those interviewed had different opinions as to whether healthcare had been improved for people with LD due to the release of VP.

*I do think that things have changed. We have the health checks now and things are better in hospital. I think people are more aware. (P. 35)*

*Over the years, like VP does, we've focused on certain areas and tried to get them off the ground, like person centred care. We've got that off the ground and it's really gone running. We've even got the government talking about person centred planning. (P. 27)*

Some participants, however, stated that healthcare had improved over the last ten years but that this wasn't due to change in policy but by meeting new people.

*I think it's different people not the changing time. It's still very, very difficult. (P. 12)*

*The nurse did recognise that she had LD and took a different approach and she came back the next day to have them done with general anaesthetic and really it was the only option for Kate. Now he was very good but she might have meant somebody who wasn't. (P. 40)*

These differing views on the improvement of healthcare for people with LD continue with varying experiences regarding discrimination.

One participant described how she hadn't felt that her daughter was discriminated against due to her disability.

*Mary's needed quite a bit of surgery. She had the spinal op' and she had her feet done and I could never say that I ever got the idea cost was in the way. I didn't feel that she was discriminated against in that way. (P. 35)*

Another participant, however, had experienced discrimination due to her daughter's LD when attempting to register her with a GP.

*I felt as though they thought the LD was nothing to do with them, you know because they weren't specialist and they didn't know her and they didn't see any reason to get to know her. I felt they were washing their hands of her (P.37).*

There were different opinions on how the label of LD can affect a person's healthcare.

*Right well my son Ben has got a LD, little bit of autism and other bits and bobs. He's never been properly diagnosed 'cause I don't think, I don't agree with some of the titles they give people with LD. LD is bad enough, they've already got one label with that and something technical with that as well. (P. 18)*

*It happened because that doctor has the label in his head that mentally handicapped people, as he called them, not even people with LD, mentally handicapped people have habits. That stopped him seeing any further than the label. (P.37)*

In contrast one participant believed that by people knowing her daughter had a LD, her care could be improved.

*She is protected by the fact that there is a certain programming there that you know people have got a set of expectations just what they're going to be dealing with just when they look at her what she's going to be capable of and by and large they're probably about right. (P. 38)*

Many participants mentioned their desire for a more holistic approach to the care of people with LD to be taken.

*The rest of us can manage with just treating the little bit of us that hurting at that particular moment but people with LD can't. There is by definition going to be multiple issues so it is more important in that way. (P. 39)*

*I think they're programmed into the medical thing treating the medical condition, which is understandable 'cause it's what they're there for but you can't just treat the medical thing if there's something else wrong with them, LD, big physical or you know dementia but you know a big thing like that, you can't just treat the medical condition. (P. 31)*

Many interviewees talked of their involvement in support groups and LD rights groups. Gaining appropriate health care for people with LD was described as a struggle and time consuming.

*How we can make a change is by pecking away and making ourselves a general nuisance. (P. 28)*

*Well as a carer getting involved with the carer's organisations, it's a door that's either all open or all shut. You can't keep it slightly open and take on a bit. You either have to do nothing or take it all on. (P.20)*

The parents and carers all considered themselves to be the advocate of the people with LD whom they cared for.

*I would never, ever, no matter, what leave Mary ever unless someone else, my son, was there and sometimes my brothers come but I would never leave her. (P. 30)*

*I slept and ate at the hospital and never left him at all because my worry was that I was the support that Ben needed and also there was a lack of understanding for the professionals to give Ben the explanation he needs. (P.22)*

Following from this many participants spoke of how they did not trust the health care services to cope without them staying.

*18 months ago Mark came here for assessment and his epilepsy has always been problematic but they would only have him here if I would stay here 24/7 and he was here for 3 months and I stayed here for 3 months. Because he needs a lot of care they don't have the means to have someone here with LD. (P. 12)*

*As soon as I expressed to his nurse that Ben had a LD within minutes they moved him into a more private cubicle and he said will you be staying with him and so I said yes and he said thank heavens for that because he knew that he needed the support. (P.23)*

The need for parental and carer involvement in the healthcare of people has, in part, been recognised and several participants spoke of how they have felt listened to.

