# The need for leadership: The impact of health action plans for people with learning disabilities living in England

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# Abstract

This thesis reports on the impact of the introduction of health action plans in learning disability services in England between 2001 and 2007. The research compares the experience of a learning disability service in the North West of England to the national position.

A mixed methodology was adopted. Firstly the experience of health facilitators nationally was examined using a self administered questionnaire to gather a mix of qualitative and quantitative data. Two local focus groups were then held with local health facilitators. A further focus group was held for people with learning disabilities who had a health action plan.

The overall finding was that leadership was a crucial factor in determining the success of policy implementation. Health facilitators identified that they were not always prepared in the role of undertaking health action plans. Training was most likely to be offered to non nursing staff, but nurses themselves identified that they did require training as this was, in most cases a new and additional part of their role. Furthermore, contradictions in roles often hindered the health action plan process for nurses. Differences between areas of the country included experience of training; methods of introduction of health action plans; people responsible for the health action plan; and eligibility for a plan. The monitoring and audit of health action plans was also sporadic and there was considerable difference in relation to what constituted a plan.

Several key themes emerged from the research. Health facilitators commented that health improvements had been identified through the use of health action plans, with more improvements being noted where health screening had informed the process. Other benefits of the health action plan included improved communication with the person with a learning disability, between professionals and carers and between carers and families. Local practice mirrored that identified nationally, with good examples provided of improved health for people with learning disabilities and cooperation with some primary care professionals.

In conclusion, the thesis identifies that there has been good practice in the implementation of health action plans and some evidence to suggest that they have helped improve health. Some practice, however, has been less positive and it is argued in the thesis that better leadership, more informed guidance, training and support would have maximised the benefits of the policy.

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# Chapter One

## Introduction

This study relates to people with learning disabilities. For the purpose of this study the definition of learning disability is that from Valuing People (DOH 2001a):

> *A significantly reduced ability to understand new or complex*
> *information, to learn new skills (impaired intelligence) with:-*
> *A reduced ability to cope independently (impaired social functioning),*
> *which started before adulthood with a lasting effect on development*
> (Department of Health 2001a p14)

There is a plethora of evidence, both nationally and internationally, to demonstrate that people with learning disabilities experience a poorer level of health service provision and access to health than does the general population (Howell, 1986, Wilson and Haire, 1990, Department of Health 1995, Allan 1999, Mencap 2006, Michael 2008). Furthermore, evidence suggests that people with learning disabilities experience different disease incidence than the general population. For example, whilst the incidence and progression rates for some diseases are found to be lower than those of the general population obesity was twice as prevalent (Oulette-Kuntz 2005, Bhaumik *et al* 2007). In addition 1 in 10 people with learning disabilities die of cancer (Cooke 1997, Hollins *et al* 1998), they have a higher rate of respiratory disease (19.8% compared to 15.5%), 50% will experience some form of mental illness (Melville et al 2002); they may experience 7 times as many oral health problems (Center for Developmental Studies 2006), and 40% will have some form of a hearing problem (Carvill 2001). Up to one third will have an associated physical difficulty and at least one third of people with mild to moderate learning disabilities have epilepsy (20 times higher than the general population).This figure rises to approximately 60% of people with more profound and multiple disabilities. Finally, they are 58 times more likely to die early than the general population (Hatton *et al* 2004), and some of these deaths are preventative.

There are many reasons why people with learning disabilities have a poorer experience of health services, including lack of knowledge, around health promotion and prevention by both paid and unpaid carers supporting them (Beange *et al* 1995, Singh 1997, Bollard 2003, Cooper *et al* 2006, and Corbett 2007); as well as lack of knowledge attitudes and updating of skills by GP's (Martin *et al* 1997, Hogg 2001, Phillips *et al* 2004, Michael 2008) and practice nurses

(Thornton 1996, Ross *et al* 1994, Smith 2002a and Mellville *et al* 2005). Some carers may not recognise that people are ill so they may not support them to access services in the first place. Once people do access services there are problems due to professionals not being aware of the person's method of communication, predisposition to certain illnesses, or their responsibility under the Mental Capacity Act (Department of Health, 2006b) to obtain informed consent and act in the person's best interest.

Despite these problems there is evidence both nationally and from international research to demonstrate that when people with learning disabilities do access health services, outcomes can be positive. For example when people with learning disabilities have had health checks a variety of unmet, treatable health deficits have been identified (Allan 1999 Barr *et al* 1999, Webb and Rogers 1999, Lennox *et al* 2001, Marshall et al 2002, Kerr *et al* 2005, Cooper *et al* 2006, Iancono and Sutherland 2006).

There have been various government initiatives in the United Kingdom (UK) to address the lack of access and knowledge about the health of people with learning disabilities, (Department Of Health 1995, NHS Executive 1998, NHS Executive 1999, Department Of Health, 2001a). There have also been pockets of documented good practice however access to health remains poor for this group of people (Health Care Commission 2005, Disability Rights Commission 2006). The most significant recent UK Government initiative in order to address this and other aspects of life for people with learning disabilities was the first white paper for people with learning disabilities in England in thirty years. Valuing People (Department of Health 2001a) concluded that many aspects of the person's life needed to be reviewed to determine how services could best support the person with learning disabilities to live a more valued life that mirrored that of the population at large[1].

This thesis will focus on one key area of Valuing People 2001 that related to health. Chapter Six of Valuing People suggested that people with learning disabilities should be supported to access services and develop a health action plan with a health facilitator of the person's choice. The health action plan would identify the health needs of the individual and how these needs could be addressed to improve their life. At the time of the publication of Valuing People, there was a marked lack of research about the introduction and benefits of health action plans.

[1] Valuing People was a UK Government initiative for England. Similar policies were introduced by the Welsh and Scottish Governments.

I was in a similar position to many people across the country, in that I was given responsibility for the implementation of this part of the Government's programme. There was little guidance for those responsible for this implementation and sparse opportunity for feedback about whether health action plans were effective. As a result, I completed a piece of practitioner research to evaluate the experience of health facilitators nationally. The purpose of the research was to improve practice locally, as well as to provide some national data about the implementation of health action plans. The national aspect of the study therefore, linked with a local piece of research that was designed to improve practice by investigating the experiences of a small group of people with learning disabilities who had a health action plan along with the experience of local health facilitators who had implemented the initiative. The local and national practices were compared as part of the research and the results are reported in this thesis.

## Personal Background and Motivation

At the time of starting this study I was a nurse practitioner with 25 years experience of supporting people with learning disabilities. My career began in one of the large institutions, in which many people with learning disabilities lived. As the institutions began to close down, with people being resettled to live back in their own homes in their local community, I moved to work in a supported living service, in the North West metropolitan borough of Rochdale, which offered people with learning disabilities 24 hour staffed support to live in their own home. Over the years I held many management roles and adapted my skills along the way.

So that the reader can understand the motivation for this study it is necessary to understand how the supported living services that I work in differed from many other supported living services across the country. In examining the implications of resettlement from the institutions, the North West Regional Health Authority developed guidance (Model District Service1982) which reiterated the importance of collaborative working between health and social care to enable effective resettlement. Many areas started to develop supported living services managed by non nursing social care staff. At the same time many learning disability nurses began to work in a nursing role within Community Teams for Learning Disabilities (CTLD). Rochdale was one of a few areas in the North West that developed supported living services that were managed by learning disability nurses. Nurses in Rochdale continued to work within supported living services until 2007, although their roles changed considerably during this time.

When this research began my role was that of a strategic health facilitator for people with learning disabilities. As part of this strategic role I introduced the concept of health action plans across supported living services in Rochdale. At this time there were three main supported living services providers. One as discussed, was supported by learning disability nurses and the other two were managed by non nursing social care staff. I facilitated collaborative work to develop a generic health action plan for use across all three services. This role included liaising with some willing GP's to develop health screening for people with learning disabilities as part of a Local Enhanced Service. By auditing the health action plans it was clear that unmet health needs were identified. The audit highlighted that health facilitators, who were not nurses, identified more health needs than those who were nurses.

I decided to undertake this research to try to make sense of what was happening locally in comparison to other areas around introducing health action plans. As I had some idea of regional practices, through my health network contacts, I decided to explore what was happening nationally. When the concept of health action plans was introduced no guidance was given as to their format. Whilst a later document gave some advice, the most common criticism I heard across the health networks' was that staff felt unsupported. Many areas had developed their own health action plans, but these varied tremendously. Locally, we developed a plan through collaboration with all providers, but this was quite large and to some extent parts of it were service led rather than individual requirements. I wanted to determine how other areas had developed their health action plans. This I planned to do using a qualitative approach with a questionnaire.

In addition I also wanted to make a difference locally to the quality of health action plans, so I decided to do this using focus groups for both people with learning disabilities and non nurse health facilitators, as these were the larger group of staff in my area that were taking the process forward. This would enable me to compare and inform national practice, whilst at the same time improving local performance and experiences.

At the start of the research I had several assumptions. I assumed that nurses would be the instigators in introducing health action plans and that these nurses, unlike myself, would be based in CTLD services. I expected that the majority of plans would be developed by the nurses and that a clear audit trail of outcomes would be available. Following regional discussions through the regional networks, I expected that the quality of the plans would not be

monitored as closely, more that the impetus was on them being completed rather that the detail of the plans being examined. Based on my own experience I expected that there would be limited involvement from primary care professionals in the development of the health action plans, and that more plans would have been completed for people in supported living accommodation rather than living with families.

Finally, my experience and that of colleagues, was that we were left to "get on with it" rather than having any formal support or training to take the process forward, and I expected that similar stories would emerge from other health facilitators. Indeed, people's lack of knowledge hindering access to health care is raised within the literature review on several levels, and I expected that this research would identify similar problems when introducing the health action plan process.

## Justification for the research

At the beginning of this research limited literature was beginning to emerge around the role of the health facilitator. However, I could find no published research that reviewed the introduction of health action plans or what if any benefits the health action planning process had meant for people with learning disabilities.

There was a plethora of both national and international evidence relating to access to health for people with learning disabilities, some of which also reported on health screening and the outcomes. For example Kerr (2004) identified that of 181 people with learning disabilities screened, 51% had unmet health needs and Lennox *et al* (2006) identified17/23 people had skin abnormalities. This is discussed in more depth in chapter two. However, this literature referred to small to medium size case studies only, with many studies having taken place outside of England, and only one study that I found related to health action plans, whilst a couple more discussed the benefits of patient held notes. These studies were locality based and none of them had reference to a larger national perspective. Whereas some of these studies acknowledged that professional and carer attitudes and knowledge could have an impact on access to health, again none of this related specifically to the health action plan process.

The data collection for this study concluded at the end of 2007. During and after the research additional information emerged which is discussed briefly below and more fully in the

literature and findings chapters. Evidence emerged to confirm the benefits of health checks for people with learning disabilities (Cooper *et al* 2006), but again this did not also relate to having a health action plan. However the benefits of hand held patient records, like the health action plan were identified by Lennox *et al* in 2008. A study by Kelly and Davies (2008) identified that whilst health action plans were being used, there needed to be wider engagement in their completion.

The importance of health checks was acknowledged by the Department of Health with the introduction of a Direct Enhanced Service (DES) for health checks for people with learning disabilities in 2008. One fundamental aspect of the DES was that work should have already been completed to develop GP registers of people with learning disabilities in each surgery. However, this in itself has proven problematic when trying to identify patients on the list for numerous reasons (Allgar *et al* 2008). In addition, GP's and their staff have to receive awareness training regarding learning disability as part of the DES. Disappointingly, knowledge and training remain an issue with professionals as reiterated by Health Care for All (Michael 2008). Carer knowledge was also further confirmed as being an issue (Iancono and Sutherland 2006, Craig and Melville 2009). In addition this lack of knowledge within acute services is highlighted in the shocking report, Death by Indifference (Mencap 2007) which identified considerable problems in the health care of six people with learning disabilities. Furthermore; the DES has been extended to 2012, as not all people have yet been offered a health check across England.

The outcomes of this research study have contributed to the evidence, and recognition that there was a need for guidance regarding health action plans by the Department of Health in 2007, but disappointingly this guidance was not delivered until 2009. In addition, Mir *et al* (2007) found when reviewing how the health aspects of Valuing People had been implemented in Leeds concluded that there needs to be leadership at all levels to share good practice and monitor outcomes.

Finally, whilst measures are being taken to improve the health of people with learning disabilities, a lot of work still needs to be done. This is confirmed by Valuing People Now (Department of Health 2009a), which in reviewing the progress of Valuing People (Department of Health 2001a) continues to identify health as an issue. Furthermore, all regions across England are involved in the Health Self Assessment for people with learning disabilities

(Department of Health 2008b). This document reviews all health services providers in one locality to identify if people with learning disabilities are receiving a fair and equitable health service, including meeting Valuing People Targets. Whereas they may have made improvements, all services have identified things that they need to do better. One benefit of the Health Self Assessment, which is discussed in more later on in the thesis, is that services are sharing all the good practices that they have developed so that people can learn from each other to improve the patient experience.

The lack of research was frustrating because I wanted to be able to examine the practices in Rochdale, to see whether they mirrored national practice, and if more health issues had been identified by nurses or non nursing health facilitators. I wanted to evaluate whether local practice reflected what was happening nationally, and to determine if local practice could be improved following the lessons learned.

After examining the literature I decided that it was important to undertake this study so that I could inform colleagues nationally, as well as locally, about the benefits, contradictions, complications and successful outcomes involved in the health action plan process. Indeed, with only small local pockets of information available in different areas, there was no actual documented benefit to the health action plan taking place. In my experience health professionals, especially GP's and commissioners require outcome measure and a cost benefit analysis before they commit to initiatives. At the time that this study commenced many areas had not progressed with health action plans, and so I felt that the information gained could be used to provide support where health facilitators were struggling to get support. I decided, therefore, that it would be useful to complete a piece of practitioner research to evaluate the experience of health facilitators of developing health action plans to provide extra data for a national evidenced based practice, in an under researched area.

## Research aims and objectives

This research examined the introduction of health action plans for people with learning disabilities from a local and national perspective. The aims and objectives of the research were as follows:

## Aims

To determine whether health facilitators and people with learning disabilities consider that the introduction of health action plans have resulted in health improvements for people with learning disabilities living in England.

To evaluate the experience of people with learning disabilities and health facilitators in Rochdale in delivering a health action plan, and compare this to the national findings to inform local practice.

## Objectives

1) To identify who was involved in the introduction and development of health action plans

2) To determine how health action plans are monitored and reviewed, and health gains are measured and reported

3) To determine what, how and to whom training was delivered prior to the introduction of health action plan

4) To identify if health screening took place as part of the health action plan and whether this made a difference to the number of health needs identified

5) To identify if health facilitators perceive any additional benefits of the health action plan

## Methods

The research used a multiple methods approach with a quantitative method for the national survey, and a qualitative method for the local investigation. The methods will be explored fully in chapter three not withstanding a summary is given below.

A quantitative approach was used for the national survey in order to gain an understanding of how health facilitators were approaching the process of health action planning. A questionnaire was developed, discussed at regional meetings, amended and then piloted. Following ethical and research and development governance approval, the research

commenced. As there is no data base of health facilitators the questionnaire was sent out electronically to each PCT across England, through the various health networks, and by advertising within the Learning Disability Practice Journal and the Royal College of Nursing bulletin. In total 117 responses were received. The data was analysed using the Statistical Package for the Social Sciences "SPSS" analysis package version 16.

A qualitative approach was used for the local survey in order to capture the experience of people involved in health action planning. Three focus groups were held within the local area. Two groups were held with health facilitators and one with people with learning disabilities. The data was recorded and analysed using thematic analysis.

## Results

The research identified that 'clear leadership' is crucial to the successful implementation of health action plans. Where areas embraced the need for change, and adapted to provide access to health through active health facilitation, the greatest progress has been made. Conversely some areas were managed by people who, rather than change, spent their energy analysing why things cannot be achieved and laying the blame on the system and lack of guidance, rather than examining what they could do to improve things.

There was a disparity in the way that community teams for learning disabilities developed and delivered health action plans across England. Some teams embraced the concept and were given flexibility to adapt, change and develop services around the health action plan process. However, some nurses clearly saw the process as an addition to their already complex role, and gave the researcher the impression that they felt that health action plans had no benefit, and that they had enough work to do already without adding health action plans to their very busy work schedule.

Respondents in the study identified that almost three quarters of people with learning disabilities had health screening as part of their health action plan, but this was not always completed by a primary care professional, so opportunities were missed to develop collaborative working. Furthermore 74% of national respondents identified health gains from the health action plan process, with one respondent identifying that, in addition to individual

benefits, the profile of health screening for people with learning disabilities had been raised, and that processes were now in place that had not been there before.

The majority of health facilitators were nurses and less than one fifth were unpaid carers or family members. Training, or lack of it, and the need to improve staff knowledge, was raised as an issue in all aspects of this research; and some areas had developed comprehensive training packages to address this.

On a national level it was identified that, as a result of introducing health action plans communication has improved between professionals, between families and paid staff, and more importantly, with people with learning disabilities themselves about the health needs of the individual with a learning disability. This was reiterated at a local level in Rochdale, whereby health facilitators identified that the health action plan had proven beneficial in improving communication with families, primary health care professionals and indeed between themselves. One health facilitator had used the plan to discuss the rationale for an individual's behaviour with the care team, and achieved successful outcomes for the person's health. Another referred to having all the information at hand during a health professional's visit, which ensured that the individual received appropriate and timely treatment.

The research locally identified that care staff required training on the rationale and process of health action planning and that the health action plans being used were more service led than individual led, and that work was needed to make the health action plans more individualised. Finally, the focus group with people with learning disabilities identified that the health action plan was useful in improving communication. All agreed that the plan had its use, but that the bigger issue was about health professionals listening to them as individuals.

## Structure of the thesis

To inform the reader, chapter two will provide a background to this study through a thorough review of the literature. Historically many people with learning disabilities were placed in institutions, supported and managed by learning disability nurses. With the NHS Community Care Act in 1990 these people began the process of resettlement back to live in smaller supported living services in their local community. This chapter will explain how, following

resettlement, most nurses roles began to develop into that of a community nurse working within community teams for people with learning disabilities. These multidisciplinary teams began to evolve and take on new roles including that of health promotion and health facilitation.  However, services in Rochdale developed differently to most areas as learning disability nurses continued working in supported living services, and developed their role to include all aspects of health. Therefore, the rationale for investigating national practice to compare with local practice is explained.  An explanation is presented, to demonstrate that the health of people with learning disabilities remains poor, despite various initiatives, and the first White Paper for learning disability in thirty years, Valuing People (DOH2001a) is discussed.

An overview of chapter six of Valuing People is given, as this relates to health and health action plans.  One of the key aspects affecting access to health care is knowledge. The knowledge of the health professionals supporting the person when they present at the clinic; the knowledge of the carer in recognising that the person may be ill, and in understanding healthy lifestyle choices, and the knowledge of the person themselves. This is discussed in some detail with both national and international studies presented to reiterate the need to make sure that people understand the health needs of people with learning disabilities that they support. Finally, an examination of some of the complex health issues and disease prevalence for people with learning disabilities is given to demonstrate why improving access for this patient group is so important. The chapter concludes with a rationale for the research and the questions posed within the study.

In chapter three, first the aims and objectives of this research are discussed, research methods for each part of the study are presented and a rationale is given as to why a questionnaire was chosen for the national aspect of the study and focus groups were utilised locally. Each part of the research design, inclusion criteria and how respondents (questionnaire) and participants (focus groups) were recruited to the study are explained. When this study commenced involving people with learning disabilities in research happened sporadically, so some discussion takes place to explain their inclusion and involvement in this study. This includes ensuring that informed consent was obtained.

During the focus groups, difficulties were encountered with the recording of the interviews so a rationale for an amendment to the research process is discussed. In addition, due to sickness, a second focus group for health facilitators was held with data being collected and agreed at

the focus group meeting. Analysis of the data is given for each aspect of the study. Finally within the study Greig's approach to the theory of change (2003) is used during the data analysis, and this concept is introduced to inform the reader.

Chapter four presents the findings from the questionnaire part of the research. As the findings of research may be used by people with learning disabilities and their carers, as well as health facilitators, data is presented in chart and table format so that the information can be used by people who are less research aware, so information is available in an accessible format. It identifies that the majority of health facilitators were nurses. It also discusses the design, content and provision of health action plans, along with training provided about the health action plan process. Evidence suggests that there were conflicting views across community teams for learning disabilities as to their roles and responsibilities in this area. This chapter reports that 72% of respondents identified that health screening occurred as part of the health action plan process, and 86% agreed that health needs had been identified as a result of the health action plan. There are also a number of other benefits identified by respondents within this chapter. Responses varied when asked if the plans were monitored and reviewed, and only 43% identified that an audit of the plan was completed. Various benefits to having introduced health action plans are discussed, alongside comments that suggest that they are of no benefit at all. Improved communication and involvement are identified by some respondents. Finally, feedback is presented to show that some health facilitators do not feel supported in their role.

Chapter five presents the findings of the health facilitators' focus groups. Participants in the focus groups were from three different supported living services the majority of whom were in management roles. To inform local practice, discussion of some findings from the questionnaire are compared, where appropriate, to the focus group findings so that it can be determined where local practice differed from the national perspective. Whilst the majority of the focus group participants had received training about health action plans they suggested that supported living staff would benefit from training and that this should be delivered by someone other than them. They identified several benefits from using health action plans and these are discussed in the chapter. Participants also gave suggestions on improving the health action plan process in Rochdale and these are presented.

Chapter six presents the findings of the focus group for people with learning disabilities. At the start of the focus group participants were unsure of the focus group process, and so in order to include them in discussions, a 'round robin' approach, where participants were initially asked to respond in turn, was used alongside reminding participants of the ground rules. These rules were to take turns and to listen to others opinions. This ensured that each person became familiar with the process. The focus group was video recorded and responses bulleted, to enable clarification of comments throughout the process. This chapter discusses the findings of the focus group and explores how participants' attitudes changed as a result of the process. Finally, all participants suggested how the health action plan process could be improved and volunteered to be part of the process to do this.

Chapter seven contains a discussion of the results of the research. Firstly, the results from the health facilitator questionnaire aspect of the study are discussed using Greigs typology of change, to demonstrate how attitudes can be instrumental to service delivery. Next, this chapter draws on the overlapping research findings chapter's four to six to discuss the main issues identified. These include leadership, health checks, communication, knowledge and training.

Chapter eight is a discussion of the research findings compared to the initial review of the literature in chapter two. It refers back to chapter two and the initial literature findings and compares the findings from this thesis research study, with current literature developed since the study was completed in order to identify if these findings remain valid today. The implications for practice are identified and insights into the local changes made as a result of this research study are presented. Limitations to the study are reiterated.

# Chapter Two

## Literature Review

## Introduction

This chapter sets the scene for the research. The background to this research is complex. Learning disability services have developed in a way that has led to considerable national, regional and local variation. Yet paradoxically, the local variants came from within a fairly simple, broad national policy. This paradox was central to the research, and elements of it are explored and discussed further in the chapter. In reviewing the literature several themes emerged. People with learning disabilities have poorer health and health access than the general population, yet evidence demonstrates that when people access health services a range of previously unidentified health issues are found (Barr *et al* 1999, Cooper *et al* 2006, Iancono and Sutherland 2006, Lennox *et al* 2008).

The health needs that people with learning disabilities have are similar to that of the general population, in that they need to be able to access services, but they may require additional support to attend, such as easy read letters or someone to help them communicate. In some cases they may need additional support due to the co morbidity of several health conditions and the complexities of their health needs.

For this systematic literature review the following databases and search terms were explored: Ovid, Medline, Cumulative Index to Nursing and Allied Health Literature, British Nursing Index, National Library for Health, Cochran library, RCN library, Norah Fry- www.bris.ac.uk, www.learningdisabilities.org.uk,www.paradigm.uk, www.arc.org.uk, www.man.ac/uk, www.kingsfund.org.

## Search Terms

Learning disabilities, learning difficulties, intellectual disabilities, health facilitation health action plans, health gain, health screening, health checks, health access, health inequalities learning disability research, person centred planning, health records, hand held records, ok

health check, communication, health improvement, learning disabilities nursing, leadership, change cultures, focus groups, user involvement in research. These terms enabled a broad search of issues related to health and people with learning disabilities.

The data bases were initially searched for articles for the ten year period from 1997 to 2007 to obtain both historical and current data. A further search was completed from 2007 to 2011 during the process of writing up the research findings. Citation tracking was also utilised for documents obtained (Hart 1998). This proved useful as by investigating the references in articles reviewed much additional data was found. Additional data was obtained and shared via the learning disability network health network about individual projects and audits completed following queries sent out around the network and by colleagues from discussion at various health network meetings. Although these were not published they did provide insight into practice happening around England. Finally, some areas offered to share local information with their questionnaire return.

Other issues identified that may affect access to health, include the knowledge of professionals, paid and family carers, and the person with learning disability themselves around both identifying that someone has a health need, and then supporting them whilst accessing health services to address this need. Professionals need to have a clear understanding of their role and how they must work with other professionals, to improve the health of this group of people. This is discussed further in some detail in this chapter. Many reports have been written about the need to improve the health of people with learning disabilities, and yet on commencing this study, and even whilst it was being written up, evidence continued to emerge that whilst there are pockets of good practice, access to health remains problematic for some people(Michael 2008).

Valuing People (DOH 2001a) gave guidance on how health could be improved, and suggested the introduction of health facilitators and health action plans for people with learning disabilities, but further guidance on how to progress with these recommendations was very slow to follow, and this resulted in wide variations and interpretation nationally as to how services develop these concepts.

To set the context for this research it is useful to understand how learning disability services have developed over the last thirty years. Historically, care for people with learning

disabilities was provided by nurses within large institutional settings. Medical care was provided by hospital doctors during ward visits and dentists situated on site. Whilst this medical support was available it is questionable as to the actual impact that care given had, indeed studies by Lennox *et al* (2006) in Australia, and Wang *et al* (2007) in Taiwan, clearly demonstrate unidentified health issues for people living in institutions. This literature review does not identify that access to health care was better or worse within the institutions simply that since people with learning disabilities moved into the community, more documented evidence is available that shows access to services is poor.

The care provision for people with learning disabilities began to change in the 1980's with the move away from institutions to supported living services; where people lived in their own homes within the community. With the advent of the NHS Community Care Act 1990 the pace of resettlement increased. This closure of long stay institutions was completed many years ago in the North West of England, but there are a few areas nationally where this is still to be achieved. On examining the implications of resettlement in the North West of England the Model District Service reiterated the importance of collaborative working between health and social care to enable effective resettlement from the institutions. Many areas therefore, started to develop supported living services managed by non nursing social care staff. People with learning disabilities were now offered opportunities to follow the principles of person centred planning (Sanderson *et al* 1997), to decide how to live their lives and whom they wish to engage with. In other words they should be viewed as an individual, and be offered the same opportunities in life as anyone else with the appropriate level of support required.

At the same time, there was an increase in learning disability nurses working in a nursing role within Community Teams for Learning Disabilities (CTLD). The United Kingdom is one of the few countries to have a separate part of the nursing register for learning disability nurses, and yet this field of nursing has been questioned over the years. A brief rationale for why this speciality is essential is given within this chapter. Nurses within the CTLD had to adapt their skills and develop new roles that included improving access to health for people with learning disabilities. Indeed Valuing People (2001a) suggested that learning disability nurses were key to moving this agenda forward.

However, Rochdale was one of a few areas in the North West of England that developed supported living services that were managed by learning disability nurses. Nurses in Rochdale continued to work within supported living services until 2007, although the roles changed considerably during this time. At the start of this research these nurses also took on the role of leading on the health agenda, rather than this being developed by the CTLD. This variation locally resulted in health access work being developed differently in Rochdale to other areas in the North West of England. The research intends to understand what practice happens nationally to compare with local practice. Therefore a description is given about development and roles of community learning disability teams in general, so that it is clear how local practice is different to that developed across many areas in England.

Access to health services for people with learning disabilities is a long standing issue and a discussion of historical health legislation leading up to the introduction of Valuing People (DOH 2001a) the first White Paper in 30 years for people with learning disabilities, is given in this chapter to demonstrate this. The Valuing People recommendations of health facilitation, health screening and health action plans are discussed comprehensively, with examples of how national and international colleagues have taken steps to address these concepts, with some limited success. It will become apparent from this that whilst there is evidence of good practice documented, it is sporadic and does not inform how these processes are being followed on a national level.

Access however, is only part of the issue. The chapter then explores how the knowledge and communication skills of all people, be they people with learning disabilities, carers, social care staff, GP's or health practitioners can impact on how access to health care is facilitated for people with learning disabilities. Examples are given along the way to indicate that access to health care is not just an issue for people with learning disabilities in England, where this research is based, and that work is taking place both nationally and internationally to ensure that people with learning disabilities start to receive equal access to treatment.

Next, a comprehensive insight is presented into the various health conditions that affect people with learning disabilities, some of which have greater prevalence than the general population. Despite this evidence many people have undiagnosed conditions purely because they do not access services. For example, in one study 92% of patients were found to have visual problems

and yet only 30% had been previously diagnosed (Van de Broek et al 2006).The problems were addressed for 22% of these people simply by providing spectacles to use.

Finally, a brief description of leadership theories is presented. These theories  are conflicting and  complex and therefore, in order to make sense of  leadership in the context of learning disability services an approach employed by the then Director of Learning Disability Services in England is introduced. The rationale for use of this approach is discussed. This chapter concludes by reiterating the rationale for the research.

## Definition and prevalence of learning disabilities

Historically, many negative terms have been used when discussing people who have a learning disability (e.g. retard, morally deficient, imbecile, mentally subnormal and intellectual disability). Even today, professionals and others have difficulty distinguishing a learning difficulty (e.g. dyslexia) from a learning disability. Whilst Valuing People (2001a) has now been updated, the definition when describing a learning disability is still currently in use. Therefore the purpose of this research a learning disability is defined as:

> *A significantly reduced ability to understand new or complex information,*
> *to learn new skills (impaired intelligence) with:-*
> *A reduced ability to cope independently (impaired social functioning),*
> *which started before adulthood with a lasting effect on development.*
> (Department of Health 2001a, p14)

Data about the prevalence and types of learning disability is conflicting, but what is confirmed is that the prevalence is increasing. More people with learning disability are now reaching old age and children born with very complex health are receiving assistive technology, which enables them to live a longer life than before. Whilst conflicting, the data demonstrates that the prevalence of learning disability is increasing. Furthermore, services are not aware of people with a mild to moderate learning disability who do not meet the referral criteria, and therefore steps need to be taken now to address access to health as the issue will be about for the foreseeable future.

At the start of this research Valuing People (DOH 2001a) estimated there to be 1.5 million people (approximately 2.5% of the population) with a learning disability living in the United Kingdom. Approximately three percent of children and two percent of adults are estimated to

be in this category overall (Emerson and Hatton 2004) The level of disability will vary from a severe disability requiring full support for all activities of daily life, to a mild learning disability where no service provision may be required, or indeed be available.

Problems arise because people with a mild learning disability are often 'invisible', that is not known to services as they and their families will often struggle on, coping with very difficult circumstances until they reach crisis point for support. These people do not meet the referral criteria for services, so they receive no additional support within their day to day lives or in accessing health services. It is not surprising then that when commencing this study that of the 1.5 million estimated learning-disabled populations, only 224,000 people of all ages were known to learning disabilities services (Emerson and Hatton 2004).

Data collection and information has developed throughout the research process and the latest information suggests that  the prevalence of learning disability is expected to increase by 1% per annum over the next 10 years until there is a prevalence of 10% of the total population by 2020 (Michael 2008). Emerson (2009) identified that there will be a 1.8% increase in the estimated number of people with profound and multiple learning disability becoming adults by 2026 and that 29% of the new adult population with profound and multiple learning disability will belong to the ethnic community by 2029. Whilst these are only estimated numbers, it is essential that services ensure that they deliver equitable access to these people in achieving their optimum health. The needs of the population will mirror that of the general population, but there are some additional predispositions to ill health that professionals need to be aware of and these are discussed later in this chapter.

## The Role of the Learning Disability Nurse Practitioner (LDP)

At the time of starting this research, the limited available literature, personal experience and anecdotal information demonstrated that the majority of health prevention/health access was supported by learning disability nurses. It would be reasonable to assume therefore that the role of health facilitator and health action plan delivery would also be supported by nurses.

The United Kingdom is one of the few countries to have a separate part of the nursing register for learning disability nurses. The continued existence of this separate role has been subject to debate. Briggs (1972) recommended that learning disabilities nursing should be replaced by a new professional grouping and Jay (1979) suggested that the role was defunct and that a

professional group with social care skills should replace it. The government of the day disagreed, and, despite several changes to the delivery of learning disability practitioner nurse training/education, nurses are still able to receive training albeit dual qualification in learning disabilities and social work, which enable the practitioner to practice as a nurse or social worker. However, the advantage of learning disabilities nurse education and knowledge is that it is drawn from a variety of experiences and sources including medicine, psychology, sociology, education and society in general This diverse range of knowledge has assisted the practitioner to be adaptable and innovative throughout the changes in service delivery (Tait and Turner 2001).

With community resettlement a significant change in the nurse's role was inevitable. Through the reconfiguration of services it became evident that other professionals, and commissioners of services, were unaware of the role and skills of the learning disability practitioner and how these could be used within the community setting. Much debate continued as to the need for this type of nursing, and in 1994 a report was commissioned by the Chief Nursing Officer to identify, with key stake holders, the skills of the learning disability practitioner; best practice initiatives involving this speciality nursing role and how best to inform interested parties of the skills that this group could offer (Kay *et al* 1995). The report concluded with overwhelming support for the role of learning disability practitioner, stating that they had a part to play to ensure others understand their roles and skills

> *by ensuring that in collaboration with others that the outcomes of their*
> *practice are made more explicit and communicated effectively*
> (Kay *et al* 1995 p 40*)*

Finally, Valuing People (2001a) suggested that nurses are to act as a specialist in their field and be a point of reference to others; yet one criticism is that other professionals are still not aware of the learning disability nurse or their role.

## Community Teams for Learning Disability

Local practice was that nurses within the supported living services helped to develop the majority of access to health care initiatives, and the recommendations of Valuing People (2001a), I was aware that in other areas, within the region and nationally, this role fell to

nurses within the CTLD. Therefore, a brief history of the development of these teams is provided so that a context is given to their role and the varying role of the learning disability nurse. The reasons for this will become more evident within the findings chapters when evidence is provided that, within the community teams, the role of the team and the nurse in improving health, related in some part to the way that the team was led and how this leadership embraced the concept of changing roles.

CTLD started sporadically in the late 1970s in some areas, but did not really start to be established until the early 1980s with the start of resettlement. Various models exist of community teams, but locally the team consists of learning disability practitioners specialising in adult, transition and children's services, a psychologist, psychiatrist, behaviour specialist, mental health nurse and the social work team provide input. Provisions are underway to develop joint working from one base with the social work team. Nationally many social work and community teams have combined to deliver joint working and these teams took the first step toward collaborative interdisciplinary working for this patient group. There are wide variations and inconsistencies in the way that CTLD function varies, but in reviewing how teams work various authors have concluded that emphasis was on health related issues, including health assessment and health promotion, and the development of collaborative partnerships with primary health colleagues to improve access to services (Mobbs *et al* 2002, Boarder 2002, Powell *et al* 2004 and Barr 2006).

Whilst this training can only be of benefit to the nurse and the people with learning disabilities that they support, care must be taken to ensure that at the same time nurses strive to promote the policies of an inclusive and not separate health service for people with learning disabilities through the development of collaborative practices (Scottish Executive 2000, Department of Health 2001a, Learning Disability Advisory Group 2001, Department of Health, Social Services and Public Safety 2004).This link with other services is vital. Too often learning disability nurses have developed services as there has been little support from mainstream services for people with learning disabilities. Whilst personal experience shows that this may have been the way forward at one time and may have resulted in some small improvements with some services, reports such as Death by Indifference (Mencap 2007) and Health Care For All (Michael 2008) show that change needs to happen strategically and health services need to take ownership of this change and their responsibility for it for services to improve.

This fits within the scope of change advocated in Valuing People (DOH 2001a).Valuing People suggests that nurses are to act as a specialist in their field and be a point of reference to others.  The ideal is that the specialist will become a health facilitator, a teacher, a health promoter and assist in the development of the services relating to health by developing links with the primary care teams. Working in this way is possible and can improve access to health and primary care staff knowledge.

Eccott and Jackson (2003) developed the Health Assessment Planned Improvement tool (HAPI). In recognising their lack of health focused skills, they completed additional training to enable them to successfully take patient histories and carry out physical assessment of patients. These skills were used to successfully assess unmet health needs, but took the process one stage further by then developing collaborative practice with their primary care colleagues to address these needs.

True collaboration is developed through communication, including that of each other's roles and perspectives. However, whilst there are some positive examples of effective collaboration (Hanson 2001, Harrison and Berry 2005a), various researchers around the country has highlighted that this communication of roles is not happening (Allen 2002, Smith 2002a). Hames and Carlson (2006) identified in a study of GP practices that 63% of respondents had never had contact with a CTLD and that 21% of these respondents had no idea what the CTLD role was. Finally, 75% of all respondents had no knowledge of what services were available from the team. During a local study in the Oxford -Anglia area Stewart and Todd (2001) used semi-structured interviews with 17 nurses, 11 operational managers and 4 special education head teachers to explore the current and future role of the learning disability practitioner. Whilst all participants agreed that the nurses had a breadth of knowledge and understanding of the complex needs of their clients, there were few similarities in their thoughts of the future role of the nurse. The teachers saw the role as a health promotion type role. The managers indicated that they should have more involvement in policy development and supporting staff through education. The nurses suggested that the emphasis should be on the development of clinical skills and facilitating access to the relevant types of care.  I would argue that in fact incorporating a mixture of all three suggestions should be used to develop the role and examples later in the literature review will demonstrate how this is possible.

In summary, this section has discussed the development of nursing within community teams for learning disability. To develop inclusive access to health for people with learning disabilities, nurses within these teams had to update their skills and develop collaborative practice with health care colleagues. The make up of teams across the country vary, but they are working towards the health agenda and need to ensure that links with other services happen. Practice in the authors' locale was different to that nationally, in that in the main, nurses in supported living services had taken on the ownership of the health agenda, whilst the local community team work more closely with families and young people.

## Historical Government Legislation

Access to health for people with learning disabilities has been a recognised issue for over 20 years and many documents have been produced to address this to some limited success. Health remains an issue today, and various reports, reporting mechanisms and incentives are available to improve and monitor access (DOH 2009a, Directed Enhanced Service for health checks, CQC). To set the scene for what has gone before a brief history of legislation leading to the document Valuing People (DOH 2001a) that this research is based on is given.

Historically, access to health care for people with learning disabilities has been poor with a consistent deficit of health screening access and health promotion for people with learning disabilities (Howell, 1986, Wilson and Haire, 1990). Previous research that involved health screening within adult day services (training centres) for people with learning disabilities identified high levels of unmet health conditions that could easily respond to treatment (Howell 1986, Wilson and Haire 1990). Indeed during screening of 65 individuals living in the community Wilson and Haire (1990) identified that only 8 people did not have treatable health problems. Furthermore this change in lifestyle, from more restricted institutionalised care to a freer environment can itself bring about new habits and risks to the individuals health status (Turner and Moss1996).

Primary health care is recognised as the key to achieving a healthy population (World Health Organisation 1978). Health promotion is defined as *"The process of enabling people to increase control over and improve their health" (*WHO 1986 p1). The UK government recognised that "people with learning disabilities have greater health needs than those of the general population" with the publication of an additional Health of the Nation Document

(Department of Health 1995). This document identified that people with learning disabilities would need to be given additional special considerations to achieve the recommendations made. It suggested that some associated medical conditions could apply and if so these would require special solutions. Secondly it advocated that health promotion and information given should be done so in an accessible format that the patient could understand. Despite recommendations the deficit in health access and promotion continued (Thornton, 1994, Kerr, Richards and Glover 1997).

A Welsh Health Survey of people with learning disabilities in 1995 identified a range of baseline health disparities for people with learning disabilities. These are presented in the table below. In summing up this survey Kerr (2004) concludes that there is a higher rate of sensory deficit, epilepsy, behavioural and psychological disturbance in the patient group than in the general population.

*Table2.1 Health disparity in people with learning disabilities (in Kerr 2004 page201)*

| Area of disparity | Example in learning disability |
|---|---|
| Increased mortality | Lower life expectancy |
| Increased morbidity | High levels of epilepsy, sensory impairment and behavioural disorder |
| Increase in negative determinants of health | High levels of obesity and underweight: low employment: fewer social connections and meaningful relationships |
| Access to services | Low rates of uptake of health promotion |
| Quality of services | High prescription rate of antipsychotic medication with no evidence of psychosis: high rate of unrecognised disease identified on health screening |

Kerr (2004) has argued that the achievement of good health for people with learning disabilities brings with it additional challenges, as people with learning disabilities *"are a heterogeneous population with varying needs who receive a similarly complex array of health needs"* (page 200). Whilst this may make good health more difficult to achieve, it does not

excuse the apparent lack of progress in improving access to fair equitable services for people with learning disabilities.

People with learning disabilities are not a homogeneous group, and have very diverse health needs. Some may only require preventative measures such as cervical screening whilst others may have 'chronic and complex problems requiring constant monitoring' (Lennox and Kerr 1997). What is evident however is that whatever the need, people with learning disabilities continue to receive an inequitable service (Mencap 2006, Disability Rights Commission, 2006). In his review Michael (2008) takes this one stage further and states "that people with learning disabilities find it much harder than other people to access assessment and treatment for general health problems that have nothing directly to do with their disability"(page 6)

Yet it is interesting to note that whilst evaluating service performance across 15 NHS Boards in Scotland, Campbell (2007) concluded that; "health services which concentrate on adequately addressing  inequalities in access and provision for those with the most complex healthcare needs have most success in addressing health needs, more generally for people with learning disabilities"(page 36).It seems that lessons could be learnt from analysing the Scottish findings more deeply and putting the lessons learnt into practice in England.

The Scottish Executive (2002) subdivided the health needs of people with learning disabilities into three groups. Those with every day health needs, for example, the need to be registered with a GP and the need to be included within national health screening and health promotion programmes and initiatives. Secondly, people who had extra needs because of their learning disability, for example any additional health needs that are specifically associated with the underlying cause of their learning disabilities such as adults with Downs' syndrome require annual thyroid function tests. More over people may need additional preparation time to prepare for health consultations. Furthermore, up to one third of people with learning disabilities have an associated physical difficulty. Additionally people with complex health needs may have a wide range of health needs that can co-exist. For example, multiple physical disabilities and profound impairments with high support needs and eating, drinking and swallowing problems which may require procedures such as enteral nutrition and those with Autistic Spectrum Disorders. In addition, many people with learning disabilities cannot read or

write, so the information they require needs to be developed in an appropriate format that they can understand. This may be pictorial, taped, or additional time to discuss issues.

Although the number of people with complex health needs is relatively small compared to the other learning disabled population the physical, medical, emotional and psychological needs are vast and require more staff time and a higher level of staff support (Campbell 2007, Mansell 1994). In addition there is often chronic general poor health due to late diagnosis of underlying conditions and non- reporting or recognition of symptoms (Beange *et al* 1995). And people with learning disabilities have a higher risk of early death than the rest of the population (Hollins *et al* 1998).

The importance of health screening was again raised with the publication of Signposts for Success (NHS Executive 1998), which informed primary health care professionals methods of good practice in health services for people with learning disabilities. This document suggested that routine health checks were a good way to identify areas of unmet need for people with learning disabilities. Additionally, Once a Day (NHS Executive 1999) gave guidance on how to support people with learning disabilities to access services. It reminded primary health care professionals that "many people with learning disabilities have undetected conditions that cause unnecessary suffering or reduce the quality or length of their lives" (page 3) The document went on to discuss ways to engage the patient group, including ways to improve access and communication, and the liaison with learning disability practitioners/community teams as a way of improving the patient experience. It also informed staff that certain genetic conditions required additional, often regular health screening assessments related to their condition (e.g. thyroid monitoring for people with Downs Syndrome). As Boarder (2002) discussed in his research this collaboration did not appear to be happening. Indeed, during research into practice nurses' knowledge regarding people with learning disabilities locally 96% of practice nurses had not even heard of the document (Smith 2002a).

Not only is access poor, Facing Facts (DOH 1999a) concluded that there were inconsistencies in the provision of health care in different parts of the country and that "Significant problems were reported with the development of appropriate and accessible primary, specialist, and

continuing health care services- especially for people with complex or additional physical or mental health needs" (page 18)

These findings were of no surprise to people with learning disabilities and their carers. Indeed they confirmed the findings of Singh (1997) and Band (1998) gathered whilst addressing issues relating to provision of health care. What is more surprising is that these issues continued to be raised (Equal Treatment: Closing the Gap DRC 2006). This reiterated that people were further disabled by barriers placed on them by external forces (Prime Ministers Strategy Unit 2004).

The NHS Plan (Department of Health 2000a) set out the intention for a person centred approach to care, with the needs of the patient being core to service provision. The plan advocated collaboration between professionals to ensure that services are shaped around the needs of the patient, families and carers. It is evident that this person centred approach did not extend to recognise the needs of people with learning disabilities. In 2001 the government introduced Essence of Care(DOH 2001c). This came about because of poor standards of care and an increase in the number of complaints by patients. The concept following on from the NHS Plan was about putting the patients at the centre of the care and viewing things from the patient's perspectives. Standards were developed by working groups of professionals and patients who developed a set of benchmarks to identify and measure best practice in service delivery. Throughout this thesis it will become apparent that the following themes continue to be a key issue in why services are failing to meet the needs of people with learning disabilities

- Communication
- Dignity and respect
- Health promotion

Despite this it is evident that there continue to be issues regarding accessing patient centred care (DOH 2008a).

## Valuing People 2001

The research reported in this thesis was designed around the health recommendations from chapter six of Valuing People (Department of Health 2001a) and the relevant sections of this document are described below. Where the literature review identified good practice that had developed since the Valuing People recommendations this is also included. This is to

demonstrate that whilst evidence of good practice exists, there is no documented evidence to demonstrate whether this practice is isolated or is occurring across other areas of the country, where practitioners have not had the opportunity to publish their work.

Valuing People (2001a), the first White Paper for people with learning disabilities in thirty years, criticised service provision to people with learning disabilities in all aspects of care provision. The policy was based on the four principles of rights, independence, choice and inclusion. It emphasised the lack of collaboration between services, and the level of choice and participation afforded to this vulnerable group. To address this it outlined ten national objectives to improve the quality of service provision by developing effective partnership working across all services. These objectives are recorded in table 2.2

*Table 2.2 Valuing People Objectives (Department of Health 2001a)*

1. Maximising opportunities for disabled children
2. Transition into adult life
3. Enabling to have more control over their lives
4. Supporting carers
5. Housing
6. Good health
7. Fulfilling lives
8. Moving into employment
9. Quality
10. Workforce training and planning

This thesis focuses on objective 6 Health. However, it recognises that all objectives are inter related as they all have a bearing on each other. Where there are issues or inadequacies in one aspect of the individual's life, for example poor housing, it can impact on the person's health which may in turn affect their opportunities for employment, leading to a less fulfilling life and so on.

In order to both monitor and support changes at national and regional level the Valuing People Support Team was set up. This comprises nine regions with a nominated lead for each region, who also took the lead on one objective from Valuing People. Alongside this, to promote

change on a local level, Learning Disability Partnership Boards (LDPB) were set up, to include local stakeholders, including people with learning disabilities. These Partnership Boards dictate funding streams and comprised representatives of service providers, so that, in theory, this should have developed collaborative working practices.

Valuing People confirmed that people with learning disabilities have more health needs than the general population, yet access services less often. It suggested that these difficulties are compounded by the ignorance of health care providers in both primary and secondary health care services who do not appear to attempt to include this 'harder to reach' group within current initiatives and consultations. To focus on health improvement on a national level the White Paper indicates that the way forward is "To enable people with learning disabilities to access a health service designed around their individual needs with fast and convenient care delivered to a consistently high standard and with additional support where necessary"(DOH 2001a page 59).