*Professor Hack has really made a difference with the epilepsy in reducing medication, actually he did listen to me. I said I just think Mark is doped up to eyeballs and his quality of life has got to be comparable to number of drugs and he did actually listen to me. (P. 13)*

Many participants, however, described their frustrations of not being listened to.

*I feel as they though they don't listen, you know, I feel as though I'm giving them real gems of knowledge that will be useful but then they don't listen. (P. 31)*

Many participants spoke of their disagreements with health professionals over the medication in particular, attributing this to the label of having a LD.

*He just wanted to give her these drugs so that she would be so zonked out she would be physically unable to do it. And if I'd gone down that way, you know, if I hadn't been so sure it wasn't a habit, she'd probably be dosed up even now. (P. 34)*

*Unfortunately the medication she is on causes a lot of weight gain and I feel as if sometimes, because there are mental health problems in this, and I feel as if sometimes sort of controlling the condition is like using the medical model in her care is too much, I wish sometimes there was more of a holistic approach used. (P. 16)*

One of the main problems of people with LD accessing mainstream health care was considered by the participants to be a lack of communication and time.

*All service users are the same. If you take the time to talk to them, and that's the problem with professionals, they don't take the time because they're doing their job. Doctors have 5 minutes for every patient. We've only just got the legislation through where we can demand a double booking for people with LD and we've had to tell doctors this they've not succumbed this the carer's have had to push this to get the ten minutes, which is barely enough anyway because you need that time to get inside a person with LD, once you've got inside of them, they're no different from anybody else it's just learning how they talk. (P. 22)*

*They try hard and they listen intently but because they don't understand they guess the rest because they still won't ask the searching questions of a person with LD because they think it's too hard. (P. 26)*

*They will just about have gotten started and the time's up so we were having to come back week after week after week and she was going through the same sort of torture. (P. 36)*

Two participants, however, did state that the lack of time and communication was due to the nature of the person with LD whom they cared for.

*I think they're more concerned about what's going to happen today rather than hygiene and health (P. 5)*

*Its equal amount of worry and emphasis to a tiny little paper cut as she would to something serious. Although she might tell the doctor things worrying her she might tell him things that, to her, at the time were equally important and equally worrying but weren't really the main thing. (P. 36)*

The majority of participants, when asked how they thought the health care system could be improved for people with LD, suggested more continuity of care, appealing to the need for routine for many people with LD. It was apparent, however, that this was a complaint of all people accessing health care.

*So then you tell the authority or whoever and they take it on board and things start to happen but then 3 months down the line it's stopped, people have been promoted up and no one's taken the initiative to carry on. So what do we do? Start all over again, it's*

*dreadful. It's easy to fix if you talk to everybody that matters in one go and then if they don't move for a year or 2 it might stick that everybody will pick up on then. (P. 27)*

*We planned a route, people with LD like a routine. So we had it suggested that it's a straight line route so you go there, there, there and then you're out they understand that then, they can see an end. But if you go taking them upstairs downstairs they start panicking but it all makes sense when you explain how they are. (P. 28)*

Similarly, more integration of services is suggested for the improvement of healthcare services.

*I think it's true of everybody there needs to be a much greater integration of what's going on. (P. 39)*

*I've brought a copy of this health care plan and literature about it had an appoint with Dr Mays that day and showed it to the line nurse or whatever and she was really delighted and she was starting to do this and she thought it was fabulous she only had to modify it. It's ridiculous they can't share these things. (P. 13)*

In order for the policies to work, or to continue to improve the lives of people with LD, many participants called for greater assessment of services.

*You must be very realistic on your assessment, how you are progressing towards it you can't pretend you're three quarters of the way there when you're not at all. And sometimes I do think that, they think they're clever ticking boxes. (P. 31)*

*It's not changing, boxes are just being ticked. I can only go from personal experience Justin was in a rehab hosp and they had the investors in people award and I don't know how they got that, I really don't. (P. 14)*

#### **4.4 Hopes for the Future**

Although participants were asked to reflect on their experiences of healthcare for people with LD, many made suggestions for future practice, as described previously, and many expressed their hopes for the future.