Valuing People (Department of Health 2001a) made several recommendations related to health. It reiterated that despite all initiatives previously discussed little had changed to improve the health care for this vulnerable group. To address this it suggested that health facilitators should be identified for all people with learning disabilities by Spring 2003 and all people with learning disabilities should be registered with a GP by June 2004.Furthermore it instructed that people with learning disabilities should be offered a health action plan, designed in a person centred way with an identified health facilitator of their choice by June 2005. These recommendations and their relevance to the thesis will now be discussed further. At the end of the chapter I have cited how this links to the research questions asked within the questionnaire design for this study.

Valuing People (2001a) recommended that health facilitation should occur on two levels. Firstly there should be a strategic (organisational) level to develop the process within each area. Secondly there should be an operational (hands on) level whereby the individual should be supported to have and implement a health action plan. Limited guidance was given as to how this should occur, with no additional funding to facilitate health action planning. Services were left to decide whether health facilitation would occur as an extension to existing roles or

by creating new specialist posts. Various studies have been undertaken to explore the role of the health facilitator and I will not explore this in depth, but give an overview of the literature available to inform the reader.

In order for there to be real change in the health outcomes for people with learning disabilities it has been suggested that *"Health action planning and health facilitation should support the mainstream health agenda and the drive to reduce health inequalities"*(Rogers and Russ 2003 page 36).In other words it is not enough to improve the individual's health. Outcomes for these health action plans should feed back into the local health agenda looking at the wider determinants of health, thus informing local health targets and agendas. For this reason, health facilitation needs to be addressed at both a strategic and operational level (DOH 2002).

However, there are three levels to health facilitation; strategic, operational and individual which together can bring about both individual and organisational change. The strategic level would involve working with the Learning Disability Partnership Board, (LDPB) and PCT, to ensure that the health action plan happens in a person centred way and that the local health economy includes the needs of people with learning disabilities in their strategic health plans. On an operational level, health facilitators will work with primary care and families to develop pro-active pathways, for all aspects of health care into primary care for people with learning disabilities. Finally, on an individual level, the health facilitators will work directly with families, carers and individuals with a learning disability to create a health action plan and recognise and address their own health needs

Matthews (2002) argues that carers are best placed to undertake health care tasks. However with the majority of health facilitators being from a social care background, it is argued that they do not have the skills to both ensure that the health action plan links with person centred planning and identify any possible health issues (Thompson and Cobb 2004, Evenhuis *et al* 2001, Singh 1997).

## Health screening

The importance of health screening was first identified by the Royal College of General Practitioners (1990) who suggested that regular medical examination and general assessment was a right for this patient group. Additionally, during two drop-in health clinics for people

with learning disabilities, Allan (1999) discovered that of the 74 people assessed, all had at least one unmet health need and Barr *et al* (1999) identified that, of 76 people with Downs Syndrome screened, 10 had undiagnosed hypothyroidism.

This was again raised by Cumella *et al* (1992). They acknowledged that GPs might have issues coping with the influx of people with learning disabilities who now live within the community, but that these issues could be addressed in several ways including annual health checks, the development of a register of these patients and training for GPs. Issues regarding GP skills are discussed later in the chapter.

Health screening was reiterated within Valuing People (2001a) with the suggestion that health screening should inform the health action plan with the outcomes assisting to update the individual's health goals. In England, Martin (2004) has been offering his patients annual health checks for seven years. Whilst developing the HAPI tool Eccot and Jackson (2003) concluded that health-screening tool was a pragmatic solution in addressing health deficits.

Kerr *et al* (2005) further demonstrate the importance of health checks. When screening 181 people with learning disabilities in Wales, they identified that over half (51%) had unmet health needs, with 9% of patients having serious health problems. Wales has become proactive with the health screening with the introduction through the Welsh assembly of the Cardiff health-screening check for people with learning disabilities. Cooper *et al* (2006) conducted a comparative study of 100 people with learning disabilities in Scotland. They identified 50 people with learning disabilities (Intervention Group) who had undergone a health screening assessment by a nurse. The outcomes of this assessment were reported to the GP and any local referral algorithms for referrals by the nurse were followed. No further action was then taken by the nurse. After one year a retrospective review of the case notes was completed to determine

- The level of new health needs detected in any way during the 1-year period
- The extent to which these were met
- The extent the ongoing health monitoring and health promotion needs were met

At the same time a matched control group of 50 people with learning disabilities were identified that had not undergone health screening. This group had only accessed the GP when they or their carer had considered a need impactful enough to request and attend a consultation. A retrospective review of the case notes were conducted as before. The results were:

i.   The intervention group(IG) had 240 health needs detected compared to 113 by the control group

ii.  176 of the IG needs were attended to. 62% of these needs had been identified at screening

iii. For the IG 321 health promotion needs were identified compared to 241 for the control group where fewer needs had been documented

iv.  66%(143/231)health promotion needs were met for IG compared to 27% (65/241) for the control group

v.   153/231(66%) health promotion needs were newly identified at health screening for the IG

vi.  107 health monitoring needs were identified and documented in the case notes for the IG. Of these 87(81%) needs had been met

vii. In comparison 97 were identified for the control group, but were not all documented. Of these 65%(63/97) were met

viii. 51% (55/107) of health monitoring needs had been newly identified at heath screening for the IG

Cooper *et al* (2006) concluded that where screening had occurred and been reported to the GP, more health improvements had been identified and occurred than where patients or carers reported issues themselves to the GP without screening taking place. However they suggested that further research was required, to determine whether the outcomes of health screening by the GP would be different to that when the screening takes place by a specialist liaison team as in this case.

Marshall *et al* (2002) reported on a learning disability nurse led clinic in Ireland. In total 464 people with intellectual disabilities were screened (24% were aged 10-19 and the remainder were adults). In all 200 (54%) were referred to 91 of the 146 GP's in the area, representing an average of 2.7 referrals per GP. This study identified that 64% of the adults and 26 % of the

10-19 year olds were overweight or obese. In total 122 people were identified for weight reduction. Furthermore:

- Blood pressure was checked for 411 people and 60 (15.6%) were identified with hypertension
- 284 were checked for cholesterol levels with 30(11%) having high and 65(23%) having moderate levels of cholesterol
- 42 (9%) of people were found to smoke
- 22 had 2 or more risk factors

In New Zealand annual health screening was introduced for people with learning disabilities (Webb and Rogers 1999). In the initial process 1311 patients were screened. This study identified that 952 people (73%) required action. In total 1,798 follow up actions were identified.

Whilst writing up this research and following on from the recommendations of the Michael report (2008) a 2 year Direct Enhanced Service (DES) was introduced for people with learning disabilities at a cost of £22million per year. This DES relates to people with a moderate/severe disability. It does not include people with a mild learning disability. This group are often the invisible population, unknown to services that it could be argued are actually more at risk, because they do not have the support mechanisms in place. The DES has now been extended until 2012.

The pre-requisites for the DES are that GP practices will have liaised with the Local Authority to share and collate information, in order to identify people with moderate to severe learning disabilities on their register who are of 18 years of age and over, and the practice (at least one GP, the practice nurse and practice manager) will be expected to have attended a multi-professional education session. They may also liaise with the community learning disability team for support. Additionally they will need to provide an annual health check using a predetermined list of requirements. These checks should integrate with the patient's personal health record or health action plan. Where possible, and with consent of the individual, carer's and support staff should be included in the consultation.

This DES addresses some of the issues raised in the Michael report, but again it is not mandatory so not all GPs will participate. Whilst it is a start in the process, more could have been achieved if this service had been mandatory. In order to promote the DES locally, it would be useful therefore to determine what, if any, health screening practices took place to inform the health action plans completed across England and what if any difference this made to the individuals health

## Health Action Plans

People with learning disabilities should be offered a health action plan, designed in a person centred way (Sanderson *et al* 1997), with an identified Health Facilitator of their choice by June 2005(Department of Health 2001a). Valuing People (DOH 2001a) also suggested that the; "Responsibility for ensuring completion of the Health Action Plan rests with the health facilitator in partnership with primary care nurses and general practitioners" (page 64)Valuing People( 2001a) suggested that health action plans will be offered and reviewed at the following key stages in people's lives:

- Transition from secondary education with a process for ongoing referral
- Leaving home to move into a residential service
- Moving home from one provider to another
- Moving to an out of area placement
- Changes in health status e.g. as a result of a period of out-patient care
- On retirement
- When planning transition for those living with older families

In reviewing the literature for this study I found three small studies (11, 23 and 25 participants) that looked at the use of hand held records/ action plans for health. Arguably, the flaw with these studies was that information was not available to determine if health actions identified had been followed up. Lennox *et al* (2006) demonstrated the benefits of completing their version of health action plans during a study of 25 people with learning disabilities in transition from care in an institution into community care in Australia. Lennox *et al* used the comprehensive health assessment programme (CHAP). The CHAP process involved the carer gathering the client's medical history, and then the GP would review this and carry out a medical assessment and complete a health care plan. Two clients did not have a medical

review by the GP. The study findings showed considerable health issues that required addressing:

- 19/23 clients had abnormal Body Mass Indexes
- 13/23 immunizations given
- 2/23 vision impairments
- 2/23mental health issues reported
- 17/23 skin abnormalities
- 10/23 medication changes
- 21/25 were on multiple medications

Of the 23 CHAP'S completed, 89 actions were recommended, an average of 3.9 per person. The true range was zero actions (1 person)-9 actions (1 person).Whilst this study suggests a high level of unmet needs in institutionalised clients in transition from a small sample size, it is not unique. However one flaw identified with this study is that it does not report the outcomes of the consequential 89 actions.

In a study across 4 supported living service providers in Rochdale, (incorporating 2 PCTs) of 205 health action plans completed 121 unmet health needs were also identified (Smith 2005). There were 140(69%) plans that had no unmet needs and the other plans averaged 1.8 unmet health needs (27 with 1 unmet need to 1 with 6 unmet needs). This resulted in 189 referrals for follow up investigations. When the health facilitators were asked 78 % (15) stated that the health action plan had been of some benefit, 7 % (15) stated that the individual benefited greatly from the plan and10 % (19) felt that the health action plan had been of no benefit at all. The study identified that the quality of the plans varied therefore a benchmarking group was set up to review this.

Both these studies highlight the fact that whilst care staff can and do supply health information to the health action plan for the individual, there must be collaboration with primary health care services to accurately assess the individual's health. Unlike the examples of successful screening initiatives discussed (Lennox *et al* 2006, Kerr *et al* 2005, Barr *et al* 1999), the Rochdale study did not utilise health screening as part of the health action plan process. This

was down to the cooperation of the individual GP as not all GPs felt that screening was appropriate.

Turk and Burchell (2003) evaluated the use of hand held personal health profiles (PHP), which had been developed prior to the suggestion of health action plans. In evaluating the introduction of PHP they identified that people with learning disabilities felt empowered for having these plans and that they aided communication with primary care staff. However, their study was very small (11 users). The study did not identify whether the use of hand held notes resulted in positive health gains for people with learning disabilities. They concluded that further research was required and are currently in the process of evaluating 250 PHP in their locality

Hunt *et al* (2001) used the Ok Health Check to assess patient health, make action plans and follow up with primary care contacts. Of 35 patients screened all needed some follow up actions and 32 people were referred onto a GP. Community nurses then worked with the individual, primary care and the carers to ensure that health actions identified were addressed. Using this approach across a 12 month period health gains were identified for all 35 patients.

Finally, Marshall *et al* (2002) in Ireland identified that 64% of his adult study sample and 24% of 10-19 year olds were found to be overweight. Of these, 122 who also had hypertension were referred to the GP or given health promotion advice. In a follow up questionnaire 3 months later, 70 people responded. Of these 29 (24%) had taken no action. The remaining 41 took a variety of actions, yet only 3 people who had been referred for weight management mentioned a loss of weight. As a result health promotion sessions were set up and 25 individuals attended. Of the 20 individuals who needed to lose weight the mean starting weight was 85kg. This reduced over the 6 week class to 81.6kg. This project demonstrated that a combination of screening and referral alone is not sufficient to ensure health change and gains. A plan of action was required along with support to achieve this action. It will be useful therefore to determine if and how other areas have combined this method to identify health gains

With the increase in the number of social care providers nationally, partnership working between primary and community care continues to be a challenge (Hudson *et al* 1997). However the use of patient held records has been found to prove beneficial as a communication tool (Curtice and Long 2002, Lester *et al* 2003). This can be addressed by setting up a working group, as in Rochdale, of all providers of learning disabilities services to look at the development of health action plans. This collaborative approach ensured that all providers were involved and informed in the development of the final health action plan. This also meant that a standardised format was used within primary care to enable the individuals care needs to be addressed in a holistic way (Curtice and Long 2002).

## Format of Plans

One criticism of Valuing People (DOH 2001a) is that very little guidance was given as to the completion of these plans. Despite the guidance issued in 2002, practitioners at the regional health networks have often discussed that this was insufficient and that more direction and guidance was required. At commencement of this study this information was not available. However, what was known was that the plan, should detail all actions needed to improve and maintain the health of the individual, by co-ordinating services and support. The plan should identify actions to improve the health of the person and the help needed for then to achieve this (Howatson 2005). In addition it was advocated that people with learning disabilities should have a health facilitator of their choice to oversee and monitor the health action plan, with training provided for this role as required (DOH 2001a and DOH 2002). This resulted in areas developing their own health action plan, hopefully, through consultation with people with learning disabilities. It is expected therefore that there will be a variety of formats and standards available around the country.

The health action plan should be a live document that can be amended and adapted over time (Harrison and Berry 2005b). It should record not only health needs but also health improvement and gains. Harrison and Berry (2005a) suggested that the plan should also include the needs of the carer. Many people with learning disabilities live at home, with increasingly older carers so this is a valid point. In their study of 62 patients they identified 'several cases' where the health needs of the carer had to be addressed and two cases where

serious health issues were identified in carers. It is critical therefore that for people supported by carers, the carers needs are also considered as part of the individuals health action plan.

Matthews (2005) reports that health action plans were slow in getting established. Reasons for this included difficulty engaging with GPs and Primary Care Teams. This research intends to discover if this remains the case nationally or whether there are pockets of good practice that disprove his suggestions. It will also be useful to identify the level of user involvement in the health action plan, as whilst Howatson (2005) discusses excellent examples of health action plan, he infers that the health action plan is to be service developed rather that person led.

Equal Treatment: Closing the Gap (DRC 2006) reported on the continuing health inequalities faced by people with learning disabilities. The report Promoting Equality (DOH 2007) responded with a number of recommendations including a firm commitment to publish additional guidance on health action plan. It is disappointing to note that this additional guidance took until 2009 to be published. The implications and recommendations of this report will be discussed later in the discussion chapters of this thesis to determine if the findings of this research concur or disagree with the outcomes.

There were several issues that could also influence the successful introduction of health action plans and health improvement for people with learning disabilities. These include the setting up of a GP register to identify a person with learning disabilities which is paramount to moving things forward. Next is the knowledge and understanding about the issue that may affect access to health care for people with learning disabilities. This is an issue across professionals, carers and people themselves and therefore this is discussed in some detail. Communication with people and the collaboration between services is the last issue of interest in this section.

Alongside developing health action plans, Valuing People (DOH 2001a) advocated that to assist with reducing health inequalities all people with learning disabilities should be registered with a GP by June 2004. The application of this recommendation has been sporadic at best. The average GP list of 2000 will include 6-8 patients with a severe learning disability and approximately 30 with moderate learning disabilities. People with moderate disabilities are

more difficult to identify as they may not access mainstream learning disability services and, therefore, do not appear on a pre-determined register (Thornton 1994). This challenge was further confirmed by Allgar *et al* (2008) whilst developing a template for use across 30 GP practices in Leeds. Some practices used the full template and some used a shortened version to search their databases for people with learning disabilities. At the same time a Leeds wide social services data base for people with learning disabilities was developed. This data base identified 1056 people with learning disabilities in the GP practice area and the GPs identified 1420.However of the 1056 identified by social services only 46% of these were on the GP lists. By combining both lists a total of 1843 people with learning disabilities were finally identified and registered a difference of 423 patients, which is most likely due to the fact that only people with severe and complex learning disability would meet the criteria to access services. This example demonstrates how complex and time consuming the process of developing a register can be.

Some areas have employed Local Enhanced Schemes (LES) to induce a payment for setting up this register and others have not yet commenced. In the strategy for the Quality Outcome Framework for 2006, 4 points were awarded for having a learning disabilities register. This incentive resulted in limited improvement in registers within the author's locale and anecdotal evidence suggests that this improvement was mirrored across the North West of England. A register alone however, is not enough. Marshall *et al* (1996) discovered during a local survey of GPs views, that not all GPs could define what constituted a learning disability. They also found that GPs felt that people with learning disabilities should receive services from specialist secondary health providers, such as psychiatrists, as they were better placed to deal with these patients. In a similar survey GPs agreed that they were responsible for the medical care of these patients, but were generally against health promotion and screening initiatives for people with learning disabilities (Bond *et al* 1997).The issues regarding GP knowledge are now included within the learning disability DES as members of the team have to attend an education session to receive payment for the DES. However, at the time that this research started, knowledge across all people providing support for people with learning disabilities to access health care remained an issue and this is now discussed in more detail.

Following a comprehensive health screening study of 120 people with learning disabilities, and a follow up questionnaire to 170 carers Martin *et al* (1997) concluded that "Support for

GP's, medical students and dentists in updating and improving skills in the area of intellectual disabilities is an imperative part of safeguarding the future for this disadvantaged group. Health care can be improved by medical training" (page 406)

Hogg (2001) has discussed in some detail that GP training regarding learning disabilities is very poor. Very limited time is given during undergraduate or postgraduate training to the health aspects affecting people with learning disabilities. Furthermore, GPs felt training was unnecessary due to the low number of patients on the caseload. Not all GPs are reluctant to review practice, as demonstrated by Martin (2004), who had been carrying out health screening practices in his surgery for the last seven years. Gill *et al* (2002) during a study of 310 GPs concluded that GPs held positive attitudes towards providing health care for people with learning disabilities. Unfortunately despite initiatives discussed, GP's remain reluctant to engage with this patient group (McConkey 2002, Dinsdale 2004).Furthermore education in undergraduate and post graduate training remains poor, reinforcing negative attitudes and behaviours (Michael 2008).

Training and awareness is not just an issue for the GP. Indeed lack of knowledge by Primary Care staff in relation to people with learning disabilities is acknowledged (Thornton1994 and Thornton 1996). During focus group interviews with three primary care teams Thornton (1994) and Thornton (1996) found that the practitioners involved in the interviews identified that training was required. It would appear that exchanges were open and frank during these meetings yet outside constraints would prevent training initiatives occurring. There was no indication as to whether training has since occurred as a result of the research or to identify if there has been any impact on access to care.

Research into the training needs of practice nurses by Ross *et al* (1994) concluded that whilst practice nurses undertook many tasks, little training (if any) had been given in some areas of their work. Although learning disabilities was not one of the categories, it could be reasonable to assume that this concurs with the gaps in knowledge for practice nurses (Allan1997, Smith 2002a). Melville *et al* (2005) confirmed this lack of training in their research to measure Practice Nurses (PN) attitudes, knowledge, training needs and self-efficacy when supporting people with learning disabilities to access primary health care. They used a postal

questionnaire to all PN in Glasgow (n=292) obtaining a high response rate of 69% (201). They identified that whilst 33% of PN had received 'some training', 45% of respondents had no training at all regarding the health needs of people with learning disabilities. Furthermore whilst contact with people with learning disabilities had been limited, 50% reported that their workload with people with learning disabilities was growing. Almost 72% of PN considered training on learning disabilities to be a priority.

Unlike previous research discussed Melville *et al* (2006a) acted on their research findings to develop a training pack based on respondent's reports for PN.  They canvassed PN from their initial research and identified 79 volunteers to receive training. Only 63 of these continued with the research. Candidates were split into 2 groups; Group one received the training pack and a 3-hour training session (n=42-67%); Group 2 received the training pack only (n=21-33%).

Three months after training, the original questionnaire from the 2005 study was completed by participants and 60 of the original PN from the first study who had not received any training (group 3). They concluded that following the training there was a significant difference between the knowledge of groups' 1 and 3 (t=3.41). Furthermore there was a significant increase in knowledge scores for groups 1and 2 following the training (t=-6.14 and t=-3.00). However, using a training pack and teaching session did not appear to increases nurses knowledge more than the training pack alone. However, following training PN reported the following changes in practice

- 67.4% offered longer appointment times
- 26% made changes to make the service more accessible
- 56% supported communication with the use of pictures, symbols or photos
- 69% reviewed their role in supporting people with learning disabilities to access primary health care

Melville *et al* (2006a) acknowledged that there were limitations to their study. They did not randomly select participants, using volunteers, who they argue were more willing to learn by the fact that they had volunteered in the first place. However, it is evident that an increase in knowledge had improved the health experience for people with learning disabilities in this

case. Finally primary care staff do have a key role in ensuring that patients and carers fully understand the nature of their health conditions and the need to maintain healthy lifestyles (DOH 2005). It will be interesting to determine therefore, what, if any, level of involvement primary care staff have had in the development of health action plans.

Our Health, Our Care, Our Say (Department of Health 2006a) suggested that the patients should be supported to self assess their health and then only attend the GP if they have identified any risk factors. Hogg (2001) argues that "self referral (to the GP) is rare again in part because of communication but also because carers do not identify health needs" (Page334).Furthermore Matthews (2005), argued that many people with learning disabilities will not have the intellectual capacity to recognise that they are ill, let alone communicate this to their carers. However, Valuing People (Department of Health 2001a) stated that;

> *"Those who live and work with people with learning disabilities*
> *are well placed to encourage healthy lifestyles. Providers of support in*
> *social settings have a responsibility to ensure that an individual's general*
> *health needs are met by developing  links with health professionals,*
> *promoting staff competence  in basic health issues and implementing*
> *health promotion initiatives"* (page 62).

Carers, whether family members supporting people at home, or paid carers in supported living services, are crucial to supporting people with learning disabilities to access health services. It would be fair to assume that carers, who support people with learning disabilities, often for 24 hours a day, could identify any changes in the individual's condition and therefore support them to access services in a timely fashion. Evidence, discussed below, suggests that this is not the case. In addition, where carers do contact services, they complain that often their opinions are ignored.

There are approximately 5.2 million family carers across England and Wales. Of this total 60% look after someone with a disability, 15% look after someone with mental/physical ill health/and or a learning disability. However 60% of people with learning disabilities live with their families. Family carers have an intimate knowledge of the individuals well being yet they continue to report experiences of being ignored or not consulted by health professionals (Michael 2008). In addition many people with learning disabilities live in supported

accommodation, with care provided by non medical social care staff and are therefore reliant on 'health management by proxy'(Cooper *at al* 2006).

Valuing People (Department of Health 2001a) suggested that social care staff and carers need to gain "Competence in basic health issues and implementing health promotion initiatives" (page 62). However, during research with practice and treatment room nurses in Scotland, to determine their knowledge and involvement of people with learning disabilities, respondents implied that unqualified carers did not have the knowledge to provide adequate health care for people with learning disabilities (Powrie 2003). They identified that carers changed regularly and did not appear to communicate with each other, with the result that medical investigations were often delayed, or that patients did not attend for appointments. Corbett (2007) suggests that the use of hand held records could assist with communication between carers and health professionals. Depending on the design of the health action plan some of these areas could be addressed quite easily. For example, all tests and on going health actions could be recorded so that even unfamiliar staff would be able to pick up the health action plan and feed back progress to the health professionals.

Carers get to know the clients that they support very well, often developing insight into the individuals needs, and are crucial to health promotion initiatives with the people with learning disabilities (Bollard 2003). Yet Singh (1997) in reviewing the role of carers when accessing GP services identified that only 33% of paid carers, and 19% of unpaid carers had received information about health care. Thereby demonstrating that to improve people's health, training is required. Furthermore Lewis and Porter (2004) reported that "The use of preventative health services amongst people with intellectual disabilities was notably low and that this trend was of particular concern among adults living independently or at home with their families (more so than among adults living in community care facilities" (page 155).

The use of preventative measures is not just down to the carer's knowledge, but also to that of primary care staff in understanding their responsibilities', people's rights and best interest. For example, many women with a learning disability are still refused a smear test because both carers and GPs assume a smear is not necessary due to the woman having a learning disability. Yet patient stories, from North West networks, continue to emerge, where pre cancerous cells

have been identified following desensitisation work and best interest discussion around the need to be involved in the screening process.

Iacono and Sutherland (2006) completed a study of 659 adults with intellectual disabilities living in Australia. Of these people 279 lived with their family and 344 lived in staff supported housing and 36 alternated between the two. They identified that those living in staffed accommodation visited the GP two to five times more than those living with their families. They suggest that this may be because relevant government authorities mandate some issues such as influenza vaccination, or that it may be associated with concerns about duty of care. They conclude that "there is a need to educate both people with intellectual disabilities and families about the benefits of appropriate health screening page" (page 161).

However, many carers have had no specific health awareness training and are therefore often unable to identify health problems that arise (Hogg 2001). Signs and symptoms of illness are often missed or interpreted as a change in behaviour, and therefore are put down to the individual having behavioural problems, rather than trying to identify the underlying cause for this. Consequently any signs and symptoms are not reported to the GP until often it is too late for preventative treatment.

In an Australian study Beange *et al* (1995) identified a mean of 5.4 medical problems per person screened. On reviewing this with carers they discovered that 65% of patients and 24% of carers had reported no symptoms. In a study of 44 GPs , practice nurses and health visitors Hames and Carlson(2006) report that nearly 40% of respondents identified that they manage to identify the needs of people with learning disabilities by asking the family member or carers. In light of the evidence to suggest that carers do not have the skills to identify health needs this is quite worrying. Conversely, even when the carer does report signs and symptoms to a health professional they in turn may put these symptoms down to the fact that it is the learning disability that is the problem and not investigate further (Smith 2006). Matthews (2002), whilst arguing that carers are best placed to undertake comprehensive assessment of health care needs with support from specialist services where appropriate neglected to discuss the training implications of such a radical change in role. Ironically however, Matthews (2005) later describes the potential consequences of lack of carer knowledge for the person with learning disabilities in a very simplistic manner. This is demonstrated in table 2.3 over the page.

*Table 2.3 Examples of problems in misinterpretation of behaviour (Matthews, 2005 page 32)*

| Observed Behaviour | Perception/Response | Actual Problem |
|---|---|---|
| Peter is vigorously scratching his feet when a carer enters the room | Carer tells Peter to stop scratching his feet or he will make them sore | Peter has a fugal infection causing itching, so he is scratching them |
| Andrew periodically rolls on the floor in a foetal position, screaming and shouting | Carers are told to ignore Andrews temper tantrum. It passes in 25 minutes | Andrew is responding to the pain of gall-bladder stones |
| James regularly dashes into the bathroom to drink large amounts of water | Cares are told it is an obsessive behaviour and to prevent James from going to the bathroom | James may be on medication causing thirst, or have a diabetic condition, or may simply be thirsty |

With appropriate support and training carers can recognise health issues for people with learning disabilities and refer them onto appropriate agencies for support. Pointu and Cole (2005) successfully demonstrated this with the development of epilepsy training for support staff. This resulted in a reduction of inappropriate admission to hospital for patients. Training is a useful way to increase knowledge, and if delivered adequately can result in improvements to care. Costello *et al* (2007) completed a small project to demonstrate this. They used two groups of staff. Group 1 n=66 carers received training regarding mental health. A comparison group of carers n=65 received no training. The knowledge regarding mental health of both groups was determined prior to the training intervention. Knowledge was reviewed four months after training was delivered. The intervention group was found to have increased knowledge, improved staff attitude and an increased likelihood of referral decisions than the non intervention group. Although the authors urged caution with the results, this small scale project would indicate that training does make some impact on care staff knowledge.

Research by Smith (2002a) was substantiated with Powrie's (2003) findings in that both learning disability practitioners and their primary health care colleagues acknowledged a deficit in skills to support the health needs of people with learning disabilities. This included difficulties in communication with both the patient and carers. Communication remains a key issue in access to health services for all (DOH 2001c) but particularly for people with learning

disabilities on several levels (Scarborough and Godsell 2006, Ziviani *et al* 2004, Smith 2002a, DOH 2001a).

During a quantitative study involving interviews with GPs (5), people with learning disabilities (3) carers (7) and advocates (2) Ziviani *et al* (2004) identified that communication was central to the effectiveness of the GP consultation. As the study unfolded they used ongoing thematic analysis to inform the questions asked in subsequent interviews. Due to time constraints they only interviewed each participant once. This could be deemed as a flaw in the research as it may have provided additional data had they re interviewed the first participants as additional data emerged. However they acknowledged this, and also the fact that the sample size was small, and related to one area within Queensland so may not be replicable.

Good communication is the key to good patient care (DOH 2001c). As is ensuring that "A person is not to be treated as unable to make a decision unless all practice steps to help him to do so have been taken without success"(DOH 2006b page 18). This includes all aspects of care and the consequences of people not receiving treatment. In a review of the literature Bernal and Tuffrey-Wijne (2008) has argued that, whilst non-disclosure may protect those without capacity to understand, it can cause distress for those people that can be helped to understand. They suggest that professionals must look at alternative ways to communicate and explain to people and that 'people with learning disabilities have a right to honest information when they have cancer'. It is suggested that this concept is inherent across all aspects of health care provision, not just cancer, and that appropriate ways to communicate should be sought by all professionals to improve access to health care that is adequate for this patient group.

Finally, improving knowledge and communication alone is not enough. To develop a meaningful and permanent solution to the issue working together with all parties is the way forward. This was raised by Barr *et al* (1999) who cautioned that screening alone was not enough and in order to ensure health gains, collaborative practices need to exist to encourage development of health promotion initiatives. This is where the Learning Disability Practitioner (LDP) using their rich and diverse knowledge base (Tait and Turner 2001) and adaptability (Department of Health 2001b) can develop a more holistic and collaborative health promotion type role (Boarder 2002, Mobbs *et al* 2002).This is reiterated by Eccott and Webster (2003)

who suggested that even when appropriately trained, the learning disability practitioner should not create 'specialist services' to further isolate people with learning disabilities by completing health assessments in isolation from their primary care colleagues (Mencap 2004, Glasby 2000). These assessments would be completed by the practitioner, away from the primary care setting with the information being fed back into primary care by the nurse. This differs from most other specialist services that the general population may receive. Usually these services would be completed within a primary care setting by a nurse or GP, and the information would be entered onto the patient's case notes. That is to say they would still be attending services to receive treatment and engaging with health professionals rather than receiving care in isolation.

Pockets of collaborative practice nationally have demonstrated that sharing skills and knowledge can lead to positive health gains for this patient group (Harrison *et al* 2005b) and the development of shared accountability for health action plans (Codling *et al* 2011). Indeed when health action plans were commenced locally, several awareness sessions were held with primary care managers. It would prove useful to identify what level of unpublished collaborative practice and health promotion activity has developed nationally, so that best practice can be shared.

Policy documents across the United Kingdom cautiously concur with both sides of this argument. They acknowledge that for some people with learning disabilities who exhibit more complex health needs, specialist services may be required. However, they fully promote the need for inclusive services rather than the separate services that currently exist in some areas (Scottish Executive 2000, Department of Health 2001a, Learning Disability Advisory Group 2001, Department of Health, Social Services and Public Safety 2004). These policies concur that the families and carers, as well as people with learning disabilities should work in partnership with services to improve access to health (Michael 2008).

This "joined up approach across agencies" approach was developed by Harrison and Berry (2004) to successfully invite people with learning disabilities into the GP practice for health screening. Harrison, a health visitor worked with community learning disabilities nurses to firstly identify patients on the register, then invite them in for health screening and provide

them with a health action plan if required. Of 60 patients initially identified they found that only 22% had a record of any consultation in the last twelve months, and that one patient had not attended the surgery for over 14 years, despite getting regular repeat prescriptions for psychotropic drugs. Patients were offered a choice of clinic or home visit for assessment. This initiative achieved a high uptake of patients accessing the health assessment, so much so, that their annual review of patients with a learning disability accessing services increased to 92% the following year.

However Harrison and Berry (2005b) caution that health needs assessment must also review the individual's lifestyle, otherwise information gathered is unrealistic and cannot be used to develop "reliable, informative or realistic health action plans"(page 18).Many patients in the study used hand held health booklets and their health action plans were included in this following the health assessment. Unfortunately whilst this article demonstrates the positive aspects of collaboration, there was no report as to the quantity of health outcomes or gains identified.

A multi agency workshop, held as part of a research project into evaluating the progress with implementing the health aspects of Valuing People in Leeds, concluded that the collaborative partnerships needed are complex. They require involvement from CTLD around health facilitation, the PCT to ensure inclusion of people with learning disabilities in local health services and Partnership Boards to commission and monitor local strategies (Mir 2007).The workshop confirmed professional's feedback that the government needed to build monitoring processes in local health services such as NSF'S and Quality Outcome Frameworks as the White Paper itself had added no value to date. Finally it concluded that "Leadership is needed at national, regional and local levels if the pockets of good practice that have been developed in various parts of England are to be replicated elsewhere" (Mir 2007 page 83)

## Health Related Issues

The following section examines literature concerning the specific health issues that may affect people with learning disabilities. It demonstrates the complexities of people with learning disabilities and their potential health issues compared to the general population a discussion so

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that the reader can understand why people with learning disabilities need to access health and routine health screening such as cervical screening in the same way that the rest of the population do. Examples are given from literature across the world that demonstrate both where people with learning disabilities are at an increased risk of disease, or where there is less likelihood of disease compared the general population. Cancer, respiratory disease and obesity are issues of concern. In addition people have often undiagnosed problems with vision and hearing and dental access also remains poor. As people are living longer they are experiencing the diseases related to old age, and are at particularly high rate of dementia. There are also concerns in accessing secondary care services and these issues are discussed next.

Studies have shown 1 in 10 people with learning disabilities now die of cancer (Cooke 1997, Hollins *et al* 1998). The distribution is different to that of the general population with higher rates of gastrointestinal cancers (roughly double) than the general population (Duff *et al* 2001). Indeed Duff *et al* (2001) identified that of 157 people who died of cancer 59 cases were stomach cancer and a further 25 had perforated stomach ulcers. Paradoxically Duff *et al* (2001) suggest that this is directly related to the incidence of helicobacter pylori, which is increased in institutionalised settings, yet is evidently not treated with simple antibiotics. Furthermore Melville *et al* (2002) have suggested that 70% of people with profound learning disabilities or cerebral palsy and 50 % with severe learning disability have Gastro-oesophageal reflux disorder (GORD) with a predisposition to oesophageal cancer.

People with learning disabilities experience lower rate of lung, breast and prostrate cancer but higher rate of testicular cancer (Cooke 1997). In a small study of four patients with Down's syndrome who had testicular cancer in Mexico, Aguilar Ponce *et al* (2008) identified that when offered appropriate treatment the prognosis was the same as the general population. They also identified that the incidence of testicular cancer in the Downs patient in the Caucasian population is on the increase worldwide. Whether this is actually an increase in incidence or the fact that diagnosis now occurs it is difficult to determine. However, it is evident that not only should people with learning disabilities, health professionals and carers be made aware of this fact, but that effective ways to support people with learning disabilities and their carers in monitoring their testicular health are required.

Whilst fewer women with a learning disability have breast cancer it does still occur. Iancono and Sutherland (2006) discovered that in comparing 100 patients seen by GP's in a 12 month period only 19% of those with learning disabilities had received a mammogram compared to 57% of the general population. Furthermore Willis *et al* (2008) found that people with learning disabilities continue to receive less opportunities for mammography that the general population. They suggested that this could be addressed by education for health care professionals in how to include this patient group in screening processes.

This was demonstrated in a project by Ramessur-Marsden *et al* (2008) in Wales to improve both breast and cervical screening uptake for women with learning disabilities. The Disability Rights Commission (DRC) (2006) report identified that the uptake for breast screening in Wales was 26% for this patient group compared to 71% of the general population and 13% compared to 84% for cervical screening. In response to this Ramessur-Marsden *et al* (2008) held a work shop for women with varying severity of learning disabilities to determine their comprehension of breast and cervical screening. Using the information gathered they developed two resource packs 'Having a Breast Screen' and 'Having a Smear Test' which were piloted and adapted and are now used to train learning disability nursing teams in Wales to support women in accessing screening services. Unfortunately this article does not identify if this has resulted in an uptake in screening attendances.

Down syndrome carries a 20 to 30-fold risk for lymphoblastic leukaemia. In a study of 120 patients with learning disabilities and childhood leukaemia, Italian research identified that the presenting features of the disease were different to non Down syndrome patients. However they concluded that treatment had improved progressively for this patient group and although the prognosis was not as good as non Down syndrome patients there was still a 75% survival rate (Arico *et al* 2008).

Approximately 50% of people with learning disabilities will experience mental ill health in their lifetime (Melville *et al* 2002).Women with schizophrenia have a 42% increased risk of breast cancer and people with schizophrenia have a 90%increased risk developing bowel cancer (DRC 2006).Conversely it is worrying that, despite the incidence of cancer, people with learning disabilities are less likely to be given pain relief and less likely to be in receipt of palliative care (Tuffrey-Wijne *et al* 2007).

In conclusion although the evidence of cancer incidence appears to be growing for people with learning disabilities, this remains disparate. Hogg and Tuffrey-Wijne (2009) concluded that further methodologically sound studies are needed to clarify the epidemiology of cancer for this patient group.

People with learning disabilities have higher rates of respiratory disease than the general population -19.8% compared to 15.5% (DRC 2006) However, in a study of 2000 people with intellectual disabilities, Hollins *et al*(1998) found this rate to be higher. They concluded that respiratory complications at that time accounted for 52% of deaths compared to 15-17% of the general population. There is no rationale for why this percentage has decreased, unless incidence of infection is being reported sooner.

There is a plethora of evidence discussing the issue of obesity and lack of exercise in people with learning disabilities. One study suggests that the prevalence of obesity is twice that of the general population (Ouellette-Kuntz 2005). Whilst completing a 30-year longitudinal study of 82 people with learning disabilities in Sweden, Gustavson *et al* (2005) identified that 49% were overweight. Of these overweight people 71% also had Down syndrome. Several studies have identified that people with learning disabilities live sedentary lifestyles and Robertson et al (2000) discovered that 80% of people with learning disabilities did not engage in the recommended level of weekly activity. Furthermore a higher rate of inactivity is more likely amongst people of less ability residing in residential care settings. During a Canadian study of 301 adults in Ontario Ouellette-Kuntz (2005) further confirms these findings. She identified that 89% of participants were found to be inactive.

Furthermore, as part of a comparative health screening project of 120 people with learning disabilities by Martin *et al* (1997) they identified that 53 (48.1%) had done no moderately intense activity over the last 4 weeks compared to 43 (93.5%)of the general population who had. Marshall *et al* (2002) reviewed a health screening clinic led by two learning disability nurses for all people with learning disabilities aged 10 and over who attended special services in an area of Northern Ireland. They identified that a total of 464 people attended and that 24% of these were aged 10-19 years of age. 12% (57) of people were not able to be weighed due to being non ambulant or having difficulties with using the equipment. Of the remainder, 64% of adults and 26% of 10-19 year olds were overweight or obese. Furthermore 122 people were

referred to their GP with hypertension. This was significantly higher for those in their 40's. This study showed an increase in the number of overweight adults (64% V 52%) from a comparable study 6 years earlier by Barr *et al* (1999).

An Australian study by Temple and Walkley (2007) conducted six focus group studies to determine what factors enabled or inhibited participation for people with intellectual disabilities in physical activity. They interviewed individuals with intellectual disabilities, support staff and family members. They concluded that it was often restraints due to the attitudes of staff and families, (time, cost, other people to support, lack of staff etc) rather than the individual not wanting to participate in any form of exercise. They identified that there were no clear policies available to staff about health promotion. A study by Craig and Melville (2009) further confirms this. They identified that carer's knowledge regarding a healthy diet and exercise was poor. Of the 63 paid care staff who took part in the study, 63.9% felt that the person with learning disabilities they supported would benefit from changing their current diet, and 82% said that the person would benefit from increasing their level of exercise. However, 18% of carers had no knowledge of the recommendations for weekly activity. Carers suggested that reasons their diet may not be changed could be due to the fact that often people with learning disabilities live with others, and do not always therefore have control over the choices of what they eat, as often one menu fits all.

In an American study investigating the provision of chronic disease management of people with intellectual disabilities, researchers identified that in one medical practice 126 (43% of the total identified) were obese, 58 (19.9%) had hypertension, 77(26.5%) had hypercholesterolemia and 13(4.5%) had diabetes mellitus (Sohler et al 2009).Finally, Bhaumik *et al* (2007) conducted a population based prevalence study in Leicester. They compared the inequalities in weight problems with adults with intellectual disabilities and the general adult population. The majority of participants were young with 74% being under 50. By comparing the Body Mass Index they determined that18.6% of the study cohort was underweight, 32.7% were normal weight, 28% were overweight and 20.7% were obese. Obesity was almost twice as prevalent in women as men. The incidence of being overweight was higher in both women

with learning disabilities and the general population for people over 25. Finally 19% of men with intellectual disabilities were underweight compared to only 2% in the general population

In a literature review by Warburg (2001) consensus varied that people with learning disabilities are between 8.5 and 200 times more likely to have a visual impairment than the general population. Almost 50% of adults with learning disabilities have some form of visual impairment; 20-30% of adults have moderate visual impairment and 1-5% have severe visual impairment or blindness. This rate increases for people with profound and multiple disabilities. In a Dutch study of 76 people with profound and multiple disabilities, 92% of patients were found to have visual impairment. Of these only 30% had previously been identified as having visual problems. These problems were addressed in 22% of patients with the prescription of glasses (van den Broek *et al* 2006). Furthermore the most important treatable causes of visual impairment are lack of appropriate glasses and cataracts. Age related macular degeneration and glaucoma are less prevalent in the aged learning disabilities population than the general population, yet can be treated if referred by well-informed staff (Warburg 2001).

Oral health problems are up to 7 times more common than the general population (Centre for Developmental Studies 2006). Often dental problems may go undiagnosed due to the individual's difficulty in communicating. For example, someone banging his or her head may be interpreted as presenting with challenging behaviour, rather than investigating the reason for this behaviour which could be that the person is in pain with a toothache. In addition people with learning disabilities are prone to experience dental anxiety. During a single case study Pragnell and Green (2008) used cognitive behaviour therapy to support 'Bill' with his dental anxiety. Therapy was used to discuss Bill's fears and support him with coping strategies to overcome these fears. Visits were built up at the dentist using the coping strategies taught until Bill received his dental treatment. Although this is a time consuming process Pragnell and Green (2008) conclude by suggesting that is a process that could be adopted by others.

Not only do 40% of people with learning disabilities have a hearing impairment (Carvill 2001) they have higher rates of hearing impairment than the general population (21% of those less than 50 years of age compared to 0.2-1.9 of general population). This increases further for people with profound and multiple disability (Evenhuis *et al* 2001). Furthermore Yeates

(1995) found that of 500 people with learning disabilities randomly chosen nearly 40% had a hearing loss that required treatment. Further analysis identified that of those 500 there were 119 people with Downs's syndrome, 56 (47%) of whom required treatment for hearing loss. Whilst identification of hearing loss may not result in compliant treatment by the individual it is often the initial diagnosis that remains elusive, with many practitioners refusing to screen people with learning disabilities in the first place.

It is often assumed that women with learning disabilities are not sexually active; despite evidence to the contrary to suggest that they have an increased risk of sexual assault; and therefore they do not need to undertake cervical screening (McCarthy 1999). In addition, understandably, practitioners remain concerned regarding the issues of consent to undertake a cervical smear (Smith 2006, Prowie 2003). Often they cite this as the reason to not offer a smear in the first place. In addition GP's still omit women from the screening register 'because they have a learning disability', without any discussion of the risk factors involved. This is despite the changes to the law. Conversely there is limited uptake of cervical screening for women with learning disabilities (only 6% compared to 82% and 19% compared to 77% of the general population Smith 2003, Djuretic *et al* 1999). Furthermore this is comparable to the Australian study by Ianocno and Sutherland(2006) where a sample of 100 women with learning disability received a much lower screening rate than 100 women of the general population(12% verses 64%). A review of the literature found that numerous reasons as to why the uptake of cervical screening is lower in women with learning disability than the general population. However Watts (2008) concluded that many of these issues "can be overcome by healthcare professionals adhering to good practice guidelines thus ensuring that women with learning disabilities have their right to access cervical screening services acknowledged"(page 524).

Access to other screening services and treatment should change with the introduction of the code of Practice for the Mental Capacity Act (DOH 2006b), which states that "A person is not to be treated as unable to make a decision unless all practice steps to help him to do so have been taken without success" (Page 18) When all steps have been taken but it is evident that capacity to consent is an issue a best interest discussion should take place. This discussion should involve all relevant people concerned in the welfare of an individual. These discussions

and outcomes should be documented in the patients notes, and occur for each incident where treatment is required.

Epilepsy is the most common serious neurological condition. Whilst epilepsy and learning disabilities are clearly separate conditions, some specific epilepsy syndromes result in learning disabilities (Whitten 2008). At least one third of people with mild to moderate learning disabilities have epilepsy (20 times higher than the general population). This figure rises to approximately 60% of people with more profound and multiple disabilities. Furthermore as the incidence of dementia is higher in the aged learning disabled population it is likely that this figure could be even higher.

Researchers disagree on the prevalence of epilepsy in people with learning disability.  In a study of 1195 patients, Cooper *et al* (2006) identified that 35% had epilepsy. However, in a study of 318 adults, Matthews *et al* (2008) identified that only 58 (18%) had epilepsy. Of these 36% were seizure free but 34% had very poorly controlled seizures. Whitten (2008) instigated an epilepsy clinic for 23 people with learning disabilities using an assessment proforma based on the NICE epilepsy guidance (2004).In a retrospective audit after the assessment she identified that

- 83% now had detailed seizure description compared to 6% at the start
- Seizure frequency was now recorded for all patients
- 76% had changes made to their seizure diagnosis
- 91% of consultations led to changes in treatment plans compared to 50% at the start of the project
- All patients had risk assessments completed compared with 4.5% before the project and 68% if participants had risks identified
- 9% of patients documented as seizure free were actually having seizures

Whitten concluded 'a highlighted lack of understanding about epilepsy' and again there was a need for education for the majority of care providers. This education if given has been proven to decrease the number of inappropriate hospital admissions (Pointu and Cole 2005).
Many of the issues that relate to this patient group have already been discussed. Lacy and Ouvry (2001) discussed research into the health needs of people with profound and multiple disability. Examples were presented where 93.8% of patients screened were underweight,

15.6% were severely underweight, all were at increased risk of pressure sores, 68.4% had epilepsy, and 21% had a high level of health care need.

Approximately two thirds of older people with learning disabilities will also have a mental illness (Melville *et al* 2002) Compared to the general population people with learning disabilities have approximately 4 times higher risk of dementia than the general population (Cooper 1997, Lund 1985, Moss and Patel 1993) People with Downs Syndrome are particularly at risk of dementia (ages 60-69 54.5% compared to 1.4% of the general population Prasher 1995) and at least 80% of these will develop late onset epilepsy (Dodd *et al* 2006)

People with learning disabilities are living longer, and therefore face the same age related conditions as the general population, but with a different frequency pattern (Janicki *et al* 2002). Cooper (1998) identified higher rates of urinary incontinence, hypertension and cardio vascular disease, and arthritis. As discussed above dementia related issues are also more prevalent. Osteoporosis is also more prevalent in the aged person with learning disabilities due in part to immobility, thyroid function and anti convulsant medication (Jancar and Jancar 1998).

Whilst the focus of this research relates to primary healthcare provision, it is important to note that access to secondary health is also an issue for people with learning disabilities. As this section has described, people with learning disabilities can be prone to chronic and acute episodes of illness. Evidence demonstrates that they have a higher rate of admission to hospital than the general population- 26% compared to 14% (Band 1998). Various reports have highlighted the issues and risks for people with learning disabilities of receiving appropriate care whilst in hospital (National Patient Safety Agency 2004, Treat Me Right 2004), issues which are not dissimilar to those described in this chapter relating to access to primary care services. These include communication difficulties, lack of training for hospital staff around both learning disabilities and consent, which may mean that people are not always offered the same treatment as everyone else, due to compliance issues or lack of discussion. Furthermore there are expectations that the individual or their family will support the individual which may result in people not taking medication and adequate nutrition.