As previously discussed, many participants considered themselves advocates for the people with LD whom they cared for. One participant describes his fear of how his son will cope once his wife and he are no longer around to act as advocate.

*That person with LD has lost their parents, lost their familiar environment lost all stability and what they do survive on is routine, they lose their routine. Which is more damning than all the rest. Losing their routine is like being pushed out of a plane, they're totally scared. Scared of everything, every person, everything they touch. When they're in that situation the team looking after them don't know what they're doing, the person with LD is so scared they lose their temper so they jump on him, pump him with drugs to calm him down. (P. 24)*

The participant then goes on to say how he has coped with this fear and acted to make sure it doesn't happen.

*Me and my wife have worked every day so that we know we can die and leave Ben to be ok, so that he's surrounded by people that understand him now these are people in social services, his key worker etc. (P. 24).*

Several participants voiced their desire for more training of staff in coping with people with LD.

*Just teaching people how to be person centred you can talk to a person with LD straight off. It's dead simple but it's hard to do in practice unless you've got to be taught how to do it. (P. 26)*

*It needs improving it needs training programmes right at induction. So if you're coming into the NHS as a receptionist or doctor, whatever you're taught how to communicate with a person with a LD. (P. 22)*

It was suggested by two participants that in order for integration of people with LD all communication and interaction with all patients must be at a level people with LD could access.

*What LD does, if you bring it all down to their understanding, lower the bar. Therefore, anybody above that bar will still understand as well it's just a matter of bringing it down to that level. (P. 27)*

*I think if people with LD were really integrated then the rules would be as pertinent for them as they are for other people without them being bent and that would be a test of real integration that those people have been thought of. We shouldn't have to bend or break rules the rules should suit your clientele they should include people with LD. If you're thinking your population is going to be normal that part of the problem. You can't just look at the ordinary ones. All of them... so rules should suit everyone. If you have to bend or break that rule there's something wrong with the rule not that person. (P. 32)*

The overall impression of this theme, as interpreted by the researcher, was that people with LD should be fully integrated into mainstream healthcare and hope was expressed that in the future it would be possible for them to access healthcare as independently as possible whilst supported by the healthcare system.

*People with LD they are part of society and they should be treated as such and integrated and I feel very strongly about that, definitely, and in hospitals hopefully that there is enough empathy in the nurses for their needs to cater to them. Why put them away? Why segregate them? (P. 18)*

As described in the previous theme, many problems still exist for people with LD in accessing healthcare, however, the participants remained hopeful that improvements would continue so that easier and more effective access to healthcare would be possible in the future. Should this be the case, the worry that people with LD may not be able to survive with a good quality of life when their carers are no longer able to act as their advocate may be eased for the parents of carers.

#### **4.5. Summary**

The participants spoken very openly about their personal and, sometimes, upsetting experiences. The colourful language used by participants creates a clear presentation of their opinions and many thought-provoking statements were made. All experiences described by participants are useful in gaining insight to the subject and, using the statements presented in this chapter, I am able to analyse that said by participants, hopefully conveying their true opinions, in the next chapter.

## **Chapter Five: Discussion and Conclusion**

### **5.1 Introduction**

This chapter discusses the findings of this study in relation to the associated literature, presented in chapter two. Comparisons will be drawn between these results and that stated in the literature review and attempts to explain these comparisons will be made. The methodology of the research design will be critically evaluated, considering the rigour and credibility of the study. Finally, recommendations for future nursing research, education and practice will be made.