Some areas have introduced the concept of a hospital liaison nurse role to support people with learning disabilities when accessioning secondary care (Foster 2005, Hanon 2003). Indeed, across the authors region, a health support network was set up to support this role and other

networks were set up nationally, so that nurses could share experiences and tools developed. Other liaison nurses have developed specific documents to improve access such as patient passports (Kent 2008), the Traffic Light Documents developed by Surrey Oaklands ,which is gaining recognition and use nationally and specific communication tools for use in hospital 'The Hospital Communication Book' by Surrey Oaklands.

Despite this some services are still failing. Death by Indifference (2007) highlighted six cases whereby people with learning disabilities died unnecessarily in hospital. An independent Inquiry concluded that several of these deaths were as a result of system failure and neglect. Consequently the Michael enquiry (2008) made 10 recommendations to improve access to all health services for people with learning disabilities. These included the need to make reasonable adjustments; training for medical staff at all levels; having systems in place to identify that the person has a learning disability and ensuring that carers are involved and consulted. Dinsmore and Higgin (2011) in completing interviews of patient experience in Liverpool, identified that issues remain and carers are still not listened to regarding the individuals care. Whilst areas are developing various initiatives to meet these objectives, training continues to be an issue and many areas are still working to 'flag' people with learning disabilities. Furthermore, whilst some areas have developed local practices that improve access to secondary health care, this remains an issue for people with learning disabilities in some areas depending on where they live.

## Leadership

It is evident from the research findings that effective leadership had a crucial role to play in the introduction of health action plans. Leadership has many definitions, but to describe this research the definition used is that it is "the behaviour of an individual when directing the activities of a group towards the attainment of a specified goal or goals" Hemphill and Coons in Anderson and Kypianou (1994).Effective leadership involves one person working with a group of people to change their practice and to do tasks in the way that the leader wants them to be done. It is about coping with changing the way that things are done. Leaders set a direction or vision of what needs to be done and then set about developing strategies to produce change to achieve that vision (Anderson and Kypianou 1994).This change includes the motivation and inspiration of their employees.

There are many theories as to how effective leadership happens. Previous research has focused on the trait verses situational leadership. The trait theorists believe that effective leaders are born and that leadership cannot be learnt. In the 1950's theorists believed that leaders had a series of traits that were inherent in a good leader (Stogdill 1974).However, there was some disagreement as to what traits make an effective leader and a limitation of the trait theory is that the leadership traits that work in one situation are not necessarily effective in another. Effective leaders may need to change their strategy dependant upon the situation they are dealing with (situational leadership).

In the 1970's Adair suggested that leadership was a trainable skill and introduced action centred leadership to demonstrate this. He suggested that there were three areas that required attention; achieving the task; managing the team or group and managing the individuals (2004). Leadership theories were developing that evolved from looking at effective traits to effective behaviours, which resulted in Tannenbaum and Schmidt (1973) investigating the authoritarian versus democratic leadership style; Blake and Mouton (1985) exploring the task focused verses the people- focused leader; and Lewin (1951)reviewing the impact of three leadership styles (autocratic, democratic and laissez-faire).

The concept of leadership and change is complex and the type of leadership required is fluid dependant upon the situation required. This study was not intended to be a review of leadership in general, but I wanted to focus on leadership to change in learning disability services based on the concepts of health action planning. Whilst reviewing the literature. I found an article, by the then, National Director of Learning Disability Services in England. In commenting on the changing culture of learning disability service provision, Greig (2003), used an approach to explain the concept of change and leadership for this change, devised by Mansell (1993) to describe how changes could be made in learning disability services.

In discussing the ethos of Valuing People (DOH 2001a) eighteen months after implementation Greig (2003) the National Director for Valuing People commented that:

*Change happens where local people want to make it happen. Governments can issue policy guidance and the Valuing People Support Team can provide a whole range of development support but the key issue is whether there is a local belief in the Valuing People vision and a willingness to do things differently* page 150

Greig relates the change concepts to the typology themes within the Mansell Report 1994. Mansell reviewed how services were delivered for people with learning disabilities who challenge services. Greig describes the three themes that Mansell identified as:

1) Removers: where people were shipped out to out of district placements so that they were no longer visible and could be denied

2) Containers where local services were developed, but in a way that 'contained ' the behaviour that challenged the service so the problem remained but was circumscribed by an environment that that meant people had little impact and even less contact with the wider community

3) Developers where local services explored and developed innovative ways of designing services that identified the needs of individuals who promoted principles which could be recognised as now being part of Valuing People (page 150).

Greig then argues that the way that services have adopted the Valuing People principles - in this case the health related aspects of the health action plan  section in chapter six, can be evaluated  utilising these criteria.

1) Removers- removing the responsibility for change and ascribing responsibility for the removal of obstacles to change to others. This group believes that it is not possible to deliver change until someone else removes all the obstacles

2) Containers where local implementation strategies remain contained within previous cultures and practices that existed for example activity takes place but it is just another name for things that they have done for years

3) Developers /innovators where it is recognised that new ways of working are required where people with learning disabilities and families are leading the change. New partnerships are made and problems are addressed by asking what new and different approaches can be used

In reviewing the literature on leadership I did consider using Lewin's autocratic, democratic and laissez-faire approach to leadership (1951) to review the data but the data streams were not accurately captured by this theory. I therefore decided to use Greig's approach to analysing the leadership styles identified. This approach was chosen for a number of reasons. Firstly it is one of the few approaches of change and leadership to be developed that describes the effects of change and attitude to change within the learning disability context. Greig's typology suggests that people's attitudes to change can impact positively or negatively on the change in question. Secondly, it relates to the issues of Valuing People (2001a) on which this research is based. Finally, in considering the above reasons, it helped me to make sense of and organise the data.

## Rationale for Research

Following the literature review, a number of questions were evident from the gaps in the literature such as whether peoples knowledge had increased about the individual with the introduction of health action plans; and if any health gains had been reported from using health action plans. Other questions developed as part of looking at local practice. In commencing this research there was limited evidence available to identify if health facilitators worked an operational or strategic level, and if they perceived there to be any benefits of working at the different levels. This study will therefore determine both the job role and the level of health facilitation that is occurring in respondents around the country. The limited available literature showed some collaboration in the development of health initiatives, and this research will identify if there was collaborative working in the development of health action plans; who was involved in using the plan and, if as shown to be the practice locally, the plan was developed to meet the individuals or service requirements.

Introducing health action plans alone is not enough. Several studies are presented where health checks or health action plans were completed, but no information was available to identify how these were monitored or reviewed, and if there were any benefits to the process followed. This

study will determine how health action plan are monitored and reviewed, and health gains are measured and reported

This chapter has discussed at length the importance of knowledge, for those supporting people with learning disabilities, to achieve their health needs. This research will identify if any training was given to health facilitators, who may include carers, as part of the process to introduce health action plans. Where possible, it will explore whether health facilitators who had received training completed health action plans that identified more health issues than those who had no training. In addition it will explore whether introducing health action plans improved carer and professional knowledge regarding the health of individuals with learning disabilities. Next, as many people are being supported by carers, it will ask if carer's issues are indeed included within the health action plan formats around the country as part of the research. Finally, it will determine if the use of a hand held record improved communication with people with learning disabilities, professionals and carers.

The evidence demonstrates that health screening is an important factor in determining people's health needs. This research will identify if health screening did take place as part of the health action plan process and if so, were a higher level of unmet health needs identified than where no screening took place at all. It will also question if indeed, health needs were identified when health screening did not take place. Finally, the qualitative aspect of the study will question health facilitators to determine if they perceive that there are any additional benefits to undertaking the health action plan that those identified above. It will also determine if health facilitators at all levels felt supported in their roles. On a local level, a closer examination of all issues will be undertaken to identify how practice matches that identified nationally, and how local practice can be improved.

## Summary

This chapter has explained how some people with learning disabilities were resettled from institutionalised care, supported by learning disability nurses, to care within the community now supported by social care staff. This closure has resulted in a change to the role for the learning disability nurse, in most cases, in that they became members of Community Learning Disability Teams. These nurses then took on many roles including that of health facilitators and health action planning. Next the value placed on the knowledge and experience of the

learning disability nurses, whilst at the same time giving examples where this knowledge alone is not enough and that learning disability nurses require the support to evolve and change practice to keep up with the changing events within service provision was discussed.

However, it was explained that local practice differed to that followed nationally. Many learning disability nurses continued to work in supported living services, and took the lead role in health facilitation, and improving access to health services for people with learning disabilities across Rochdale. This resulted in CTLD playing a much smaller role. This is most important to understand how local practice informed the choice of research topic.

The incidence of learning disability is increasing, and this increase is expected to continue with a higher prevalence of people with complex health needs.  An exploration of the historical context concerning access to health, up to the commencement of the research was given. The White Paper, Valuing People (2001a) was introduced and the recommendations and concepts of health facilitation, health screening and health action plan were discussed. Examples have been given where health action plans had identified unmet heath needs for people with learning disabilities. Some discussion took place regarding who should act as health facilitators, and the local experience of the introduction and training around this were discussed. The literature review identified pockets of good practice around the provision of health care and health action plans for people with learning disabilities but there was no published information at the time of this study to identify what was happening nationally, and to determine whether the introduction of health action plans had made a difference to the health experience of people with learning disabilities on a national or local level

Next the Valuing People (2001a) recommendations for GP registers were discussed and this identified issues regarding GP knowledge. However, knowledge regarding health and how to support access to health remains an issue for other primary care workers and carers alike. Examples of good areas of practice, although somewhat limited, were presented to demonstrate that where support has been given to share this knowledge and awareness, positive health gains have again been made for people with learning disabilities.

Next evidence was presented to demonstrate how people with learning disabilities face inequitable access to health services, along with a detailed explanation of the different aspects of health that specifically affect this patient group to fully inform the reader.

What is evident is that, despite the recommendations within Valuing People (Department of Health 2001a) little appears to have changed nationally to improve inclusion of this patient group. Many critics suggest that this is because Valuing People is a White Paper and does not carry the same weight as a National Service Framework (NSF). Whilst academics may debate as to the value of NSF's, it is apparent that some changes have resulted in patient care from them.

For example, following the Coronary Heart Disease (DOH 2000b) NSF points were awarded within Quality Outcome Frameworks to follow specific pathways to address this condition and all patients should then follow a set care pathway once diagnosed. These outcomes are monitored and reviewed on an annual basis, and incur both payment by results and recommendations for improvement.

Without a doubt, people with learning disabilities should benefit from the existing NSF's once a condition has been diagnosed. For example, some people with learning disabilities are more at risk of coronary heart disease (Turner and Moss 1996), and are living longer so are therefore prone to the same age related illnesses as the rest of the population (Evenhuis *et al* 2001). They will therefore benefit from the NSF for Coronary Heart Disease (Department of Health 2000b) and Older People (Department of Health 2000c) respectively. This is however where the problem continues. Treat Me Right. (Mencap 2004) and Closing the Gap (Disability Rights Commission 2006) both discussed studies to demonstrate that the health system continues to fail individuals who have a learning disability.

A brief review of leadership theories was presented. These theories are many and complex therefore the approach used by Greig, to understand the concept of change within learning disability service provision was introduced to make sense of the leadership issues in relation to this study.

Finally, the rationale for this research and some of the questions to consider has been given. These are discussed further in the next chapter.

# Chapter Three

## Method

### Introduction

This chapter explains the research question aims and objectives and examines the methods chosen to explore the research question. This practice based research asks the question "Has the introduction of health action plans for people with learning disabilities actually made a difference". The aims of this study were; to determine whether health facilitators and people with learning disabilities; consider that the introduction of health action plans have resulted in health improvements for people with learning disabilities living in England; to evaluate the experience of people with learning disabilities and health facilitators in Rochdale in delivering health action plans; and compare this to the national findings to inform and improve local practice.

As a multi- method approach is utilised, the rationale behind the use of a questionnaire for the national part of the study is presented. Firstly the explanation of the recruitment method analysis and data presentation is given. Following difficulties in obtaining research governance approval data was not collected from each PCT across England, but there was sufficient data from each of the nine Valuing People regions collected to ensure that all areas were involved.

Focus groups were held in Rochdale with health facilitators and people with learning disabilities to gather their experiences of the health action plan process. The rationale for this method and the process for recruitment and focus group research are presented. Firstly the focus group for health facilitators is discussed, including how, due to illness and equipment problems it was necessary to hold a second focus group and change the method of recording. Difficulties with the recording process of one focus group resulted in changing to video recording of one group and documenting and verifying information at the end of another focus group.

Next, an in depth discussion is presented about the focus group for people with learning disabilities. Research involving people with learning disabilities is emerging, but, at the time this research was undertaken, there were still concerns about involving this patient group in research. This is discussed in some detail and explanation is given as to how the research

process was adapted to be more inclusive. This included involving people with learning disabilities in developing accessible participant information, and having individual meetings with potential participants to discuss the process fully. This helped to ensure that informed consent was obtained. Finally a review of the ethical considerations of the research process is addressed.

## Research Aims and Objectives

This study asks the question "Has the introduction of health action plans for people with learning disabilities actually made a difference?" The aims and objectives of this research are.

## Aims

To determine whether health facilitators and people with learning disabilities consider that the introduction of health action plans have resulted in health improvements for people with learning disabilities living in England

To evaluate the experience of people with learning disabilities and health facilitators in Rochdale in delivering health action plans, and compare this to the national findings to inform and improve local practice.

## Objectives

1) To identify who was involved in the introduction and development of health action plans

2) To determine how health action plan are monitored and reviewed and health gains are measured and reported

3) To determine what, how and to whom training was delivered prior to the introduction of health action plan

4) To identify if health screening took place as part of the health action plan and whether this made a difference to the number of health needs identified

5) To identify if health facilitators perceive any additional benefits of the health action plan

## Method

Different aspects of a phenomenon can be studied following a single approach to research (Parahoo 1997). However a more comprehensive picture can emerge by using a combination of methods. Denzin (1989) refers to this process as method triangulation. This research followed a triangulated approach, in the use of questionnaires, for a quantitative approach and focus groups for a qualitative approach. A multiple method approach can overcome the bias and deficiencies of a single approach, through the strengths and validity of the other (Carr, 1994). Indeed with the growing emphasis in nursing to move away from the "softer" qualitative approach, by exploring people's feelings and experiences, the incidence of combined approaches is increasing (Copnell 1998, Shih 1998).

Furthermore Boland *et al* (2008) successfully demonstrated that using a multi method approach in learning disability research is effective by evaluating service provision regarding health promotion requirements in Ireland. They used a triangulated approach gathering data from three sources (clients with learning disability, service providers and carers) and argued that "All three sources are needed to build a complete picture" (Page 207).This study reflects their method in that not only has it given a national perspective from health facilitators it has focussed in on the local perspective of health facilitation in practice and has compared this with the experience of some of the people with learning disabilities, in receipt of the service in Rochdale.

Therefore a qualitative approach using focus groups with people with learning disabilities and heath facilitators is used. Within the health facilitator focus group a small questionnaire is used to gather demographic data. To complement this, a quantitative approach using questionnaires nationally was undertaken. The reason for the choice of methods is explained more fully throughout the chapter. Ryman (2004) suggests that when methods are combined one method is always given greater prominence. The quantitative aspect will be the primary focus to determine health facilitator perspectives nationally, with the focus groups being completed to inform practice on a local level.

## Quantitative Method

Questionnaires can be used to collect factual information, as well as providing information on people's attitudes, beliefs and knowledge. They give control to the individual as they can be self- administered, and respondents can choose not to answer questions that may cause them discomfort. (Parahoo 1997). The use of questionnaires allows an analysis of the relationship between selected variables (Oppenheim 1992). Data collected is useful for planning, evaluation and comparative purposes (Parahoo 1997).

Questionnaires allow the researcher to remain objective, therefore reducing the potential for bias, as they are unable to influence the outcome (Denscombe, 2003). Depending upon the design they provide hard, measurable, factual data that looks at causal relationships and can later be replicated to test the theories generated (Polit *et al* 2001). Additionally, questionnaires have the advantage of providing large samples of data in a short period of time with the questions being asked in a consistent way (Parahoo 1997). It allows the researcher to gain a snapshot of how things are at a specific period in time (Denscombe, 2003). They are also a quicker and more cost effective way to gather a large amount of information, across a wide range of respondents from different localities at the same time, than other research methods. Finally, they allow for the respondent to complete the questionnaire in their own time, coming back to the questions if need be rather than being tied to a specific time and place to be involved in the research.

One of the main disadvantages of questionnaires can include a low response rate. One way to address this is by targeting a large sample. Furthermore, although it is difficult to determine the response rate at the outset, the selection criteria for this research means that only people interested in participating will actually commence the questionnaire, and this fact should reduce the possibility of non completion and return of the questionnaire. Additionally, respondents may not understand the concept of the question, and cannot clarify its meaning with the researcher, or may choose not to answer questions. This possibility can be reduced by piloting the questionnaire before general distribution, so that the chance of ambiguous questions can be reduced. In addition, respondents may find that pre-coded questions do not allow for their choice of response, and they may be forced to choose an answer that does not represent their views (Bowling 2006). One way to overcome this is the inclusion of "other" as an option. For the purpose of this study some questions used that option.

However, it is also recognised that a disadvantage of open ended questions within the questionnaire means that this researcher could not probe, and clarify responses with the respondent as they were anonymous. This has proven to be the case with some respondents in this research study. Nevertheless, the benefit of reaching a large number of respondents, and receiving additional information was considered to be a key factor in this part of the research, and so this issue is accepted as a limitation of the study. Finally, respondents may become bored with the questionnaire if they feel that the questions hold no interest for them (Bryman 2008). This can be alleviated by the appropriate design of the questionnaire, and selection criteria of respondents.

A combination of open and closed questions was used within the questionnaire. Closed questions allow for comparison of responses and to facilitate analysis of data. (Polit *et al* 2001) The disadvantage of closed questions means that rich data may be missed, so where applicable questions asked for other responses to be indicated (Polit *et al* 2001). A variety of open questions were used to elicit a richer data source. To help eliminate tedium the questionnaire had some questions that gave a list of possible responses as a tick box but still allowed "other responses" so as not to miss the opportunity to gather additional rich data.

Careful consideration was given to the length of the questionnaire. Whilst the length of a questionnaire can alter response rate, Bowling, (2006) gives conflicting examples (Cartwright 1988 and Hoffman *et al* 1998) as to the validity of this argument. Cartwright noted a marked increase in response rate between a one and three page questionnaire, yet both authors cite similar response rates between eight and sixteen page (Cartwright) and four and sixteen page (Hoffman) questionnaires. They do not identify why this may be, but Bryman (2008) suggested that if questions are salient to the individual they are more likely to respond to them, than if too many non salient questions are included.

## Pilot

In order to test this theory the length of the questionnaire was discussed, and reviewed at the Northwest Health Facilitation learning disability network. Feedback was received on the wording of some questions, and these were amended to either remove ambiguity, or allow the

opportunity for an "other, please comment" response, thus not forcing respondent choice (Bryman 2008). The length of the questionnaire was debated, but the consensus of opinion was that although the questionnaire could be deemed quite long (37 questions and 10 pages), all questions were relevant and should remain..

Following amendments, and in order to test that the questionnaire format was clear, precise, and to remove any potential remaining researcher biased questions, it was again piloted anonymously with critical colleagues, who were health facilitators. Feedback concluded that the questionnaire was fit for purpose, and that no additional changes were required to remove any ambiguities. Therefore the pilot group data was included in the research findings.

## Sample Size

In order to prove that there is a relationship between variables a specific number of respondents are required. The difficulty is deciding sample size for this study is that at the time of the research no national data base was available to identify the number of health facilitators across England. However, it was anticipated that interest would be shown due to the subject matter and the fact that this was the first example of research into this topic. Therefore it was agreed at ethical review that the outcomes of this research would be determined from the number of questionnaires received by the researcher rather than as a percentage of the number of questionnaires sent out against the number of questionnaires returned.

## Recruitment

Bowling (2006) suggested that a response rate of 75% is good for surveys. As discussed earlier it is impossible to determine how many health facilitators there are in England as there is no national database. It was imperative therefore that all methods to improve response rate were used.

Therefore in order to maximise recruitment the following methods were utilised: Firstly, all health facilitators that belong to the three main health networks in England were targeted. These networks are utilised by professionals with a keen interest in improving the health of

people with learning disabilities, and Bowling (2006) suggests that the response rate can be increased by the saliency of the topic to the respondents, so a good response rate was anticipated. Additionally the leads for the nine Valuing People regions were contacted to disseminate information across their networks. As these leads cover England it was anticipated that this method could increase the response ratio. Next a request for respondents was placed in both the Learning Disability Practice Journal and The RCN bulletin, to target health facilitators that may not receive information from other services. Finally, to determine if other health practitioners facilitate health action plans, all Primary Care Trusts in England were approached for research approval.

In order to increase response rate further a covering letter and participant information sheet was distributed with the questionnaire (Bryman 2008). The letter and information sheet included the rationale for the research, discussions regarding confidentiality and contact information for the researcher if required. The questionnaire was sent electronically to allow further distribution by the health networks, Valuing People officers and PCTs. Respondents could either complete electronically or return by post. Electronic responses were numbered without review and the email deleted. This ensured that when data was input the respondent remained anonymous to the researcher. Return of the questionnaire assumed consent.

Both Bowling (2006) and Bryman (2008) have discussed improved response rate when reminders and a copy of the questionnaire are resent after a selected time period. This could be due to a number of factors, such as capacity, sickness or being on leave when the original information was sent. Due to the length of time that research governance approval took within some areas a general reminder and questionnaire was sent around the networks after three months. It is difficult to determine if this increased the response rate as questionnaires were being received throughout the research process, in part I believe due to the varying differences in individual approval times. The following inclusion criteria were applied;

Respondents must be a health facilitator, with experience of completing health action plan with or on behalf of people with learning disabilities living in England.

## Issues with recruitment

Gaining Research and Development approval for this project from the PCT's proved to be extremely difficult. At the time the approval process commenced there were 246 PCT's across England. Whilst some of these sat within research consortiums this still meant that 54 separate Research & Development applications needed to be completed. During the process of obtaining approval the PCT's reconfigured and reduced and in some cases this delayed approval further.

To complicate issues different consortiums requested additional information. There were delayed approval meetings due to restructuring and some areas were generally quite unhelpful. Following discussions with South Manchester Ethics Committee (the Local Research Ethics Committee, that also acts as approval for MREC, where approval had been granted for the research), it was agreed that the process would commence with those areas that approval had been received from and the other areas would not be involved in the research process. In all approval was received in a timely fashion from 35 consortiums.

Other methods considered for this part of the research were semi structured interviews, interviews over the telephone and focus groups. Whilst these methods would have allowed more in depth probing and clarification of any ambiguity (Bowling 2006, Bryman 2008) they were discarded for the following reasons:

**Time factors for researcher**. In order to gather the amount of data required visits to at least nine Valuing People regions around the country would be required to gain a representational perspective. These visits would not help to identify if any primary care staff are actually involved in the process of health action planning, as all PCT's would still need to be involved to identify this. Transcription and analysis of data would then take much longer, and may not have gathered as much information as the use of questionnaires. In addition to these issues, had telephone interviews taken place, a large number of participants, across a variety of services and Valuing People regions, would have needed to be interviewed to gather a representative selection of opinions. By using the questionnaire approach, it was more likely that a larger, more representative sample could be obtained than interviews in other formats.

**Time factors for participants**. Participants would require at least an hour out of the workplace, and then additional time to confirm transcripts. If telephone interviews had been used they would have had to take longer to be involved and in addition may have had difficulty finding somewhere to have a confidential conversation in a busy working environment. The use of questionnaires would result in one simple, short contact to complete. Also as discussed earlier, with the questionnaire the respondent could complete it in stages when time permitted.

## Data Analysis

Quantitative studies can be used both to measure the effectiveness of interventions (Polgar and Thomas2000), and to identify the effects of any relationships on outcome measures (Munro 2001). As the aim was to identify both, whether the introduction of health action plans has resulted in health gains and to identify what, if any, combination of factors make a positive outcome more likely descriptive statistics are used.

The quantitative data was analysed using the Statistical Package for the Social Sciences "SPSS" analysis package version 16. Where further analysis was required and in order to enable the researcher to dig deeper and understand if some aspects of the health action planning process impacted each other Spearman's correlation matrix was used.

 The majority of this questionnaire was set out to gather quantitative data; however, so that rich data was not missed some questions were left open ended. Where there was the possibility that another alternative answer was possible the option of other allowed a comment to be added and some questions were left open ended to gather the individual's thoughts and comments if they chose. This additional data was analysed using thematic analysis.

The information is presented in pictorial format in chapter four, using bar charts and pie charts rather than graphs, so that the data can be presented to people with learning disabilities, carers and staff in the same way and in a way that is easy to see and follow. This format of pie and bar charts has been used locally in feedback to groups of people with learning disabilities, and staff and carers so is becoming a familiar process in sharing information. Furthermore, many

learning disability nurses do not have a research background so to be useful, data needs to be presented in a format that is understood to enable it to be utilised in practice.

Questions 28 onwards asked questions to provide insight into the quality aspects of the research so were left as comment boxes to allow a fuller exchange of information. This data was entered onto an excel spreadsheet. Where possible this information was themed into groups of similar context to present information in chart formats or tables with additional information in narrative format as appropriate.

As discussed in chapter 2 the concept of leadership and changing the culture and ways of delivering services, is complex. Therefore the approach used to understand the concept of leadership and attitude to change used by Greig, the then National Director of Learning Disability Services in England, is used to make sense of the findings. Greig's approach identified that there are three types of process/attitudes that can influence progress or not for change. These are removers, containers and developers and the data was analysed using these three themes.

## Qualitative Method

There had been a growing emphasis in recent years for gathering information on consumer input around both health care provision and service delivery (Community Care Act 1990, Patient and Public Involvement 1999b, NHS Plan 2000a).

This study aimed to determine whether health facilitators and people with learning disabilities, consider that the introduction of health action plans have resulted in health improvements for people with learning disabilities living in England. It also aimed to evaluate the experience of people with learning disabilities and health facilitators in Rochdale in delivering health action plan and compare this to the national findings to inform and improve local practice. Whilst the quantitative (questionnaire) aspect discussed, will provide some insight into what is happening nationally, I also wanted to explore what was happening locally so that the research could suggest service improvement to make the experience more beneficial to people living in Rochdale. I intended to do the local part of the study through the use of focus groups so that I

could get an in-depth insight into people's experiences. Involving people with learning disabilities in research is essential, but at the time that this research took place the evidence supporting this inclusion was limited, but this gave me more determination to make it happen.

In considering the evidence presented and in order to evaluate the introduction of health action plans in Rochdale with both health facilitators and people with learning disabilities, I determined that the use of focus groups was the way to proceed. Whilst the evidence suggests that emancipatory research is on the increase for this project inclusive research is used. With the size of the research project and the skills of the researcher I decided that at this time an emancipatory approach would be difficult, but this is something that could be considered in the future. People with learning disabilities were involved in the research as part of the focus group and they were involved in the design of the consent form.

This research involved the use of two types of focus groups. One focus group was for any non nursing staff who acted as health facilitators, and one for people with learning disabilities who have had a health action plan. Focus groups are used to increase knowledge and understanding of social phenomena, rather than provide statistical information (Bowling 2006).Criticism of qualitative research is that it is not representative of the population as a whole and therefore is not generalisable. For the purpose of this research it is intended to identify issues that affect a small population to inform and change practice on a local level. Therefore, generalisation of information is not an issue.

Additionally, the usual process within qualitative research is to continue to gather data until saturation has occurred (Bryman 2008) and no new information is received. The main focus of this research is the quantitative aspect and the focus groups information is to supplement and further inform local practice. For this purpose two focus groups only were intended: one for people with learning disabilities and one for health facilitators, with a small group of participants therefore it was unlikely that the saturization process will occur

Bowling (2006) has described focus groups as: "Unstructured interviews with small groups of people who interact with each other and the group leader" (page 394). Focus groups differ

from interviews in that the researcher acts as a facilitator, introducing topics for discussion and encouraging participants to interact to respond (Polgar et al 2000). They allow the researcher to elicit a wider variety of responses than questionnaires, as the researcher can probe responses and clarify ambiguities (Bowling 2006, Bryman 2008). In addition participants are able to listen to and debate with other participants about subjects in which they have an invested interest. (Morgan 1998).Morgan also commented that the explicit difference between an interview and a focus group is the use of the group interaction process in the collection of research data.

Sample size does not need to be large in qualitative research (Polgar *et al* 2000, Silverman 2001, Parahoo 1997). However a major issue with qualitative research is that participants do not always attend as promised. For this reason it is necessary to over recruit participants. There is a variety of conflicting information recorded regarding sample size with Polit *et al* (2001) suggesting that focus group size should range from five to fifteen people and Krugar(2004) suggesting seven to ten.

Bryman (2008) has suggested that smaller groups are possible if they are very involved with the topic. For this reason and to account for attrition rates and management of this project the original aim was to recruit a maximum of eight people with learning disabilities, and twelve health facilitators for the focus groups.

For this part of the research the non random concept of purposive sampling was used. Silverman (2001)has suggested that purposive sampling allows for the recruitment of participants with particular characteristics, in this case people with learning disabilities in Rochdale who have had a health action plan for one focus group and health facilitators who have completed a health action plan for the other focus group.

Furthermore, Silverman suggested that purposive sampling is broad enough to include variations in perspectives and views. As the aim was to invite participants from all service providers across Rochdale it was anticipated that there would be a variety of experiences as all service providers had different ways of working. Bowling (2006) also referred to this method as judgement sampling, and suggested that participants are selected because they have

knowledge that is valuable to the research process; in this case the local experience of receiving and participating in the health action planning process, and the realities of implementing health action plan within Rochdale.

As discussed the health facilitator questionnaires were circulated around health facilitation networks where, it was expected that the majority of participants would originate from nursing backgrounds. To address this bias a social care health facilitator focus group and a focus group for people with learning disabilities was utilised.

To address the potential bias of the "power relationship" (Polit *et al* 2001) the researcher was not involved in recruiting any of the participants. However, as the researcher has worked in the area for some time, it was likely, that once participants have been recruited that she will know at least some of them. This in fact was the case with the researcher being familiar with several of the participants. However at the time of the study the researcher had no day to day working involvement with any of the participants. The development and progression for each focus group process is now presented.

## Health facilitator focus groups

Through previous consultation with service providers, Rochdale had developed a health action plan format that was shared across all supported living services providers for use**.** This document was quite large as whilst it had been developed as a health action plan for the individual, services had requested that it include documentation that was required by the supported living services regarding the individual's health as well as including a health action plan.  Training sessions had been provided for health facilitators across service providers when the health action planning process had first been introduced.

Potential participants for the focus groups were identified by social care managers. Such purposive sampling is appropriate for the qualitative nature of this study. In order to maintain confidentiality these managers were fully briefed about the focus group in order to answer any questions that arose. Social care managers shared information about the study, with people who expressed an interest in this study, thus giving them the opportunity to discuss the process and information with their managers. If they raised any questions that the manager could not

answer this, information would be shared with the researcher and an answer provided. No issues arose that needed further clarification. To protect confidentiality managers informed the researcher when they had identified potential participants.

Once participants were identified the researcher contacted them to confirm their consent and arrange a convenient meeting time and venue. The following inclusion criteria were applied:

> Participants must be health facilitators with experience of completing health action plans with or on behalf of people with learning disabilities in the researcher's locale

The focus groups were undertaken with staff who acted as health facilitators within three different social care providers offering supported living services for people with learning disabilities in the borough of Rochdale. Ground rules were addressed at the start of the process to ensure that participants did not manipulate the conversation (Krugar 2004). The original proposal was that interviews would be tape recorded, following consent from participants. This would enable accurate transcription of the data after the interview. Unfortunately on the day only two people attended, the poor attendance was due to staffing issues and sickness. The health facilitator focus group was taped. A colleague assisted by operating the tape recorder and taking field notes during the interview process. Where possible field notes of responses were also made by the researcher, for example when closed questions were asked responses were recorded using tick charts. In addition the health facilitators were given a short information sheet to complete to gather limited background information.

The original proposal was to tape both the focus groups using a tape recorder and microphone, purchased specifically for the research process. Despite numerous examples of testing the equipment prior to the meeting, the sound quality was poor, making it extremely difficult for transcription purposes. This resulted in the transcribing process being very onerous. Fortunately, I was able to ask the participants to clarify any areas that were particularly difficult to hear, however they could not recall all conversations exactly, which meant that valuable information may have been lost.

Following completion of the focus group the researcher and her colleague completed a post interview comment sheet to reflect and analyse their feelings, impression and thoughts about the interview. Detailed impressions of participant's behaviours, which cannot be recorded on the audiotape, were made to assist analysis. First indications of emerging themes were noted by the researcher, which were later compared to the actual data interpretation.

Due to the poor recruitment rate and the problems with the recording equipment it was necessary to hold a second focus group to collect data. I contacted South Manchester Research Ethics Committee requesting to conduct an additional focus group and to collect the data differently. Instead of taping this group, the information was recorded in bullet points. Participants also had the opportunity to record additional comments on flip chart paper. This enabled me to confirm that the data collected from the group was accurate at the end of the process. Changes were made to the original consent form to confirm that the interpretation of information recorded was accurate.

Data was transcribed from the audio recordings and the second focus group and anonymised to ensure confidentiality. To reduce observer bias and enhance the credibility and confirmability of the interpretations participants were asked to verify that the interpretations were accurate (Morgan 1998). Indeed the focus group participants were very helpful in clarifying some of the analysis due to the difficulties encountered with the recording equipment. With the second focus group accuracy of the bulleted points of information was verified by participants as part of the process. Following confirmation of accuracy data was coded, using an editing analysis style (Polit *et al* 2001) and thematic analysis completed. Morse and Field (1996) suggest that analysis follows four stages: comprehending, synthesizing, and theorising and re-contextualizing.

The data was read and reduced into emerging categories manually, by the use of various codes. Further analysis was utilised to generate theories, which were then reconstructed into a meaningful picture of the phenomenon of health action plan for further analysis. Emerging themes were compared with those identified post interview to determine if accurate interpretation had occurred. Data is presented as a narrative report to include direct quotes from participants as appropriate. In analysing the data from both focus groups the findings

from both groups were consistent with each other. Therefore in the findings chapter they are presented as one group.

## People with learning disabilities focus group

Valuing People (DOH 2001a) put the emphasis on services to be empowering, offer choice and inclusion for people with learning disabilities in all aspects of their day to day lives. Despite this people with learning disabilities often remain discriminated against and excluded from participation in research due to external factors (PMSU 2004). Their experiences of research are most likely that of being "done to" rather than consulted (Walsmley 2001). However Rose (2001) has argued that whilst people with learning disabilities views are complex, they should have a voice in the services that they receive. It is the researchers responsibility then to look at how people can be involved as part of the research design process.

Involving people with learning disabilities in research is paramount if we are to understand the issues from their perspective. This is not always easy (Cambridge and McCarthy 2001, Young and Chesson 2006); indeed it took careful planning and preparation to involve people in this study. But their involvement should even be done when the subject matter is very difficult. For example Tuffrey- Wijne *et al* (2007b) evaluated end of life care with people with learning disabilities and stressed that

> *If both user –involvement and person centred care are taken seriously, it seems imperative to establish the views of people with intellectual disabilities on what they value at the end of life* (page 81)

Tuffrey- Wijne *et al* (2007) used their previous knowledge of working with people with learning disabilities to use an adaptive form of Nominal Group Technique. They used it in a way that participants could understand in order to identify what issues were important to them at end of life. They concluded that "People with mild and moderate intellectual disabilities are capable of giving their opinion and indeed should be asked to do so" (page87)

Walsmley and Johnson (2003) have suggested that inclusive research was a term that involves people with learning disabilities as active participants in the research process and that this is

also known as participatory research. Walsmley (2001) has suggested that this participatory approach is concerned with the experience of people with learning disabilities. The researcher works in partnership with participants using qualitative methods whose aim is to interpret and explain the lived experience of people with learning disabilities. Participatory research can cover a range of approaches, from taking part in a big way, to actually being only being interviewed as part of the research process. Gilbert (2004) has suggested that this means that people with learning disabilities can participate in research, but that they are not in control of the process. If they were in control of the process this would be termed emancipatory research.

Brooks and Davies (2007) have suggested that people with learning disabilities are the "experts of their own experience". In participatory research with people with learning disabilities to develop a tool to measure feelings they concluded that "Our work is demonstrating that people with a learning disability can bring their enthusiasm, knowledge and commitment to a participatory project" (Page 36).They suggest that to develop this type of approach time is needed to build relationships and capacity for participatory research.

Furthermore in their research into palliative care and people with learning disabilities Tuffrey-Wijne *et al* (2008) concluded that

> *Our own experience of research participants with learning disabilities suggest that they were enthusiastic, not only because of the empowering experience of being listened to, but also because of an understanding that through participation they could make a contribution that would help their peers* (page 186)

Although their research methodology was slightly different to the focus group approach used in this research this is a valid point. Focus group participants in this research thesis were able during the discussion to advocate on behalf of others who were less able to communicate than themselves. They could debate with each other that whilst they could all speak for themselves the health action plan would be beneficial to those who were less able as a good way to communicate their health needs when attending health appointments. They were also willing to be involved in looking at how the health action plan process could be further developed and improved upon locally.

Fortunately, evidence demonstrates that participation in and recognition of the importance of inclusion in research is improving for this group (Tuffrey-Wijne *et al* 2007a, Department of Health 2006b, and Gilbert 2004). Whilst observations may have been used in the past in studies about behaviour (Bell 1999) qualitative research is increasingly used to access the views and experiences of people with learning disabilities (Walmsley and Johnson 2003). Gilbert (2004) presented a comprehensive review of various studies involving people with learning disabilities in research that have utilised a range of strategies and methods and included the use of narrative reports and story telling a case study approach and action research. Gilbert concluded that

> *The population of people with learning disabilities is complex and diverse, which means that the tailoring of methods to the range of individuals involved is required if lay knowledge is to be accurately understood* (pages 306-307)

Walmsley and Johnson (2003)have argued that the extent, to which qualitative research is truly inclusive depends on how it is initiated, designed and implemented , therefore the use of semi-structured interviews are useful ways of gathering information from this patient group.

Boland *et al* (2008) used this method to evaluate service provision regarding health promotion requirements in Ireland. The methodology within this study reflects their approach. Not only will it give a national perspective from health facilitators in England, but it has focussed in on the local perspective of health facilitation in practice and will then compare this with the experience of some of the people with learning disabilities in receipt of the service in Rochdale. People with learning disabilities were involved in the design of the consent form for the study prior to gaining ethics approval. A small number were then involved in a focus group.

Boland *et al* (2008) further discussed how other researchers had reported issues around communication and that soliciting the views of people with learning disabilities had been fraught with difficulties but as Gilbert had surmised in 2004 suggested that these problems can be overcome by adapting the approach that they had taken. They concluded that they had found the experience "Positive and personally enriching" (page 207). With careful planning

and consideration then, there is no reason why this group of patients cannot be involved or consulted in the research process.

Yet, people with learning disabilities are a heterogeneous group, with wide variations in both intellectual ability, ability to think abstractly and in the differing life experience encountered. Therefore research done with one group cannot be generalised (Silverman 2001) to another as experiences may differ. This part of the research used semi-structured focus groups to provide a local perspective of people with learning disabilities experiences with the health action planning process.

Fraser and Fraser (2001) used 3 separate focus groups with people with learning disabilities to identify their knowledge about health promotion services and concluded that a focus group "Is an appropriate method where group discussion is needed" (page 231). McCallion and McCarron (2004) took this one stage further and suggest that focus groups are useful for discussions as they help to reach points in the focus groups where participants reach agreement or disagreement. They demonstrated that focus groups work most successfully when

1) there is a specific agenda
2) appropriate participants have been recruited
3) meetings are effectively moderated
4) there is a systematic analysis and interpretation of the results

One advantage of focus groups is that the researcher can observe subtle behavioural changes, thus picking up both verbal and non-verbal cues (Polgar *et al* 2000). It is often more difficult for people with learning disabilities  to verbalise their thoughts so cues can be observed and acted upon to "tease" out answers. In addition, if any signs of discomfort are observed the researcher can remind participants that they can withdraw from the interview at any time without reprisal.  This was proven during this focus group. At times during the beginning of the discussions, two participants were observed to disagree with comments (shaking head or becoming agitated at responses) but sat there and did not speak. It was obvious to the researcher that they disagreed with what had been said, but they remained impassive, not joining on with the conversation at all. To encourage them to express their opinions and in order to facilitate their involvement and get them to join in the conversation I asked them

questions directly to which they then responded. At this point, even though they joined in with the discussion, they still appeared unsure of their answers and somewhat lacking in confidence. However as their confidence grew all participants interacted together and at times challenged each others assumptions, without any prompting by the researcher, resulting in a healthy debate of the issues (Bryman 2008, Bowling 2006).

Bollard (2003) recognised the importance of using focus groups for people with learning disabilities and suggests that "The focus group is advocated as an appropriate tool that can "collectivize" the experiences of people who may have limited communication skills" (page 156). Bollard continues suggesting that focus groups are also useful because they provide the opportunity to hear the thoughts of often silent voice and that this can be achieved by using a variety of mediums to aid communication.

It was anticipated, by previous experience of facilitating groups with people with learning disabilities, that it may be necessary to break for refreshments part way through the process. Whilst this may be unusual and stem the flow of conversation it may assist in gathering additional rich data. Furthermore, in a group setting it is more likely that participants will feed off each other to get the conversation flowing than on a one to one basis. Although it took some time for this process to happen participants did indeed start to talk and challenged each others ideas to provide valuable insight into what was happening around their health action plan.

Focus groups allow participants to challenge each others comments which may result in a more realistic view of what they actually think, and they allow participants to raise issues that are important to them (Bryman 2008). Focus groups are particularly useful for involving people with learning disabilities (Walmsley and Johnson 2003) and can provide a rich source of insight from participant's perspectives. Finally, focus groups allow the researcher to explore issues that participants feel may have an impact on health action plans and support them to explore how these can be addressed.

Initially the research proposed that the focus groups be audio taped. Following the difficulties encountered with the recording of the health facilitator focus group, I had concerns that the

interpretation of communication by people with learning disabilities may prove more difficult from an audiotape than at first expected. Some people may communicate in a slower less clear to understand way than others and this may not come across as well on audiotape alone.

I felt that the use of a video recorder would enable the recorder to focus in on the individual speaking at that time. This should help to clarify what the person is saying.

The use of video recording was being used in this way within the service more and more and had proven to be a successful way of working. Furthermore to ensure that information was not missed the discussion was bulleted on flip charts as it was given and participants were asked to confirm that this information was accurate at the end of the focus group. In order to facilitate this change a notice of substantive amendment was sent to and agreed by South Manchester Research Ethics Committee in June 2007.

Mick *et al* (2008) have discussed the use of video recordings as a tool to improve service delivery for people with learning disabilities. Although this article was written after the data collection for the current research study, they suggested a number of issues to consider, on the use of video recordings with people with learning disabilities which were employed in this study. They suggested that careful attention needs to be paid to the issue of consent; the procedure for inviting people to participate needs to be rigorous, with explanations of what the recordings are for and how they will be used, and that the individual can withdraw at any time without recriminations. This process was followed as part of the consent process.

One disadvantage of focus groups is that some people may manipulate the conversation (Kruegar 2004). To address this ground rules were agreed at the start of the process. The use of ground rules in research with people with learning disabilities has proven successful for other researchers (Abell *et al* 2007). At the start of their research project it was agreed that whoever was holding the pen would be able to speak and the others had to wait until the pen got to them. After a few false starts this process worked well for Abell's group. In order for people with learning disabilities to understand this concept the ground rules were minimal and they were reinforced by the researcher as necessary throughout the process. The main ground rules were similar to ones used by the researcher previously in similar meetings. These are:

1) To take turns in speaking

2) To listen to what other people have to say

3) To not interrupt

4) To respect peoples opinions , even if you think they are wrong

5) Confidentiality

Another disadvantage is the possibility of acquiescence, with participants telling the interviewer what they think they may want to hear, rather than their own opinions (Bowling 2006). In order to address this issue questions followed a pre-determined, semi-structured format, which was sent to participants prior to the focus group allowing them to consider the questions prior to the meeting. This assisted the people with learning disabilities who may have needed additional time to consider responses and may have needed help with articulating them.

Finally cost implications (travel, suitable venues, and refreshments for participants and the vast amount of time to transcribe and verify data) could be seen as disadvantages with undertaking focus groups. Fortunately for the purposes of this research the venue and refreshments were provided free of charge and support was given in release time to transcribe the data collected.

## Recruitment and process of focus group

Walmsley and Johnson (2003) have suggested that one way that people with learning disabilities may be selected for focus groups is by insider status. Prior to commencing this research I had worked across services providers in the borough to co-ordinate the development of the health action plan. This put me in the fortunate position that I already had good working relationships with the managers which enabled access to discuss the research proposal at the design stage (Lennox *et al* 2005). This was useful as some researchers have found that organisations can effectively block access to potential participants by gate keeping any requests for involvement (Lennox *et al* 2005). Furthermore, due to the support for the project the managers were then able to fully discuss the research rationale with their managers who would support them in the recruitment process for both focus groups.

Consequently, potential participants were identified by social care managers. Such purposive sampling is appropriate for the qualitative nature of this study. In order to maintain confidentiality, these managers were fully briefed about the focus group in order to answer any questions that arose from either staff or potential participants so that the researcher would have no contact until potential participants were identified. These managers then shared this information with people with learning disabilities who had expressed an interest in the study. Potential participants then had the opportunity to discuss this information with carers/family that they were familiar with. To protect confidentiality it was planned that if any questions were raised that the manager could not answer the information would be shared with the researcher and an answer provided. This did not prove to be necessary. Managers then informed me of potential participants. The following inclusion criteria were applied, that participants must;

I. Have a health action plan and live in the researchers locale
II. Be able to verbally communicate
III. Be able to participate in group discussion and turn take
IV. Be able to offer ongoing consent to process
V. Be able to participate without carer support in order to maintain group confidentiality

Whereas this research aimed to gather the perspectives of a small group of people with learning disabilities it acknowledges that it could be considered flawed due to the inclusion criteria. It does not allow for the involvement of people with profound learning disabilities who cannot verbally articulate or who may need support to be involved in a focus group. Walsmley (2004) has suggested that "reliance on more able people with learning disabilities may not be the best route to reaching the least advantaged" (page 59) and Cambridge and McCarthy (2001) have suggested that focus groups are not the best method of involving this group of participants. Therefore it does not does not develop a truly participatory approach (Williams 2003). However, it is interesting to note, that on several occasions during the focus group, participants did actually make reference to the fact that health action plans were of use for this group of people who have difficulty in communicating verbally. Due to the time factors within this study it was decided, however, that at this time this particular group of

participants were not appropriate. Further research could in the future be developed to adapt a more inclusive approach.

To address the potential bias of the "power relationship" (Polit *et al* 2001) I was not involved in recruiting any of the participants. However, as the researcher had worked in the area for some time, it is likely, that once participants were recruited that I would know at least some of them. It may be argued that this knowledge of participants could cause problems with acquiescence with the participants giving the answers that they think that I want them to give. However, Dockrell (2004) has suggested that acquiescence with people with learning disabilities in interviews can occur because the questions asked are too difficult to understand, so that the participant does not always understand what it is they are being asked and that there is a need "to establish that the respondent's understanding of the words is the same as the interviewers" (page 164)

In order to address this I developed a research package for the study. This package consisted of a participant information sheet, consent form and letter of explanation. These were all reviewed by people with learning disabilities to ensure that they were fit for purpose and that they could be understood. This adapted method had proven useful in other studies (Lennox *et al* 2005 and Cameron and Murphy 2006) and as previously discussed 80% of people with learning disabilities have issues around communication. Whilst participants in this study would need to be able to verbally communicate, due to the nature of the focus group approach, it was possible that participants may have poor or no literacy skills. Therefore the information was produced using simplified language, large font size and some pictorial information. If participants could not read, staff could discuss the information with them. Interestingly at the ethics committee comments were made about the use of a picture of a person in a wheelchair on the consent form as the reviewer felt that this was inappropriate. Once it was explained that people with learning disabilities had been involved in the design and had chosen this picture as they felt that all people with learning disabilities should be represented there were no further issues.

Dockrell(2004)has also suggested that the ability for the researcher to read the situation and adapt as required is important and that "Familiarity with the interviewer may be important" (page 164). Giving an example from children's services where familiarity with the individual

had increased tests scores. Once participants were identified, I visited the individuals, to both confirm their understanding of the research and to ensure that they fulfilled the inclusion criteria. Lennox *et al* (2005) suggested that making home visits was one way to improve recruitment. However my main reasons for the visit were to ensure that the person understood the process and that they were not being coerced into involvement with the research. This visit also enabled participants who did not know me to become familiar with me (Walsmley and Johnson 2003). Consent was obtained using the adapted pictorial form discussed above. This form included a section whereby if the person is not able to give written consent, verbal consent could be witnessed by a carer and the researcher, this was necessary for one participant.

At this visit the purpose and process for the research was discussed with the person with a learning disability. This discussion was broken down into stages with the opportunity for the person to ask questions at each stage. The individual was encouraged to relate back to the researcher what this process was, in their own words, so that I could determine that they understood what was expected and were not just agreeing to a take part because I was there or because the carer had asked them to take part (Cameron and Murphy 2006). This initial visit also allowed the research to gauge the comprehension levels and verbal communication abilities of the participants. This enabled me, to both, support, and encourage, involvement of participants in the process.

Each participant was given a letter about the focus group and a set of questions for them to consider prior to the actual focus group. This was to assist those participants, who needed additional time, to consider responses and who may need help with articulating them. It enabled them to ask me questions, if they did not understand what the questions they would be asked meant. It also gave them the opportunity to talk through the questions, if they choose to do so, with a carer or family member. It could be considered that this may be an opportunity for their carers/family to influence answers, but the experience of the researcher in previous types of group meetings suggests that this is the chosen method that the participants would prefer. Additionally on the day carers/family would not be present, so participants had the opportunity for free speech. This information was brought to the focus group by three

participants as a useful prompt and served as an aide memoir for the researcher on writing up the interview.

During the visit to gain consent, I explained to each potential participant what would happen and why I was using a video instead of an audio tape recording the focus group. I also explained that there would be someone in the room video recording the conversation, and someone in the room taking notes, neither of whom would take part in the discussions within the group. These people would not repeat anything that was said in the room to any one else. I explained that whilst the conversation would be recorded on video, it would remain confidential as only I would have a copy of the video and after the research was completed this would be destroyed. I explained that whilst I may use their comments and conversations in reporting on the research, they would be anonmymised so that no one would know who they were or who had said what. They all consented to the videoing of the focus group

At the start of the focus group the basic ground rules of listening, respecting each others opinions and giving everyone the opportunity to speak in turn were reiterated and agreed. Consent was reconfirmed at the commencement of the focus group, and participants were reminded that they could discontinue with the interview at any time. The focus group lasted approximately one hour with all participants staying to the end. The focus group was video recorded and bullet point notes were also made at the time, and confirmed as accurate with participants. Questions followed a pre-determined, semi-structured format. Three participants brought their 'aide memoirs' prepared after the consent meeting and at times used these as a prompt.

Ideas presented were also written down on a flip chart as the group progressed. At various points this information was read back to participants, who were asked to clarify what had been recorded. This had two benefits. Firstly it enabled me to ensure that I had correctly interpreted what was said, and secondly it enabled participants, who may not have initially commented, to add to the discussion at this point. This technique proved quite successful.

None of the participants had been involved in focus group discussions before, and on several occasions, it was necessary to remind people of the ground rules so that they would remember

to listen to what other people had to say and take their turn. Also initially, whilst participants were becoming familiar and comfortable with the process, it was necessary to follow a round robin approach to encourage people to become involved in the process. This too worked quite well and participants soon began to join in of their own accord.

It was interesting to watch the group dynamics of the focus group evolve during the interview. Two participants appeared to be at very opposite extremes. One was very negative throughout about the whole process about their health action plan. The other was quire positive and constructive about the health action plan process and could articulate very clear benefits to the plan. At times they also became quite challenging of the negative attitudes being expressed by this person.

The other two participants (who shared a house), needed encouragement at the start of the focus group, but participated more and with less encouragement as the group progressed. However, participant 2 was much quieter than participant 1 who quite often tried to give their interpretation on what the housemate was trying to say. This was challenged by the researcher on several occasions by asking participant 1 to let participant 2 speak for themselves, whilst also reminding them of the ground rules. This is a prime example, where the researcher having some knowledge of participants, is actually of benefit when conducting focus group interviews with people with learning disabilities. It is possible that a less familiar facilitator may have accepted the interpretation of participant 1 as a supportive measure, and valuable data may have been lost. Furthermore, aspects of the individual's body language may have been missed, and therefore opportunities to encourage people's involvement in the discussion could have resulted in a less rich collection of information.

## Other methods considered

Other methods considered for this part of the research were semi structured interviews, and questionnaires. Whilst both of these methods could have provided information they were discarded for the following reasons. In the case of questionnaires, many people with learning disabilities have poor literacy skills and would require support in the completion of the questionnaires. This could result in;

- The person feeling inadequate
- The potential bias of the power relationship (Polit *et al* 2001). Participants may respond in the way that they feel support staff/carers want them to.
- Incomplete answers/accounts as they don't want to cause upset
- The support person putting their own interpretation on questions and answers

With both groups a more in depth discussion and analysis of local practice was required, and this could not be achieved by questionnaire alone.

Semi-structured interviews could have been used to gather information but they would not allow in-depth discussion to take place between people with learning disabilities, or staff from the different organisation locally, which may have allowed the researcher to compare practices.

## Ethical Considerations

Parahoo (1997) has suggested that there are six ethical principles demonstrated within four rights of participants to be considered when undertaking research. For the researcher the issue that was prominent was that of consent or the right of self determination, for people with learning disabilities.

In order to consent to being involved in research, the individual needs to understand what it is they are consenting to. They need to be able to receive the information, digest it, and consider the implications of the research process, making an informed decision about whether or not to be involved in the research process. Issues' regarding capacity to consent has hindered people with learning disabilities from becoming involved for some time with researchers wary of involving this patient group and ethics committees not helping by classing this group as vulnerable people (Lennox *et al* 2005). Cameron and Murphy (2006) also cite the "Difficulties with attention, memory and ability to transfer recently learned materials" (page 114).I would argue that the issues is surely how the researcher adapts the process to include all groups of people in the research process to accommodate individual need rather that the difficulty that this may present.

Cameron and Murphy (2006) discussed how they overcame these issues by informing of the use of visual information, additional time to discuss and explain the research process and using the expertise of carers to observe this process to determine if the people with learning disabilities that they recruited to their study were actually making informed choices about being involved in the research process. I would argue that the use of an information pack and the individual interview with each participant demonstrate that informed consent was obtained. Furthermore in observing the participants, closely throughout the focus group, I was able to identify if the person began to feel uncomfortable. In asking during the process if participants were alright to continue continuing consent was maintained.

Indeed, Dye *et al* (2004) have argued that the concept of capacity to consent to inclusion in research is flawed. During an assessment of capacity several people with learning disabilities were deemed unable to consent following usual guidelines, yet continued to participate in the process, some withdrawing at a later stage, thus making a choice to withdraw as any other participant may do. Indeed the concept of assessing the capacity of people with learning disabilities to be involved in research could be deemed as discriminatory as the general public are not assessed as to capacity to consent and valuable information could be lost by excluding this patient group (Walmsley and Johnson 2003). This is a valid point as consent was taken from health facilitators without any assessment of their understanding at all.

In the case of questionnaires consent was implied by the return of the form. Respondents could choose not to consent by either not returning the form or by not answering all questions.

The next consideration is that of non –malfeasance. Assessment indicated that there were no risks of harm identified in taking part in this study. Interviews took place in the participant's locale at a mutually convenient place and time to reduce anxiety, discomfort and inconvenience for participants. Participants were able to withdraw from the research at anytime, and did not have to respond to any aspects that they felt uncomfortable with. Whilst participants may not directly benefit from taking part in the research, it is envisaged that the outcomes will benefit both health facilitators, and people with learning disabilities locally and nationally, as the evidence has contributed knowledge; where there a distinct lack of knowledge surrounding any benefits or difficulties with the introduction of health action plans.

People have the right of full disclosure. Participants were informed of the nature of the research through a letter informing them of the purpose and proposed dissemination of the research prior to participation. A summary of the research findings was made available to all participants if requested. This enabled them to clarify any concerns with the researcher at source. Following the focus groups participants received copies of the transcribed information so that they could verify that the information was accurate before analysis of data commenced.

Finally, the right to privacy, anonymity and confidentiality were addressed. Confidentiality and anonymity were offered to all participants within the accompanying information inviting participation in the research. All data was stored and accessed according to Caldicott Guidelines (DOH 2003), NHS and NMC (2002) and Clinical Governance policies. Data was made anonymous at the earliest opportunity by using a code for each participant of the focus groups. These codes were stored separately from the transcripts. Any direct quotes from the focus group were rigorously scrutinised to ensure anonymity. All information was stored in a locked cupboard and data input on a password protected computer within the researcher's office, with access limited to the researcher and their supervisor only.

## Summary

This chapter asked the question "Has the introduction of health action plans for people with learning disabilities actually made a difference?." Also the research aims and objectives were presented. These were to gather a national perspective, to determine whether, health facilitators and people with learning disabilities consider, that the introduction of health action plans have resulted in health improvements for people with learning disabilities, and a local perspective by evaluating the experience of people with learning disabilities, and health facilitators, in Rochdale, in delivering health action plans and compare this, to the national findings to inform and improve local practice. In addition the research identified who acted as health facilitators and took the lead in introducing health action plan to identify if the local practice of learning disability nurses in supported living services leading on health was replicated elsewhere.

Different methods of research were considered for each part of the research and the rationale for their rejection was given. The chapter discussed in some detail the use of questionnaires for the national study and focus groups for the local study. Difficulties with both parts of the study were identified. For the questionnaire several areas were slow in releasing research and development governance approval and so these areas were not involved in the study. However, representation from across England is evident in the findings. For the focus group there were issues with equipment failure resulting in videotaping of the focus group for people with learning disabilities. A high rate of sickness with the health facilitator's focus group resulted in a second focus group taking place, and data was collected differently by using flip charts and confirming accuracy at the end of the meeting.

The recruitment processes for both elements of the research were discussed. Participants for both groups were approached and given information by social care managers as the researcher was well known in the area and therefore did not want to unduly influence participation. Issues affecting user involvement in research for people with learning disabilities were discussed as were the rationale for carrying out part of the research with a user group to improve local practice in developing health action plans. Participants for the learning disability focus group were visited to ensure that they understood the research project and that informed consent was obtained.

Data was analysed using Statistical Package for the Social Sciences "SPSS" analysis package version 16 for the questionnaire, and thematic analysis for the open ended questions with in the questionnaire and the focus groups. Finally, in order to put the findings in context Greig (2003) approach to change within the learning disability context was used. This concept suggests that there are three attitudes to change, and that these can influence if change is embraced or hindered. The next four chapters will present the findings from the research study. A final integrated discussion chapter will bring the overall findings together.

# Chapter Four

## Questionnaire Findings

## Introduction

This chapter describes the findings from the national questionnaire aspect of this research. The study asks the question "Has the introduction of health action plans for people with learning disabilities actually made a difference?" The aim of the questionnaire was to determine whether health facilitators in England considered that the introduction of health action plans have resulted in health improvements for people with learning disabilities living in England.

The questionnaire was designed to identify how health action plans were developed and introduced, who had been involved in the health action planning process, what if any, quality monitoring and reviews had taken place; if training and support had been given to health facilitators and if health gains were identified as a result of this process. The questionnaire utilised closed (quantitative) and open (qualitative) questions and therefore the evidence will be presented to reflect that. Some discussion of the qualitative data takes place in this chapter.

In total, 117 questionnaires were received from across England where respondents met the criteria for involvement. There were several additional questionnaires received where respondents did not meet the essential criteria of having to have completed health action plan so these were discarded. As there was no national database for health facilitators, it was not possible to assess whether the sample size was representative of all health facilitators, making the use of inferential statistics inappropriate. Where further analysis was required, Spearman's correlation matrix was used to enable the researcher to dig deeper and understand if some aspects of the health action planning process impacted upon each other.

The results are therefore presented as a percentage of the 117 responses received and not relative to a return ratio of questionnaires. I have used descriptive statistics and presented the information in chart format so that the data can be presented in an accessible way to people with learning disabilities, carers and staff in the same way and in a so that it is easy to see and follow. Furthermore, where numerous examples of comments were received these have been summarized into tables to inform the reader. In depth discussion of the quantitative aspects of the questionnaire research data is presented in chapter seven, the findings are now presented.

# Data Presentation

## 1.In which Valuing People region are you based?

Responses were received from all nine Valuing People regions and are shown in the figure below.
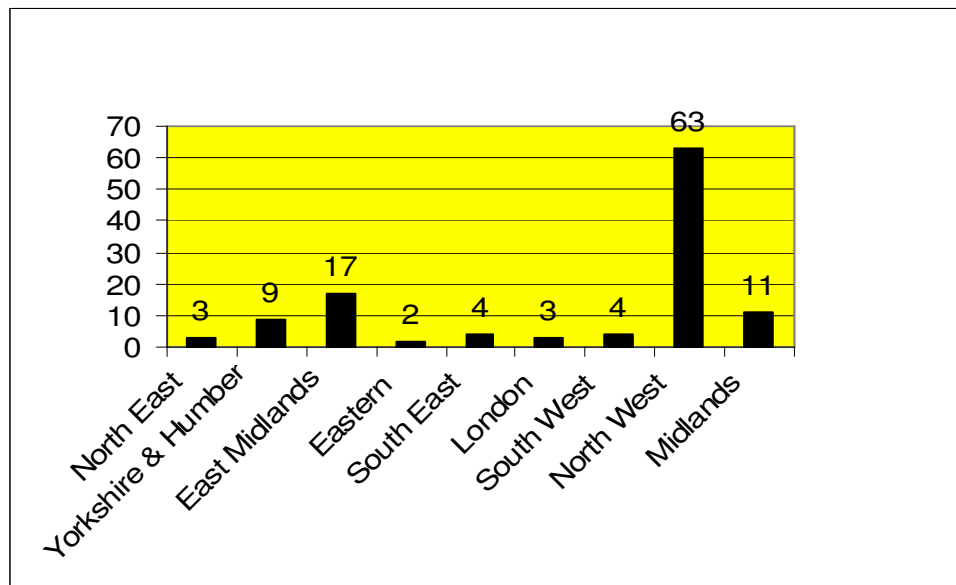


*Figure 4.1 Valuing People Region of Respondent*

## 2. What is your role in supporting people who have a learning disability?

The majority of respondents 57% (66/117) were from a nursing background. Of these 28% (33) were nurses with the learning disability community team, 16% (19/117) recorded that they were health facilitators and 12% (14) worked within residential service provision. One respondent did not answer this question. The answers are shown in figure 4.2.
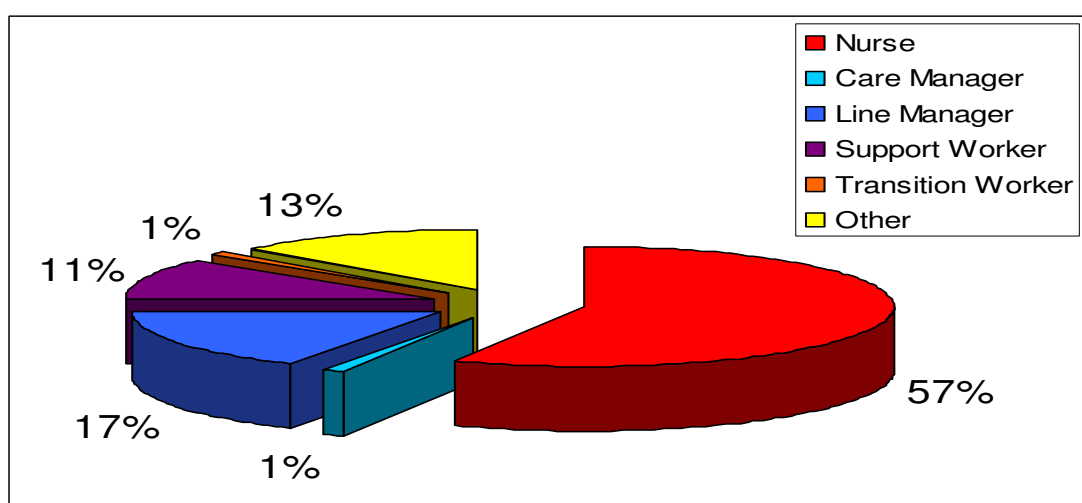


*Figure 4.2 Role of respondent*

Other included:

- Service manager for mental health
- Service manager for PCT
- Health facilitation assistant
- Community matron for vulnerable adults
- Support workers (4)
- Trainee Assistant Practitioner
- Deputy manager

### 3. If employed, who do you work for?

It is not surprising that as the majority of respondents were nurses that they were employed at this time by primary care trusts (62%-72%). Two respondents did not answer this question. The answers are shown in figure 4.3.
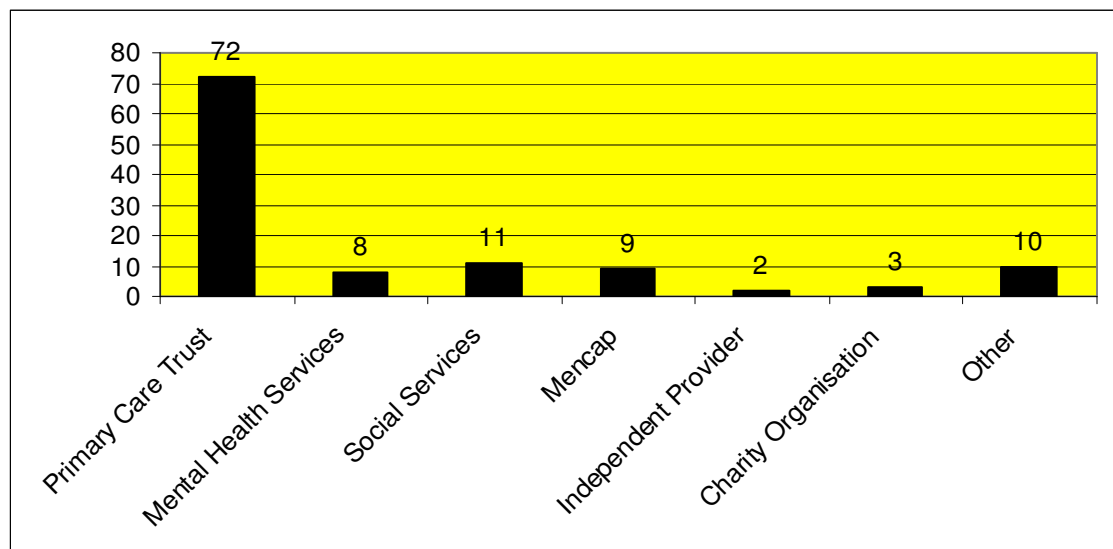


*Figure4. 3 who employed respondent*

Other answers included:

- Learning Disability Trust (5)
- Learning disability and mental health trust
- PCT
- G.P practice
- Care trust
- Social service department

**4. What is your role?**

Thirteen (11%) respondents operated at a strategic level with one third (33%) operating at both a strategic and operational hands on delivery model. The majority of respondents (56%) acted at an operational level and therefore was not able to influence strategic direction. To move the health facilitation role forward it was anticipated that the majority of health facilitators would indeed be "hands on" to facilitate and coordinate the health action plan. However the remaining respondents acted at a strategic level with 11% having a remit purely as a strategic health facilitator to move the health action plan process and the health agenda for people with learning disabilities forward.

**5.  How many health action plans have you facilitated?**

*Table 4.1 Number of health action plans facilitated*

| *Number of HAP* | *1-10* | *11-20* | *21-30* | *31-40* | *41-50* | *51-100* | *101-150* | *151-200* | *300* | *Missing* |
|---|---|---|---|---|---|---|---|---|---|---|
| *Number responses* | 66 | 13 | 7 | 3 | 3 | 4 | 2 | 2 | 2 | 15 |

Due to the wide range of plans completed the answers were placed in groups of ten up to 50, then fifty up to 200 and finally 2 answers were 300. The frequency of health action plan completed ranged from1-300, with the mean of 24. As table 4.1 demonstrates the majority of staff had completed up to ten plans (66) with only six completing more that 100 plans. Respondent 94 nurse residential said that they had done "100 as their previous job was completing health action plans as a main part of the role" Another health facilitator who had completed 300 plans identified that they were specifically in a role that focused on health action planning. Finally, although 15 respondents did not answer this question they were not excluded from the results, as their other answers indicated that there had been involvement in the health action planning process.

There were a number of comments received and these were themed into training, difficulties with facilitating health action plans and contradictions in role. Some respondents had completed health action plans and had acted as a training resource regarding health action plans to other services and GP practices. These comments are listed in table 4.2

*Table 4. 2 Comments regarding training*

| |
|---|
| Provided training for provider services in my area on how to complete health action plans. All organizations approached me for training |
| Given advice to clients and carers in the development of these |
| Developed and facilitated training to paid carers-over 200 due to be audited to see how many plans initiated, piloted health screening template-rolled out to 64 practices |
| Provide health action facilitation training to adult placement carers and residential care homes as community nurses also do plans with new referrals if appropriate our nursing assistant provides health facilitation to clients we support long term |
| As a community nurse part of my role is to facilitate health action plan training so although the figure above(24) is actual health action plans facilitated I have overseen many others |
| This has been by offering training, advice and support to carers, people with learning disabilities and advocates. I have supported some people to complete the health action plan but my role is more strategic than operational. |
| I have completed 5 plans as their health facilitator, however I have been involved in teaching and supporting carers to complete health action plans and this has been for a further 10 people. We are currently in the process of completing health action plans. |

Several respondents identified that there were difficulties within their current role that hindered the number of health action plans completed. Respondent 45 (Community Nurse) identified that they "Only do health action plan for longer term client for CTLD where there are no carers to complete-devised framework with training and general health prompts for carers"

And a third respondent, 55, (clinical services manager) suggested that their input into health action plans was "Sporadic-as specialist support team only raises profile/offer health action plan not maintain facilitation as close case once episode of care complete we discharge off caseload and that they were not best placed to be ongoing health facilitators"

Several respondents suggested that there were some contradictions in their role, as either other priorities took over or that health facilitation was not always seen as part of the role.

Respondent 39 (nurse health facilitator) commented that it was "very difficult to do more (health action plans) as part of joint team and are asked to do "traditional social work" i.e. duty, appropriate adult, vulnerable adult etc"

This reflects the current issues of joint working within community nursing teams, whereby nurses work alongside social work colleagues. A common complaint raised by nurses at local health networks is that they are losing their identity as nurses as the social work aspects of the job appear to take over. Respondent 49 (nurse health facilitator) said "6(haps) in previous role as community nurse, as healthcare facilitator no direct client contact work" The concept of a health facilitator having no client contact in itself is strange unless this is a strategic role where changes are being directed at a board level. It would appear that this person has moved on from playing an operational role although this is difficult to confirm for certain.

Several additional comments were received that show the range of how health action plans were facilitated, regardless of the role of the health facilitators. Respondent 50(community nurse) said that "Additional role is to co-ordinate health action plan with colleague and training and helping others to be facilitators so oversee most of them" Respondent 58 (community nurse) commented that they had undertaken a "Pilot with 6, 18 (year olds) at transition" that there was no specific "health facilitator" (role) and that they ", work in children's team as part of Children and metal health services (CAMHS)", whilst the "adult team work with GPS re health action plans."

Respondent 13 (line manager residential) commented that they had "Facilitated for 6 clients and have helped to keep record which is easily accessible for staff, line managers and other agencies e.g. district nurses". Whilst respondent 6 (line manager residential) commented that a "Health action plan (was) developed for all service users following health screening"; and respondent 112 (community nurse) suggested that "Each open case had a health action plan therefore I would estimate 30 this includes the cases closed who had a health action plan" Respondent 111 (nurse residential) identified that they were "Currently attempting to provide health action plans to clients who are being discharged from service- 300 in services"

Finally, two respondents identified that they had a more strategic role that involved more than just facilitating health action plans and training. Respondent 95 (nurse health facilitator) was very specific and identified that "My role is generally more strategic and I only have a small caseload. Often my involvement is to resolve issues or to support the facilitators of people with complex needs to get started on their plans. I would not be involved long term"

Whilst respondent 96 (nurse health facilitator) was expansive and commented that they had completed "Approximately 120 so far but my role is to set up and coordinate the process. But saying this I have made several home visits to explain process to carers and people with learning disabilities also I deliver all the training regarding health action plans to carers , GP practice staff etc "

**6. How many people with learning disabilities live in your town or city?**

Of 117 respondents only 77 (66%) answered this question. The responses ranged from 2-12,000. Due to the wide range of answers they have been grouped in the table below. Evidence suggests that at least 2% of the population have learning disabilities. Therefore some of the lower data collected would indicate that some respondents did not understand this question, as it most unlikely that an area would only have 2 people with learning disabilities in it. Therefore this data should be treated with caution. In rural areas, however, it is possible that lower numbers of people are evident. Table 4.3 gives the range of responses to this question.

*Table 4.3 Number of people with learning disabilities living in area*

| Number people | 0-99 | 100-500 | 501-750 | 751-1000 | 1001-2000 | 2001-3000 | 3001-5000 | 10000 | 12000 |
|---|---|---|---|---|---|---|---|---|---|
| Responses | 6 | 22 | 10 | 8 | 8 | 11 | 10 | 1 | 1 |

**7. How many people have a health action plan?**

Unfortunately, 86 respondents from 117 (73%) did not know the answer to this question and 4 respondents (3%) did not answer the question at all. Of the 27 responses received the numbers of people with learning disabilities who had a plan ranged from 3 to 5,000.The majority of respondents (25) reported that between 3-300 people with learning disabilities had a health action plan, with one respondent indicating 550 and one indicating 5,000.

Without further information it is difficult to identify why one area appears to have such a high response incidence of health action plans. However one respondent had identified 300 plans being completed because they were in a specific role to undertake this, but from responses received this is not common practice. Furthermore within the authors locale where a co-ordinated response to health action plans across social care providers and families, occurred the number of plans completed was no where near that high which would suggest that this response is treated with caution.

**8. How long have you worked with people with learning disabilities?**

In total 62 % of respondents had worked in the service over 10 years, 18.8% had worked 6-10 years, 17.5% between 1 and 5 years and only 1 person had worked in the service for less than one year. One respondent did not answer this question.

**9. Who took the lead in introducing health action plans in your locality?**

Four respondents did not answer this question. The responses are shown in figure 4.4.
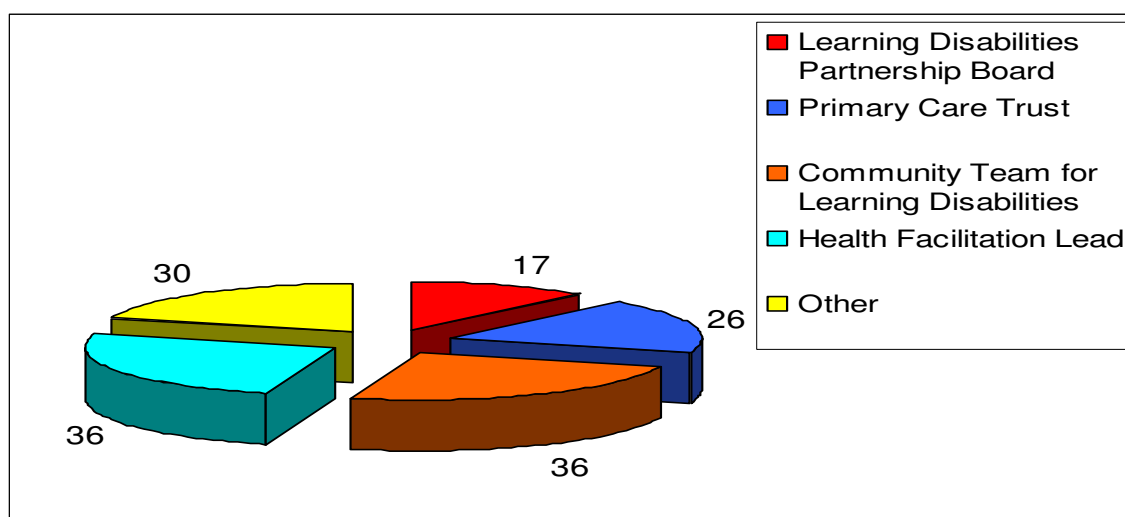


*Figure 4.4 Who took the lead in introducing health action plan*

Several comments were received. These were mostly positive but one respondent identified that whilst some work had gone on to introduce health action plans, there was still some way to go to get it right. Health action plans were introduced "As part of the good health task group

strategy and introduced via an agreed training structure for paid staff. Unpaid carers do not have access yet to the structured training. Need to be aware individual service providers have been initiating plans on an individual basis" Respondent 42 (community nurse)

Other included given were:

- Professional development nurse
- Head of service
- New group tasked with introduction and development of health action plans
- Role involves research into and advising practitioners re introduction of health action plan
- Children's learning disability services
- No lead identified- community team developed framework
- PCT lead learning disability nurse
- They sent out information on health action plan but not detailed was done by me using legislation and guidelines from the government
- Community nurse as an add on job

Respondent 96 (nurse health facilitator) explained further how they had developed the health action plan themselves "A group of interested community nurses developed a proposal which we presented to the Assistant director for LD. She took the proposal and created the Health Care Coordinator Roles, one of which I currently hold. As HCC we then wrote the process and piloted it. We are now currently working on rolling out our plan"

Finally respondent 64 (line manager residential) commented that "Trust learning disabilities service and local authority developed independently of each other" Overall, the majority of these findings mirror those of Mir (2007) who also identified that health action plans were developed by individual services across Leeds with no co -involvement with each other.

**10. Was the design of the health action plan led by the learning disability services?**

The design of the health action plan was led by the learning disability services in 83 %( 97) of cases. There were 9 (8%) non responses to this question. The other 11 (9%) responses to this question are listed in table 4.4 over the page.

*Table 4.4 Who led the Design of health action plan?*

| |
|---|
| • As part of the good health task group strategy |
| • Learning disability service and local authority developed plans independently of each other |
| • By partnership working with primary care |
| • From funding from the LD Partnership board |
| • PCT LD nurse lead |
| • Use two formats- one from another area and one developed locally |
| • A group of interested nurses developed it |
| • Community nurse as an add on job |
| • Role involves research and advise to practitioner re Health Action Plan and health facilitation |
| • Head of service |
| • New team tasked with introduction and development of Health Action Plans |
| • Professional development nurse |
| • Mencap |

**11. Who was involved in the design of the health action plan?**
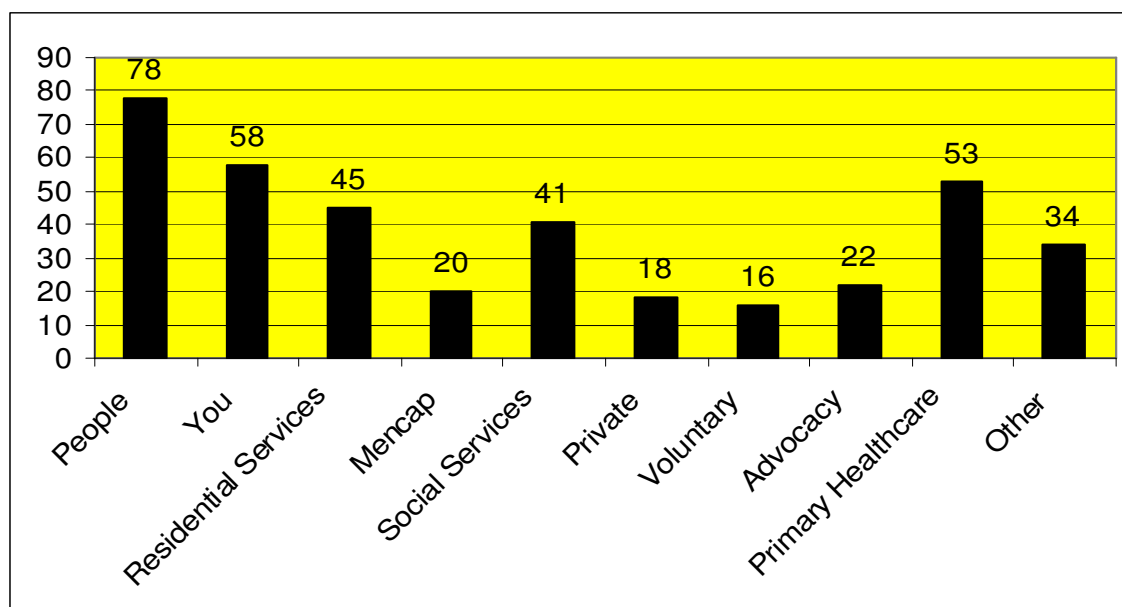


*Figure 4.5 Who was involved in the design of the health action plan*

Two respondents indicated that the health action plan was offered at the end of a health screening process.

Other answers included:

- Health task group
- Research project
- Family/Carers
- Allied health professionals/school nurses
- Practice development nurse
- Person centered planning team
- Practice nurse
- Health team
- Managers/staff
- Community learning disability nurses
- Partnership board allocated LDDF monies for a health facilitator
- Graphic designer
- Integrated teams- speech and language therapy
- The Health Action Plan Guidance was produced within the health action plan Subgroup and consulted upon widely via the 3 Partnership Boards

Interestingly, only one person (respondent 35 community nurse) commented that the design of the health action plan had been designed "In partnership with the person centered planning process" Despite this concept of person centeredness being suggested by Valuing People (DOH 2001a) as key to the health action planning process. Although Respondent 42 (community nurse) commented that this question was "Not applicable as health action plans if person centered should be dictated by the individual".

Several others agreed with this sentiment suggesting that:

- All health action plans are individual and there is no design template
- Service user version of health action plan individually designed with support from carer and photos symbols communication aids
- I try to make the process person centered so don't always use the standard form/process

Finally Respondent 104 (community nurse) commented that the "Health action plan was designed at strategic level therefore I am unaware of who was involved. I believe it included people with learning disabilities". Although I agree entirely with this sentiment it is interesting to note that out of 115 responses to this question only 78 indicated that people with learning disabilities had actually been involved in the design of the health action plan. This is not unexpected as although question ten identified that in 83% of cases the design of health action plan was led by learning disability services not one response indicated that the design was led by people with learning disabilities, even though the finished plan would actually belong to them.

**12. Was the health action plan piloted after design?**

The health action plan was piloted after design in 59 % (69) of cases, in 10% (12) it was not and in 30% (35) of cases respondents did not know- 1 person did not answer this question at all.

**13. Were any changes to the format made as a result of the pilot?**

Of those 69 cases where the health action plan was piloted, changes to the format of the plan were made as a result in all but 6 cases; resulting in 91 % (63) of health action plan being amended after the pilot.

**14. Does the health action plan contain the following?**

One respondent did not answer this question. Only 86% of respondents indicated that some type of documentation was available that related to the individuals ability to or not to give consent. In a small sample of plans 14% (26) of health facilitators included information about the carers needs. These responses are shown in figure 4.6 on the next page.

*Figure 4.6 Pages that the health action plan contains*



**Does the HAP contain**

- Consent Form
- Best Interest Form
- Refusal Form
- Carer's Needs

33%

29%

24%

14%
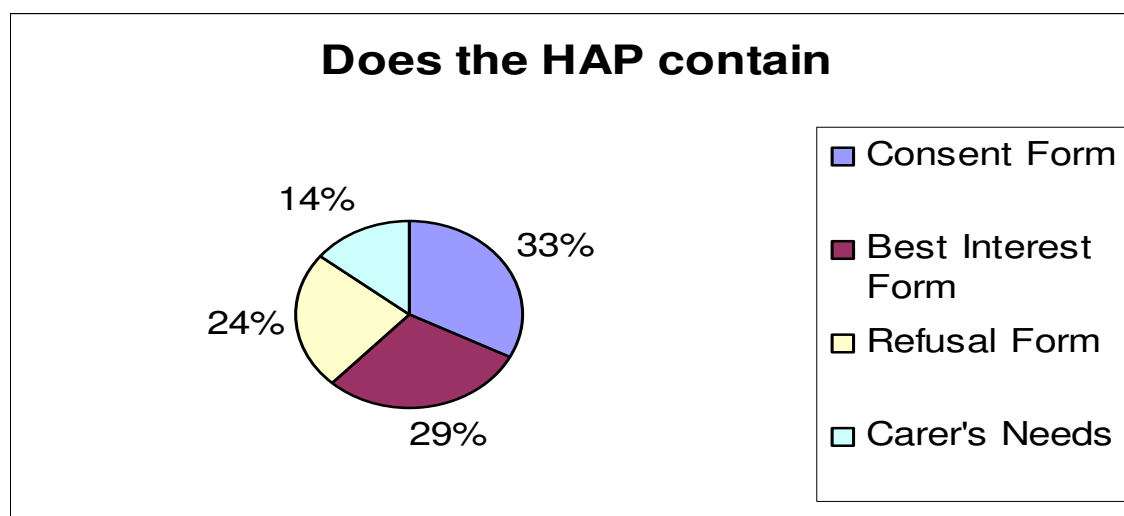
**15. What other information is included in the health action plan?**

All respondents answered this question. The number of respondents that had this information included within the plan and are shown in table 4.5.

*Table 4.5 Information included in the health action plan*

| General Health | 11 | Medication | 110 |
|---|---|---|---|
| Family Health history | 91 | Epilepsy | 99 |
| Records/outcomes appointments | 96 | Admissions to Hospital | 83 |
| Syndrome specific information | 82 | Communication | 101 |
| How to recognise if I am in pain | 90 | Screening histories | 85 |
| Mental Health & Well being | 106 | Death & Dying | 41 |
| Women & Men's Health | 106 | HAP Goals | 98 |
| Lifestyle / Healthy Living | 106 | Diabetes | 89 |

In addition 33 respondents indicated that there was a variety of other information included in the plan. This is listed in table 4.6 (number of respondents for information included)

*Table  4. 6 Additional information included in health action plan*

| | |
|---|---|
| • Sexual Health 2 | • Nutrition and lifestyle 2 |
| • Blood test 2 | • Culture and ethnicity 1 |
| • Immunisation 4 | • Hospital grab pack 1 |
| • Equipment 2 | • When I die 2 |
| • Skin and hair 3 | • Funeral plan 1 |
| • Main supporters for health 1 | • Feet 2 |
| • Hearing 6 | • Continence 2 |
| • Oral health 4 | • Vision 5 |
| • Mobility 6 | • Emotional needs 1 |
| • Any needs not addressed and why they were not addressed 1 | • Things I like to do that may not be good for me 1 |

Several respondents commented that the plan was individual and therefore would be adapted as appropriate. This meant that some, all or none of the above information would be found in the health action plan.

Respondent 41 (nurse health facilitator) commented that they are "Currently using 3 different formats, one is more physical assessment for complex patients who find it difficult to access mainstream, then a basic health diary, health screening template for primary care. But all these as outcomes of health action plan" and respondent 45 (community nurse) commented that they also included a "reference handbook of general health facts, communication, consent, behaviours etc"

Several respondents did not see the health action plan as the end product to contain all the information listed in the tables above. They replied that they used a different concept and the comments below demonstrate a much more individually led concept of health action planning process than many of the others received. Respondent 95 (nurse health facilitator) commented that "Our health action plan guidelines are a checklist of things to think about, we provide space for making notes.  The facilitator is then expected to develop an action plan that is accessible to the person from the discussion"

Another discussed various methods of health action planning and also indicated that their process had involved primary care as the health screening tool had been adapted to accommodate the individual's health action plan of choice.

> *In the area for which I am responsible, we are not using a standardized format of health action plan   screening tool but encouraging residential services (with a lot of support) to create a health action plan meaningful to each individual. As a result some service users have a book, some have created a PowerPoint presentation that is interesting and informative, and some will have a collection of objects of reference/story bag to enable them to understand as much as possible about their health or health appointments.  The format of the screening form that is used in conjunction with primary care has been created to be adapted to include all of the above as it asks very broad open questions such as clinical diagnosis, current and previous medical investigation and treatments etc.*
> (Respondent 101 community nurse)

This method represents a true person centered approach (Sanderson *et al* 1997) which, as further discussion throughout the thesis demonstrates, was not the approach used by many areas. However, Respondent 36, a practice advisor, offered an alterative view in commenting that "with the exception of the health action plan goals we see all the other areas as belonging to the assessment of health needs, whereas we view the plan to be the health related goals that the person has chosen to address together with all the relevant information as to who will support and monitor these" This is a fair point as some respondents appear to have a simple plan that just indicates the individuals health action goals whilst others have developed a much more complex plan that contains a lot of other information.


**16. Who funds the printing of the health action plan?**


Nine respondents did not answer this question. The responses are shown in figure 4.7 over the page.

## Who funds printing of HAP?

- Primary Care Trust
- Community Team for Learning Disabilities
- Residential Service Providers
- Person Who Plan Belongs To

10%   2%

39%

49%
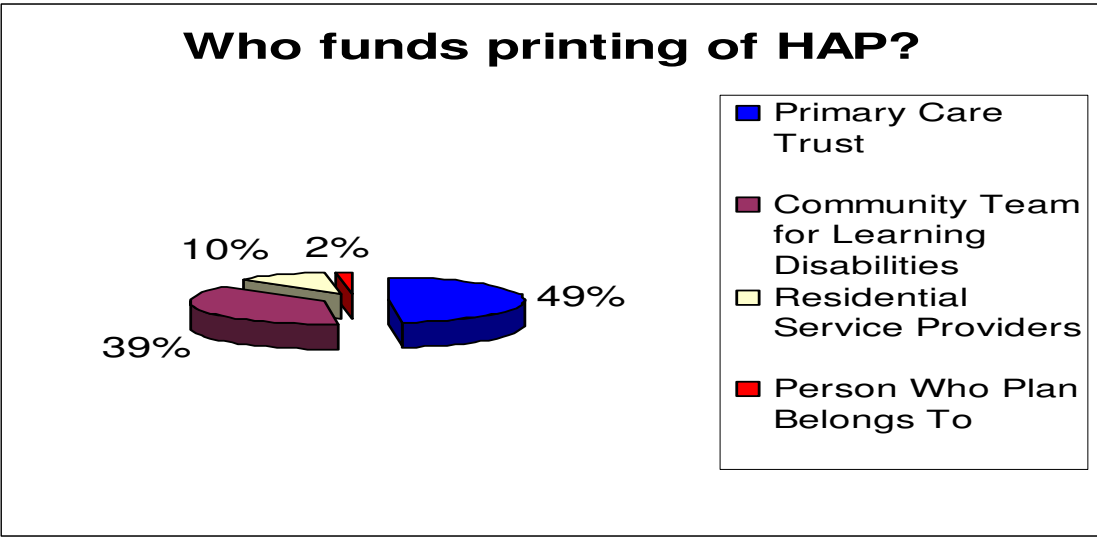
*Figure 4.7 Who funds the printing of the health action plan?*

In addition funding was by provided as listed in table 4.7:

*Table 4.7 Other sources of funding for health action plan?*

| External funding  6 sources | Other 15 responses |
|---|---|
| PCT funds folders children's team funds printing | Social services |
| LDDF | Practice nurse prints off |
| Charity | Section 31 monies |
| Joint funding/PTC/SS | Individual basis |
| Sponsorship 2 | Funds raised by community nurses |
| No answer 9 | General practice |
| | Mencap |

As no funding for resources was allocated by the government for the health action planning process this has become an issue in developing health action plans. Indeed, one area commented that although the community team have funded the first 2000 copies of the health book and 1000 copies of guidance notes, no further funding was available for continuation sheets etc or for the final 1500 copies that they estimate they may need. They did not offer any comments as to how this would be addressed.

**17. In what formats is the health action plan available?**

One respondent did not answer this question. The other responses are shown in figure 4.8 and table 4.8 below.
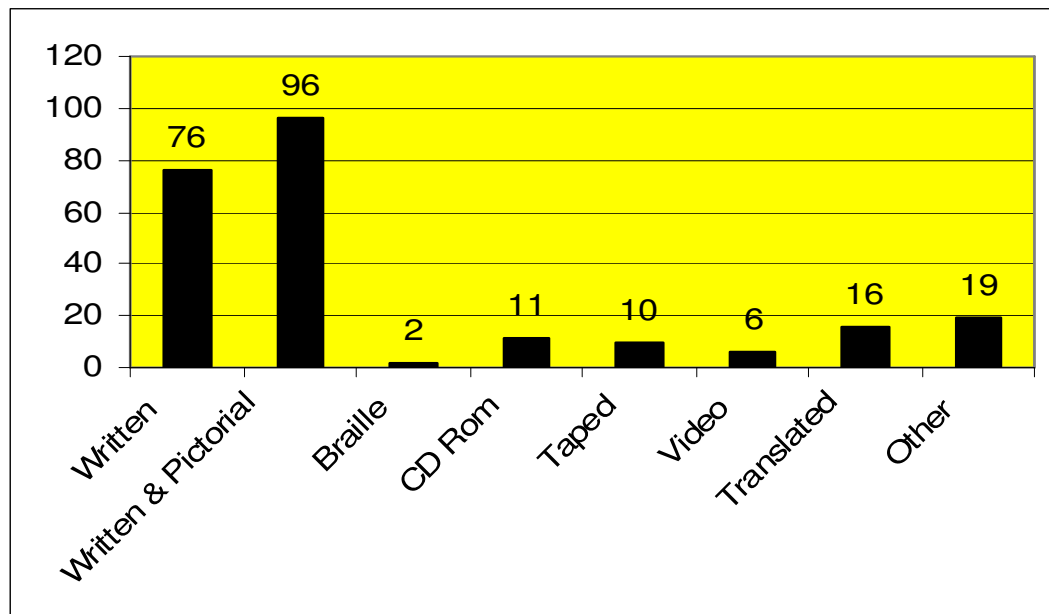


*Figure4. 8 Formats that health action plan is available in*

Nineteen respondents identified other formats of health action plan available as in table 4.8.

*Table 4.8 Other formats of health action plan available*

| |
| --- |
| • Carer makes accessible for individual ( 4) |
| • Large print (2) |
| • Individual (3) |
| • Trying to get it done in Braille |
| • Talking hand held document |
| • Limited words all symbols Punjab/Urdu |
| • CD format being investigated |
| • A4 &A5 handbooks |
| • Verbal nothing that costs money |

One nurse health facilitator was explicit in answering this question and commented that"It's the responsibility of the carer to make the written info accessible to the individual following advice from the practice nurse. It is not a massive document produced in isolation it is specific to that person's health needs. It is owned by primary care and the individual" (Respondent 31) Furthermore a community nurse, respondent 101 had already given a comprehensive response to this when responding to question 15

> *In the area for which I am responsible, we are not using a standardized format health action plan screening tool but encouraging residential services (with a lot of support) to create a health action plan meaningful to each individual, as a result some service users have a book, some have created a PowerPoint presentation that is interesting and informative, and some will have a collection of objects of reference/story bag to enable them to understand as much as possible about their health or health appointments. The format of the screening form that is used in conjunction with primary care has been created to be adapted to include all of the above as it asks very broad open questions such as clinical diagnosis, current and previous medical investigation and treatments etc* (Respondent 101 community nurse)

Another nurse health facilitator commented that: "One plan developed on computer by person with learning disabilities. (It is the) responsibility of carer to make information accessible to individual, following the advice from the practice nurse. It is not a massive document produced in isolation it is specific to that person's health NEEDS. It is owned by primary care and the individual," Respondent 41

Although some areas do appear to produce plans in other formats the majority of health action plans 73 % (172) around the country continue to be written/written pictorial. Some respondents were able to offer several formats of health action plans in their area and others commented that they would endeavour to provide the plan that was most appropriate for the individual. "The team would take a flexible approach to provide a plan in whatever format the person requested. Until now only written and pictorial plans have been issued by the community nursing team. We have no way of knowing how they are presented in residential services" (Respondent 36 practice advisor)

**18. How many pages are in the plan?**

There were 20 non responses to this question. From the responses received the mean plan had 21-30 pages. However plan size ranged from a couple of pages to over 51 pages demonstrating a large difference in size. This is to be expected as no guidance was given to the format of the plans.

The responses to this question are summarised in table 4.9.