### **5.2 Findings**

#### **5.2.1 Bad memories from the Past**

As the results presented under this theme demonstrate, some participants reflected on the process of diagnosis of LD describing how hard it was to gain access to information and support. In particular, two parents, who had children over 35 years of age, described how there appeared to be a lack of services for people with LD at the time their children were diagnosed. This correlates with the depiction of healthcare in the UK at this time. In the late 1970s, during the childhood of those people with LD, a Conservative government was in power (Burton and Kagan, 2006). It is recognised that this period of time marked an economic downturn in the UK when the government focused more on improving the economy than providing welfare (Atkinson, Hill and Le Grand, 1987; Gilbert, Cochrane and Greenwell, 2005; Burton and Kagan, 2006).

People attempting to access healthcare for people with LD during this time would have faced a government that did not encourage dependence on the state, meaning they would have struggled to find services catering to their needs. Those participants that did not remark upon improvements over time, comparing more positive, recent

experiences to how hard it was in the past, cared for younger people with LD for whom better services may already have been available (DoH, 1992; 1995).

None of the people with LD included in this study had ever lived in the institutions or long stay hospitals described in chapter two. However, the participants themselves were all over the age of 50 and so would have been aware of this type of organisation. Scandalous revelations of the appalling care provided to people with LD at some of these institutions and hospitals, such as Ely Hospital in Cardiff, were publicised around the 1970s (DHSS, 1969; Inskip, 1974) and, therefore, would have been fresh in the minds of the participants during the time in which their children were diagnosed with LD. The reports detailing the low standard of care and attitudes towards people with LD reflect the discrimination, lack of support and understanding described by participants when receiving diagnosis for their children during this time.

One way in which the results did not reflect the literature is in the lack of evidence revealing any improvement of services during this time. According to the literature, there were campaigns to improve the lives of people with LD during the 1970s (Stevens, 2004). Better Services for the Mentally Handicapped (DHSS, 1971) was released and Wolfensberger's concept of Normalisation was also published in 1972, adding to the drive forward in improving the lives of people with LD. Results of this study should, therefore, have shown some evidence that attitudes towards people with LD were improving. However, the participant's descriptions of healthcare for people with LD offer no proof of this. In theory, the complaints made by participants about the lack of understanding and support they received is more in keeping with descriptions of care prior to the time in which they described. Therefore, in this way, the results of this study do not wholly correspond with the literature review.

The participants of this study cared for adults with LD aged between 23 and 40, therefore, only the history and politics surrounding attitudes towards people with LD since the 1970s is directly relevant to the lives of people with LD included in this study. The experiences of the participants, however, describe harsh attitudes and

discrimination which, according to the literature review, were more in keeping with the history and politics before this time (DHSS, 1971; Wolfensberger, 1972; Stevens, 2004; Gilbert, Cochrane and Greenwell, 2005; Mencap, 2010). A study by Charnock (2000) suggested that, although policy development since the 1960s showed good intentions of improving the lives of people with LD, inconsistencies in care were still present due to the lack of a strong political drive forward leading to a failure to put these good intentions into practice. Further to this, there was a continued inequality of care provision for people with LD (Charnock, 2000); A theory which may explain why the participants still described experiences of discrimination post 1960.

The bad experiences during the early stages of the participant's involvement in caring for people with LD, coupled with the reports in the media revealing terrible standards of care available to people with LD, have clearly had lasting impact on participants. Through the publication of VP (DoH, 2001) it was hoped that not only would services be improved for people with LD but that it would also remedy the mistakes of the past (Young and Quibell, 2000; Burton and Kagan, 2006). It is clear from this study, however, that these mistakes are still fresh in the memories of participants and so may possibly affect the current perceptions and experiences of healthcare for people with LD described in this study.

### **5.2.2 How Things are Now**

In this section of the results it is clear that some improvements in healthcare for people with LD have been made with the release of VP (DoH, 2001). Although, there were some critical points of view there were also statements of praise and recognition of the improvement of services, which were completely absent in the section "Bad Memories From the Past". The differences in opinion as to whether VP has been successful in improving the health of people with LD provides a possible indicator of inconsistencies of care provision from area to area. The participants all came from different areas of the UK, which may explain some of the variation in the results. Similar inconsistencies

in care were highlighted in the literature review (Fyson and Simons, 2003; Mir, 2007) and the results of this study support these criticisms, showing VP to have only limited success.