*Table 4.9 Number of pages in health action plan*

| 1-10 | 11-20 | 21-30 | 31-40 | 41-50 | 51+ | No reply |
|------|-------|-------|-------|-------|-----|----------|
| 13 | 21 | 20 | 17 | 15 | 10 | 20 |

**19. Who acts as health facilitators in your region?**

One respondent did not answer this question. The other responses are in figure 4.9 below.
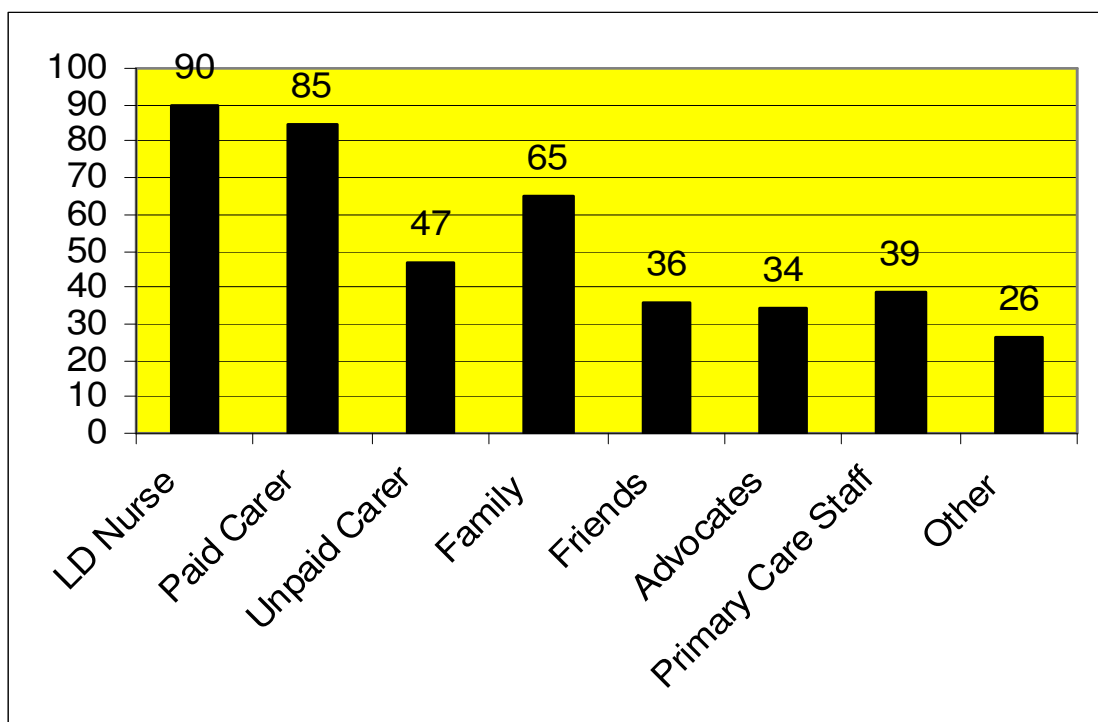


*Figure 4.9 People who act as health facilitator*

Others who act as health facilitators include:

- Voluntary organisations
- Health facilitation assistants
- Community support workers 2
- Strategic health facilitators 3
- Whoever is chosen by client/knows them best 5
- Social care and health staff
- Social services
- Service user with GP-but rare!
- Anyone

Respondent 76, a nurse health facilitator added that "There are strategic health facilitators, however is responsibility of all those involved in the persons care and most importantly the person themselves in acting as their own health facilitator" Furthermore, respondent 31 (nurse health facilitator) sums this up by commenting that "There are strategic health facilitators, however I am trying to get the message over to all stakeholders that EVERYONE who looks after/cares for a person with learning disability will be a facilitator of health…..it's everyone's business and I think the term is confusing and misleading"

In adding any comments in question 37 respondent 42(community nurse) concurs and suggests that "I feel many community nurses have developed a title "health facilitator" which implies that they are the people to "do" or "lead" health action plans. This is very dangerous and not in line with what was set out in Valuing People. It is also an insult to carers to intimate that a "paid" carer or professional needs to be a health facilitator".

Certainly from the evidence provided in this questionnaire, there are a variety of people, professionals and paid/ unpaid carers involved alongside nurses in implementing health action plans. From the evidence above (discounting "other" who are a mixed selection of health facilitators) 182/422 (43%) of health facilitation would appear to be undertaken by non professional/unpaid carers. It is important therefore to ensure that all health facilitators are adequately trained and supported in their role. Indeed in answering this question respondent 95 suggested that there were two levels to health facilitation in commenting that:

*Community learning disability nurses will provide specialist advice on health action plans for people with complex needs and will initiate plans for people but will identify someone in the circle of support to take on the facilitation role long term.  In some instances the CLDN assistant will lead on plans.* (Respondent 95 nurse health facilitator)

**20 Was training offered to health facilitators prior to commencing health action plan?**

Training was offered to 77 % (90) of health facilitators prior to commencing health action plans.  There were 5 respondents who did not reply to this question and 22 (19%) of health facilitators indicated that they had not received any training at all. There were a range of comments regarding training. These are summarised in tables 4.10 and 4.11 below.

*Table 4.10 Positive comments regarding health action planning training received*

| |
|---|
| • We are training everyone involved in the process |
| • Training delivered to new staff or as refreshers |
| • On going training and 3 monthly meetings for facilitators |
| • Opportunity for 1:1 discussion, self directed learning. |
| • Mandatory training for managers and key person |
| • Training give to all service providers |

*Table 4.11 Negative comments rgardinge health action planning training received*

| |
|---|
| • No we have used internet and networks that are available. Use of research and literature |
| • Training has stopped at this point |
| • Nurses were not offered formal training themselves |
| • Only some facilitators were able to access training |
| • Limited to professional paid carers |
| • No training for health facilitators of assistants. One nurse in each patch  had role changed with training between us |
| • Given plans and CD Rom and left to get on with it- no formal training |

In addition, several respondents had commented on training in answering question 5 about how many health action plans they had facilitated. Respondent 42(community nurse), when answering question 9 also identified that health action plans have "Been introduced via an agreed training structure for paid staff. Unpaid carers do not have access yet to the structured training".

Some respondents commented that this training was only delivered to certain groups of people. Respondent 42 community nurse identified that training was delivered: "To paid staff who are commissioned service providers" Whilst another, respondent 37 (a nurse health facilitator) took an holistic approach in commenting that "Training was rolled to all primary care staff, staff within residential care, day services, voluntary, independent services and service users" Whilst respondent 64, a line manager residential, whilst answering question 36 identified that they felt unsupported in their role and they "Haven't had training and none was available. There appeared to be an assumption that as a qualified nurse I'd already know what I was doing"

Only a few respondents commented that this training was extended to staff and or carers that were not being paid, with two respondents identifying that; "Plans are in place to develop a DVD about plans for parents to give them an overview of what a plan is. In addition supported training sessions are being developed and delivered to small groups of parents" (Respondent 95 nurse health facilitator)Respondent 104, community nurse, suggested "Training is offered by the community nurse team to paid and unpaid carers etc". However this respondent also commented that despite delivering training" The community nurses were not offered formal training themselves"

Finally respondent 43, a nurse health facilitator, commented that their training was "Delivered to managers of organizations to disseminate down to their staff". What is evident is that a variety of literature suggests that carers require the knowledge to support people with learning disabilities accessing health care (Wang et al 2007, Valuing People 2001a, Hogg 2001, Singh 1997) so it should be expected that this requirement around increasing knowledge should include health action plan delivery. The issues regarding training are discussed further in chapter seven.

**21. In what format was training being delivered?**

Responses to this question are presented in figure 4.10 on the next page. However, Twenty four respondents commented that other types of training were used. These included developing training packs, via an email and having a website with down loadable booklets.
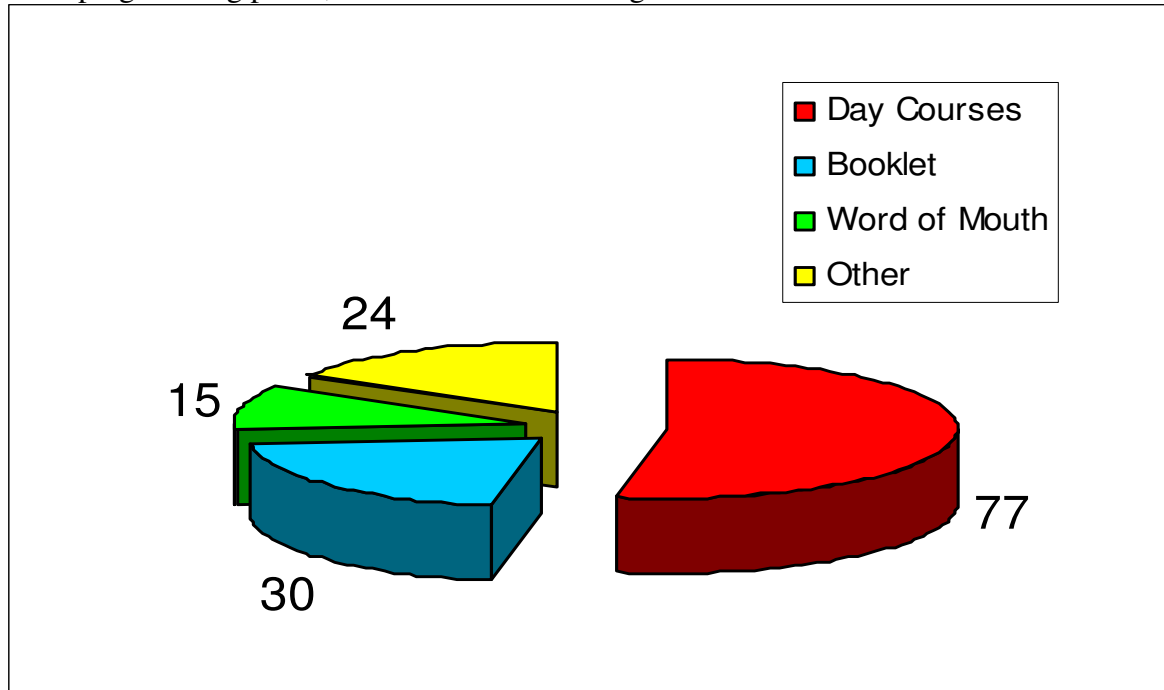


*Figure 4.10 Format of training offered*

Several respondents gave details about the content in their training. Some training appears to cover the basic concepts of the health action planning process. One community nurse respondent 35 commented "A course is being run every other month by social care re health action plan process. Community team for learning disability nurses were asked to present the role of the health action plan facilitator and a brief overview of how health action plans should work"

However, other correspondents offered a more holistic approach by looking at the health facilitation process in more detail. One community nurse commented that;

> *We run a monthly two day workshop looking at concepts of health in general, health needs pertaining to gender, age, ethnicity, economic status, health needs pertaining specifically to people with learning disabilities. Purposes of health action plan; who should be involved in plan, what plan should contain how to start (Opportunity for 1:1 discussion with learning disability nurse, and chance for self-directed learning around specific syndrome or health issues). How to create an accessible plan (half day facilitated by learning disability nurse and/or speech and language therapist) How to use primary care services more successfully* (Respondent 101 community nurse)

Another health facilitator nurse (respondent 103) replied that "Training given on completing health action plans, the role of health facilitators and information about what is known about the health needs of people with learning disabilities and ongoing support and monitoring"

Finally, a third approach starts with the general concept of health facilitation, and then focuses in more on the individual aspects. This community nurse (respondent 102) delivered training by offering; "Awareness training session then more specific training i.e. to staff teams" As is evident from these responses the delivery or non delivery, who the training was delivered to and the format and depth of training varied around the country.

## 22. Was training useful?

Responses from the 90 respondents who received training 91 % (82) stated that they had found it useful.

## 23. How are health facilitators chosen?

Two respondents did not answer this question. The responses of the 115 respondents are recorded in figure 4.11 over the page.
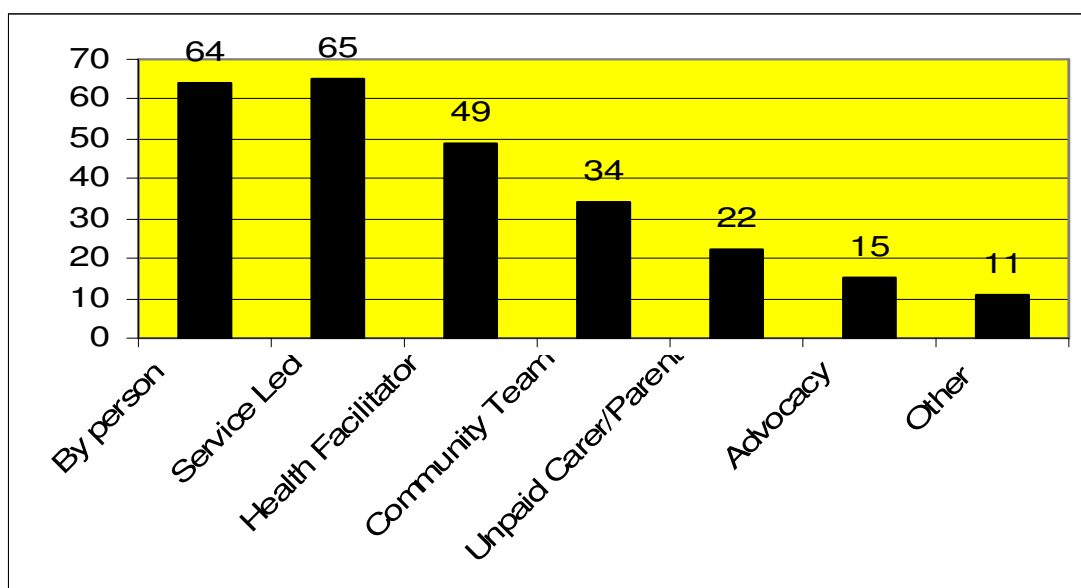
*Figure 4.11 How health facilitators are chosen*

The other ways recorded as to how health facilitators were chosen is summarised in table 4.12 below.

*Table 4.12 Other ways that health facilitators were chosen*

| |
|---|
| Dependant upon the persons ability to choose facilitator (4 respondents) |
| If unable to choose discussion with family/carers re who knows them best |
| Usually in group homes key worker as they know person best |
| Via person centred planning where possible |
| Managers support staff to identify appropriate person |
| Health action plan can be offered as part of nursing-social intervention |
| Referral to health facilitator for area |
| Initially community nurse-looking to pass this on |
| Elected self combined with practice nurse |

Eighteen respondents commented further on this process. Using thematic analysis the comments indicated three approaches to facilitating health action plans

The first concept was that process of health action planning was service led with the consensus that the individual could choose their own health facilitator. However, it was clear that the expectation was that residential services would provide health facilitators rather than the community nurses. One community nurse(respondent 104) commented that "All residential services were given training and the responsibility fell on them to provide a health facilitator, this is usually the persons " key worker"; and that "The community nurse team are currently checking with all homes to ensure the health action plans are being completed and that they have a health facilitator"

In some areas community nurses would only provide support initially to people who were "Living independently or with family, health facilitator will initially be community LD nurse or Practice Nurse, but we would be looking to pass on responsibility to a person of the service user's choice" and that " in residential services the health facilitator is usually key worker" (Respondent 101 community nurse) This format of providing health action plans mirrors the comments of respondent 95 in answering question 19 who talks about training all staff but that nurses would take on the health facilitation role when working with more complex cases. One community nurse (respondent 49) summarized this nicely; "in main- health facilitators for residential services key workers, health facilitators for day centre's staff at day centre, those who lived with carers were staff from community nursing team"

The next concept of choice of health facilitator was that of the choice being made by the individual. Whilst this is the ideal, respondents acknowledged that there were difficulties achieving this which are shown in table 4.13 over the page.

*Table 4.13 Difficulties in achieving individually chosen facilitators*

| |
|---|
| ▪ The health action plan states it should be the choice of the individual but often it is the key worker if the person is in residential or supported living. |
| ▪ Each health action plan is unique therefore the person best placed to act as facilitator may change with each health action plan. They are all, however, monitored by Primary Care to ensure they are based on good information |
| ▪ Training promotes the choice of health facilitator by the person with learning disabilities; however this is not always possible as the person chosen may be unable or unwilling to act in this role |
| ▪ Individual filofax format allows health facilitation to be actioned by whomever person chooses. Guidance/support is the offered by the community nursing teams/and/or/health facilitator |

One nurse health facilitator (respondent 79) suggested that this individually led concept should go one stage further in that support should be given by: "Whoever is best placed and chosen by the person to give required support for each health action e.g. health care assistant for supporting at out patients appointment, community support assistant assisting with healthy eating programme, or parent offering foot care." Finally respondent 31, a nurse health facilitator, concluded that "The person with learning disability should feel comfortable with the person they want as their health facilitator". Indeed this may be the ideal process but the evidence does not indicate that this is the case in practice.

Lastly the concept of community team involvement in the health facilitation process was identified. From these responses it is clear to see that some professionals see it is a part of their role to facilitate health action plans and others do not. Examples of this are shown in tables 4.14 and 4.15.

*Table 4.14 Community nurses see health action plan as part of their role*

| |
|---|
| ▪ Those referred to the community team for a health facilitator will be given an allocated community nurse and they will fulfil this role. |
| ▪ Community nurses who have an open episode of care for a person, who does not have anyone else to work as their facilitator, will automatically, become their health facilitator. |
| ▪ Individual case looked at. Health facilitation to be actioned by whoever people with learning disabilities wishes. Guidance /support is then offered by the community nursing team/and/or health facilitator |

*Table 4.15 Community nurses do not see health action plan as part of their role*

| |
|---|
| ▪ All residential services were given training and the responsibility fell on them to provide a health facilitator, this is usually the persons "key worker". |
| ▪ Community team do not facilitate the plan only co-ordinate process. The facilitator is normally identified from service users day to day support team |
| ▪ We do not see community nurses as first port of call as needing to be involved in everyone's health action plan. Our health strategy identifies priority groups for the community team to be involved or lead the development of any health action plan for those going through a period of transition (and not in receipt of a commissioned service).It is everyone's role (who cares or supports a person) to develop a health action plan with the individual. |

The difficulty arises that if professionals cannot agree between themselves on who should facilitate health action plans, how are people with learning disabilities to determine who can be their health facilitators? In adding any comments to question 37, one respondent actually sums this up in saying that;

> *The assumption that primary care staff will take on the role of health facilitator is correct but I feel clear definition is required between health facilitator and health facilitation coordinator as anyone at any level (operation/strategic) will be undertaking health facilitating activity but only particular individuals will be assuming responsibility for coordinating and evaluating, instigating direct action for an individual*
> (Respondent 42 community nurse)

**24. Who has been involved in the completion of health action plan?**

All respondents answered this question. The answers and numbers of responses are shown in figure 4.12 below.
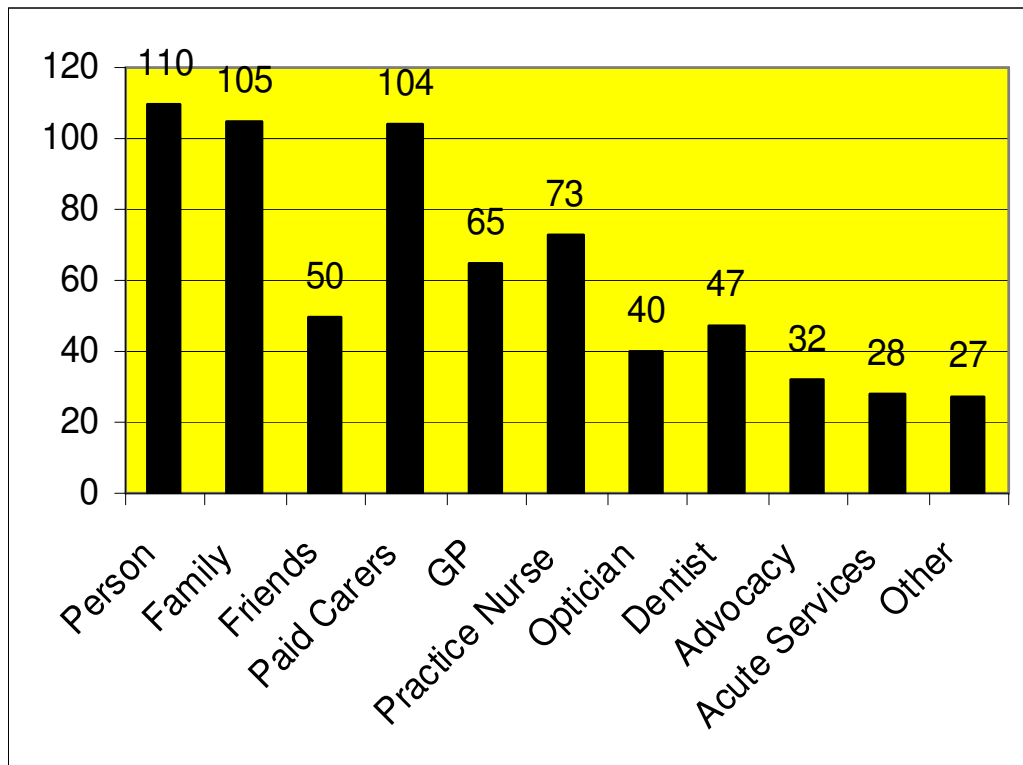


*Figure4. 12 People involved in completion of the health action plan*

Table 4.16 below summarises the other 27 responses received.

*Table 4.16 Other people involved in the completion of health action plan*

| Staff team | Community support workers (2) |
|---|---|
| Learning disability nurse (6) | Social worker |
| Pharmacist | Chiropodist |
| Allied Health Professionals | Physiotherapist |
| Epilepsy clinic | Speech therapist |
| Neurology | Occupational therapist |
| Day services | Diabetic clinic (2) |

This demonstrates a wide variety of people have been involved in the completion of health action plans. It is interesting to note that respondents indicate a high level of primary care involvement in the plan (234 primary care contacts -35% of total involvement). What this question does not answer however, is their level of involvement in the process.

**25. Did health screening take place to inform the health action plan?**

13 respondents did not answer this question. Of the remaining 104 answers received 28% (29) said that screening did not take place and 72% (75) of responses health screening did take place to inform the health action plan. The responses are summarized in figure 4.13 below.
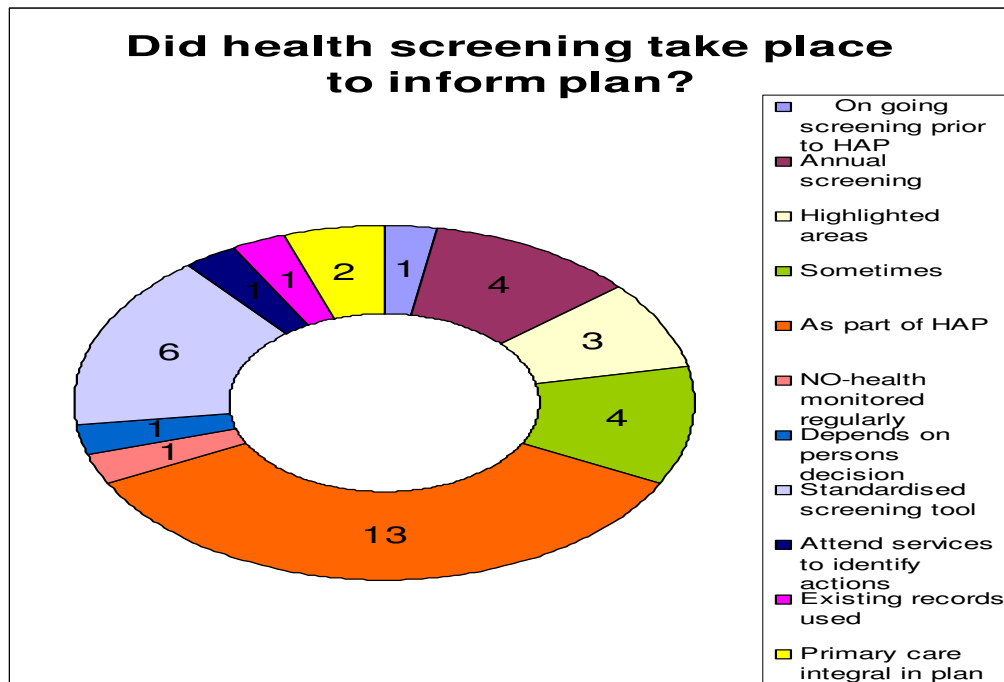


*Figure 4.13 How health screening took place*

There were 44 respondents who offered additional comments. These are summarised in the section below. In some cases screening had taken place prior to the health action plan, indeed one nurse health facilitator (respondent 31) answered that "This (screening) is an integral part of health action plan. Primary care staff will not be responsible for health action plans that do not originate from their staff. They cannot be requested to sign off the health action plan when they've had no involvement." Furthermore Respondent 6 a line manager residential commented earlier that a "Health action plan (was) developed for all service users following health screening"

Others agreed and this screening process formed two categories. The first category was screening by primary care professionals as listed in table 4.17 over the page.

*Table 4.17 Health screening by a primary care professional*

| |
|---|
| • All health action plans begin with a full health assessment in primary care to ensure that needs are identified by a qualified primary care health professional. |
| • In the pilot one doctor developed screening tool - used as example in recently produced GP toolkit to have all relevant information to hand for primary care sector to initiate health screening and health action plan process. Main problem was GPs identifying learning disability patients on register with use of read codes in first place |
| • For those in supported accommodation or residential homes the responsibility has been left to the Carers" to utilize GP services to complete the health screening. |
| • Facilitators are told a plan can start at anytime, but are advised to ask their practice for a health check or well person check. |

However, not everyone agreed or was in a position for primary care to undertake screening. Therefore screening was completed by a learning disability nurse as identified in table 4.18 below.

*Table 4.18 Health screening by a learning disability nurse*

| |
|---|
| • The community nursing team has devised an initial health assessment which fits with the Single Assessment Process. This is a specialist learning disability nursing assessment |
| • Health screening is completed by the community nurse for those living independently |
| • One respondent identified that although screening did not take place "primary care professionals may be involved as a result of health action plan, e.g. referrals made to physio, community dental service, audiology, occupational therapist". However they also commented that they "do ensure visit for health check where not visited GP for some time" |
| • The learning disability nurses often use the OK Health check |

Furthermore one nurse health facilitator (respondent 103) identified that "We are currently working with our primary care teams to offer health checks as part of the health action plan but as yet this is not standard practice due to financial constraints".

Another nurse health facilitator (respondent 95) commented that "Facilitators are told a plan can start at anytime, but are advised to ask their practice for a health check or well person check.  The people who live in (area) who are registered in practices that are doing health checks all were offered health checks"

One nurse health facilitator (respondent 97,) identified that screening had not taken place prior to the health action plan, commencing but commented that "The health action plan has identified that health screening is necessary". Adding, that in their area screening will now be incorporated into the health action plan process.

This practice mirrors the early developments of health screening undertaken by learning disability nurses in the literature (Cooper et al 2006, Curtice & Long 2002). However as the introduction of the learning disability Direct Enhanced Services regarding health checks has been introduced since this research was undertaken, it would be useful to identify if this has had any impact on the health screening process and to see if primary health care have taken more responsibility for this due to a payment for the screening process being available.

**26. Have current health needs been identified as a result of health action plan?**

Four respondents did not answer this question. Of the 113 responses 86 % (97) of responses said that current health needs were identified as a result of the health action plan, with 14% (16) saying that they were not.

**27. How have these been addressed?**

There were 15 respondents (13%) who did not answer this question. This means that 5 out of 20 respondents who identified that health needs were not identified or who did not answer the previous question answered that referrals were made as a result of the health action plan. Of the 102 people who responded the range of answers are shown in figures 4.14 and 4.15.

*Referrals to:*
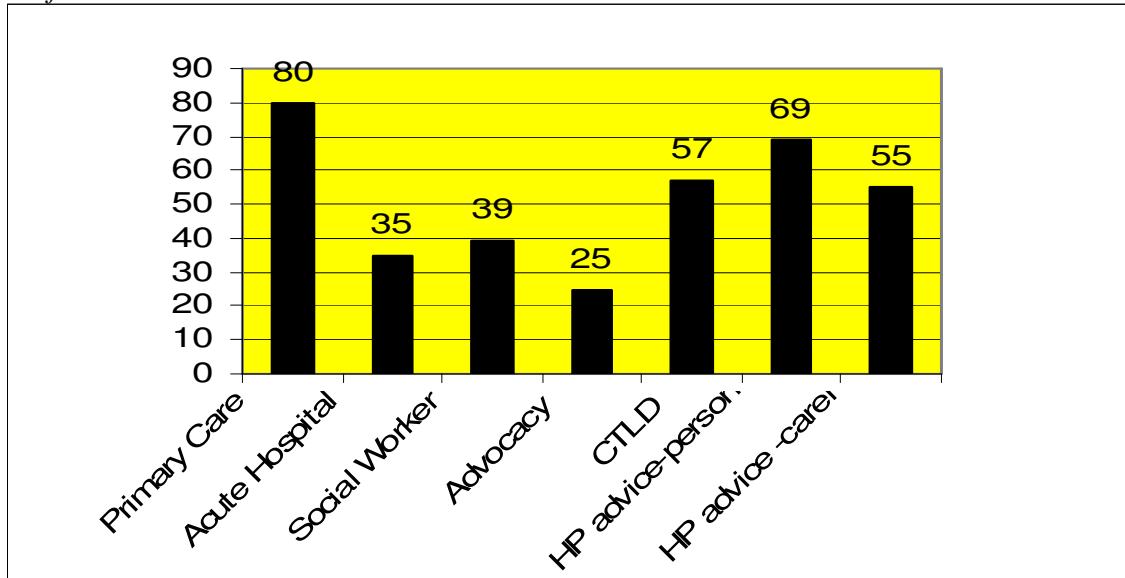


*Figure 4.14 Health needs addressed by referral to listed services*

*b) Reports to:*
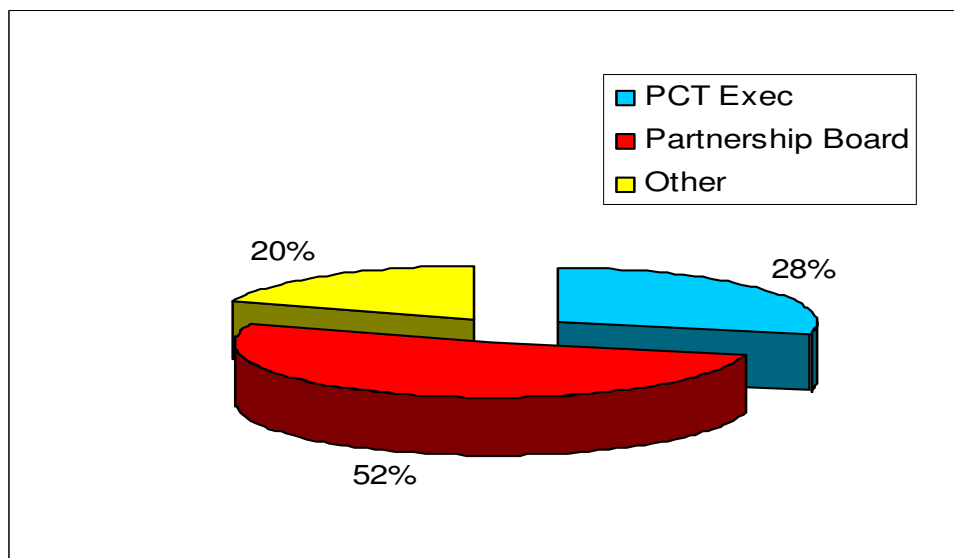


*Figure 4.15 Heath needs addressed by reports to listed services*

The other 27 responses included, reports to up a key objectives group, the independent sector, by making recommendations for commissioning of care packages and they did not have enough evidence yet.

**28. Have health gains been identified as a result of health action plan?**

In 74 % (87) of respondents health gains were identified as a result of the health action plan. 13 % (15) said that they had not and a further 13% (15) did not respond. One respondent commented that as a result of health action planning 54 health gains were identified across the plans completed. Examples of health gains reported and the number of respondents that reported them are listed below in table 4.19.

*Table 4.19 Examples of health gains reported as a result of health action plan*

| Weight reduction/dietary advice | 10 | Smoking/stopped/advice given | 4 |
|---|---|---|---|
| Medication review | 3 | Dental Check | 2 |
| Improvement in ongoing medical condition | 8 | Diabetes | 2 |
| Physical and mental well being | 2 | Visual problems | 3 |
| More screening | 2 | Education re primary healthcare issues | 1 |
| In some cases | 1 | Hearing problems | 1 |
| Nearly always | 1 | Continence | 1 |
| Illness identified- service provided | 3 | Gains in accessible information | 1 |
| Outstanding tests done | 1 | More awareness of health | 1 |
| Gains in pathways | 1 | Improvement | 2 |

Comments:

48 respondents gave comments and some noted additional benefits to having had a health action plan besides the obvious health gains. These are summarized in table 4.20 on the next page.

*Table 4.20 Additional benefits to health action planning process*

| |
|---|
| Increased activity in health promotion areas with some services setting up specific health promotion activities: |
| People with a mild learning disability have found them useful in being more aware of their own health needs and actions they need to take to stay healthy. |
| They have enabled carers to consider health needs that they may previously not have considered |
| Enabled health staff within CTPLD to consider areas for health promotion and look at running specific groups for people as well as individual work |
| Parents comment that the transfer to adult services is smoother and they all felt better informed because they have a health action plan |
| Wide range of health and social issues |
| GP surgeries have established Learning Disability registers and are offering health checks to people. |
| The Learning Disability Service and GPs are working closely to make sure that people with learning disabilities receive appropriate care |
| GP surgeries are able to advise the Learning Disability Service, giving stats on things like obesity/learning disability so that we can plan and target "healthy lifestyle" support |
| In some cases identification of health needs subsequently met, increasing quality of life or improving health |
| Care/support packages have been changed when new health and lifestyle needs have been identified. |
| More information and advice has been given out on various health topics, e.g. screening. |
| Many individual health gains, gains in pathways and information in accessible format. Education of primary and secondary care workers has proven useful |

One community nurse respondent (58) who had been working on a pilot programme with children as transition to develop health action plans commented that "Parents comment that the transfer to adult services is smoother and they all felt better informed because the have a health action plan" However, another community nurse (Respondent 102) commented that health gains had been made "on an individual level but not a strategic or operational level" suggesting "that there was still work to do".

**29. How are these reported?**

There were 81 responses to this question. The responses and the number of respondents are listed in table 4.21 below.

*Table 4.21 Health gains reported as a result of health action plan*

| Via health action plan | 31 | No formal system | 3 |
|---|---|---|---|
| Team meetings | 6 | Peron centred meeting | 2 |
| Team manager | 6 | Family | 2 |
| Primary care/GP | 6 | Annual review | 2 |
| LDPB | 5 | Key worker | 1 |
| CTLD | 4 | Completion of form | 1 |
| Monthly reviews | 3 | GP referral | 1 |
| Good health task group | 3 | Referral to health team | 1 |

Other responses include:

- Parents report verbally. Also the regular screening appointments that are made ensure the health needs are addressed.
- The last page of the health action plan is for the person or their carer to complete once the plan is completed, this asks how useful it was and if any new needs have been identified. These are returned to me to collate.

- A copy of the actual plan (not the full health info file) is returned to the community nurse team. However it has not been decided how these are to be processed and reported within the team.
- There is a page on the back of the plan, which provides a summary and action points. This is sent to the GP via the Learning Disability Service.
- Some information is anecdotal.

## 30. Who is responsible for monitoring health action plan?

There were 106 responses to this question and 11 non responses. The responses are summarised in figure 4.16 below.



**Responsible for monitoring HAPS**

Legend: Line manager, Community Nurse, Care staff, Health facilitator, Health team, Practice nurse, Team manager, Service, LDPB, Individual, Other
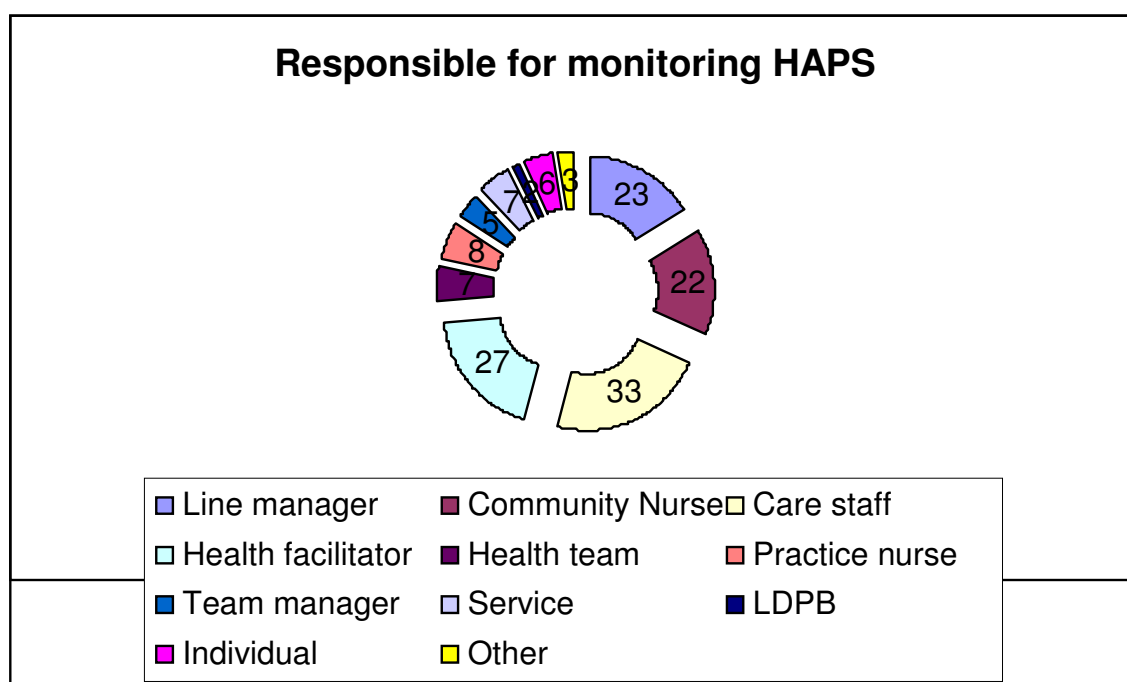
*Figure 4.16 Who is responsible for monitoring the health action plan*

Other answers included: no one monitored the plan, they had no data base and that they were developing benchmarks. The majority of respondents included the health facilitator or line manager and staff team in the monitoring process. There are a small number of reports monitored by the LDPB. This reflects practice locally where the board do not appear to monitor progress. There were only 6 examples of service users being involved in the review. It is difficult to ascertain if this is the case or if respondents did not record it. Three areas have

health facilitation co-ordinators to assist the health facilitators. Other responses are listed in table 4.22 below.

*Table 4.22 People responsible for monitoring health action plan*

| |
|---|
| • The facilitator, however we are looking at developing our own quality benchmarks with the intention of checking that people are doing good plans. This in itself is difficult because if plans are truly person centred then they may not be as good as we would like them to be. |
| • Health facilitator has the overall responsibility. CTLD monitor and review as part of the review process at least yearly |
| • Time factors-Community nurses seem to have got this responsibility however they have not been allocated time for this and therefore due to caseloads this has not been practical. A third year student and temporary nurse took the responsibility for a short time whilst working within the team. |
| • Primary health care facilitator in post who monitors process overall. Individual health facilitators monitor health action plan with service user |
| • On going issue as staffing levels resources do not allow for the responsibility for monitoring to fall to the nursing team. Responsibility will be agreed on  an individual basis |

**31. How are health action plans monitored and reviewed?**

There were 99 responses to this question. The responses identified both who completed the review and the frequency that the health action plan was reviewed. This data is shown in figures 4.17 and 4.18 on the next page.
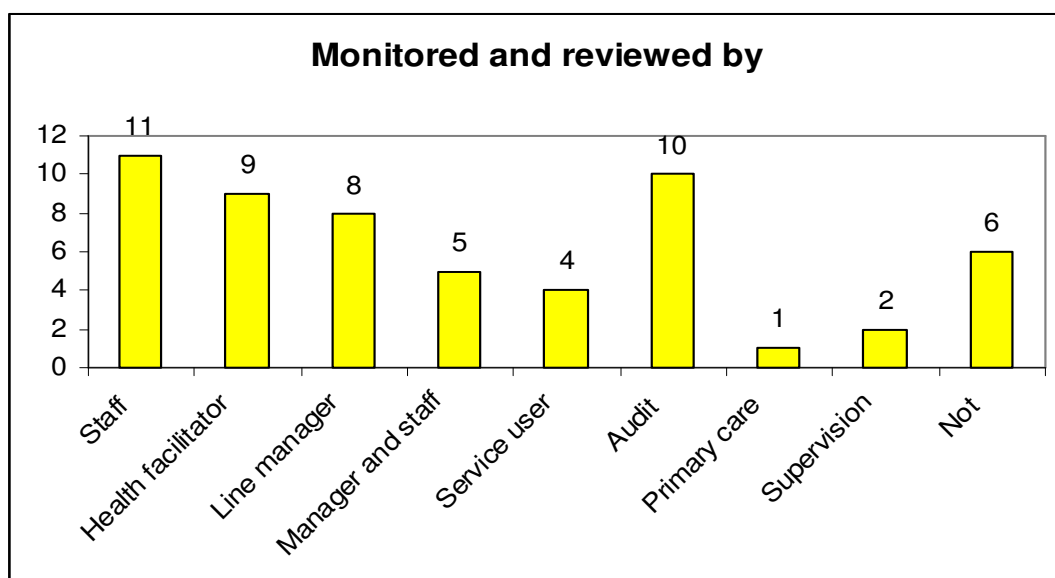
*Figure 4.17 Who monitored and reviewed health action plan*

Six respondents indicated that the health action plan was not reviewed and 10 suggested that the review was completed by audit. The audit was completed by a health subgroup (4), through internal audit (4) and through a database (2).Responses indicated that the frequencies in which health action plans were reviewed varied (see figure 18 over the page.) The majority response was that plans were reviewed monthly, followed by an annual review.
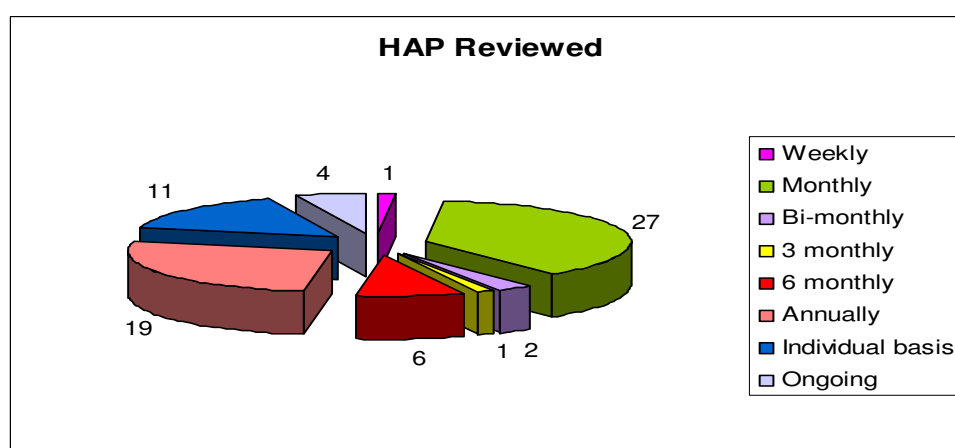


*Figure 4.18 Frequency of health action plan review*

Comments on how health action plans are reviewed received are presented in table 4.23 on the next page.

*Table 4. 23 How health action plans are reviewed*

| |
|---|
| • LDT hold database and contact individual to ensure review undertaken. |
| • Audited by subgroup, who drew up and implemented health action plan. Review monthly by line manager |
| • By person themselves where possible with support, by CTLD ,if open case, by care staff, by strategic health facilitator if complex case |
| • Data base held by health facilitator |
| • Health facilitator has the overall responsibility. CTPLD monitor and review as part of the review process at least yearly |
| • In process now, envisage looking at quality in terms of how improvement in persons lifestyle and actual health. Audit will inform and direct improvement |
| • Repeat assessments by the initial primary care professional. |
| • Progress on goals, reviewed annually, but updated at least monthly, more frequently if needed |
| • At present health action plans are not methodically reviewed /monitored. Community nurses read health action plans as they are received and immediate action taken if necessary. Long term goals etc are not acted upon at present. |
| • There is a database which provided information regarding whether a person has been offered a health action plan and what the outcome was |
| • Health facilitator review at intervals, 3 months to 3 years depending on the person |
| • The co-ordinator monitors the health action plan process to review. The facilitator then takes over the health action plan and oversees the action plan with the service user and hopefully the GP |
| • Reviewed by community nurses if involved with client. Residential service providers are responsible for monitoring those of their clients |
| • Paid carers or the person responsible for that persons care, the practice nurse or myself depending on the situation and health problems |
| • Named person from each service provider is link person responsible for monitoring haps |
| • Read and update when details change e.g. needs, tests, health, new information received |
| • Annually at general review. If health needs change or deteriorate the community nurse will be aware and alter plan accordingly. If no nurse allocated the referral made |
| • Yearly reviews organised, updated on current health needs, and identified screening completed as per health action plan. Done on a face to face basis. |
| • We have started doing follow up visits 2 months after training is delivered but this is only to gather data on if the plan is started and also to offer advice. We direct to Valuing People Support Team benchmarks at this point but are not measuring quality as a good plan can take up to 6 months to develop. |
| • Health action plans are sent to the community nurse team, by the facilitator, who read them in weekly allocation meetings to check for quality/standards. They are then returned to the facilitator to revise if it is felt necessary. |

**32**. **Has an audit of health action plans been done?**

Seven (5%) respondents did not answer this question. However 53 (45%) respondents said that an audit had happened, 41 (35%) said audit did not happen and16 (14%) did not know if audit happened.

**33. How is the quality/standard of health action plan monitored?**

In total 88 respondents answered this question (75%). The results are shown in figure 4.19 below
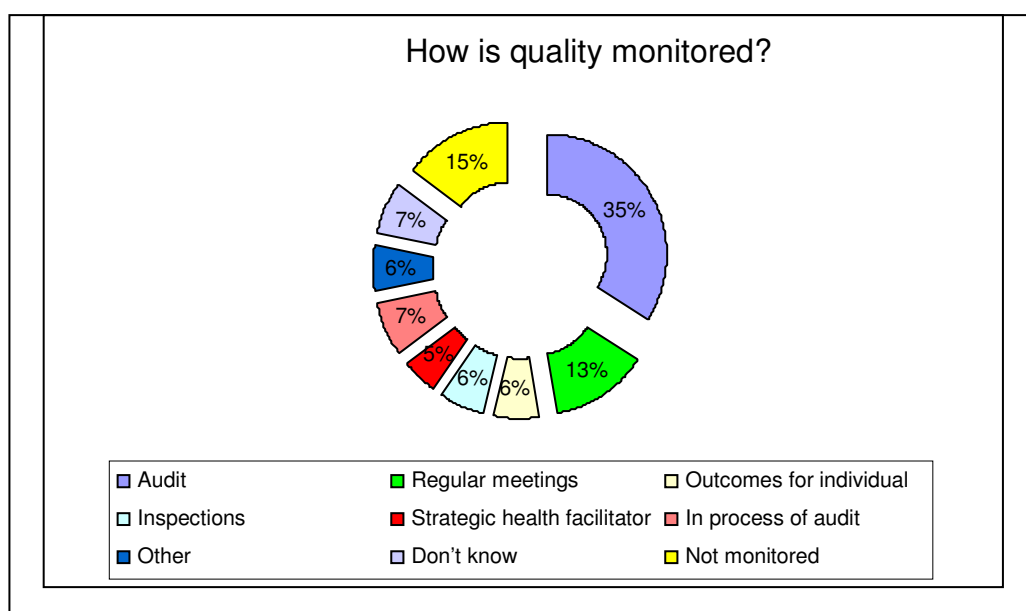


*Figure 4.19 How is quality of health action plan monitored.*

Twenty eight respondents monitor quality via audit, 6 are in the process of auditing, 12 respondents do not monitor quality of the health action plan and 6 don't know. Examples of responses are in table 4.24 over the page.