Many participants of this study focused on the discriminatory judgements and attitudes of healthcare professionals that they had experienced when caring for a person with LD accessing healthcare. This sub-theme of discrimination also had varying results. One participant stated that she never felt that her daughter was discriminated against when needing surgery. However, another participant described how she felt that a GP had discriminated against her daughter because he did not believe that caring for someone with LD was his responsibility.

These variances in opinion may be due to the type of care needed and the services involved in that care. The release of VP (DoH, 2001) signified the recognition that people with LD are entitled to the same rights as the general population (Fyson and Simons, 2003; Young and Quibell, 2005; Burton and Kagan, 2006; Forbat, 2006). As discussed, VP also provided people with LD positive rights so that they are able to exercise the same rights as the general population. It is through these positive rights that discrepancies over responsibility for the healthcare of people with LD might have arisen. It has been argued that the specialist practices developed for people with LD to help them to access the same rights as the general population have also sustained the inequalities present in mainstream healthcare (Mir, 2007). For example, surgery is a technical skill which must be undertaken by a surgeon and no LD specialism can provide the same service. Therefore, treating a person with LD in need of surgery can be seen as no one's responsibility other than the surgeon's. In contrast, many specialist LD services are available through colleges and day-centres for people with LD and many people with LD have regular contact with specialist LD nurses. There is some evidence to show that these services offer more efficient care to people with LD than mainstream healthcare (Manthorpe, et al, 2003) and so it is possible that the

participant encountered a GP that assumed a specialist service for LD would be more appropriate in treating her daughter.

Care of people with LD is now part of the QOF, the framework through which GPs are paid, and so it should be clear that GPs are responsible for the care of people with LD (QOF, 2010). The participant who experienced this discrimination was right to question the motives of the GP and depending solely on specialist services is unacceptable and against the aims of VP (DoH, 2001; Lindsey, 2002; Mir, 2007). This example demonstrates one way in which VP has not been successful.

When participants were asked how they thought healthcare for people with LD could be improved, many suggested that services needed to be more consistent. Some participants called for greater integration of services and information-sharing to allow for more consistent care. This point of view is consistent to that discovered in the literature review (Charnock, 2000). One of the main barriers in implementing the integration of services and utilising the practice recommendations of VP is in knowing accurate information about people with LD (Mir, 2007). Information regarding people with LD cannot be easily shared due to data protection legislation (Emerson and Hatton, 2004; Mir, 2007). Compiling information on people with LD would also require full diagnosis of patients which many participants considered as labelling. Labelling was another sub-theme detected in the results of this study and, again, participants varied in their opinions on labelling people with LD. Whilst some embraced labels as a means of understanding LD, others did not. By not fully diagnosing people with LD, accurate information may not be obtainable and, therefore, challenges still exist in further integrating services. In this way, participants opinions expressed under one sub-theme contradicted that said in another sub-theme. Without labelling a person as having a LD, health authorities may not identify them and offer a greater quality of integrated care, as wished for by participants and demonstrated by their statements, categorised under different themes. It is possible that those participants who disagreed with labelling feared discrimination, when VP actually aims to end discrimination. To

achieve integration between services it may be necessary for participants to acknowledge VP's aims and accept that people with LD must be labelled in order to achieve these aims. Adding to this, attention must be paid to all themes, addressing the participant's concerns as a whole as they all interlink and are dependent on each other.

The literature review describes how the formation of VP and VP Now and their implementation relied heavily on the input of carers of people with LD (DoH, 2001; Fyson and Simons, 2003; Manthorpe, et al, 2003; Forbat, 2006; DoH, 2009). The results show, however, that this involvement is often considered a strain by participants. Although participants complained about their involvement, many did state that they considered themselves advocates for people with LD and, therefore, recognised the importance of their involvement. A way in which this complaint may be resolved is by the services listening to parents and carers of people with LD so that they are recognised and appreciated for their input. Although some participants described experiences in which they had felt listened to, others stated that they had been ignored. The literature review did highlight this issue as a limitation of VP and VP Now (Foster and Simons, 2003; Manthorpe, et al, 2003; Forbat, 2006; Mir 2007) and the results of this study emphasise this.

Following this, many participants expressed that they did not believe healthcare professionals demonstrated effective communication skills when dealing with people with LD, adding to the need for them to be fully involved in their care. This problem was recognised by Forbat (2006) and this study suggests that improvements still need to be made.

The literature review highlighted that studies centred around adults with LD are generally more concerned with quality of life as a whole, not specifically health care (Walden et al, 2007; Grant & Ramcharan, 2001). The results of this study enforce this as participants spoke of the need to apply a more holistic approach to healthcare for people with LD. Healthcare professionals were accused by participants of

concentrating solely on the medical model of health rather than the person as a whole. The research concerning quality of life, therefore, needs to be utilised further in evidence based practice.

The contrasts in the literature review when compared to the results of this study highlight the need for full and reliable assessments of the services for people with LD. Many participants suggested that services were simply “ticking boxes” instead of fully practicing the aims of VP and VP Now. VP Now (DoH, 2009) uses direct quotes from carers and people with LD as examples of the successes of VP (DoH, 2001). This study, however, independent of the DoH, has highlighted that more needs to be done so that improvements may be seen by all people with LD and their carers.

### **5.2.3 Hopes for the Future**

Although participants were asked to reflect on past experiences, many spoke of their hopes and fears for the future of healthcare for people with LD.

When describing how they acted as advocates for people with LD, many participants admitted to being fearful for the safety of the person with LD for whom they cared for, should they not be able to continue to act as advocate. This fear reveals concerns that healthcare services will not be able to act with the same empathy and passion that the participants have demonstrated in caring for people with LD. A similar study conducted by Sardi, et al (2008), found that this is a common fear among parents and carers of people with LD. Although this study was fairly recent, the similarities in findings emphasise that more must be done to alleviate these fears and to reassure parents and carers of people with LD that healthcare services are equipped to care for people with LD without input from parents and carers. The struggle participants faced in their need to be fully involved with care was further discussed in this chapter and the fact that it has reoccurred under the title of this theme emphasises its importance.

Participants also discussed their desire for a more comprehensive education of all staff in dealing with people with LD. VP did state that all staff should receive more

training (DoH, 2001), however, ten years on from the release of VP it is clear through this study that the participants have not experienced these benefits yet. Some of the literature, discussed in chapter 2, suggests that parents and carers should not only be involved in the planning and implementation of policies but also in the training of staff (Foster and Simons, 2003; Forbat, 2006; Mir 2007). As previously discussed, many participants already found the policy's reliance on their input to be somewhat of a struggle. This further involvement may, therefore, add to that struggle. The involvement participants have in the training, planning and implementation of care for people with LD may seem a struggle due to the fact that many participants did not feel listened to, also discussed earlier in this chapter. Some literature suggested that specialist services may offer more benefits to the health of people with LD compared to integrated services (Lindsey, 2002; Manthorpe, et al, 2003; Mir, 2007). The majority of participants, however, expressed their hope that services could evolve to include the care of people with LD. Many participants suggested that by "lowering the bar" so that all healthcare information is accessible to people with LD, the aim of inclusion would be met. Although this would mean people with LD are more integrated into mainstream healthcare, the information may be inappropriate for the general population as it may be considered patronising (Foster, 1996). Efforts are already being made to provide accessible material for people with LD by VP and VP Now (DoH, 2001; 2009) and also other organisations such as Mencap. These easily-accessible materials may be considered a compromise so that the general population is not adversely affected by the integration of people with LD into mainstream healthcare.

### **5.3 Limitations of the Study**

Now the findings of this study have been discussed it is important to consider the limitations of the methodology so that the rigour and trustworthiness of it may be addressed, adding to the credibility of the study.