*Table 4.24 How the quality of health action plans is monitored*

| |
|---|
| • Partnership board has recently commissioned a quality review of the health action plans developed as part of the training to review quality, evaluate effectiveness of training. Commissioners ask commissioned service providers if they have developed haps but they do not measure the quality of any health action plan! |
| • Inspections twice yearly, ongoing through key workers |
| • To date only numbers of health action plans has been monitored, about to launch a quality audit as team objective for the coming year. |
| • By outcomes and nurse led discussion |
| • By outcomes for the individual with learning disability  i.e. any changes to their life |
| • Through completion of feedback form and yearly review. This is then used to make any changes and to inform practice within the CTPLD |
| • Summary sheets are also viewed by myself and GPs |
| •  Routine monitoring, auditing its effectiveness and patient stories |
| • In process of developing audit tool to measure quality of health documentation |
| •  Health action plans are sent to the community nurse team, by the facilitator, who read them in weekly allocation meetings to check for quality/standards. They are then returned to the facilitator to revise if it is felt necessary. |
| • No formal mechanism in place |

In discussing how plans were monitored the following respondents also demonstrated effective systems for reviewing goals. "Progress on goals, reviewed annually, but updated at least monthly, more frequently if needed" (Respondent 52 line manager residential)"Named person from each service provider is link person responsible for monitoring health action plan" (Respondent 49 nurse health facilitator)"Monitored monthly- progress on goals, reviewed 6 monthly" (Respondent 54 line manager residential)

In answering how health action plans are monitored respondent 52 a line manager residential makes specific reference to the use of a form for "health action plan progress on goals" This

response matches 98/117 (83.7%) of respondents who identified that a progress on goals sheet was included within the health action plan that they support.

Whilst some areas have audited the health action plan process Respondent 29 who identified as health facilitator – not nurse, did have a process to monitor and review health action plan but who did not currently audit these plans commented;

> *Our health action plan is a person centred tool-which fits with the aims of Valuing People. Many areas complete a health assessment with individuals and refer to this as a health action plan, although admittedly this is very valuable. Our plan is more difficult to audit that an assessment based model- and indeed there is no statutory requirement for someone to have a health action plan at all, so targets set by Department of Health will be difficult to meet as some people do not want a health action plan. Until there is a national auditing system and a universal health check carried out through primary care, results are hard to analyse, as many areas have different tools. We hope that health checks will be included in the next Quality Outcome Framework.*
>
> (Respondent 29 health facilitator – not nurse)

This last comment relates to the framework by which GP's can earn extra payments by conducting certain procedures with patients, in this case health screening/checks for people with learning disabilities. Since this research was conducted Direct Enhanced Services have been introduced, which include the development of a health action plan, but again these are not mandatory. In addition, data is now collected by the Department of Health to identify how many people with learning disabilities have had health checks by PCT area across England. However, this data does not include any recording or analysis of the outcomes of the screening process, which is unfortunate as this data could have been used to inform the local and national picture of disease prevalence so that each area could respond to this and also it would have given evidence, or not, as to the benefits of health screening on a large scale.

**34. Did the health action plan aid communication with health professionals about the individual's needs?**

There were 99 responses to this question, with 51 additional comments in all. Of these 91% (85) commented positively that health action plans aided communication, 8% (14) commented that they didn't and 1% (1) a clinical services manager(Respondent 55) commented that they

did but "only if learning disability nurse involved. I have found that when a health action plan was completed by a non-health staff, (there were) many omissions in the development of plans. Obvious areas (were) missing and joined up thinking with relevant professionals" Thematic analysis was used on the 51 comments and a summary of responses is discussed in the areas identified from the analysis below.

The health action plan was identified as a good source of information by 20% of respondents. Respondent 51 (line manager residential) commented that it "Gives an account of service users health needs. Health professional can see health needs without having to read through lots of paperwork". And respondent 10 (nurse residential) wrote that it "Has all individuals" info in so if staff do not know it is recorded" Finally respondent 35, (community nurse) confirmed that "It brought together an accurate picture of service users health issues, past conditions, present and future health needs. It identified gaps in services and in most cases empowered the service users/carers to be more vigilant in keeping up health appointments and why it is so important to take care of your health"

In addition 17% of respondents suggested that it enabled discussion/engagement with health professionals. Respondent 43 (nurse health facilitator) suggested that the health action plan "Improved relationships tremendously" With Respondent 102 (community nurse) informed that there was a "Referral to practice nurse/G.P if there is a health need/health action that cannot be met by the health facilitator" "All the health professionals involved have been very accommodating and eager to use health action plans"

Respondent 31 (nurse health facilitator) said the plan was useful in "Highlighting other issues such as dysphagia and you rely on other health professionals to become involved. GP openly encourages as he feels supported in the holistic care of the individual" and the "Plan picks up on things in past missed or overlooked quite often" (Respondent 109 nurse health facilitator). Respondent 76 (nurse health facilitator) commented that the plan "Identified health needs that may have gone undetected and allows primary care to be proactive. Also enables primary to identify specific health issues alongside syndromes"

Some respondents suggested that the health action plan provided education for staff (Health and carers) about the health needs and people with learning disabilities. This was achieved in

one case "Through liaison with one lady's GP this led directly to active engagement in working with the GP practice to reduce the number of home visits and work toward desensitization to attending the GP practice"(Respondent 42 community nurse). It has also" been an invaluable tool in educating practice nurses in specific health needs of people with learning disabilities and how to address health needs, communication skills etc" (Respondent 101 community nurse).

The health action plan has also improved communication with acute services for 10% of respondents. "In some cases it has been used in hospital admissions" (Respondent 33 nurse health facilitator.) Respondent 67 (line manager residential) said that it "Encouraged better communication with acute services and better awareness of service involvement required" and the plan was "Provided to ITU and recovery ward on one occasion" (Respondent 15 nurse residential). In total 8% of respondents said that it did not aid communication. However, Respondent 28(nurse residential) commented that although they thought health action plan did not aid communication "I feel it provides a clear structure to follow in case of treatment or medication reviews or changes".

**35. Do you feel that the introduction of health action plans has resulted in measurable health gains for people with learning disabilities?**

There were 104 responses to this question. In total 74% (86) of respondents said yes and 18% (18) said no. Sixty respondents added comments to their response. The comments were themed into positive and negative to give a full picture of respondent's thoughts on the issue. Within this the comments were put into emerging themes and the answers are summarised below.

Many positive comments were received. These included that problems were identified and treated (8). An example of this was given by a nurse residential, respondent 94"Full health screening for people with learning disabilities has flagged up health issues which were undiagnosed previously. On several occasions people have been able to get treatment for these conditions, avoiding more serious health problems later. It has enabled specialist nurses to liaise with generic health professionals to inform them of specific health problems that can

occur with certain syndromes". Respondent 32, a health facilitator assistant concurred with this stating that "Many simple check ups missed normally are now being routinely carried out"

The health action plans provided more knowledge for carers. "Previously carers and young people were unclear or unaware of their health needs and who was involved in monitoring the services delivered "(Respondent 58 community nurse). Respondent 103 (nurse health facilitator) responded that the health action plan "Has identified new needs. Has increased the awareness of people with learning disability" Finally there was "More knowledge by carers and team leaders through learning with health action plan" (Respondent 3 line manager residential). They helped to ensure that the same standards of service received by people with learning disabilities. An example was given by a trainee assistant practitioner within a GP practice respondent 106 whereby the introduction of health action plans resulted in "Unmet needs met, expansion of screening to those with educational difficulties"

There was also less chance to miss things as routine appointments were made. Two examples are: "Service users are now having screening tests which everyone else is offered" (Respondent 51 line manager residential); and "Potentially raised awareness of services/screening to "carers"/clients which previously they may not have considered accessing therefore health should improve" (Respondent 108 community nurse)

The plans were useful to monitor/measure effectiveness. Examples of this are an "Increased awareness of health issues and services available. Also due to more effective recording and monitoring of health care needs" (Respondent 67 line manager residential). In addition respondent 98(community nurse) identified that gains were "Certainly measurable in terms of canvassing opinion of people with learning disabilities and health action plans" However, another community nurse disagreed with this suggesting that measurable gains were not identified because "As no structured system has been instigated as part of the contractual process for care managers to review quality." (Respondent 42)

Not all respondents felt that health gains were identified. These comments are summarised in the table 4.25 on the next page

*Table 4.25 Measurable health gains have not been identified*

| |
|---|
| Many plans unrealistic |
| Not in all cases. Given opportunity for health info to be collected/received /stored in accessible format |
| Due to close monitoring of health anyway I don't feel that it has identified any health gains respondent 28 |
| Not made much difference |
| I think that this need to be a role allocated to one particular worker |
| I believe health action plans could be a good tool to measure health gains, however at present they are not being used to their full potential. |
| At this stage unsure as PCT's /primary health care team are still reluctant in engaging with process |

Respondent 34, a nurse residential, summed up their conclusion that health action plans had not resulted in measurable health gains in commenting that "I believe that they could be very positive if recognized as a live document in a multi- disciplinary setting. Unfortunately there seems no cohesion and no follow up". This response would suggest that the health action plan has been completed but that after that nothing has happened with it. Similar flaws in follow up with health screening were discussed in the literature review(Lennox et al 2006).This suggests that there needs to be a mechanism in place to review the health action plan with a named individual to monitor the plan to ensure that progress is made.

In answering whether health gains have been identified respondent 42, a community nurse, commented that "There needs to be a clear distinction made between a health action plan (which should be person centered) and a "care plan" which I feel is about how any carer (paid/unpaid) is going to meet the need they have identified within their health action plan"

One respondent suggested that although the health action plan process itself may not have made much impact, the resulting liaison and increased contact with services and thus the raised awareness within primary health care, may be the way that better services are received for people with learning disabilities. Although some respondents did not answer this question the following comments were received:

*I believe if health action plan   is done properly it will do but at present we do not have the evidence to prove this.  This is also similar to the work of health promotion for the general population as this often is not measured* (Respondent 95 nurse health facilitator)

Respondent 101 (community nurse) commented that there was "Only one significant discovery thus far which was a case of previously undiagnosed hypertension. Feel it more likely that health gains will be realised in longer term future as a result of primary care services being better skilled and more able to provide better and more responsive generic health services for the client group. "A similar theme was raised by respondent 76, a nurse health facilitator, who commented that gains were "Not just health action plan but I feel regular health screening results in reducing health inequalities and ensure the persons health need is being met" Finally, respondent 92, a nurse health facilitator suggested that health gains were not the only positive aspect of a health action plan identifying that "Service users have gained empowerment. One service user enthused to me "I will be able to go to hospital appointments by myself." This increase in confidence and better inclusion in ones own health meets Valuing People (2001a) objectives.

### 36. Do you feel supported in your role?

There were 105 responses to this question. Of the 105 responses 82 (70%) felt supported, 23 (20%) did not feel supported in their role and 12 (10%) did not offer a comment either way. The answers were divided into positive and negative comments and then themed and are summarised below.

It is interesting to note that respondent 7 (a nurse residential) commented that "I work closely with health facilitator; feel I have more support than others due to my support for the health action plan" This could imply that those who do not work as closely with the health facilitator may not get as much support as those that do. It would have been useful to follow this comment up for clarification, but unfortunately this is one of the disadvantages of questionnaire use in research that follow up is not possible.

Positive comments that suggested that staff felt supported by various colleagues, teams, networks or managers and these responses are summarised in table 4.26 below.

*Table 4.26 Examples of positive support identified by respondents for the health action plan process*

| |
|---|
| The health facilitation team is very helpful and always available |
| Enough information to read guidance from health team |
| Help available by phone or visit to health action plan team |
| I feel supported by immediate line manager |
| support from line manager followed by training to equip me with knowledge re haps |
| Regular meetings with other facilitators |
| Have the support of both LD team and CTLD team |
| My integrated team is a very valued, well supported team with everyone's role supported and recognized. Health and social care now work together very well. |
| By the national network and local networks |
| The various networks, both email and events have provided valuable information and support |

Other respondents commented that they felt supported by the PCT/GP. Respondent 31 (nurse heath facilitator) replied "Especially by the PCT (who want to reduce the health inequalities and hospital admissions) and by the GPs who want to see responsibility of care across all stakeholders" Respondent 56, a community matron for vulnerable adults, suggested that the "PCT has consistently supported service improvement for people with learning disabilities and ensures that a high profile is maintained within the organisation". Furthermore, respondent 76 a nurse health facilitator commented that they felt supported "By the PCT who want to reduce health inequalities of this vulnerable patient group and reduce hospital admissions. Majority of GPs are very supportive of this". In addition, respondent 40 another nurse health facilitator found the "Partnership board and PEC (PCT board) both interested and supportive. Audits identify where health uptake for people with learning disabilities is low, Partnership board and PEC supportive in helping to address these issues"

However, respondent 23, a community nurse, suggests that this help is not available to all and comments that "health action plans are one part of a busy role- and we can develop further though support is offered to professionals- do not feel this happens for the people using services" Finally, a community nurse (respondent 102) commented that they felt supported "On an individual level of completing health action plans but not on a strategic or operational level".

Comments where respondents felt unsupported were again themed into the categories below. Some, though not all comments have been included to summarise the comments received. Issues arose when there was no lead for the health action plan process. Respondent 58 a community nurse reported that "We don't have a health care facilitator. The post holder left after one year and the post has been frozen (18 months).There is no strategic planning or monitoring and there are no funds to produce health action plans". This lack of support was reiterated by respondent 36 a practice advisor, who identified that without a lead staff had to add to their role to facilitate health action plans "Health facilitation has never been a priority in this PCT .The trust failed to appoint a specific health facilitator role. Nothing would have happened here were it not for a highly motivated and committed CTLD who unofficially took on health facilitation as part of their role"

Several health facilitators reported difficulties in engaging with primary care that left them feeling unsupported in their role. Respondent 103 (nurse health facilitator) was profusive about the complexity of their role.

> *I am employed by the PCT, paid by LDDF and managed by social services. It has been incredibly difficult to move this agenda forward. The PCT has no money to support my role were not involved in the designing of my post and so consequently have taken no ownership. My post is two years which is up in July I have only just before Christmas had my job description agreed under Agenda for Change. CTLD has been reluctant to take on any of the work related to health action plans including monitoring and reviewing. Primary Health care Teams are aware of the lack of support from the PCT so again whilst they recognise the need to do something they are reluctant without additional resources. Unfortunately this has made it very difficult to progress greatly but I am determined to keep battling on and raising awareness of the health needs and hope that the audit will back up the known evidence so that people will recognise the value of this role* (Respondent 103 nurse health facilitator)

Another health facilitator who was not a nurse revealed that they were working on "Short term temporary contracts, (with) no learning disability lead at PCT - will change with merger. Often difficult to get primary care (GPS) to address issues around health inequalities for this group of people, or look at ways of improving communication with these patients" (Respondent 29) Whilst respondent 101 a community nurse suggested that the "PCT (are) very demanding in terms of statistical information on numbers of health action plans undertaken, but not particularly helpful in terms of engaging GP practices in the process or solving issues that have arisen. PCT very good at saying that they fully support health action plan initiative, but recently withdrew locally enhanced service payments to GPs for undertaking health action plans"

In addition to the difficulties experienced by some health facilitators, some respondents identified that the Learning Disability Partnership Board were not supportive in developing the health action plan process. Respondent 36 a practice advisor, suggested that "The partnership board gave very little attention to health, tending to focus on the other areas of Valuing People in the belief that primary care services would just get on with providing for this client group" And respondent 55 a clinical services manager suggested that "Learning Disability Partnership Board have not been proactive in Valuing People process- who to lead /monitor etc specialist community team have struggled to tackle- we should support but not lead process"

Since the data collection for this study took place new guidance was issued to Learning Disability Partnership Boards to support them to become more effective (DOH 2009c). It would be interesting to determine if this would make a difference to these findings if the study were repeated.

Five respondents identified that issues relating to lack of time for the health facilitation role and or lack of training were issues in the lack of support that they felt. These comments are listed over the page:

i. As community nurses we were provided with the health action plan files but we have not had any training about completing the health action plan but most importantly we have not had any guidance on what to do with the plan once completed. ( Respondent 104 community nurse)

ii. We have also been told that we must complete the health action plan and utilise them fully however we have not been given any time or resources for this and management have been unclear on our responsibilities (Respondent 103 nurse health facilitator)

iii. Haven't had training and none was available. There appeared to be an assumption that as a qualified nurses I'd already know what I was doing (Respondent 64 (line manager residential)

Others identified that there were issues with an increase in their work load without any additional support that resulted in them feeling unsupported. Respondent 103 a nurse health facilitator commented that "CTLD has been reluctant to take on any of the work related to health action plans including monitoring and reviewing." Respondent 67 a line manager residential suggested that health action planning "Has resulted in considerable increase in workload. Is audit led therefore increased documentation and stricter timeframes. Majority of increased work has fallen to health facilitators who already had increased responsibilities i.e. home managers" Finally, Respondent 50 a community nurse remarked that "Sometimes but we are not given anywhere near enough time to do a proper job, but we have no funding and try to do them as well, as our normal job"

Some respondents identified that others involved in the process did not always realise the benefits of health action plans and that this could hinder them in their roles. The responses are example of this. "Not everybody in the team sees the benefits of health screening and health action plans. Some GPs see it as creating more work for them" (Respondent 32 health facilitation assistant) "I do not feel that all services and carers recognize that they have a role to play in supporting and maintaining health" (Respondent 47 nurse health facilitator) With others identifying that "Trying to change practice in undertaking health action plans has met resistance from senior nurse" (Respondent 87 community nurse). Furthermore some respondents felt that less importance was given to the role commenting that "Although in other areas a "health facilitator" with a strategic role has been appointed to take the lead in the

process and devote time to service development and research in our area it is diluted to all of us to take it on a s part of our role" (Respondent 82 nurse health facilitator)

One respondent suggested that "The role can be very isolated at times. Without any clear national direction for some time, it leaves it up to each area to develop local plans which results in a lot of inconsistencies across the country and also means that national support can sometimes be harder to get because we all do things differently" (Respondent 95 nurse health facilitator)

There appears to be a very mixed response to whether people have been supported, and the issues involved, which is summed up by the following community nurse respondent "Mixed review. Yes, supported by learning disabilities team and partnership board. Not supported by PCT. No recognition of importance of health action plan locally" (Respondent 107)

**37. Do you have any other comments?**

Again a variety of additional comments were received. Thirty five respondents (30%) answered this question and made comments. As will be evident to the reader, some of these comments have been inserted in the relevant sections of these findings. However, the responses have been themed and include the fact that change take time to happen, completing the plans is very time consuming and that residential carers need lots of support and do not use plans properly.

Respondent 34 a nurse residential added that; "The health action plan appears to be regarded as just more paperwork to complete (once).There is no evidence of dynamic application, which is a great shame and a waste of resources/time/effort" Respondent 102 a community nurse summed up the time issues with this comment: "The health action planning link person was allocated to introduce health action plans in. Unfortunately, this was an "add on" to a full time job. Therefore health action plans were introduced on an individual level with awareness days and training sessions offered. This role unfortunately could not develop on an operational and strategic level".

Comments were returned relating to the development of information. Some were positive comments and some negative. These are summarised in tables 4.27 and 4.28.

*Table 4.27 Positive benefits of information developed*

| |
|---|
| Improved client care by enhancing communication |
| Recording information benefits and easier to access |
| Useful to keep records together |
| Difficult to audit |
| Parents comment is useful for communication |
| Local format will not meet all needs but can be adapted |
| Very useful for carers and new health facilitators |
| Useful to take to appointments |
| Website and talking books about to be launched |
| Other health professionals very positive and have used plan |

*Table 4.28 Negative benefits of information developed*

| |
|---|
| National networks could do more |
| Haps do not cover enough of people's needs- more information needed before health action plans introduced |
| Little interest from primary health care |
| Unless must do PCT reluctant to take on responsibility |
| Carers in residential services have not made fill use of the book- they require lots of support |

Respondent 36 a practice advisor added that "I feel that the advice given via Valuing People and the accompanying guidance notes was confusing and lacking in direction. I don't think the concepts of health facilitation and health action plan was adequately piloted before being

introduced" Again this lack of guidance appears to be a common theme and is discussed below. What is evident from this research is that where the health action plan was piloted (59 % of respondents) 63% of cases changed the health action plan format as a result. It would appear then that a pilot would have been a good way to progress with the initiative.

Some respondents gave mixed reviews about the benefits of the health action plan process. These are shown in table 4.29 below.

*Table 4.29 Benefits of health action plans*

| |
|---|
| Already receiving through reviews, so less issues being identified as result of health action plan |
| Useful for maintaining health but no benefits as yet |
| Individual benefits identified- important as does not just sit on shelf |
| Bridged link between learning disabilities and primary care, health action plans are necessary for people with learning disabilities |
| Health action plans have improved client care by enhancing communication |

A few respondents identified issues around GP involvement in the health action plan process. These are shown in table 4.30 below

*Table 4.30 GP issues in the health action plan process*

| |
|---|
| Would like to see GPs take lead with support |
| Feel we are creating more work rather than supporting them |
| Need awareness raising |
| Do not have enough time |
| Not supportive |

## Problems encountered.

Many comments were received regarding implementing health action plans with several health facilitators criticising the lack of national guidance. These issues are summarised in table 4.31 and discussed over the page.

*Table 4.31 issues affecting implementation of health action plans*

| |
|---|
| Not statutory |
| Targets need setting |
| Some clients still do not receive equal service |
| Health action plans regarded as more paperwork |
| Advice given by Valuing People lacking in direction and confusing |
| Concepts of health action plan not adequately piloted before being introduced |
| Everyone is doing health action plans differently |
| Helpful if there is a definition of what a health action plan is |
| Lacks clear guidance/leadership/direction DOH could have done more to support health improvement initiatives |
| Lack of centralised funding speaks volumes for what government think |

Lack of national guidance and direction appeared to be a common theme identified by respondents. The comments below cover the general consensus of opinion. Respondent who reiterated several times that guidance, is needed concluded by commenting that:

> *I do feel that the way forward is through targets and by ensuring primary care carry out annual health checks-however this needs a strong lead at the Department of Health who can cascade information and make it happen. It is often felt that the Valuing People support teams do not have enough clout or cohesion to achieve collective aims.* (Respondent 29, a health facilitator not a nurse)

Respondent 101 a community nurse concurred with this sentiment adding that the "DOH could have done a lot more to support health improvement initiatives for people with learning

disabilities. Lack of centralised funding speaks volumes for what central government really think of "Valuing People" .Respondent 102 a community nurse identified that the problems were not related to guidance issues but more that "health action plans are still being introduced in (my area) but the changing role of the Community Nurse with the Care Management role has been an additional barrier".

Finally comments were offered by some respondents to bring the focus back to the real issue of introducing health action plans.

> *I think it is important to remember that everyone is perhaps doing or implementing health action plans differently. To me the most important part is to ensure that a person with a learning disability is being offered an annual health check and that it should just not be a 100 page document that will just sit on the shelf. Each persons health needs are different hence the plans will be unique for that person* (Respondent 41 a nurse health facilitator)

Respondent 32 a health facilitation assistant concluded that "Some clients do still not receive an equal service" Finally, respondent 29 a health facilitator, not a nurse sums up the findings of this research when commenting that "health action plans do make a difference to the lives of people with learning disabilities, but need more national recognition"

## Further Examination of the Data

Although, sample size meant that the use of inferential statistics was not feasible, some limited additional examination of the data was completed using Spearman's correlation matrix to determine if there were some aspects of the health action plan process had that any impact on each other.

**Question 1**

**Have nurses undertaken more health action plans than health facilitators who are not nurses (Q 2 role by Q5 number of health action plans completed)?**

The relationship between professional role (Q2) and completion of health action plan (Q5) was investigated using Spearman's rank order correlation. There was a small negative correlation

between the two variables $r_s = -.339$ n = 116 p = .001. This indicated that being a qualified nurse in this sample was associated with completion of a higher numbers of health action plans.

This result is not unexpected as the evidence to date indicates that the introduction of health action plans has been a nursing led initiative. It would be interesting to repeat this analysis, as since this research concluded, social care providers should be more familiar with the health action plan process and these results may be different.

**Question 2**

**Were more health action plans completed by health facilitators who had received training (Q 5 number of health action plans completed by Q 20 training received)?**

The relationship between training received (Q20) and completion of health action plan (Q5) was investigated using Spearman's rank order correlation. There is a weak negative relationship between the two variables, not attaining a significant difference rs = -.249 n = 112 p = .001.

This indicates that in this sample, training had hardly any bearing on the number of health action plans completed. However, as more plans were completed by nurses it could be argued that training was less of an issue for non nurse health facilitators. Furthermore as 77% of health facilitators had received training prior to the introduction of health action plans I would suggest that this information should be treated with caution.

**Question 3**

**Does the number of pages in the health action plan have any impact on the number of plans completed? (Q 18 Number of pages in plan by Q 5 number of health action plans completed)?**

The relationship between number of pages in the health action plan (Q18) and completion of the health action plan (Q5) was investigated using Spearman's rank order correlation. There was a very weak relationship between the two variables that was not statistically significant $r_s = .153$ n = 97 p = .155. This indicated that in this sample the number of pages in the plan had no bearing on the number of plans completed by the health facilitators. This is interesting as by examining the numerical data alone from question 18 a variety of plan sizes were implemented ranging from 1-10 pages to 51+ pages. Slightly more plans were completed in the 1-30 page range (54/99) but there were still a considerable number of respondents who had completed larger sized plans (42/97).

**Question 4**

**Where health screening took place, were more health needs were identified than where screening did not occur? (Q 25 health screening took place by Q 26 current health needs identified as a result of the health action plan)?**

The relationship between health needs identified (Q26) and health screening occurring (Q25) was investigated using Spearman's rank order correlation. There was a medium positively statistically significant correlation between the two variables $r_s = .551$ n = 75 p = .091. This indicated that in this sample, more health needs were identified where people had health screening as part of the health action plan process than where no screening occurred.

**Question 5**

**Where health screening took place, and health needs were identified did more health gains occur? (Q 25 health screening took place by Q 26 current health needs identified as a result of the health action plan by Q 28 health gains identified as a result of the health action plan)?**

The relationship between screening taking place (Q25) health needs identified (Q26) and health gains identified (28) was investigated using Spearman's rank order correlation. There was a weak to moderate statistically significant correlation between the two variables $r_s = .397$ n = 75 p = .001. This indicated that there is a relationship between identifying the health need and the consequent health gain. That is to say that where health needs had been identified these had resulted in health gains for the person with learning disability.

**Question 6**

**Were more health needs identified by nurse health facilitators than non nurse health facilitators (Q2 role by Q 26 health needs identified).**

Further analysis by SPSS demonstrated that in 65/112 responses (72.8%) of nurses remarked that they had identified heath needs compared to the other categories of health facilitators.

**Question 7**

**Were there more health gains identified by nurse health facilitators than non nurse health facilitators (Q2 role by Q 28 health gains identified).**

The relationship between professional role (Q2) and health gains identified (Q28) was investigated using Spearman's rank order correlation. There was a negative correlation between the two variables that is not statistically significant $r_s = -.061$ n = 116 p = .001 .This indicates

that the role of the health facilitator has a very small effect on identifying health gains and that screening is more important than the skills of the health facilitator.

**Question 8**

**Were there more health gains identified by nurse health facilitators than non nurse health facilitators, where training had taken place (Q2 role by Q 20 training by Q 26 health gains identified).**

The relationship between professional role (Q2) training (Q20) and health gains (Q 26) was investigated using Spearman's rank order correlation. The correlation between role and identifying health gains was not statistically significant, but when training was given the correlation between the two variables was positively significant $r_s = .558$   n = 116= p = .001

Therefore this indicates that (as identified above), the role and experience of the health facilitator is not relevant to identifying health gains but that training is crucial to support the health action plan process, and to increase the likelihood of health gains being identified. It should be noted that 10 respondents identified health gains. These may have been more experienced health facilitators but this aspect was not explored within the research report.

**Question 9**

**Where the health action plan was piloted and changes made were more health action plans completed (Q 12 piloted by Q 13 changes made by Q 5 number plans done)?**

The relationship between health action plan piloted and changes made (Q13) and completion of health action plan (Q5) was investigated using Spearman's rank order correlation. There was a negative correlation between the two variables $r_s = -.223$ n = 116 p = .040. This indicates that where fewer plans have been done health facilitators are more likely to make changes to the plan.

## Summary

This chapter had presented the results of the questionnaire survey. It has identified that data was gathered for across all 9 Valuing People Regions, and that the majority of respondents were nurses (57%), who were, unsurprisingly employed by  PCT's (72%) and that 43% were non nurses or carers. Various aspects of the issues involved in introducing health action plans in England have been identified, with some discussion where appropriate.

Data presented has identified who took the lead in implementing and designing the health action plan and the various sizes, formats and contents that these plans can take. Some discussion regarding training has been presented, but training is an issue that affects all strands of the research findings and consequently this is discussed in more detail in the integrated discussion chapter seven.

Evidence had been presented that demonstrates the incidence of health screening; health gains identified, the perceived benefits of health action planning and the issues affecting effective monitoring of the health action plan from the respondent's perspectives.

Challenges regarding the implementation of health action plan have been raised. Finally, several key themes emerged from these findings. These were that training had an impact on the delivery of health action plans; there was conflicting data as to how health facilitators were chosen; some benefits to having a health action plan have been identified and that communication had improved with Primary Care, families and carers as a result of the health action planning process.

Finally some limited additional data was presented using Spearman's rank order correlation to demonstrate if the results of one variable had impacted upon the outcomes of another variable.

Further in depth analysis of data will take place in chapter seven, where the issues will be discussed using a concept of change that has been used previously to good effect in analyzing learning disability provision .

These key themes also became apparent from the focus group research. Therefore in order to compare the findings of the different elements of the research, they are discussed more fully in the integrated discussion in chapter seven.

# Chapter 5

## Health Facilitator Focus Group Findings

### Introduction

This chapter discusses the findings from two focus groups for health facilitators in Rochdale. It will compare some of the findings to the data collected about the experience of health facilitators on a national level, and discuss in detail what is happening regarding health action plans across three supported living services providers in this locality. Benefits of the health action plan process are identified, alongside difficulties encountered in using the health action plans and suggestions on how the local process can be improved to make it more person- centred and useful for those involved. Finally the chapter provides recommendations to improve local practice.

The aims of the focus group research are to evaluate the experience of health facilitators in Rochdale in delivering health action plans, then compare this to the national findings to inform and improve local practice. Initially, it was planned to have one focus group, but due to sickness only 2 attended the initial focus group discussion. Whilst they provided a wealth of information, it was not sufficient or representative of all supported living services providers so a second focus group was arranged. As the results from both groups were consistent with each other they are presented as one group of findings.

Both focus groups were held in a meeting room at the researcher's base as this was the most central meeting point. The first focus group with two participants lasted for an hour. The second group with eight participants lasted an hour and forty five minutes. Both were held in the afternoon to minimise disruption to services provided.

It is acknowledged that the focus group is a sample of health facilitators locally, but there is representation from the three service providers who introduced health action plans in Rochdale. Therefore, where it is appropriate, comparisons to the health facilitator questionnaire responses are made to understand how practice locally, relates to what is happening nationally.

Throughout these findings reference and comparison will be made to the findings from the health facilitator focus group (HFFG) and the health facilitator questionnaire respondents (HFQ).

## Findings

The two health facilitator focus groups were undertaken with ten staff, who acted as health facilitators. These staff worked within three different social care providers who offered supported living services for people with learning disabilities in the borough of Rochdale. Until recently, six of the health facilitators had worked with the opportunity for clinical advice and support from learning disability nurses with the health action plan process. The other four health facilitators would require a referral to the community learning disability nursing team to gain any clinical advice and support.

There were 9 women and one man involved in the 2 groups of varying ages and experience. All but one participant were acting as managers within supported living services. The remaining individual was a support worker. Participants had worked in the supported living services from 2 years 8 months to 19 years with the average length of time being 9.5 years service. In addition four (40 %) of the health facilitators focus group(HFFG) participants had been in the service over 10 years compared to73 (62 %) of health facilitator questionnaire respondents (HFQ).The number of completed health action plans ranged from 2 to 15 with the mean being 4.7. Several participants had completed a number of health action plans and were in the process of completing more. More plans had been completed by health facilitators who did not have learning disability nurse support. These participants had worked in numerous supported living services whereas the other health facilitators had remained in the same supported living service for some time.  All participants appeared to be experienced in the health action planning process. The majority of participants stated that health facilitation was part of their role. No one indicated that they had been chosen by the person with learning disabilities to act as their health facilitator. This aspect will be discussed further in chapter seven.

Whilst the sample size of the focus group is small, all supported living services providers were represented. Therefore I wanted to understand, if the practices in Rochdale were similar to that happening nationally, so comparisons are made to the results of questionnaire part of the study. The range of services involved in completing the health action plan compared to the range of

services involved by HFQ respondents. For example 9 (90%)HFFG participants identified involvement of family in the health action plan compared to 89.7% (105) of the HFQ. However, what is interesting to note is that from the HFFG responses received, 40% (4) participants only involved paid carers, family and the person with learning disabilities in their plan. They did not identify any involvement of any other services in the health action plan. This is somewhat disturbing as three of these health facilitators had direct links to a learning disability nurse and I would have expected that they would have used the learning disability nurse input and would therefore have been more likely to involve primary care in the process. Indeed only 2 participants who had the opportunity for learning disability nurses involvement actually used this input.

Staff from other supported living services did use learning disability nurses support by involving a nurse from the learning disability community team regarding a specific issue relating to challenging behaviour.

Involvement from health services in the completion of the health action plan was comparable for GP and dental involvement, but slightly different for practice nurse, optician and acute service involvement, across both HFFG and HFQ respondents.  Examples were given by the HFFG where primary health care staff wrote in the health action plan. Two participants did not mention involvement of the people with learning disabilities in their plan at all. The ethos of health action planning locally was to include people with learning disabilities in the health action plan although it was acknowledged that for some people this may prove difficult, with a best interest discussion taking place, but attempts should still be made. This result compares to the HFQ where 6 %( 7) of respondents had not involved people with learning disabilities in the health action plan.

Finally, only 4 (40%) participants across the focus group actually involved friends of the person with learning disability in the health action planning process. This is comparative to the findings in the HFQ group where 42.7 %( 50) of respondents identified friend's involvement in the health action plan. This is interesting because if person centered approaches were truly used in the health action plan process (Sanderson et al 1997) then the using the circle of involvement principle, all people that were of importance to the individual would be involved in the plan. For example, if a health action was to increase the level of physical activity then is reasonable to expect that this could be achieved by the individual joining a friend to participate in an activity

such as swimming rather that relying on staff support alone. It would appear that a valuable opportunity may have been lost then by both HFFG and HFQ to extend health related activities by encouraging the support of the person's friends and families. This in itself is not inclusive practice as many people in the general population would participate in activities such as going to the gym or attending a slimming class with friends.

Furthermore this demonstrates that not all areas across England and indeed locally in Rochdale are using person centred concepts when considering all aspects of a person life (Sanderson et al 1997). Certainly the local evidence from the HHFG findings confirms this. The participants who had indicated the inclusion of friends in the health action plan had all under gone Person Centred Plan training as part of the pilot within Rochdale. Not all members of the focus group hade received this training yet and it would be interesting to review these outcomes in future after this training had been delivered to identify whether practices had changed.

A series of pre-planned questions were asked of participants and these are now discussed in detail.
.
1) **Did you have any training regarding health action plans?**

This question produced a mixed response. In total 7/10 of the group had received training. Another participant had been offered training and commented that: "I was booked on the training but I did miss it through sickness". (Participant 1)

One participant felt that the plans were self explanatory; one felt that training was very limited, and two participants commented that they felt the sessions were information giving rather than a training session. One participant had half a days training with a learning disability nurse followed by an update to clarify problems. What is known is that training was offered to all providers at the time that health action plans were introduced.

2) **Would training have been useful? If yes how?**

Two participants, neither of whom had attended training, suggested that it would have been useful to have a couple of completed health action plans to look at as an aide on how to complete the plan.

> *I think there are a few areas in a health action plan that can be open to interpretation and I think it would have been helpful possibly, - to look at a couple of other health action plans that people have done and sort of try to look at what's best in there and the best sort of format* (Participant 1)

Participant 2 agreed stating, that although they had managed to complete health action plans initially in a familiar house, since moving to a new house

> *We (themselves and staff) haven't put in what needs to be put in, what doesn't (need to be in) and there's quite a lot of empty pages. We would have really benefited from looking at one (a completed health action plan)* (Participant 2)

Other participants did not suggest this method of training. However, from the information received, most of the group (7/10) had received training and generally had considerable experience in completing health action plans. Some of these health facilitators also had support from learning disability nurses, who had either been involved in the development of the health action plan process used across services or had completed many plans, themselves, which may have had an impact on knowledge received and shared. Furthermore, participant 3 commented that training was useful in that in made the "transferring of information from other documents into the health action plan easier" as the training made the process easier to understand.

Participants were then asked if they thought that training would be useful for support staff and if so how this should be delivered. Participant 1 suggested that this training for staff would be useful. They suggested that often staff think that it is the service manager who keeps making changes to practice rather that understanding that these changes are made at a national level and that the service manager is just implementing them and commented that

> *It's (health action plan) not just a whim I'm on or a whim that the organization is on because it's a nationwide thing and to put that sort of passion across it would be a better way for them to absorb the information needed.* (Participant 1)

All participants agreed that training for support staff would be useful, indeed participant 4 felt 'Often they (staff) don't put in enough detail" They suggested that this training could be developed to support staff with the health action planning process. Indeed it could help to clarify

with support staff what the forms are used for. Participant 1 related that support staff do not always think about the forms and how it relates to the individual. They gave the example that

> *So it may be that sort of the epilepsy, this person's not got diagnosed epilepsy but they might have recorded almost loss of absences or other aspects that you know have been attributed to some sort of seizure but because it's not epilepsy they don't fill in the epilepsy pack* (Participant 1)

This relates to an additional pack developed by the epilepsy nurse specialist that would usually only be completed by someone who had been confirmed as having epilepsy. This issue may be that the managers also need to be familiar with the forms and what they are used for. This could be achieved by the use of a completed health action plan as an aide memoire, as suggested earlier by participant 1.

This lack of clarity could result in both a loss of current information and misinformation in the future. However I would argue that if this information is required in this way for the individual in question then the manager should already be instructing staff how to use these forms specifically for that individual as training would only give an overview of the health action plan process. As all health action plans should be based on individual need (Valuing People 2001a) and the local format was developed as tool to adapt as required, it is down to the health facilitators to instruct staff on how they should be utilized in the best way to support the individual.

In relation to the point raised regarding epilepsy awareness, Pointu and Cole (2005) demonstrated that providing training to social care staff regarding epilepsy helped to improve the care given when supporting people with epilepsy. It is reasonable to suggest, that as well as providing training regarding the use of the health action plan, it would be beneficial to cover various aspects of health including health promotion within the training to improve carer knowledge.

 Participant 2 agreed that training for support staff in what the forms were used for would be useful, identifying another area where information could be given to staff (about mental health issues) by commenting that in their experience using the forms had helped long term staff to "think about how somebody acts,…… at certain times of year and things that they wouldn't even think about before"

This was in relation to the addition of emotional and mental health aspects to the plan. They discussed how for one individual, it had been useful to help staff think about how behaviour and mental health may be different at different times of the year for individuals. This demonstrates that discussion about the forms in teams can help the team to both focus on and understand the individual needs more fully. These comments suggested that staff did not fully understand the rationale behind health action planning. Indeed participant 1 went as far as to comment that training;

> *Will get more of the staff on board…..  I don't want them (health*
> *action plans) treated like they've treated a lot of other  formats and*
> *documents that's been brought in to sort of make it more practical*
> *and the service better to be disbanded 3 or 4 years later oh and we're*
> *now on to this new thing.*( Participant 1)

This comment related to the issue that staff were dissatisfied that various forms of different documentation had been introduced over the last few years. Staff were both confused and did not fully understand why documentation was introduced; often expressing that it was on the mangers whim and not for the benefit of the person with learning disabilities. Again it could be argued that the reason for the introduction of health action plans should initially be discussed by the managers of the service, but if this can be assisted by training, that can only be of benefit to people with learning disabilities in the long term. However, there was some disagreement about how this training should be delivered. Participant 1 suggested that the training should be delivered by an "Outsider to the group as this would emphasize its importance".

Participant 2 also felt that training should be delivered by someone other than the manager otherwise;

> *You're still looking at ones person's interpretation of that*
> *information aren't you? You're still looking at what my idea is, or*
> *what an individual manager's idea is because of that.* (Participant 2)

This is a valid argument as without training or information received and relayed it is the person's interpretation of data to others that could be at fault. One useful way to overcome this could be the suggestions made by participant 1earlier to "Look at a couple of completed health action plans to identify how they had been developed".

Obviously the plans would be anonymised, but this option would appear to be a useful tool to develop as an aide memoir and teaching tool for staff. This could easily be achieved and an

electronic copy kept for referring to as all supported living providers now have computers in each area to support the service users. Furthermore this would also enable staff to understand that health action plans are a national issue and that they are not just an additional piece of paperwork was developed locally.

Participant 6 discussed how the health action plans had been audited within the services as part of the health action plan benchmarking process. Feedback was then given as a result of the audit on how the plans could be improved. Indeed the mental health information discussed earlier was developed as a direct result of identifying gaps in data from the audit. Therefore participant 6 suggested that;

> *The people who audit the health action plans should give the training*
> *as they know what is needed and as they had already identified where*
> *any gaps had been within the current plans.* (Participant 6)

The people who did the audit had been involved in the original design of the health action plan and consisted, mostly of learning disability nurses, who had a more in depth knowledge of the health issues relating to people with learning disabilities. By utilizing a lessons learnt approach this group of health facilitators could not only assist staff to understand the rationale behind health action plans' but could also assist staff to become more aware of some of the health related issues that affect people with learning disabilities. This would fit in with the concept of Valuing People (2001a) which suggested that nurses are to act as a specialist in their field and be a point of reference to others and the recommendations of the United Kingdom Nurse Consultant document A Vision For Learning Disability Nursing (2005) suggested that to be 'effective change agents' learning disabilities nurses need to:

> *Be politically aware. To understand national agendas and how they*
> *can use and work with them to influence practice* (page 35)

As discussed, there was some debate amongst participants as to how training could be delivered. Participant 2 commented "I think that would be a really good idea to access people's team meetings and house meetings- and speak to all the staff." The majority of participants agreed that attending team meetings would be a good idea as it would give staff the chance to ask questions and relate information and any questions to their individual service users. Indeed this concept would fit with Valuing People (2001a) recommendations that that social care staff

and carers need to gain "Competence in basic health issues and implementing health promotion initiatives" (page 62).

Attending this meeting would also allow staff to focus on individual people and issues/concerns if appropriate. However, participant 10 disagreed and commented that team meetings were limited and that it would be a better idea to have a separate meeting. They suggested that you could; "Have a few teams together -, although this would need some coordinating (cover at houses)"

Others disagreed suggesting that some staff would not feedback to their teams. This was challenged with the suggestion that staff from different areas would feed off information and ideas from each other. I would argue here that it was the manager's (in this case they were all health facilitators) responsibility to ensure that staff do feedback from training by making it a requirement of attending that training in the first place. This feedback could be done as part of the staff team meetings, when all members are staff should be present. Some of the issues discussed regarding training about health action plans appear to be obstacles put in place by the health facilitators, who are looking for someone else to solve the problem rather than trying to resolve the issues themselves.

Grieg (2003) describes this as the remover typology. This typology describes people who ascribe the responsibility for the removal of obstacles to change to others. This group believes that it is not possible to deliver change until someone else removes all the obstacles. In this case I would suggest that discussion would need to occur with senior managers of services as to how training should take place and then the process could move forward. It was suggested that;

> *A train the trainer concept could be used and that someone could then come to individual team meetings so that questions could be asked* (Participant 9)

Despite further discussion a consensus of opinion was not reached about how training should be delivered. However, what was agreed was that support staff did require training regarding health action plans and that this training should be delivered by someone other than the line manager. As training is an issue identified within the other parts of this research it is discussed further in chapter seven.

3) **How did you find completing health action plan (too long/short/ok)?**

Participant 8 found it "Long winded at first – gathering information could be difficult with differing opinions documented"

These differences of opinion could be seen as a positive effect as it would encourage staff to discuss the individual that the health action plan was about. Indeed it would put the individual at the centre of the plan which is the aim and link the plan with the person centred approach of care planning (Sanderson *et al* 1997). Participants commented that using the health action plan had encouraged staff to sit down and talk to the person about their health in a way that had not happened before. Discussing differing opinions can result in improved insight into why people do things in certain ways. Participant 6 gave an example where this had proven useful when discussing behaviour, for example for someone who was not sleeping. Often people with learning disabilities behave and interact differently around different staff and their families. By sharing information about the issue, successful ways of encouraging the persons sleep patterns can take place as staff share what works for them when they are supporting the individual to get off to sleep. This has resulted in improved sleep patterns, reducing distress for the person.

Furthermore the gathering of information would indicate that this is a useful tool as obviously the information was not available or not known in the first place. However; the consensus was that the length of the health action plan was just about right and easily led, once staff became familiar with it. An example of this was given;

> *I found it really useful say for taking to hospital and things like that…*
> *everything you need to know about that person (you) just need to look*
> *at everything that's in there (the plan).… how they eat, how to*
> *communicate etc.*( Participant 2)

This related to the Hospital Grab Pack which is part of the local health action plan format. This document contains all relevant medical information needed in an emergency, until a familiar staff can attend with full information that may be required. Again it is suggested that this is of benefit to the people with learning disabilities' experience of health services. One of the issues raised in previous studies relating to difficulties with people with learning disabilities accessing health services was the lack of knowledge by carers (Smith 2006, Powrie 2003, and Hogg 2001). This comment would suggest that the use of this local health action plan tool does

aid communication with health services and enable the carer to have enough knowledge to support the individual in the first instance until someone who is more familiar with the person arrives.

Participants agreed that there was too much duplication of information with the health action plan and other documents that they needed to complete, with participant 1 giving the following example where duplication occurs:

> *If anybody has been to a medical appointment you've then got the*
> *information obviously in the tenants drug sheet and the medication*
> *file to change, you've then got it in the tenant profile you've then got*
> *the emergency pack, you've got it in the hospital grab pack and*
> *you've got it in the health action plan.*( Participant 1)

However this participant agreed that "I really don't know how to address that".
This is a valid point as if staff need to duplicate information repeatedly it is possible that mistakes may be made. Furthermore recent instruction from the Department of Health regarding patient's notes actively discourages this duplication of information, suggesting that one set of notes should be kept. Other participants concurred and suggested that since new documentation had been added there appeared to be a lot more duplication of information and suggested that this should be looked at in a review of the documentation. Participant 4 said that "There was duplication of information until it had all come together"

However, some benefits to the health action plan were suggested. Participant 7 suggested that "information in the plan was useful for unfamiliar staff". It has proven useful for staff to familiarize themselves with the individual and to get to know them better. Participant 8 said that the plan was "just right once familiar with plan" and participant 9 said that it was "good to help forward plan (appointments, activities)". This was because it helped to make appointments and follow up appointments for health related activities and ensure that staff were on duty to support people to attend them.

Finally participant 2 added that they had added a chronology sheet to their health action plan to assist staff in finding information straight away. They discussed the benefits and gave the following example of how this had been useful in supporting staff in completing the document

> *Because I found it a lot easier than going through all the information.*
> *If somebody's had blood test and you ring up for the result of a*
> *blood test and they'll say what was it for so you don't have to go*
> *right back to the blood test, its down there.* (Participant 2)

Consensus was that an index sheet would be a useful addition to the health action plan and that this should be developed by the people that designed health action plan.

## 4) Was the health action plan useful – why/why not?

Many examples were given to support the usefulness of the health action plan. These benefits followed the themes of providing information, ability to forward plan, increased knowledge, responsibility for the health action plan and improved relationships with primary care. These answers were themed and are discussed in more detail below.