In order to increase the rigour and trustworthiness of a study the methodology must be described in full (Koch, 1994). The methodology of this study was presented in chapter three, however, even with this full description, it is not without limitations.

In gathering participants for this study convenience sampling was used. Convenience sampling is criticised by much of the literature as bias can easily be introduced into the results and errors may occur (LoBiondo-Wood and Haber, 1998; Dempsey and Dempsey, 2000; Polit, Beck and Hungler, 2001). It is therefore suggested that convenience sampling should, if possible, be avoided (Gerrish and Lacey, 2010). The sample size used was also comparatively small to the actual size of the target population. This limitation of the study means that the transferability of its results is questionable as the sample size may be considered too small to draw assumptions encompassing the entire target population. Due to these limitations the rigour and trustworthiness of the study are limited, however, due to strict time limitations these compromises were necessary.

To maintain the ethical considerations of this study, only members of charity organisations involved in the lives of people with LD were approached. Only those who volunteered to be interviewed were selected for participation in this study. The participants in this study, therefore, clearly wished to be very involved in the lives of people with LD and had strong opinions on the topics discussed. There may be members of the target population who are not so involved or have differing views, however, due to the sampling of this study, they were excluded. This is potentially a huge limitation of the study as those people with LD, who do not have contact with anyone as passionate as the participants of this study, may be very vulnerable and would possibly benefit most from this research. Speaking directly to people with LD would be inappropriate without training and experience and, in order to ensure that this study was ethical, participants were only involved on a voluntary basis, therefore, these limitations were unavoidable.

Possibly the biggest limitation of this study was the inexperience of the researcher. To counteract this meticulous records of the interviews, documentation and analysis of all stages were kept in a systematic way, as suggested by Mays and Pope (1995). Semi-structured interviews were also selected as a compromise between the methods of questionnaires, which would not produce as in-depth results, and unstructured interviews which are far more difficult to conduct (Barriball and While, 1994). The semi-structured interview technique did, however, prove to have some limitations and disadvantages. Occasionally irrelevant subjects were discussed which wasted time. At times I also felt my own characteristics limited the response of the interviewee. Due to my age, sex and position as a student nurse, participants may not have been as truthful as they may have been when interviewed by a person of similar characteristics to themselves. This Hawthorne effect, in which a participant's response to a question may be altered due to the fact they know they're being studied, must also be considered with any study (LoBiondo-Wood and Haber, 1998; Gerrish and Lacey, 2010)

It must be remembered, that stated by participants was split under themes for the benefit of analysis. All themes are inter-linking and must be embraced as a whole in order to recognise the true nature of the results. As discussed in chapter three, qualitative research is often criticised for its subjectivity (Sandelowski, 1986; LoBiondo-Wood and Haber, 1998; 2002) and, therefore, qualitative research should, ideally, have more than one analyst so that the results of the study are more reliable (Gerrish and Lacey, 2010). Due to the time constraints of this study, this was not possible. Although this study did not have a second analyst and the sample size was small, the reliability of this study is shown by the fact that recurrent themes were found in the results and that many of the results correspond to the literature review. To counteract the limitations, quotations from participants were used to illustrate the points made in the results chapter, as suggested by Gerrish and Lacey (2010), to enhance the trustworthiness of the research.

In an attempt to enhance the trustworthiness of this study written transcripts were produced in a timely fashion after the interviews were conducted. Initial notes and impressions were made in the margins of each transcript so that personal beliefs and bias could be separated from the actual data produced. It would have been preferable to return the transcripts to the interviewees to validate the results further, however, due to the time limitations of this study this was again not possible.

Through the audit trail of this study I have presented the decision making processes of each stage of the research. I have been transparent in my decisions, however, due to the limitations of this study, as discussed above, care must be taken when reviewing the results so that unfair conclusions are not drawn as a result of these limitations.