The health action plan was also useful in gathering of information from various sources. It enabled staff to identify family history. In some cases health facilitators made contact with families as part of the health action plan process to gather previously unknown family medical information. Participant 7 commented that; "One client's sister had input at the beginning as part of best interest (discussion) regarding family (medical) history"

Furthermore, participant 6 commented that there was "ease of access to information" and participant 3 that "all information was in one place". This improved the ability to forward plan. For example current medical checks were noted alongside a review date so that future appointment could be made. Participant 6 commented that it was useful for "monitoring that checks (for example regular monthly checks on the ladies' breasts) were happening" and participant 7 identified that it helped to "forward plan appointments and monthly reviews, for example the dentist/doctors"

Participants commented that overall, knowledge had increased in several ways. This included staff using the health action plan to talk to families to gather information that was then shared with staff, increased awareness of previous medical issues, use in emergency admissions and understanding when regular check ups were due. Knowledge was identified in the literature chapter as a key issue in improving access to services and this aspect is discussed further in the

integrated discussion chapter as it relates to both groups of health facilitators. However, Participant 2 commented that the health action plan had been useful in that they were

> *Learning things as well about the tenants that I didn't know because I'm going in sort of with fresh eyes asking questions about them.*( Participant 2)

Participant 5 also acknowledged this increase in knowledge and listed several benefits of the health action plan;

> *Staff gain knowledge of - past illness/treatment - medication – emergencies (information for use by unfamiliar staff) – hospital (appointments) – (identifying individual) support needs* (Participant 5)

Other participants agreed collectively adding that  they were also able to review past medical history and treatment received, current and previous medication used and that issues of routine checks such as breast screening and podiatry were covered. This aspect in itself is useful then as staff are not only taking time to get to know the individual better, therefore making the plan more person centered (Sanderson et al 1997) but are also talking to families to gather medical information that was not previously known and which in some cases is relevant to pass on to the GP so that hereditary conditions are known

Participants then identified that the health action plan had been useful to support emergency hospital admissions as a first point of information. This was particularly useful if the staff supporting the individual was an unfamiliar member of staff, which sometimes could happen due to staffing issues. Furthermore some participants worked in a service that operated an on call management system whereby a manager would attend emergency admissions out of hours. This manager may not be familiar with the individual so would be able to use the information contained in the health action plan  to inform hospital staff of the basic information required until a more familiar member of staff could arrive the next day. Participant 5 summed this up saying that "the grab pack enables a smoother transition to the hospital in an emergency" Finally, participants acknowledged that the health action plan was a useful tool for new or unfamiliar staff to read to help them get to know the individual.

One issue raised at this point was that there needed to be a named individual to take actions forward in the health action plan, otherwise actions may not happen. Participant 4 raised the

issue saying "that in order for goals to happen it was important that a person was identified – for items on the Action Plan". This led to some debate amongst participants and they discussed the implications of not having an individual named as the person to assist the person with learning disabilities to take their health goals forward. It was agreed that a named individual should be responsible for monitoring goals and that issues were being addressed, but that this person would not necessarily be the person that completed the activity all the time. For example if the health goal was to attend swimming each week it would not always be possible for the same member of staff to support the person every time, but they would oversee that the swimming was taking place regularly by monitoring the health goal set. Participants agreed that it was important to have a named individual otherwise no one would take responsibility for the action and examples were given where plans had fallen down in the past because no named person had been identified. It was also agreed that each plan may have several different named individuals to offer support, but that usually these were the person's key workers.

Next, participants identified how the health action plan had improved relationships with primary health care when answering this question. Two participants gave examples where the health action plan had been useful in liaising with primary care staff, who had completed the health action plan when giving treatment.

> *One of the gentlemen had a catheter change and quite complex needs*
> *around dementia and things like that. So district nurses referred to it*
> *(health action plan) ….But you know I've not found problems in the last*
> *12 months getting outside agencies and other professionals to sign it,*
> *to comply to it.* (Participant 1)

And participant 2 commented that they had "used it with district nurse, doctors, incontinence (nurse). You know everybody's efficient". To clarify the researcher asked "And have they actually written in the plan"? Participant 2 commented "not every time I've asked for, but quite a few. You know instead of me writing it and getting them to sign it they've actually wrote in it".

In comparison, whilst there were examples of primary care involvement in the health action plan within the questionnaire findings, no participants made specific reference to primary care services documenting the care given within the plan. There were also no examples of this level of involvement given by any other participants in the focus group.

**5) Would you change anything?**

Some discussion on this took place during question four. However, in order to present these findings in a more cohesive way they are discussed in this question. In general, participants were satisfied with the way that the health action plan functioned, and Participant 2 had no changes to suggest. However the other participants had several suggestions of changes that could be made to improve the local health action plan. These changes related to the size of the health action plan , the use of an index, archiving of information, the format of the documentation, ways to improve/assist the use of the plan and development of protocols regarding the use of the health action plan.

The first areas of concern raised by participants related to the size of the plan, lack of index and archiving of information. Participants raised issues over the size of the document and how big do we permit it to be. It may be of interest to know that the size of these health action plan within the services fell in the range of 1 to 50 pages (as per the questionnaire groupings).This compares to 17.5 %( 15) of questionnaire findings. Furthermore 84.2 %( 71) of HFQ respondents had plans that were 40 pages or less in size and 11.7 %( 10) had plans of over 51 pages, although the average size of plan was 21-30 pages long. This makes the local health action plan considerably bigger than other areas of the country.

Much discussion then related to the use of an index to assist in the use of the health action plan. Participant 4 identified that "A clearer in depth indexing system to ensure continuity of the health action plan in all areas of the borough" (is needed). Whilst participant 5 agreed and suggested that;

> *The health action plan was such a big document and sometimes you*
> *need information in a rush. This was hindered by information not being*
> *indexed, which meant that sometimes documents were missed, or misfiled*
> (Participant 5)

Some participants of the focus group discussed how they had developed an index for the file so that they were easer to navigate. It was agreed that it would be useful if a generic index was developed so that could be shared across services providers who could use or adapt them. Furthermore the HFFG felt that the use of a generic index would be beneficial to staff who

may work in many different services as they would be familiar with the format of the plan and should find it easier to locate information whichever person they were supporting at the time.

The next issue raised was about the archiving of information process, with participant 4 raising the concern of "How do we archive information?."

The archiving of information was an important issue that was raised. Some people with learning disabilities have multiple medical conditions, and consequently have a large number of medical appointments, so would use a lot more pages within the document that others, which could increase the document, size considerably. HFFG participants were unsure about the information that needed to be retained and what needed to be archived and the timescales involved before information was archived. Furthermore, as they worked for different service providers, each had their own thoughts on this issue but consensus of opinion was that guidance was required for archiving of information.

Several comments were discussed in relation to changes that could be made to assist staff in using the health action plan. Participant 5 suggested changes to the appointment sheets to allow staff to write more information in the boxes as staff had found this a real issue. For example GP visits "as there was insufficient room to write the outcomes of the visits or if medication was changed" This was despite them encouraging staff to write in additional boxes if required the staff still tried to fit the information in the first box on the page.  Other changes that would be of benefit were suggested by participant 6 to "amend the review sheets", participant 8 "use of review sheet or my health action plan Action Plan, or amalgamate both together" and participant 3"staring a new action plan every year with outstanding issues to be carried forward"

Participants then identified several areas where they felt improvements to the health action plan could be made to assist them to act as health facilitators more effectively. Participant 8 suggested the idea of "developing different flow charts so that staff understood which sheet needed to be completed following interventions for example changes to medication". This particular issue would involve completing several of the pages within the health action plan. .For example there would be the medication sheet, doctors appointment sheet and maybe other instructions as dictated by individual providers. Some times staff may get confused thus forget to complete all relevant information. Participant  7 suggested "developing a yearly planner to

remind when certain checkups need to be booked" During the discussion some participants said that had already done this themselves and had found that is was very effective in ensuring that check ups were not overlooked.

Participant 10 suggested "ensuring that information required is in the plan". For example if sedation is required (an example was given for someone prior to a dental treatment) is the information in the plan about what level of sedation is required, what staffing is required, best interest discussion and so on. This is very important as one complaint from clinicians is that often carers do not have the appropriate knowledge to support people with learning disabilities (Beange et al 1995). In the example presented, the individual requires a set amount of sedation half an hour before setting off to the dentist to calm them down. They require 2:1 staffing support and a longer appointment time would have been arranged. If this information was not recorded and the regular staff were off duty there would be no notes to refer to which would most probably result in a poor experience for the individual. It is likely that they would become distressed, all the previous work undertaking in getting the person to attend the dentist would be undone and the appointment time would be wasted. It is vital then that sufficient information is documented, in case circumstances change and people that know the individual best are not available. Another example of this is given later when discussing improved communication.

The final change to the plan suggested was the introduction of protocols. Although this does link to assisting staff in the previous section it was identified that a protocol was needed to cover some aspects of the health action plan. Whilst this would require further consideration participants suggested that things to include were: who can access the health action plan, how access is monitored and who monitors the health action plan. Finally, participant 4 reiterated that "A clearer in depth indexing system to ensure continuity of the health action plan in all areas of the borough" (is needed)

**6) Did the health action plan make a difference? How?**

Participants agreed that the health action plans had made a difference. They agreed that they promoted a proactive way of supporting someone's health, rather than the reactive way that had previously existed. The staff groups were now proactive in following up appointments and making action plans following an appointment so that things did not get missed. Collectively,

they agreed that the health action plans had improved communication with the individual, carers, primary care staff and between support staff themselves. The plans had also increased carers knowledge and to some extent had been useful to rule out physical illness as the cause of behaviour, examples of this are now presented.

The health action plan aided communication with carers and primary care staff. Participant 5 suggested that primary care professionals were prepared to discuss a person's health, as evidence was provided, rather than a "do as we say attitude" that had been experienced previously. The information contained in the health action plan provided documented evidence that could not be ignored. Participant 7 gave an example of this by identifying that they had been

> *Monitoring weight changes for an individual, for a while which they then discussed with the GP. As they had evidence of weight loss the GP agreed that there must be an underlying cause for this and investigations were completed leading to a faster diagnosis*
> (Participant 7)

and resolution to the health issue. Their experience had previously demonstrated that without this evidence it would have taken some time to convince the GP that there was an issue to investigate in the first place. In addition this evidence could be used by all carers supporting people with learning disabilities, even those who were unfamiliar with the person that they were supporting. Indeed this lack of knowledge when supporting people with learning disabilities had been identified in an earlier study in Rochdale (Smith 2002a) as one of the factors that hindered access to health services. Furthermore, in completing the health action plan and gathering this information the carer's knowledge around both the individual and their health related issues had increased sufficiently that they felt enabled to debate the evidence with primary care staff if required. This increased insight was recognized by Boland (2008) but this insight is often not enough for professionals to listen to carers views (Michael 2008). Recognizing carers' values and input is acknowledged in the learning disability direct enhanced service (DES) for health screening for people with learning disabilities within primary care. GPs have to demonstrate how they have involved carers, where appropriate, in the discussions when completing the health screening process. However this research occurred prior to the DES but this example does demonstrate the value of providing accurate information to get the best from health service provision.

Unfortunately, not all participants could report the same level of success as participant 7. However participants 1 and 2 gave examples earlier when answering question 4 whereby they had used the health action plan with primary care staff and some had written in the plan and participant 8 also identified that as a result of the health action plan "Professionals provide more understandable information and are prepared to discuss matters." This is interesting to note and would suggest that whilst there were some pockets of collaborative practice taking place locally where carers were involved in discussion about the individuals needs (Boland 2008, Michael 2008), there is still some way to go before all primary care professionals acknowledge the benefits of the health action plan . It would be interesting to determine, if this research were to be repeated locally, if the introduction of the Direct Enhanced Service would have any influence on primary care involvement improving.

Participant 2 identified that discussions had taken place with family members to gain information of family medical histories that hadn't occurred before the introduction of the health action plan. They commented that "the health action plan helped to build a relationship with one family member who was very quiet" As a result they had managed to gather some background health information that they did not have.

The health action plan had also aided communication between all carers and an example was given by participant 1. Previously a key worker had taken responsibility for care of a service user. This key worker was very protective of their role for the individual. All information about the service user was in the key workers head and not shared with the team or documented. This key worker went off long term sick and staff used the health action plan to follow things up and document information. Participant 1 commented that previously

> *People would have been oh she'll be back in a couple of months and
> I'll just leave it, I'll just leave it. Whereas they're (health action plan)
> very promoting, and you will check this up every month so you follow
> things up.* (Participant 1)

Now any member of staff has all the information to hand and can support the service user with their health needs. Again it was also highlighted by participant 3 that the health action plan was "Good for unfamiliar/ emergency staff to read".

An example was given how the health action plan could be used to rule out a physical cause for episodes of challenging behaviour. Participant 1 explained what would usually happen if a referral was made to the learning disability team for support for an individual who was exhibiting episodes of challenging behaviour;

> *Before you attributed any behaviour you had to look at some sort of physical need. And one of the first questions that the community nurse would quite rightly ask is have you checked dentist? Have you checked this? Have you checked that? It's there isn't it that yes they have been checked; they have been checked but 3 months ago* (Participant 1)

They went on to discus how the health action plan could help to rule out a physical cause of the behaviour and thus 'speed up' the support plan for the challenging behaviour developed by the learning disability nurse;

> *Whereas without that health action plan…, you wouldn't necessarily (know they'd) been checked. The health action plan has promoted that regular check-up and therefore the sort of knock on effect is we've been able to say that it's definitely its not that…. Before health action plan came in I always had to say well yes I'd better check on that and I'll check on that. They're there and you can look at it and you know that criteria's been actioned so you're pretty sure it's nothing health wise.* (Participant 1)

Participant 9 summarised this benefit by stating that the health action plan could provide "Clarification that it was factual and evidence based if used correctly" but added that training was needed to make this happen. Another example of an additional benefit was given where the plan had been used to chase up equipment required when none had been delivered;

> *You've got dates to refer back to. I found it really useful. Wheelchair assessments funnily enough, I know it sounds silly but you can chase them up as its taking so long, but you have the exact date to give them and when you phoned and who you talked to.* (Participant 2)

Previously this information would have been archived by this organization as the original request for information had commenced in the previous calendar year. This is an unexpected benefit of improving communication which other participants had not considered but is useful to demonstrate that the health action plan keeps all relevant information together.

Participant 8 also felt that a benefit of the health action plan was that it provided information on screening that was accurate and up to date and also that it was thorough in that it enabled all issues to be followed up and there was a clear process to follow with named individuals responsible. It was also useful in an emergency and participant 5 identified that "the grab pack enabled a smoother transition into hospital in an emergency". This is of particular benefit as one of the keys issue mentioned by health professionals; particularly GPs is regarding the wasted appointment times that occur by carers attending appointments without the correct information (Zivani et al 2004). This benefit concurs with that of Corbett (2007) whereby held records hand can improve communication between carers and health providers. Finally participant 10 said that the health action plan had made a difference because it was "(For the) Individual using a person centered approach from staff (and) services with GP involvement"

### 7)      How do you monitor plans? Who is involved?

Participants had differing ways to monitor health action plans, but all plans were monitored monthly. Some monitored them themselves and other encouraged staff to monitor then they would check that staff had monitored the plans correctly. Participant 2 commented that they review them but

> *Recently we've been using them everyday especially going to a new place, not really knowing any of the staff there. Any information that I need I've got from the health action plan.* (Participant 2)

Several additional comments were given as to how plans were monitored and these are presented in the table 5.1 on the next page.

*Table 5.1 Monitoring of health action plans*

| | |
|---|---|
| Good idea for staff to do – get them involved in health action plan | Go through whole plan with key worker, any actions documented on action plan – signed |
| Monthly reviews monitored to check it's done | Nominate people to do health action plan and oversee it |
| Need training on how to review (staff) | Set days to monitor so that all staff get familiar with review |
| Discussed with families | Recently using everyday as new area |
| Key worker | Thought for team leader to review |
| Manager | Delegate tasks to key worker |
| Done on own (if no one about) | Staff team |
| Useful to have year planner | Staff do reviews |
| Mentioned at ELPS | |

Local practice then is to monitor plans monthly with varying groups involved in the monitoring process. This is comparable to the health facilitator's questionnaire findings in that a variety of people were responsible for reviewing health action plans. Furthermore this process of monthly review mirrors the questionnaire findings whereby monthly review was the most prevalent frequency of review (38%).

However the introduction of monthly reviews was not welcomed at the commencement of the process. Participant 1 commented that;

> *I must be honest at the beginning I thought what on earth I need a monthly review of them for. I really did. But I think I've actually changed my opinion on that. Because…… its just keeping that communication and keeping that team focused on that patient and what's happening* (Participant 1)

This participant also commented that this change in practice was about "being proactive. Whereas before we had a history of being quite reactive" They suggested that staff also were now seeing the benefits of this.

**8) Did service users/families get involved/give any feedback regarding health action plan**

Not all participants had involved people with learning disabilities or families in the person's health action plan. Participant 2 said that they had mostly done them themselves previously, but "recently the tenants I support now have got involved in them". Participant 2 explained that they were now working with a lady who could only spend ten minutes at a time on the health action plan so progress was slow. However, they had also realised that there were additional benefits to involving the person in their health action plan in commenting that;

> *I just think its getting to know her, you know like I wouldn't know*
> *she'd got fed up with something sort of like only ten minutes that's*
> *enough. I wouldn't have known that if I hadn't sat down with her to*
> *do her health action plan.* (Participant 2)

As a result they now worked together for short periods, but as a result they were obtaining a comprehensive picture of the person for their health action plan. Participant 1 said that around "A third, probably about 50% health action plans initially started off with service users been involved". Participant 3 added an additional way of involving service users in their health action plans commenting that "health action plans were discussed with the tenants at tenant meetings and that they thought this was a useful way to do it". It would have been interesting to get the perspective of the service users on this, as I personally would not like everyone I live with to know all my personal health issues.

Participant 6 identified that "Service users had been involved throughout the process and had shared information that care staff had previously not known". Whilst this is encouraging it does again question the concept of person centered plans and why these discussions had not taken place previously.

Furthermore all participants confirmed that they had found the development of the health action plan to be a useful way to engage with some family carers, and information had been provided and improved relationships were built with family members as a result. An example of this was given by participant 2 who identified an additional benefit to involving a family member in the health action plan process by commenting that;

> *At one time I supported a tenant whose mother was a very quiet lady*
> *that didn't talk much, this built a relationship because she didn't*
> *have anyone else to talk to and once we got talking about her son and*
> *things like that she go onto other things.* (Participant 2)

This led to a better relationship with the mother and more information provided to support the service user in all aspects of support. Participant 1 identified that in talking with the family about the health action plan  the family had also used the health action plan  to support the person attending health services "I've had a couple of families, say she was going to hospital sometimes planned, sometimes in crisis they have taken the grab pack with them." This led to further discussion by participants regarding the lack of information that was given by hospital staff on discharge from hospital. This was despite the hospital grab pack containing a discharge summary sheet. It was agreed that some additional work was required to address hospital discharge and information given.

Not all participants indicated family involvement in the health action plan. This was for various reasons such as no family involvement at all, service user choice and lack of response to requests for support from family members. Similarly not all people with learning disabilities had the capacity to be involved or understand the concept of the health action plan. Where this was the case the health action plan was completed by carers and families using a best interest discussion process.

**9) Do you feel supported in your role as health facilitator? If not how could this be done?**

Two participants had just got on with health action planning as they had both had missed the training. Participant 1 stated that "information was cascaded at managers meetings and that they knew who to contact if they needed advice/support". Participant 2 said that

> *I haven't had any training with regard to completing the health action plans. I carried on and got the experience myself through completing a number of plans and sitting down and discussing as a team.* (Participant 2)

 Participant 2 continued by discussing some of the issues they had with staff understanding health action plans and how they had worked to overcome them;

> *Quite a few staff said to me that they are unsure of how to complete plans and what information is needed and that they can't do them. I tried to sit down with staff, rather than just me completing the plan, and trying to get them to understand what is needed and what needed to be done differently, to take time to complete and add information as this is obtained, such as dentist etc.* (Participant 2)

Both participants thought that training for staff would support them in the role of managing the health action plan process. The other participants felt supported but agreed that there were issues regarding training. Participant 7 said that "they had half a days training with a learning disability nurse and they could contact them to clarify issues". Participant 6 said that "they had been given information rather than training"

All participants agreed that regular training sessions would be useful .These sessions could include how to do breast checks, specialised training for the care team for example epilepsy, cervical screening etc and training for support staff so that they could help to support the health facilitators.

**10) Any other comments?**

Participant 1 stated that the health action plan layout was too rigid. They accepted that certain things needed to be in the plan but suggested that the layout of the plan was too standardized and this was to benefit the staff so that

> *(Another health facilitator) could come into my house and I could go into their house and everything would be the same. But there is little bits of that that's always niggled me, because that's not service (user) led to me. You might say it's a necessity for staff, I don't particularly think it is. I think the more service (user) led that they are that would be better for that person.* (Participant 1)

They suggested that each plan should be individual and that "where you put and how you put it (information) is where you plan (for the individual"). This comment about how plans were very service led is similar to the findings of an interim audit developed and undertaken by Kelly and Davies (2008). They conducted an audit to establish a standard of health action planning in their locality. They identified that the health action plans were "Not service user friendly, person centred, individualistic, accessible or informative" (page 2)

As a result they set up a working group which included people with learning disabilities to review the health action plan process. A new filofax style system was developed and introduced. In auditing this new format with 100 service users, providers and family carers 32 responses were received. Of these 32 people all participants felt that the new format was appropriate and user friendly. Whilst this is a small return on the audit it does demonstrate how

changes can be made. Indeed some discussion then took place regarding how the format had been developed locally as an initial process to get the health action plan in place and that the plan should still be individually led, which had originally been discussed at the original training which both participants 1& 2 had missed.

Participant 1 discussed various formats for health action plan and expressed a wish to work with service users to develop more personalized alternative formats of health action plan such as scrap books or DVDs'. However as yet, this had not happened.

Participant 2 commented that they, prior to the focus group,

> *Had never really thought about health action plan and involving one*
> *service users more in the completing of the plan but now after discussing*
> *it, I'm thinking about involving them more in that and with appointments*
> *and things like that.* (Participant 2)

From this focus group meeting both participants intended to change their practice. Participant 5 took a different tack and commented "That the health action plan role should be in job descriptions so that staff realise it is their responsibility". Participant 6 commented that "You must take responsibility to update appointments" and "sign something" to prove that this is done. Finally all participants were interested in continuing to be involved in developing the health action plan process after the focus group finished. These focus groups presented some real benefits to the health action plan process locally. However, they also identified many issues to address to improve the process and set the agenda to take health action plan in Rochdale forward.

## Summary

This chapter has discussed how health facilitators from three social care providers in Rochdale were recruited to the focus groups, and how, due to sickness and equipment problems a second focus group without recording equipment was held. As findings were comparable from both groups they have been presented as one group.

Some discussion and comparison has been made between the national findings from the health facilitator questionnaire group and the local practices developed by the health facilitator focus

group participants. However, some further in depth analysis of data is presented in chapter seven which reflects issues identified by participants in all three aspects of the research processes used in this study namely, training, choice of health facilitator, benefits of the health action planning process and communication.

This chapter has identified several benefits for all involved in using the health action plan. These include benefits for the individual, for example, by recording health issues to support GP appointments and by having discussion and involvement with the families to collect information. There are also benefits for the individual staff member, for example, by bringing staff together to discuss the individual, their issues and how best to support the person. Finally, there are benefits for the service in that a coordinated approach is taken by using a document that keeps all historical and current data in one place. Indeed the health action plan has proven to be useful during both planned and emergency health appointments/admissions and has encouraged proactive rather than reactive health processes.

This chapter has also identified that whilst there are some benefits to using health action plans, including improved communication, improved health outcomes for the individual with learning disabilities and improved carer knowledge about the individuals health the health facilitators suggested that training for support staff needs to be addressed. There was no consensus on how this training should be delivered but several ideas were identified.

It has demonstrated that health facilitators locally did not need to be nurses for health gains to occur and has identified the importance of having a named person who is responsible for monitoring the health action plan and how this is achieved locally.

Finally participants have identified several ways in which the health action plan process in Rochdale needs to be improved to move forward to improve health outcomes for people with learning disabilities living in the borough by for example making the health action plan more user friendly and individualised. All participants expressed an interest in taking this process forward and several identified that they would be working with individuals to make the health action plan more person centred by using alternative formats following the focus group.

## Conclusion

This research has shown that the health action plan in Rochdale is working, in some areas, to good positive effect, yet improvements can be made to the process and participants are willing to be involved in this. This research has identified that within the health facilitators focus group cohort, the health action plan process was service led, by health facilitators who were managers, some of whom had the remit for health action planning and health facilitation as a core part of their role. All managers were experienced in both their management role and the completion of health action plans. They felt supported in their role as health facilitators and knew who to contact for advice and support if it was required. However not all health facilitators were using person centred concepts in the development of the health action plan. Therefore some health action plans were developed with the involvement of families and carers only and did not include other relevant people important to the person with learning disabilities outside of this circle.

The size of the health action plan developed was the right size, but resulted in a lot of duplication of information with service related documentation. Flaws were identified within the plan alongside suggestions on how to overcome these flaws. One of these flaws was the design of the health action plan in that it was not very accessible to some people with learning disabilities. The participants were keen to develop more individualized plans and some were going to address this after the research. The health action plan had proven useful to engage people with learning disabilities, their families and carers in identifying previously unknown medical histories for individuals. Evidence of involvement from primary care professionals was apparent, but there remains work to be done to improve this level of involvement.

For the health action plan process to improve training is required for both health facilitators and care staff about the purposes, process and benefits of health action plan. This training should include the importance of named individual's responsible for monitoring and management of the health action plan; although consensus on other aspects of the training could not be agreed upon.

# Chapter 6

## People with learning disabilities focus group

## Introduction

This chapter will present the findings of the people with learning disabilities focus group. This aim of this focus group was to evaluate the experience of people with learning disabilities in Rochdale whilst receiving a health action plan and compare this to the national findings to inform and improve local practice.

Although initially six participants were identified, the final numbers of participants in this focus group was four; three female and one male. Their ages ranged from mid twenties to mid forties.  The participants were supported by three different care providers, and two participants lived in the same house. Three participants had family involvement and all participants had at one time lived at home with their parents, but now lived in supported living services. All four participants had a mild to moderate learning disability and were able to give fully informed consent on the initial visit to discuss the research project and at the start of the focus group. Two participants attended the focus group independently, whilst two were supported to attend by carers. These carers then waited elsewhere in the building whilst the focus group was completed.

The focus group was held at the researcher's office as this was centrally based, with wheelchair access and ample parking. The focus group lasted for an hour and fifteen minutes and no breaks were required.

During the focus group, three of the four participants brought their question sheet, and prepared answers with them. At times they referred to these answers, with one participant asking me to read the answers to prompt them, as they were unable to read very well. Three of the  participants commented that it had been useful to have these questions to prepare as they had been able to have discussions with staff and ask staff, where they could not write themselves to make note of their answers, in case they forgot something that they wanted to discuss. These 'crib sheets' proved very useful and I went through them to make sure that nothing had been missed. One participant did not discuss any of the questions with staff or

make notes as they were confident enough to give their answers as the questions were raised. The outcomes of the focus group are now presented.

## Findings

**1) How long have you had a health action plan?**

Two participants were unsure and answered

Participant 1 "quite a long time"

Participant 2"a while"

Participant 3 "three years"

Participant 4 "10 months*"*

**2) Did staff involve you in completing your health action plan?**

All participants were involved in completing their health action plan.

Although Participant 4 commented that staff "Would do if I let them"

The researcher asked them to clarify response "So do you do your own plan then?"

They responded

> *No. I leave it all to them. If they need a little help and they don't know what to put then they'll ask me the question but for the rest of the time I stay out of it. I don't mind that- I can't be bothered doing it myself.* (Participant 4)

This negativity about the plan remained until the last question of the focus group. Although it is difficult to confirm why, I would suggest that part of the reason for this is because this person felt that a health action plan had been forced on them, as part of local process when introducing health action plans. They had not been able to discuss it; therefore they felt that they had no choice in having one.

Participant 3 commented that staff had completed their plan "By talking through it with me. As in taking it step by step"

Participant 2 at this time needed encouragement to join in the group, but later in the discussion as she became more comfortable and familiar with participants this became less of an issue. Participant 2 described how they had 2 copies of the health action plan – one that staff had completed and one that they had done in their own hand writing. This was a much bigger copy

as they used large writing in the plan. They felt that it was important to keep their own copy of the plan as it "was about them".

**3) Did staff listen to what you had to say?**

The consensus was that staff listened, although participant 1 said that staff only listened "Sometimes". Participant 1 expressed concern that staff used this opportunity to discuss "Diets and the eating of salads", which they did not want to discuss.

Participant 3 had found the experience helpful and said that "Staff listened to what they had to say".

Participant 4 stated that staff "Would listen if they allowed them to but that they just leave them it to them"

**4) Who else was involved in completing your health action plan?**

This question prompted a lot of discussion. Initially participants discussed who had been involved which brought forward answers such as family, mum and dad and friends, who had helped to provide information that they themselves did not know. However, participant 4 had a different perspective. They suggested that they didn't want their father involved in their health action plan and that the information should remain confidential. They then went on to say that:

> *They did not want all his information sharing with everyone. It was their information. I didn't want staff to know so I didn't tell them everything.* (Participant 4)

This individual had a strong belief that their information should be kept private and not shared with other staff. This was again raised later in the interview which resulted in a good discussion, which is explained further in question 7.Whilst other participants agreed that information should be confidential consensus was that staff needed to know the information to support the individual with their health needs. Indeed participant 3 suggested that the health action plan had helped them and staff to build relationships with the individuals parents. Staff had had to contact the individual's parents' to obtain some of the family background health information and this in turn had helped to improve communication with all parties.

**5) Are you happy with your plan?**

Generally participants were happy with their health action plan however they all had additional comments to make. Participant 4 expressed concerns about the health action plan in that "I was given one and I was not asked if I wanted one". Their attitude toward health action plans was negative throughout the interview, as they felt that they could speak up for themselves and therefore did not need a health action plan and that "Staff had enough to do without more paperwork".

But this person also commented about the health action plan that "Its all right it does its job". However, this person then went on to discuss how the use of alternative formats could improve the plan. They suggested that "You could do it on a computer it's probably easier". They discussed how they had their own laptop but also that they would not complete their health action plan on the computer. Their opinion was that if it was on a computer it would be easier for staff to complete and that it would be "It's just less paperwork".

In a later discussion all participants said that they would like their health action plan available on a computer and that they could all have access to one in the home. Furthermore participant 3 commented that;

> *I would like it on a computer as well because I can't read the writing (in
> the health action plan as it is too small)* (Participant 3)

Participant 1 said they were happy with their health action plan;

> *Part of the time but that they had some issues with actions that were
> set as they did not always agree with them* (Participant 1)

(These specifically related to diet and were a common theme from this individual throughout the focus group). They also suggested that "Some people help with the health action plan more than others" as in that they (staff) are willing to take time to sit and discuss the plan with them. This response could raise concerns in that for the health action plan to be person centre (Sanderson et al 1997) the individual should be involved in the process. This includes the setting of person health actions (goals) for the individual that are agreed with, not on behalf of the individual. However, as discussion continued it became apparent that this person quite

often changed their mind so it is possible that they had agreed at the time the goals were set. Indeed this issue was followed up, with the person's permission, after the event and was found to be the case.

Participant 2 was happy with their plan but stated that they "Didn't take it to the hospital or to doctor's appointments as they didn't need to (take it)." This was because they had staff to support this person to appointments. These staff would have referred to the health action plan for relevant information before supporting the individual to attend the appointment.

Participant 3 asked the researcher to read out their answer to this question that they had brought with them. The written answer was that;

> *I like my health action plan because it gives lots of information about my personal health issues if needed* (Participant 3)

They then continued talking about this and commented that they were happy with their plan stating that they had been in hospital a few times and that;

> *Medics had used the health action plan and (they) stated how helpful it had been* ( Participant 3)

This participant was the most positive individual about their health action plan throughout the focus group. The usefulness of the health action plan to share information was raised by the health facilitator's focus group and communication is discussed further in chapter seven, as it was an issue raised by all elements of the research project.

**6) What do you like about your plan?**

Participant 4 who didn't see need for the health action plan liked "Nothing about their plan and couldn't be bothered with it". When asked why, they commented that;

> *It's a waste of time -- because nobody looks at it. The people who look at it are me and the staff who write stuff down in it otherwise it just sits on a shelf and does nothing* (Participant 4)

Participant 2 "Doesn't like their plan, but doesn't know why."

Participant 1 liked the fact that "Some people help with the health action plan more than others".

Participant 3 liked it because "it was my plan." The health action plan gave them independence and;

> *I tell the staff what to write and they write it for me because I can't write very well. And also it helps me to do things for myself. They thought that it was an excellent plan* (Participant 3)

## 7) What do you dislike about your plan?

Participant 4 had very strong feelings about their health action plan. They suggested that it was a "Waste of time and they don't need one." They also commented that "Nobody looks at it". This individual went to the doctors on their own without staff support and was able to tell the doctor the reason for the visit and relay this information back to support staff. However, they felt that;

> *Any information should only be recorded if staff asked them if it was alright to do so beforehand* (Participant 4)

and because of this they did not tell staff everything that had happened. They discussed the following example of why this was;

> *I went somewhere for special tests which were private to me. Staff wrote it down (the information about the tests) and I asked him, I didn't want that (information) in the diary so he scribbled it out and got in trouble for it. I didn't want that (information) put in a health action plan. It was put in the health action plan and I scribbled it out myself because I didn't want all the staff knowing what had happened* (Participant 4)

The researcher "so you think there some information that should be shared and some that is not and that's down to the person's choice". Participant 4 "Yes"

Discussion then took place regarding the recording on information. It was agreed that this participant was capable of speaking up and remembering information themselves but that not

all people were able to do so. Other participants reminded participant 4 that not everyone was as able as them, and they may need the information writing down. Furthermore many different members of staff support people with learning disabilities within supported living services therefore it is vital that information is recorded and passed on. This is particularly of benefit for future use to reflect back on patient's histories if returning to the doctor with similar complaints.

Whilst it could be argued that this information should be on the individual medical notes, experience dictates that this is not always the case. In addition appointments times are now reduced so previous information may get overlooked. One of the common themes for primary health care practitioners is that carers supporting people with learning disabilities do not have the knowledge of the individual health issues and often time is wasted and nothing achieved(Powrie 2003, Singh 1997). It is obvious then, that confidentiality and recording of information remains an issue. Furthermore participant 4 obviously had some additional issues regarding confidentiality as they had previously commented that they did not want information sharing with their father. In conclusion to this discussion participant 4 argued that "I went for some tests and they all came back negative so really it didn't need to be put down". Finally, this participant felt that the there was "Too much paper & paperwork for staff" and the health action plan added to this.

 Participant 3 challenged this suggesting that;

> *I feel that the staff that are putting all the work into your plan and spending time with you, you've got to think (name) the staff are trying to help you they're not pushing you to do it, they're trying to tell you to do it on your own because you' re more independent than me* (Participant 3)

Participant 4 "I don't need a health action plan"

The researcher: "Do you think it's because you are more independent that you don't need it?"

Participant 4 "I don't need one because I know what's going on in my own body. I think really that I shouldn't need one"

Participant 3 "But do you think someone who isn't as able as you might need one"

Participant 4"If it's done differently"

Participant 3;

> But people are different (name) you've got to see our point of view.
> We've got an excellent plan covered because they have to be covered
> for us (Participant 3)

The researcher to clarify,

> What they're saying is you should have a health action plan but
> you didn't have to have a health action plan   you could have said
> you didn't want one( researcher)

Participant 4 "*I didn't get asked*".

If this is accurate then it causes some concern as the concept of health action plan is supposed to be person centred. Valuing People (2001a) recommended that everyone should be offered a health action plan not that everyone should have one. Giving someone a health action plan without asking if they want one does not follow this concept. What is even more of a concern is that when the concept of health action plans was introduced locally the issue of people refusing a health action plan was discussed. The agreement was that people were to be offered a health action plan and that if they refused this was to be documented. Furthermore they were to be reoffered the opportunity of a health action plan after 6 months. It is difficult to determine what has happened in this case as this participant did not want help to address this outside of the focus group.

Participant 2 "Didn't like their plan" but "didn't know why".

Participant 3 "liked their plan"

Participant 3 discussed their plan and concluded that they;

> *Needed to speak up more when they were not happy with their plan"*
> *and that "staff need to consider all views* (Participant 3)

Including the individual's opinion when completing their health action plan. Again this related to dietary issues for this individual.

**8) Has your plan been useful to you? How?**

Participant 4 reiterated their earlier comments in that, as they felt that they could speak up for themselves they did not need a health action plan and that "Staff had enough to do without more paperwork"

Participants 1 & 2 agreed that their health action plan had been useful at the doctors, although the plan had not been taken every time. They also commented that sometimes the doctor actually wrote in the plan.

Participant 3 expressed several ways in which the plan had been useful. They felt that is was;

> *Useful for monitoring my health and it helped communication*
> *between staff and my family* (Participant 3)

On one occasion they had taken the health action plan with them when they went into hospital. The health action plan had contained all the information about their health which had been useful for the hospital staff.

Participant 4 discussed how they had taken their health action plan to hospital but had not used it because the information required had not been in the plan at this time (details of when they had last had a tetanus shot). This demonstrates that the plan is only as useful the information recorded in it and that the plan needs to be kept up to date. However participant 4 said that they did agree that the plan would have been useful, if the information had been recorded, and that staff "Can write in the plan what happened"

Participant 3 then discussed how they had taken the health action plan to the doctors but concluded that "Sometimes they had felt excluded from conversation between doctor and support staff" And that "If the doctors speaking to a member of my staff they talk over you"

The researcher asked this participant to expand and clarify and they responded;

> *The doctor does he talks to my staff and he bugs me talking to the staff about the situation and he(doctor) just goes not so good what's the matter with (participant 3). I've spoken up myself and said look you're speaking to me I'm the patient* (Participant 3)

The researcher "and does that make difference?"

Participant 3;

> *Yes when I talk to the GP that I've got something wrong with me and the doctor talks to my staff that's not very good* (Participant 3)

This comment restarted the discussion with other participants. Participants 1 & 2 who needed staff support to attend the doctors or other appointments agreed that they also had experienced this previously but not at the moment. Participant 2 said that the doctor talked to them and participant 1 said "Quite a lot because he tends to fill me in with a lot of things."

Participant 4 commented that the doctor did not listen to them and that "When you want him to do something he won't because he says he knows what is wrong with me. I get told that constantly". They went on to say that it was no good seeing another doctor as "All the doctors in that practice stick together."

In later discussions about involvement in the health action plan participant 1 commented that "But you find different people from outside they do tend to ignore us." And participant 3 brought up the subject of confidentiality again when they were visiting the physiotherapist. The physiotherapist had been talking to the staff accompanying them about treatment etc and not to them. They had challenged this and commented that;

> *They should be talking to me not the staff. I told them straight you talk to me not the staff. He's going I m sorry but I need to talk to the staff as well. I said no you don't talk to me I'm your patient* (Participant 3)

Interestingly, participant 4, who as discussed earlier that they did not want staff to know all their information and had removed this information commented that "I think that staff needs to know what's going on or they can't support you properly."

And participant 1 agreed commenting that "(participant 4) is right in a way. Staff has a right to know what's going on" but went on to say that "But the doctor or whoever should be talking to you and not ignoring you and not just talking to your staff. You wouldn't like that would you?" In response participant 3 answered "They can talk to you while the staff they can listen, there's a way to do it"

The group concluded that some health professionals did not did not listen to them. Again this is not unexpected. Whilst conducting earlier groups with people with learning disabilities in the borough, one of the themes then was the same. Information shared on the national health networks had shown that training sessions for professionals that involve people with learning disabilities have made a difference for them when experiencing health care and this is something that could be looked at locally. This group expressed interest in helping to take training initiatives forward locally.

### 9) Where do you keep your health action plan?

Participants 1, 2, & 3 kept their health action plan with their other files in *"the office"*.

Participant 4 answered that "Mine used to be kept in the office but now its kept upstairs in the bedroom. All information about me was given to me and put in my control"

In discussing this, participants 1 & 2 said that they would need to ask to staff to see a copy of their health action plan as it was kept in the office and they had decided that they would like a copy in their bedrooms so they would ask staff for a copy of one when they went home.

Participant 3 said that "They couldn't keep a copy in their bedroom because another service user may rip it up". In discussing this further they accepted that this was just the way it was and that they were happy with this.

**10) Would you like any changes to your health action plan? If so what?**

The general consensus of all participants was that the health action plan needed to be more "*user friendly*". Discussion around this concluded that having an electronic copy on the computer would be a good idea as people could add to it as necessary.

Participants1 & 2 identified that they would like something more visual and decided a video would be best for them.  Participant 2 commented that;

> *They would put all the information in the health action plan*
> *on a video and that they would talk in the video themselves* (Participant 2)

This would be a big step for this participant as they found it very difficult to speak up for themselves, although they had been more involved in the group as time went on.

Participants1 and 2 concluded that they would speak to staff about this when they went home.

 Participant 3 also commented that they would like their health action plan on a video commenting that;

> *I'd like to have a video as well because I can't read very well, which*
> *means I've got to read all the writing and think about what the words*
> *said. I struggle with reading* (Participant 3)

Participant 3 also suggested that some of the pages in the plan needed changing and should include their friendships as their friends were important to then and they helped them to feel healthy. This would fit with the person centred approach which looks at all the people involved in the person's life.

Participants 1 & 3 felt that the health action plan could help them to become more independent, if taken in stages (step by step) and that there was information that could be added to the plan to help them achieve this.

All participants agreed that they would be interested in working together to make health action plan more accessible for people.  Participant 4, who had been quite negative about the whole process up to this point, became quite animated and suggested that this could be achieved by developing some sort of board game around health and health action plans;

> *I think it (health action plan) should be user friendly. It should either be*
> *on video, which is ok; I would prefer it to be in a game. A game that comes*
> *up with the same answers you normally put in your health action plan  but*
> *it's in a game and people might find it easier to use as a game rather*
> *than reading it* (Participant 4)

Participant 4 continued to explain why they thought a game would be a good idea;

> *Some people if they had a tape because they cant communicate with*
> *others. Some people can't read or write or communicate as well as*
> *others….so you need something for everybody* (Participant 4)

The other participants agreed with this, giving examples of people that they knew. Participant 4 continued discussing their idea suggesting that it should be;

> *Something like monopoly for example you throw a dice and take a card.*
> *If there was something like that was put onto a computer the staff could*
> *read what was on the screen and they could like point to the answer* (Participant 4)

They suggested that whatever is developed it should be an interactive programme that took you through the process step by step so that it was easier for staff to understand and that there should be training for all (staff and tenants) in how to use it. Finally they suggested that the health action planning process should be made easier for staff and that an electronic rather than a paper version would help to achieve this. The inaccessibility of the plans mirrors the findings of the audit by Kelly and Davies (2008) as previously discussed in the health facilitator focus group chapter. They set up a working group to develop user friendly health action plans. Therefore it is suggested that a working group is required to address this issue locally. This group would involve working with people with learning disabilities and health facilitators locally to determine how the plans could be developed to be more individual and user friendly, whilst still maintaining the standards that were required by social care providers.

## 11) Have you any other comments?

Participant 1 reiterated that they wanted to keep a copy of their plan.
 Participant 3 commented that "Sometimes the staff forgets about me as an individual" and the health action plan is a way for them to look at me as one.

## Researcher Observations

The experience of conducting this focus group was enlightening to the researcher. Four very different individuals came together to offer their opinions on the health action plan in Rochdale. Two participants were at opposite ends of the spectrum in that one was very disillusioned with the whole process, whilst another was overly enthusiastic. The other two participants had mixed feelings, and one needed extra encouragement to become involved in the process at all.

It was interesting for me to watch as the interview unfolded how participants became bolder and began to challenge each other in their comments, although participant 1 did not challenge throughout.

Useful information came out of this focus group which will be discussed in the conclusion section of this chapter, but one issue that came forward was the enthusiasm towards the end of the process when participants expressed an eagerness to become more involved in the process. This enthusiasm was also noted by Tuffrey Wijne et al (2007) during their research into palliative care and people with learning disabilities where they concluded that;

> *Our own experience of research participants with learning disabilities*
> *suggest that they were enthusiastic, not only because of the*
> *empowering experience of being listened to, but also because*
> *of an understanding that through participation they could make*
> *a contribution that would help their peers* (page 186)

What was even more interesting to observe was how through discussion and debate, one participant changed their view completely. Participant 4 had commenced this discussion quite adamant that their information was private and confidential to them, but by the end of the group acknowledged and argued with others, that staff needed this information to support the individuals with learning disability that they are responsible for. Part of the reason for this I would suggest is that this individual had not had the opportunity to discuss both the rationale and use of health action plan with anyone other than the staff who supported them. This debate offered opportunity for them to discuss and learn from the experience of others. If that is all

that come from this particular piece of the research, then I would argue that it has been valuable for that aspect alone.

## Summary

This chapter has discussed how this focus group was facilitated and conducted by the researcher, so that all participants were encouraged to become involved in the interview process. Whilst encouragement was needed to get all participants to contribute at the beginning of the process, all involved grew in confidence during the focus group and some lively debate followed.

Participants discussed how they were involved in developing their health action plan and commented that staff had listened to them during this process but one participant felt that they had been given a health action plan even, though they did not want one. During the discussions however they began to realise the benefits that the plan had for people who may be less able than themselves.

Participants identified that the health action plan had improved communication with families, carers and professionals about the individual's health but that there were changes that could be made to improve the plan. Improved communication was identified in all aspects of the research and this is discussed in more detail in chapter seven.

Interestingly, during the focus group, participants raised issues about how health care professionals supported people with learning disabilities accessing health care, in that they often ignored the person with a learning disability and talked to the carer instead. They suggested how this could be improved by talking to them and including the carer rather that ignoring them and agreed that improvements are required. During the discussion, one participant who was very negative about the health action plan process began to listen to other people's opinions and conceded that the health action plans were of use to people who were less able than themselves, who may need someone to speak on their behalf, but that for them they remained of little use and were more of a tool for staff than themselves. The group decided that changes were needed to the health action plans in that they needed to be more

individualised and in an easy to understand format. All members of the discussion group were happy to support developing plans in this way after the focus group interview.

## Conclusion

This research has identified that whilst the health action plans introduced within Rochdale are working to support the people with learning disabilities involved in the focus group to identify and address their individual health needs, this group of participants suggest that improvements to the existing format are required. Indeed, one person who felt that they did not need a plan at this time agreed that the health action plan would be of benefit to people who were less able than them. The plan needs to person centred, and discussed with the individual, to determine who they do, or do not, want to be involved in the plan.

The existing format itself needs to be reviewed so that more user friendly, individual formats that the person with learning disability can understand and be involved in are required. These health action plans need to be developed in conjunction with people with learning disabilities rather than service led as the existing plans are.

Whilst it is important for information to be shared where people with learning disabilities need staff support, this needs to be done in an appropriate sensitive way and systems need to be in place to support this. Furthermore paid care staff need to be made aware that people with learning disabilities do not have to have a health action plan and can refuse one.

This research has identified that health action plans have improved communication for the people involved in the focus groups. However, this group of participants suggested that health care staff do not always acknowledge and speak to them when they are attending appointments, this needs to be reviewed further.

# Chapter Seven

## Integrated Discussion

### Introduction

This chapter presents the research findings in relation to the literature review. By the end of the chapter it will be clear, that although little guidance, or investment was given to introducing health action plans nationally; where the concept was embraced with clear, strong leadership, progress has been made. Health action plans have been developed in a variety of formats, with staff feeling supported and confident in their role. Conversely, where this support and leadership were lacking, numerous obstacles and excuses have resulted in confusion and lack of guidance for some learning disability nurses. This is evident in the results of the questionnaire when some community nurses, explicitly suggest that health action plan are the responsibility of others and that they have enough to do without adding to their already extensive role.

This chapter is in two parts. Firstly, by using a concept of change model, that I feel best suits the attitudes to change within the learning disability context, the results of the national health facilitator's questionnaire are discussed. This concept and why I chose to use it are explained within this chapter. The aim of this part of the study was to determine whether health facilitators and people with learning disabilities consider that the introduction of health action plans have resulted in health improvements for people with learning disabilities living in England. In total 117 responses were received and these responses suggest that there were several key themes that influenced the successful implementation of health action plans. These are the development of the health action plan; the level of health facilitation practiced; the level of primary care involvement and development of collaborative practice; health screening initiatives and the community nurse role with health facilitation. These issues are discussed using Greig's(2003) typology of change to inform the reader how attitudes can influence practice outcomes.

Throughout the research analysis, it became apparent that several themes were interrelated to all three strands of the research process. The following themes were identified across all groups within the research study: training and knowledge; choice of health facilitator;

communication; the benefits of the health action plan and leadership This chapter will proceed to identify those themes and give an in-depth discussion as to what issues were identified within the research and how the findings of each part of the study has informed the recommendations presented later. It will give an in-depth discussion of the findings and how these findings relate to any others studies that the author has identified.