#### **5.4 Recommendations**

Nursing research is of little value unless the knowledge generated is incorporated into practice (Fain, 2004) and despite the strong belief that nursing needs to be an evidence based profession, uptake of research findings in practice is slow and inconsistent (Smith, 1998; Gerrish and Lacey, 2010). Following from this research I will make recommendations towards the future of nursing education, practice and research so that the efforts to improve healthcare for people with LD made by this study may be recognised.

With regards to nursing education this research shows that it is vital for nurses to have better training in communication and the specialist needs of people with LD. There currently exists a branch system in which nurses specialise into adult, children's, mental health and learning disability nursing early in their training. This branch system of nursing education means that people with LD are considered to be a speciality. With the release of VP (DoH, 2001) and the strive forward for the inclusion of people with LD, only educating one branch of nursing in the skills of nursing people with LD may be considered to continue the exclusions within healthcare. There is a debate

surrounding specialist versus mainstream healthcare, with regards to people with LD. This debate is discussed by much of the literature, threatening the continuation of the LD branch of nursing (DHSS, 1979; Charnock, 2000; Mitchell, 2003). Research has shown, however, that specialist LD nurses are needed and appreciated by LD patients and their carers (Manthorpe, et al 2003). To compromise between the two views and take the best from both practices it is necessary for all branches of nursing to receive at least basic training in the care of people with LD, especially regarding communication and time management. There is clearly a need for specialist professionals in the area of LD healthcare, emphasised by this study, however, education in LD healthcare must also be integrated further into mainstream healthcare. This integration would comply with policy and the wishes of the participants of this study. Better training in the care of people with LD would then easily translate into improved practice in all branches of nursing.

By improving practice through better education, parental worries about what will happen to their children once they are no longer able to care for them may also be eased. Furthering from this, more attention must be paid towards health services for the elderly with LD, as suggested by earlier research (Foster, et al, 2006; Walden, et al, 2007). In order for parents and carers to feel more at ease with their participation in policy making and implementation they need to feel more listened to. Fyson and Simons (2003) also suggested that by involving parents and carers of people with LD in training schemes they would feel that their efforts and involvements were listened to and not feel that they are struggling.

Discussing the limitations of this study has highlighted several areas which may be addressed by further research. To build upon the conclusions drawn from this study and increase the trustworthiness and rigour of nursing research regarding the care of people with LD, methodical triangulation maybe introduced by adding another dimension to the results through quantitative methods (Smith, 1998; Gerrish and

Lacey, 2010). Focus groups with people with LD would also be beneficial to the research associated with this topic.

## **5.5 Conclusion**

The aim of this study was to explore the perceptions and experiences of parents and carers of people with LD when accessing healthcare. Through the interview process and the results generated, as presented in chapter four, this aim has been achieved. The findings of this study have been varied with participants describing both good and bad experiences. In many ways the experiences described by participants and the suggestions they have made correspond with the literature studied in chapter two, particularly with reference to the political influences upon LD policy and procedure. Some themes noted in the findings chapter of this study contradict each other which the literature review does not account for. For example, labelling people with LD both enables them to access services whilst still discriminating against them, as perceived by some participants.

This study has been successful in addressing its objectives of identifying how care for people with LD may be improved and highlighting areas for future research. Participants felt strongly that education should be improved and this has been accounted for in the recommendations section of this chapter with particular reference to improved communication skills. More effort also needs to be made in order to allow the parents and carers of people with LD to rely more on healthcare services so that they are not put under too much strain and can be assured that, should they be no longer able to act as advocate for the people under their care, people with LD are cared for effectively.

The limitations of this study have been accounted for and it is clearly stated that the results of this study should be regarded cautiously in light of these limitations.

Despite this, many valid issues have been raised and the true voice of participants has been displayed in the results.

Completing this study has been extremely challenging, however, I very much enjoyed meeting and interviewing participants. I discovered that this subject is close to the hearts of many people concerned in the lives of people with LD and that they all have strong opinions and views which must be acknowledged. I hope that through this study they may convey their experiences to a wider audience. The entire process of this study has given me valuable research experience and broadened my knowledge of LD, hopefully improving my future practice as an adult branch nurse.