As this chapter will switch between all aspects of the research and in order to present the evidence the following abbreviations are used:

Health Facilitators Questionnaire (HFQ)

Health Facilitators Focus Group (HFFG)

People with learning disabilities focus group (SUFG)

## Questionnaire discussion

Community teams for learning disabilities developed at a different pace across the country for a number of reasons resulting in different nursing team formations and practices. This variety of experience is reflected in the findings from the health facilitator questionnaire. From the results it is evident that practices have developed, according to the working guidance and leadership of the various community team managers and service providers supporting people with learning disabilities. This variety in practice and way of working is not unique to learning disability service provision but the constraints that can be imposed by different ways of working need to be considered. Examples are presented to show that where attitudes and leadership are less strong, obstacles are allowed to hinder the progress of health action plans. In addition it is evident that similar to the practice identified locally in Rochdale, some community nurses do not see health action plans as their responsibility whilst others clearly do.

As discussed in the literature review leadership theories are numerous and complex. Lewin's (1951) autocratic, democratic and laissez-faire leadership styles were considered for the analysis of data, but Greig's (2003) approach to understanding of change and leadership within the context of learning disability services is used for several reasons. Firstly it is one of the few concepts of change to be developed that describes the affects of change and attitude to change within the learning disability context. Greig's approach suggests that people's attitudes to

change can impact positively or negatively on the change in question. Secondly, it relates to the issues of Valuing People (2001a) on which this research is based. Finally, in considering the above reasons, it helped me to make sense of and organise the data. Greig suggested that there were three types of leadership styles in implementing change:

1) Removers- removing the responsibility for change and ascribing responsibility for the removal of obstacles to change to others. This group believes that it is not possible to deliver change until someone else removes all the obstacles

2) Containers where local implementation strategies remain contained within previous cultures and practices that existed for example activity takes place but it is just another name for things that they have done for years

3) Developers /innovators where it is recognised that new ways of working are required where people with learning disabilities and families are leading the change. New partnerships are made and problems are addressed by asking what new and different approaches can be used

I will now discuss how the evidence fits with these theories. Although the number of contributions in this part of the research are small they do include response from all Valuing People regions and a variety of disciplines have been involved in the completion of the questionnaires ranging from nurses of various job roles and levels of experience(57%) to care managers and support workers. Furthermore this research confirmed that like Rochdale, community team for learning disabilities have developed in various ways across the country. The variety of responses received fits within the adapted typology suggested by Greig.

**Removers**

The examples identified below demonstrate how some respondents can put obstacles in the way of achieving change. One respondent who had throughout the questionnaire made reference to lack of support and progress, despite demonstrating some evidence of health action planning commented that ;

> *I am unable to work effectively with my client group due to general*
> *lack of support. Health care is secondary to mental health at this*
> *present time* (Respondent 111 nurse residential)

Although again some work had been completed in developing health action plans respondent 36 a practice advisor suggested that progress was poor for reasons outside of their control

> *I feel that the advice given via Valuing People and the accompanying*
> *guidance notes was confusing and lacking in direction. I don't think the*
> *concepts of health facilitation and health action plans was adequately*
> *piloted before being introduced*

And continued by stating that:

> *The partnership board gave very little attention to health, tending to*
> *focus on the other areas of Valuing People in the belief that*
> *primary care services would just get on with providing for this*
> *client group*

These respondents cite the issues that prevent them from successfully implementing health action plans rather than looking at ways to overcome the problems. They appear satisfied to assign "blame" to others for why health action plans did not progress rather than looking at their role within this. Fortunately, very few examples were identified within the study, with the majority of respondents identifying more positive examples of practice.

## Containers

This group of respondents demonstrated how previous practices had continued. Some examples are given below. One example of this is given by a nurse health facilitator, when discussing who is to act as a health facilitator for the individual, identified that "The health action plan states it should be the choice of the individual but often it is the key worker if the person is in residential or supported living" (Respondent 103).

In this case the responsibility has been given to the key workers, who oversee all aspects of the individuals care plan, as this is what has always been done, without any consultation with the person about who their choice of health facilitator would be. This in itself can prove detrimental. As discussed further in the health facilitator's focus group findings in chapter 6,

one key worker took responsibility for an individual's care, not sharing any information with other staff. Consequently when this staff went off sick no information was documented anywhere about the person with learning disabilities, so staff had to start their health action plan again. Although this example was the only one raised through out the research study it emphasises the importance of accurate documentation in the health action plan process.

When asking if health screening took place to inform the health action plan respondent 20 a nurse residential commented that "No screening took place prior to health action plan because health is monitored closely and regularly" This resulted in the usual practices continuing. It is not possible to determine if this resulted in any less health improvements, but it does demonstrate that some staff continue to work as before without considering alternative methods of working. Indeed I concur with respondent 41 (community nurse) and 56 (matron vulnerable adults) who identified that health screening

> *Is an integral part of the health action plan as we cannot determine*
> *someone's health needs without them receiving a health check.*
> (Respondent 41)

And the matron added that;

> *All health action plans begin with a full health assessment in primary*
> *care to ensure that needs are identified by a qualified primary care*
> *health professional* (Respondent 56)

Indeed, further analysis of the data concluded that more health needs are identified where people had health screening as part of the health action plan than if they did not. However this group did not actively appear to go out and seek the health screening to explore if this made any difference but were satisfied to continue working as they had before.

Whilst discussing how many health action plans they had completed respondent 55 a clinical service manager commented that their input into health action plans was;

> *Sporadic-as specialist support team only raises profile/offer health*
> *action plan not maintain facilitation as close case once episode of*
> *care complete we discharge off case load*(respondent 55*)*

Again this practice follows what already exists, in that once people (cases) are referred to the community team and specific issues are addressed, cases are closed and the nurses move on to the next case. What this example shows is that it is not always possible to discharge people

when implementing health action plans and that some thought and consideration needs to be given into passing over the role of health facilitator to an appropriate person to support the person with learning disabilities when the nurse withdraws their service.

## Developers

Encouragingly many areas demonstrated the developer typology in developing the health action planning process and appear to have made considerable progress in introducing health action plans. Some of these examples are discussed below to show what can and has been achieved by developing new ways of working. Even though this research was completed before the Darzi report(2008) these health facilitators were already developing ways of working using the Darzi principles of putting the patient at the centre of care, and developing collaborative and innovative ways of delivering care and services. To inform the reader they are placed in similar themes.

## Developing the health action plan

An example of this is the development of the health action plan. Although 83% of respondents suggested that the health action plan design was led by the learning disability services in most cases it appears that a variety of people were involved in the process with one respondent identifying that a "New team (was) tasked with introduction and development of health action plans" (Respondent 53 community nurse) And respondent 47 (nurse health facilitator) commented that

> *Part of role (is) to encourage people to act as health facilitators and*
> *develop health action plans I help school nurses with final year*
> *students, comprehensive, assessment/health check/plan to*
> *maintain /improve health* (respondent 47)

Not all areas indicated this. One respondent clearly demonstrated the 'constraint' typology in carrying on practice as usual by responding that "Trust learning disabilities service and local authority developed independently of each other" (Respondent 64 line manager residential). This response mirrors the research findings of Mir (2007) where individual services in Leeds developed health action plans with no co involvement of each other.

However, respondent 75 a community nurse offers the following comment;

> *There are strategic health facilitators, however is responsibility of*
> *all those involved in the persons care and most importantly*
> *the person themselves in acting as their own health facilitator* (respondent 75)

This concept again puts the principles of Valuing People (2001a) and Valuing People Now (DOH 2009a) at the core in supporting people with learning disabilities to have more say and choice in their lives and the services that they receive and truly encompasses the principles of changing the way that services are developed with the people who are receiving the service at the core of these changes.

In discussing the development of health action plans in the absence of any provided template one respondent demonstrated how they had taken the initiative to develop new ways of working commenting that ;

> *A group of interested community nurses developed a proposal which we*
> *presented to the Assistant director for LD. She took the proposal and created*
> *the Health Care Coordinator Role (HCC) one of which I currently hold. As*
> *HCC we then wrote the process and piloted it. We are now currently working*
> *on rolling out our plan* Respondent 96 (nurse health facilitator)

This innovative person centred way of working was again demonstrated by respondent 101 a community nurse when discussing the health action planning process. Not only had they worked very hard to develop individual plan relevant to each person by

> *Encouraging residential services (with a lot of support) to create a health*
> *action plan meaningful to each individual, as a result some service users*
> *have a book, some have created a PowerPoint presentation that is interesting*
> *and informative, and some will have a collection of objects of reference/story*
> *bag to enable them to understand as much as possible about their health or health*
> *appointments* (respondent 101)

But they had worked with primary care to adapt the health screening tool to then accommodate this process. Another example of this process was given by respondent 55 a clinical service manager supplied information that the GP had taken on the development of a screening tool that then was shared across the PCT to support the process;

> *In pilot one doctor developed screening tool - used as example in*
> *recently produced GP toolkit to have all relevant information to hand*
> *for primary care sector to initiate health screening and health action*
> *plan process* (Respondent 55)

## Collaborative Practice

Another example of this collaborative practice was shown by respondent 31 who commented that;

> *It's the responsibility of the carer to make the written info accessible to the individual following advice from the practice nurse. It is not a massive document produced in isolation it is specific to that person's health needs. It is owned by primary care and the individual* (respondent 31)

Respondent 103 nurse health facilitator also identified many issues that were hindering the progress of health action plans that were outside of their control but commented that

> *Unfortunately this has made it very difficult to progress greatly but I am determined to keep battling on and raising awareness of the health needs and hope that the audit will back up the known evidence so that people will recognise the value of this role* (respondent 103)

This commitment to continue to challenge obstacles is one of the factors that differentiate the container and developer typology. In this case the respondent has identified issues that hinder progress but instead of using these constraints to stop progress they have found an alternative way to move things foreword.

In discussing the monitoring and review of health action plans, respondent 92 nurse health facilitator identified collaborative development with provider services by commenting that the review was carried out by;

> *Community nurses and professional care providers for 'their' users and the health facilitation team for the remainder of population. Service user are reviewed annually by Health and Social Care facilitators with the team and problems reported via them and actioned accordingly* (respondent 92)

And in identifying who acts as health facilitator, respondent 95 another nurse health facilitator described how they worked with the individual circumstances as;

> *We train anyone wanting to be a facilitator, mainly paid carers. CLDN (community learning disability nurses) will provide specialist advice on health action plans for people with complex needs and will initiate plans for people but will identify someone in the circle of support to take on the facilitation role long term. In some instances the CLDN assistant will lead on plans* (respondent 95)

The concept of 'people within the circle of support' taking on the role of health facilitator is taken one stage further by respondent 79 nurse health facilitator when discussing how health facilitators are chosen in commenting that:

> *Whoever is best placed and chosen by the person to give required support for each health action e.g. health care assistant for supporting at out patients appointment, community support assistant assisting with healthy eating programme, or parent offering foot care*( respondent 79)

This is a truly innovative way of working, which looks at the skills of all involved in the persons care but with constraints on service it is difficult to see if this could be replicated across other areas. Indeed, this was the only comment of this kind received. However, in discussion with community nursing teams, and in reviewing the information that appears on the various learning disability health networks there is evidence that community nursing teams are developing health promotion type training/awareness events for people with learning disabilities so the concept is possible to achieve with some thought and planning by services.

It is suggested that these awareness sessions could be extended to support staff so that they too can encourage healthy life styles with the people with learning disabilities that they are supporting to develop health action plans. Indeed, several examples where training in various health issues did result in improved health gains have been discussed in the literature review in chapter 3 (Pointu & Cole 2005, Costello et al 2007). It is not a huge leap therefore to consider that this could be extended to include health promotion type issues. Training will be discussed later in the chapter.

## Community Nurse Involvement.

One of the key issues raised by this research is the conflicting opinions of community nurses as to their remit and involvement in health action plans. The responses fit with Greig's typology (2003) and demonstrated how attitudes to health action plans can be governed by the level of support and conflicting priorities of the managers of the community nurse teams providing health action plan support. Furthermore this study has identified that in areas where health facilitators were in specific roles regarding health action plans considerably more plans had been completed, with one health facilitator completing 300 plans as part of the process.

This is discussed further referring to the container and developer typologies to demonstrate how conflicting attitudes have either hindered or helped with the provision of health action plans.

## Containers

Several examples are given, from community nurses, who work within a very tight remit to continue to do what they have always done, without any apparent regard for individuals who do not fit the existing criteria. One community nurse identified a very clear strategy whereby;

> *We do not see community nurses as first port of call as needing to be involved in everyone's health action plan. Our health strategy identifies priority groups for the community team to be involved or lead the development of any health action plan for those going through a period of transition (and not in receipt of a commissioned service.* (Respondent 42)

And another community nurse remarked that;

> *The community team does not facilitate the health action plan, only coordinate the process. The facilitator is normally identified from the service users day to day support team (*Respondent 35)

Finally a third community nurse identified that;

> *Community nurses who have an open episode of care for a person, who does not have anyone else to work as their facilitator, will automatically, become their health facilitator.* (Respondent 104)

## Developers

Other community nurses took a different view with respondent 112 commenting that "Each open case had a health action plan therefore I would estimate 30, this includes the cases closed who had a health action plan". This example does not clarify what happens to the plan and who monitors it once the case is closed. However respondent 95 nurse health facilitator gave some clarity on this in their response

> *Community learning disability nurses will provide specialist advice on health action plans for people with complex needs and will initiate plans for people but will identify someone in the circle of support to take on the facilitation role long term. In some instances the CLDN assistant will lead on plans* (respondent 95)

Furthermore a community nurse clarified that they had given training to residential services and that they were now in the process of "Checking with all homes to ensure the health action plans are being completed and they have a health facilitator" (Respondent 104) This is a change to the usual way of practicing and demonstrates how the team had developed to look at inclusive ways of working to support other health facilitators. Finally a community nurse, respondent 101 did not see health facilitation as their long term role and one suggested that they would initially provide support to people;

> *Living independently or with family, health facilitator will initially*
> *be community LD nurse or Practice Nurse, but we would be looking*
> *to pass on responsibility to a person of the service user's choice*
> *and that in residential services health facilitator is usually key worker*
> (respondent 101)

## Involvement of primary care services in the health action plan

In reviewing the outcome of question 24, respondents identified that there had been involvement in the health action plan from 46% of practice nurses and 56% of GPs. One flaw in this study is that it does not identify exactly what that level of involvement was. Indeed, in discussing involvement in the health facilitator focus group one group showed a higher more explicit involvement from primary care staff (writing in the plan) than the other. Furthermore participants in the service user focus group identified that some GPs did not even acknowledge the plan.

However whilst it could be argued that this involvement meant that a large number of respondents had no involvement by these professionals in the plan, the level of involvement is quite high. In comparison a pilot study by Eccott & Webster (2006) of 94 people with learning disabilities who had a health action plan identified that only 7% of respondents had received help from primary care professionals when completing the plan.

In addition, although 70% of respondents had taken their plan with them only 10% identified that professionals had written in the plan, with 5% identifying that professionals had refused to provide information for the health action plan. Whilst this questionnaire did not specifically

ask that question, examples of professional's writing in the health action plan were given by the health facilitator's focus group. Similarly, Kelly & Davies (2008) also identified a need for wider engagement of primary health care involvement in health action planning in their audit. These findings demonstrate then that in some areas work needs to be undertaken with primary care colleagues to improve the use of the health action plan.

## Health screening

The literature review identified that health screening is an important factor in determining people with learning disabilities health needs. This research study identified that there were 72 % of respondents who identified that health screening took place to inform the health action plan. This screening formed two distinct categories;

1) Screening by a primary care professional
2) Screening by a learning disability nurse using a variety of specifically designed screening tools

One nurse health facilitator HFQ respondent felt that involvement of the primary care team was crucial as;

> *This (screening) is an integral part of health action plan.*
> *Primary care staff will not be responsible for health action plans*
> *that do not originate from their staff. They cannot be requested to sign*
> *off the health action plan when they've had no involvement*
> (Respondent 31)

An example was also given where one GP developed a toolkit to use in the process. Where health screening had been undertaken by the learning disability nurses, some areas had developed their own screening tools whilst others used ones that had been developed and were recognized within the learning disability community such as the OK health check. An example of this was given by respondent 98

> *In some of the health action plans completed it (OK health check)*
> *was the main basis Also due to the Head to Toe Health Screen; we do*
> *this with nearly every person who is referred to our Community*
> *Nursing team* (respondent 98)

However not all community nurses facilitated health checks indeed one community nurse HFQ responded that in supported accommodation the "Responsibility has been left to the carers to utilize GP services to complete the health screening" Respondent 104. One respondent identified that screening had not taken place prior to the health action plan commencing but commented that "The health action plan has identified that health screening is necessary". They added that screening will now be incorporated into the process. However one community nurse respondent 77 identified that

> *We are currently working with our primary care teams to offer health checks*
> *as part of the health action plan but as yet this is not standard practice*
> *due to financial constraints*( respondent 77)

During discussions at regional networks the issue of finances has been raised as an issue.

Health screening is an important part of the health action plan process. However, not all people with learning disabilities were offered a health screen. This remains an issue. Whilst writing up this research and following on from the recommendations of the Michael report (DOH 2008) a 2 year Direct Enhanced Service (DES) was introduced for people with learning disabilities at a cost of £22million per year. This DES relates to people with a moderate/severe disability.  It does not include people with a mild learning disability. This group are often the invisible population, unknown to services but it could be argued are actually more at risk because they do not have the support mechanisms in place.

The pre-requisites for the DES are:

I. Practices will have liaised with the Local Authority to share and collate information to identify people with moderate to severe learning disabilities on their register who are of 18 years of age and over.

II. The practice (at least one GP, the practice nurse and practice manager) will be expected to have attended a multi-professional education session. They may also liaise with the community learning disability team for support.

Details of the DES

1) Practices will be expected to provide an annual health check for patients on the Local Authority learning disability register. The Cardiff health check protocol is recommended or a locally agreed protocol

2) A list of requirements were listed to be included in this check

3) Health checks should integrate with the patient's personal health record or Health Action Plan. Where possible and with consent of the individual, carers and support staff should be included in the consultation. Practitioners should liaise with appropriate support services

However this process remains voluntary so not all GP practices will take up this initiative, therefore some people with learning disabilities will continue to be penalized by the post code lottery, depending on where they live. There was a vast improvement in the number of health checks reported between 2008/9 and 2009/10 of 103%. However, Emerson and Glover (2010) reported that the range of health screening completed ranged from 30% in the South East to 55% in the South West. This demonstrates that post code lottery remains an issue. Whilst this increase is positive more could have been achieved if screening/health checks had been made mandatory.

The DES includes liaison with the CTLD as part of the process. It also places the responsibility for the screening process on primary care whilst offering the opportunity for CTLD involvement as pat of the process. This is a positive step, as whilst health screening took place, in some cases the screening was completed by a learning disability nurse. From the evidence some nurses implied that this was the only way that screening could happen as they were not able to engage primary care in the process. As a practitioner, I can relate to this and understand the reasons why this happened. However, if these nurses continue to undertake this screening, primary care can continue to absolve responsibility for the patient's health and nothing changes. It is to be hoped that with the advent of the DES this situation has changed and it would be interesting to determine if this has happened in future research

These findings are similar to a study by Aronow & Hahn (2005) conducted in America. Their study reported the findings of a pilot RCT whereby a group of 201 people with learning disabilities were selected to undergo a comprehensive series of health screening tests. These

screening tests were already used within the general aging population in America, to determine health risks and strengths for the individual but were adapted for use with this group of participants. All participants underwent baseline screening and were then randomized in to 2 groups. Both groups received a comprehensive report and suggestions for health improvement measures. Group one also had the facilities of an advance practice nurse who would visit up to 3 times to monitor and offer advice and support to the individual as well as carers to improve their health. Aronow and Hahn concluded that health improvements had occurred in both groups and acknowledged that further studies were needed to determine if one method had better outcomes that the other. This study then reiterates the findings of Aronow and Hahn in that although health facilitators with varying skills and experience conducted health action plans health improvements were made where screening had taken place and that the screening was more important than the experience of the health facilitator.

Finally, the need to inform health action plans with health checks is confirmed and reiterated in Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance;

> *Health checks will only have their full impact if they encompass health action planning and if people with learning disabilities can then access the services they need to maintain and improve their health. This requires good communication and partnership working across a range of services, including primary care, local government, public health, mental health services, and acute care and specialist services* (DOH 2009b) page 5

It would be interesting if this research was replicated or followed up to investigate whether this had in fact made a difference to the incidence of health screening and consequently the incidence of health needs gains reported.

## Integrated findings

As discussed in the introduction throughout the research analysis it became apparent that several themes were interrelated to all three strands of the research process. These are now discussed.

## Leadership

Reviewing the findings using Greig's typology or approach to leadership and change helped to identify that leadership can influence the implementation of health action plans. Even though little or no guidance was given at the beginning of the process, "developer" type managers went on to move the process forward, whilst other nursing teams as presented earlier, put obstacles in the way to hinder progress. Yet this leadership can be shown at many levels.

On a local level one group of staff developed their proposals and the management took it forward:

> *A group of interested community nurses developed a proposal which we presented to the Assistant director for LD. She took the proposal and created the Health Care Coordinator Roles one of which I currently hold. As HCC we then wrote the process and piloted it. We are now currently working on rolling out our plan* (Respondent 96 nurse health facilitator)

Whilst Respondent 56, a community matron for vulnerable adults, suggested that the

> *PCT has consistently supported service improvement for people with learning disabilities and ensures that a high profile is maintained within the organisation* (Respondent 56)

Furthermore, respondent 40 another nurse health facilitator found the "Partnership board and PEC (PCT board) both interested and supportive". However, where this leadership did not appear to be in place respondents commented that they felt, isolated, had no lead for health action planning process, were unsupported and had difficulty getting people on board. Respondent 36 a practice advisor, suggested that "The partnership board gave very little attention to health, tending to focus on the other areas of Valuing People in the belief that primary care services would just get on with it" And Respondent 58 a community nurse reported that;

> *We don't have a health care facilitator. The post holder left after one year and the post has been frozen (18 months).There is no strategic planning or monitoring and there are no funds to produce health action plans* (Respondent 58)

Issues were also identified around leadership and guidance by both focus groups identifying that areas had not fully grasped the concept of supporting people with health action plans even though managers should have informed them in the first instance.

During the HFFG Respondent 4 raised the issue that in order for goals to happen it was important that "A person was identified – for items on the Action Plan" And yet this was a fundamental part of the plan. As such aspects of the plan were not being monitored or followed, but this was easily addressed.

In addition during the SUFG another example was given when Respondent 4 expressed concern about the health action plan in that "I was given one and I was not asked if I wanted one". Again as previously discussed misinformation about the process was not being addressed by management. The issues regarding leadership on a national level were also raised. Respondent 36 a practice advisor added that;

> *I feel that the advice given via Valuing People and the accompanying guidance notes was confusing and lacking in direction. I don't think the concepts of health facilitation and health action planning was adequately piloted before being introduced* (Respondent 36)

Lack of national guidance and direction appeared to be a common theme identified by respondents. The comments below cover the general consensus of opinion. Respondent 29, a health facilitator not a nurse who reiterated several times that guidance, is needed concluded by commenting that:

> *I do feel that the way forward is through targets and by ensuring primary care carry out annual health checks-however this needs a strong lead at the Department of Health who can cascade information and make it happen. It is often felt that the Valuing People support teams do not have enough clout or cohesion to achieve collective aims.* (Respondent 29)

Respondent 101 a community nurse concurred with this sentiment adding that the;

> *DOH could have done a lot more to support health improvement initiatives for people with learning disabilities. Lack of centralised funding speaks volumes for what central government really think of Valuing People* (Respondent 101)

These leadership issues need to be addressed to ensure equity of practice across services.

## Training and knowledge

One key issue identified within this research was the issue of training. This is not surprising as training and knowledge is a key issue affecting access to health services for people with learning disabilities as discussed within chapter two.

It is interesting to note then that of the 117 responses to the health facilitator questionnaire (HFQ) training was offered to only 77% of respondents prior to commencing health action plans. These respondents were a mix of disciplines:

- 57% (66) were from a nursing background
- 12 % (14) of these nurses worked in supported living services
- 11% were support workers
- 17% were listed as line managers

In addition 56% of respondents identified that they had an operational, i.e. hands on role in completing health action plans, with 33% identifying that they had both a hands on and strategic role meaning that 22% of respondents who completed health action plans at an operational level had received no training prior to introducing and completing health action plans.

Training came in a variety of different formats, but where staff received training 91% of staff had found it useful. There were a number of areas where considerable and on going training was available to all staff. Some respondents were not as fortunate with respondent's negative comments" including that training was;

- Limited to professional carers
- Nurses not being offered training at all or examples of just being left to get on with it
- No we have used internet and networks that are available. Use of research and literature
- No training for health facilitators or assistants. One nurse in each patch had role changed with training between us
- Given health action plans and CD ROM and left to get on with it- no formal training

The Department of health (2001a) advocated that

> *Providers of support in social settings have a responsibility to ensure*
> *that an individual's general health needs are met by developing links*
> *with health professionals, promoting staff competence in basic health*
> *issues and implementing health promotion initiatives* (page 62).

Yet only 70 % of health facilitator focus group respondents (HFFG) who worked in supported living services had received training with 10% missing training due to illness. Some questionnaire respondents matched health facilitator focus group experience in that managers were trained and expected to cascade this information to staff. Respondents from the HFFG suggested that where staff had not received training an example of a completed plan to use for reference would have been useful on several levels with participant 1 commenting that

> *As there are a few areas in a health action plan that is slightly, can*
> *be open to interpretation and I think it would have been helpful possibly,*
> *- to look at a couple of other health action plans that people have done*
> *and sort of try to look at what's best in there and the best sort of format*
> (Participant 1)

And Participant 2 concurred stating that without training

> *We (them and the staff ) haven't put in what needs to be put in, what doesn't and*
> *there is quite a lot of empty pages. We would have really benefited from looking at*
> *one (a completed health action plan)* (Participant 2)

However, during the HFFG managers identified that support staff should receive training regarding health action plans to help them to understand the reason for the health action plan and the benefits from having one and that participant 3 felt "Often they (staff) don't put in enough detail".

Within this area of supported living the support staff were involved in the day to day completion of the health action plan, with the line manager/health facilitators retaining overall responsibility for the plan. This meant that if the support staff attended an appointment with the individual they would then complete all documentation relating to that both within the health action plan and the persons home environment. This was also raised with the HFQ group where respondents identified that training was offered to carers and families supporting health action plans.

One community nurse, when answering question 9 also identified that health action plans have "Been introduced via an agreed training structure for paid staff. Unpaid carers do not have access yet to the structured training" (Respondent 42).

Some respondents commented that this training was only delivered to certain groups of people. One respondent identified that training was delivered: "To paid staff who are commissioned service providers" (Respondent 42. It is imperative, therefore that staff are informed as to what they are doing and why they are doing it. A further example of this was given by participant 2 who commented that the use of a new mental health related form within the health action plan had caused staff to

*Think about how somebody acts… at certain times of year and things that they wouldn't even think about before* (participant 2)

The HFFG did not feel that they were best placed to deliver this training but that it should come from the Learning Disability nurses who had introduced the health action planning concept. They suggested this is because

*Otherwise you're still looking at ones people's interpretation of that information aren't you. You're still looking at what my idea is, or what an individual manager's idea is because of that.* (participant 2)

Participant 3 suggested that the training should be delivered by an "outsider" to the group as this would "Emphasize its importance" and that people who audit the health action plans should give the training as they know what is needed. Indeed this method of training was given by some HFQ respondents to good effect. Respondent 102 a community nurse identified that they gave "Awareness training session, then more specific training, for example to staff teams"

During further debate amongst participants of the focus groups as to how training could be delivered, the majority of participants suggested that attending team meetings would be a good idea. This would give staff the chance to ask questions and relate information to their individual service users.

Valuing People (Department of Health 2001a) suggested that social care staff and carers need to gain "Competence in basic health issues and implementing health promotion initiatives" (page 62).Yet there continues to be a plethora of information that suggests that carers have not

gained this knowledge or competency to date (Matthews 2005, Powrie 2003, Hogg 2001, Beange et al 1995 ). I would suggest that the government missed the ideal opportunity to influence this change when they failed to include a mandatory health module of National Vocational Qualification Level 2 in Special Needs and a mandatory health aspect to The Learning Disability Framework. They missed a further opportunity to do this in the refreshed document Valuing People Now (2009a), as whilst it advocated that

> *The workforces across services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the Valuing People Now priorities for all people with learning disabilities*

It did not go far enough in determining how this could be achieved. Michael (2008) recommended training for both post and undergraduate staff regarding the health needs of people with learning disabilities. The National Minimum standards, of Care Homes for adults, (standard 19), requires annual health checks for service users. If care staff do not receive training to understand the importance of these health checks how can it be ensured that people with learning disabilities are receiving the care that they are entitled to? One HFQ nurse health facilitator respondent took this one stage further suggesting that "I do not feel that all services and carers recognize that they have a role to play in supporting and maintaining health" Respondent 47. This corresponds with the HFFG comments that staff did not fully understand the rationale behind Health Action Planning and that training "Will get more of the staff on board" (participant 1).

The use of appropriate training to help carers understand health related issues has been known to demonstrate an increase in carers' knowledge (Boland 2008, Costello et al 2007 Pointu and Cole 2005). Some HFQ respondents identified that they used an holistic approach when training staff about health action plans with one respondent giving a very detailed explanation of the training provided:

> *We run a monthly two day workshop looking at concepts of health in general, health needs pertaining to gender, age, ethnicity, economic status, health needs pertaining specifically to people with learning disabilities. Purposes of HAP, who should be involved in HAP, what HAP should contain how to start (Opportunity for 1:1 discussion with learning disability Nurse, and chance for self-directed learning around specific syndrome or health issues). How to create an accessible plan (half day facilitated by learning disability nurse and/or speech and language therapist) How to use primary care services more successfully*
> ( Respondent 101)

Whilst another HFQ identified that they gave "Awareness training session then more specific training for example to staff teams" Respondent 102 community nurse This matched the suggestion of respondent 2 from the HFFG: "I think that would be a really good idea to access people's team meetings and house meetings- and speak to all the staff." What is evident then is that a structured approach to training has proven to be of benefit to people acting as health facilitators.

Informing staff as a group has proven to be beneficial. Temple and Walkley (2007) discussed that staff identify time factors as reasons why people with learning disabilities do not undertake physical activity. Using this as a study staff could explore both the importance of setting agreed, realistic, achievable goals within the health action plan and their part in working to help people with learning disabilities to achieve their goals, and also bring in the elements of health promotion as discussed above.

Indeed some responses from this study have cited an increase in knowledge as a benefit of the health action planning process for all staff. Participant 2 from the HFFG commented that the plan had been useful in that they were:

> *Learning things as well about the tenants that I didn't know because*
> *I'm going in sort of with fresh eyes asking questions about them*
> (Participant 2)

And Participant 5 in the 2nd HFFG added that;

> *Staff gains knowledge of - past illness/treatment - medication –*
> *emergencies (information for use by unfamiliar staff) – hospital*
> *(appointments) – (identifying individual) support needs* (Participant 5)

An increased awareness was also identified by respondent 67, line manager residential from the HFQ group who remarked upon "Increased awareness of health issues and services available".

And respondent 96 nurse health facilitator from the HFQ commented that not only had it increased awareness but that it;

> *Helped to baseline current needs, has raised awareness and had a*
> *positive impact on communication between primary care staff and*
> *people with learning disability, their carers and other health and*
> *social care professionals* (respondent 96)

Whilst participant 3 HFFG added that there was "More knowledge by carers' and team leaders through learning with health action plan"

One line manager residential from the HFQ, took this further suggesting additional benefit to awareness by commenting that;

> *Potentially raised awareness of services/screening to "carers"/clients*
> *which previously they may not have considered accessing therefore health*
> *should improve* (Respondent 108)

One respondent from HFQ had an innovative way to develop this training for families;

> *Plans are in place to develop a DVD about plans for parents to give them*
> *an overview of what a plan is. In addition supported training sessions are*
> *being developed and delivered to small groups of parents*
> (Respondent 95 nurse health facilitator)

Finally one of the HFQ respondents suggested that there were additional benefits for people with learning disabilities in that "Has identified new needs. Has increased the awareness of people with learning disability" (Respondent 103 nurse health facilitator)

However, this increase in knowledge alone is not enough. The need to set agreed, realistic, achievable goals was highlighted by one member of the focus group for people with learning disabilities (SUFG). They said they were happy "Part of the time but that they had some issues with actions that were set as they did not always agree with them" Respondent 1. These specifically related to diet and were a common theme from this individual throughout the focus group reinforcing that goals needed to be agreed as this individual was often in conflict with the support team over their diet and what they felt were restrictions on their choices.

What is apparent from the results of this study is that the quality and depth of training varied across the country. Indeed not all health facilitators were offered training before taking on the

role and staff, including learning disability nurses, felt that this hindered the introduction of health action plans. One community nurse HFQ suggested that the issue went further than training in that;

> *As community nurses we were provided with the health action plan files but we have not had any training about completing the health action plan but most importantly we have not had any guidance on what to do with the health action plans once completed* (Respondent 104)

Issues around appropriate training for health facilitators was also identified in the study of Health Facilitation and Learning Disability by Mir et al 2007. They gave several examples of issues related to training regarding health facilitation and health action planning.

Firstly some learning disability teams had offered training to health facilitators and this had gone down well. Some community teams however identified that they had received no training in the role and were unsure themselves; leaving one manager to comment that

> *There needs to be training……so that they don't overstep the mark, but they actually enable people to access advice rather than providing it themselves* (page 83)

Finally Mir et al identified areas that once the community team withdrew there had been a lack of training and identification of health facilitators to take over the role from the nurses. The report concluded that resources must be provided to

- review skills and knowledge within community teams to ensure they are equipped to carry out health facilitation activity
- to ensure training for health facilitators
- to raise awareness of mainstream services

Locally, practice matched Mir et al in that with the reconfiguration of services there is no longer a health team to provide training and at present there is no health facilitation training in practice for new health facilitators or within supported living services for support staff.

From the survey there was a mixed response, with some areas at the time of the study having monthly workshops, on line training packs and one area had developed an organizational

process around training. It is evident that this is a key area to consider in reviewing how the health action plan process moves forward, both at a local and national level.

Whilst the style and delivery of training varied the benefits have demonstrated that training in the use of health action plans, rationale of process and health benefits is instrumental in the health action plan process, proving of benefit to both the health facilitator and person with learning disabilities alike. On a local level, services need to identify how this training is to be delivered to ensure that the health action plan process is fully understood so that the people they support benefit from their health action plan and improvements to their health.

## How health facilitators were chosen

This question brought mixed but some similar responses from all study groups. Answers from the HFQ indicated that 19.1% (22/115) of respondents indicated that unpaid carers or parents were health facilitators. This high number again reiterates the need for adequate training for all involved in the health action plan process. This was not replicated by the HFFG as all health action plans were led by paid staff, in a managerial role who had taken on the health facilitator role as part of their job, with the exception of one respondent who, although a paid member of staff had volunteered.

This theme of being service or paid staff led was consistent with responses from the HFQ which identified two themes of comments to support this.

Firstly some nurses suggested that health facilitation was part of their role "Those referred to the community team for a health facilitator will be given an allocated community nurse and they will fulfil this role" (respondent 97).Whilst other nurses saw it as their role but only where ;

> *Community nurses who have an open episode of care for a person, who*
> *does not have anyone else to work as their facilitator, will automatically,*
> *become their health facilitator*( Respondent 104 community nurse)

However this respondent also added that;

> *All residential services were given training and the responsibility fell on them to provide a health facilitator, this is usually the persons "key worker"*

Other nurses agreed with this concept and felt quite strongly that it was not part of their role and that the responsibility lay with the paid support services to take on the health facilitator role;

> *Community team does not facilitate the health action plan only co-ordinate process. The facilitator is normally identified from service user's day support team (*Respondent 35 community nurse)

Indeed one community nurse summed this up as;

> *We do not see community nurses as first port of call as needing to be involved in everyone's health action plan. Our health strategy identifies priority groups for the community team to be involved or lead the development of any health action plan for those going through a period of transition(and not in receipt of a commissioned service).It is everyone's role(who cares or supports a person) to develop a health action plan with the individual* (Respondent 42)

In some areas community nurses would only provide support initially to people who were;

> *Living independently or with family, health facilitator will initially be community learning disability nurse or Practice Nurse, but we would be looking to pass on responsibility to a person of the service user's choice" and that" in residential services health facilitator is usually key worker* (Respondent 101)

This concept would fit with Valuing People (DOH 2001a) recommendations that learning disability nurses should be a specialist in their field and act as a point of reference to others. They would support the initial plan and then pass it on, remaining available for support if required.

Other HFQ agreed with the HFFG concept that health action plan should be service led commenting that "All residential services were given training and the responsibility fell on them to provide a health facilitator, this is usually the persons" key worker"

In summary then one HFQ nurse health facilitator respondent suggested that;

> *In main- health facilitators for residential services*
> *keyworkers, health facilitators for day centres staff*
> *at day centre, those who lived with carers were staff*
> *from community nursing team* (Respondent 49)

However despite the concept of health action plans being person centred (Sanderson et al 1997) only 65/115 (56.5%) HFQ respondents suggested that the health facilitator was chosen by the person with a learning disability, with none of the HFFG identifying that the person with a learning disability had chosen their own health facilitator. Furthermore, from the SUFG Respondent 4 made a point of commenting that they were "Given one (health action plan) and I was not asked if I wanted one". As this respondent was quite able and could speak up for themselves they felt that they did not need a health action plan and that: "Staff had enough to do without more paperwork"

Obviously imposing a health action plan on an individual is not appropriate and goes against the concept of Valuing People (2001a) which suggested that people should be offered a health action plan but it is their choice if they have one. Again this issue could be addressed if training was delivered to all health facilitators before commencing the process.
What is evident from these findings is that there are a variety of methods around the country that health facilitators are chosen, which some times move away from the person centred approach in that they are service led, rather than individual led. Whether that is by the attitudes and experiences of service providers or the various community learning disability teams reflects on the process followed "Community team does not facilitate the health action plan only co-ordinate process". Respondent35 community nurse

This in itself is confusing and again suggests a lack of guidance and direction which could be argued results in the "post code" lottery approach to health facilitation in various areas. This conflict is not acceptable and it would be interesting if this mixed approach is still evident following Darzis' recommendations relating to person centered quality care.

However, one respondent HFQ had grasped the concept of the health action plan and individual choice in commenting that the;

> *Individual case looked at. Health facilitation to be actioned by whoever people with learning disabilities wishes. Guidance /support is then offered by the community nursing team/and/or health facilitator* (respondent 44)

Whilst this may be the ideal scenario, in order to be realistic several issues need to be considered. For example if there is no family involvement or close circle of friends involved with the person in receipt of supported living services then the role of health facilitator will fall to staff. However, it can still be possible for the individual to choose which member of staff they wish to be their facilitator rather than the services dictate that it be their key worker.

An example of this was given by participant 1 in the SUFG who in discussing whether they were happy with their plan commented that "Some people help with the health action plan more than others" And was willing to take time and listen to them. It would be ideal then if this individual had chosen a health facilitator who they felt listened to them and who could support them through the process.

Conversely it should also be considered who is most inappropriate to act as health facilitator. Although some people may still live with their families they may not choose to have a family member acting on their behalf. Participant 4 SUFG gave a prime example of this in commenting "(That they) definitely did not want their father involved in the plan". Fortunately this person was receiving support from services so had an alternative choice available to act as their health facilitator; but this may not be the case for some people. The fact that people with learning disabilities may not want their family to be their health facilitator needs to be considered when developing local health action plan processes so that alternatives, including advocates can be considered.

## Benefits from having health action plans

Responses from all research groups indicated that the health action plan did make a difference for people with learning disabilities and that there were many benefits to the health action plan process. These benefits are discussed below.

When asked, 72 % of HFQ respondents identified that screening had taken place prior to the health action plan .When asked if health gains had been identified as a result of the health action plan 112/117 HFQ people responded. Of these 87 (74%) suggested that health gains had been identified as a result of the health action plan and 15(13%) said that they had not. A break down of these negative responses is given in table 4.25 in chapter 4. However this response indicates that health gains were still identified for some people who were not screened. One respondent identified that 45 health gains had been identified across the plans that they had facilitated. Others reported additional gains to the health of the person with learning disabilities and these are reported below.

Respondent 94 HFQ nurse residential commented that the benefits of the health action plan had exceeded the gains of the individual in that;

> *Full health screening for people with learning disabilities has flagged up health issues which were undiagnosed previously. On several occasions people have been able to get treatment for these conditions, avoiding more serious health problems later. It has enabled specialist nurses to liaise with generic health professionals to inform them of specific health problems that can occur with certain syndromes*(Respondent 94)

Both HFFG groups also suggested that the gain to health was bigger than the individuals health gain and commented that;

> *The health action plans promoted a proactive way of supporting someone's health rather than the reactive way that had previously existed. The staff groups were now proactive in following up appointments and making action plans following an appointment so that things did not get missed*( participant 1)

Respondent 95 nurse health facilitator HFQ commented that "I believe health action plans could be a good tool to measure health gains, however at present they are not being used to their full potential".

Improved communication, both with the individual whose plan it was, their family, and staff within primary and secondary health care and between care staff was evident in the findings from each strand of the research.  Indeed 85/99 HFQ responding said that the Health Action Plans improved communication with professionals about the individuals needs. These themes will now be explored, presenting evidence from the findings.

## Communication with health service providers

Previous research has shown that carers attend GP practices with poor knowledge about the health of the people with learning disabilities that they are supporting (Powrie 2003). This research has identified that the health action plan is a useful tool to address this as all relevant knowledge is contained in one place, so that even unfamiliar staff can refer the GP or primary care staff to the relevant section of the health action plan. Examples of this are given below. The health action plan also aided communication with carers and primary care staff. Participant 5 HFFG suggested that primary care professionals were prepared to discuss a person's health as evidence was provided rather than a "do as we say attitude" that had been experienced previously as the information contained in the health action plan  provided documented evidence that could not be ignored

Additionally 20% of HGQ respondents also suggested that the health action plans were a good source of information in that it;

> *Gives an account of service users health needs. Health professional*
> *can see health needs without having to read through lots of paperwork*
> (Respondent 51 line manager residential)

In addition the information in the health action plan had "Enabled a smoother transition into hospital in an emergency" Participant 4 HFFG.

The HFQ respondents also identified improvements to communication with 17% saying that it enabled discussion/engagement with health professionals and respondent 58 community nurse commented that "All the health professionals involved have been very accommodating and eager to use health action plans".

Participant 3 from the SUFG  identified how their health action plan had been useful when going to hospital and commented that "Medics had used the health action plan and stated how helpful it had been" This was confirmed by HFQ respondent 67 line manager residential who added that the health action plan "Encouraged better communication with acute services and better awareness of service involvement required" However, not all HFQ respondents felt that the health action plan improved communication and respondent 68 commented that "It was still same- sometimes poor".

Various members of the HFFG gave examples where the use of the health action plan had improved communication with the person with learning disabilities. Participant 2 commented that they had done the health action plans themselves before but now "Recently the tenants I support now have got involved in them". This participant then discussed how she had spent short periods of time with one lady building up her health action plan which she would not have considered doing before.

Participant 3 expanded on the theme of communication and commented that "health action plans were discussed with the tenants at tenant meetings and that they thought this was a useful way to do it." This case was in relation to health eating and exercise where both tenants were planning menus and activities for the week, and were happy to discuss issues in this way.

Respondent 84 support worker HFQ also identified additional benefits to the communication aspect of the health action plan  that resulted service user involvement with their plan in that "Tenants (were) making their own appointments" Finally, participant 3 SUFG identified that in completing their plan "Staff listened to what they had to say" However participant 4 SUFG

added that "Staff only listen sometimes" If this is the case then this needs to be addressed as everyone has the right to be listened to.

Participant 3 reiterated that the plan had both improved communication and given them independence commenting that "I tell the staff what to write and they write it for me because I can't write very well. And also it helps me to do things for myself".

Several examples were given whereby the health action plan had helped to improve communications with families through their involvement in the process. Families had passed on information regarding medical histories that had previously been unknown Participant 2 HFFG identified an additional benefit to involving a family member in the health action plan process by commenting that;

> *At one time I supported a tenant whose mother was a very quiet lady that didn't talk much, this built a relationship because she didn't have anyone else to talk to and once we got talking about her son and things like that she go onto other thing.* (Participant 2)

Finally participant 3 SUFG commented that the health action plan was useful as "It helped communication between staff and my family". In addition to this the HFFG identified that improved communication occurred between staff supporting people with learning disabilities. Participant 1 identified an issue where other staff had used the plan to support an individual rather than relying on one carer who was off sick and who had previously kept all the information contained in the plan "in their head".

Participant 2 HFFG also suggested that using new forms within the plan had involved staff in discussions about the individual needs that would not have been considered before.

Outside the main themes discussed above some other benefits to the health action plan were identified by various groups. The HFFG in discussed in chapter 6 identified that there were many other benefits to the health action plan. Some of these are reiterated in the tables over the page.

*Table 7.1 Additional benefits to the health action plan identified by HFFG*

| |
|---|
| Ability to forward plan appointments. |
| Factual plan of current and past medication |
| Able to review past medical history |
| Ease of access to information |
| All information in one place |
| Person identified – against actions on the Action Plan |
| Changes of attitudes by GP regarding care provision by primary care |
| Health action plans were good for unfamiliar emergency staff to read |
| All health issues were followed up as health action plan thorough |

The HFQ also identified additional benefits and again some of these are presented below.

*Table 7.2 Additional benefits to the health action plan identified by HFQ*

| |
|---|
| Increased activity in health promotion areas with some services setting up specific health promotion activities: |
| GP surgeries are able to advise the Learning Disability Service, giving stats on things like obesity/learning disability so that we can plan and target "healthy lifestyle" support |
| They have enabled carers to consider health needs that they may previously not have considered |

Respondent 103 nurse health facilitator HFQ identified one very important benefit to the health action plan process. They commented that

> *People with a mild learning disability have found them useful in being more aware of their own health needs and actions they need to take to stay healthy. They have enabled carers to consider health needs that they may previously not have considered Enabled health staff within CTPLD to consider areas for health promotion and look at running specific groups for people as well as individual work* (Respondent 103)

This is of particular importance as referral criteria for some community nursing teams does not include people with a mild learning disability and are often not in receipt of services so 'slip through the net' often only accessing help when they are in crisis. Obviously this health facilitator has found a way to address this that needs to be considered by others. In addition participant 3 SUFG identified that one benefit of the health action plan was that it had helped "Them and staff to build relationships with their parents" Participant 2 HFFG had also commented on relationship building with families to gather information that had not previously been known.

Finally two individuals identified how the health action plan had led to personal development and fulfilment. Participant 3 SUFG commented that "They liked their plan because it gave them independence"

And respondent 92 nurse health facilitator HFQ identified where "Service users have gained empowerment. One service user enthused to me I will be able to go to hospital appointments by myself". This in itself is some achievement and reflects why the health action plan process needs to be implemented correctly.

**Monitoring and review of health action plans**

Nationally there were a variety of people responsible for monitoring the health action plans (See figure 16 page 102). However some respondents stated that there was no review and that there was also no data base available, (within community team for learning disabilities), of who had a health action plan. Some community nurses raised this as an issue as this was another "add on" to their role with no additional time to undertake the review and respondent 49 a community nurse went further by saying that;

> *Community nurses seem to have got this responsibility however they have not been allocated time for this and therefore due to caseloads this has not been practical. A third year student and temporary nurse took the responsibility for a short time whilst working within the team.* (Respondent 49)

Only six respondents said that the LDPB monitored reports about the progress of health action plan, which mirrored the practice happening locally. The health action plans were reviewed over varying amounts of time, ranging from monthly (within some of the supported living

services) to annually within the community team for learning disabilities. One community nurse, respondent 76, commented that;

> *At present health action plans are not methodically reviewed/*
> *monitored. Community nurses read health action plans as they are*
> *received and immediate action taken if necessary. Long term goals*
> *etc are not acted upon at present* (respondent 76)

Interestingly, whilst the health action plans were monitored regularly within the health facilitators focus group, the group raised this problems that there were no designated lead for each action on the health action plan action plan and that they had added this to the sheet so that someone took responsibility. Adding a responsible person in the scenario above may have helped with long term health goals being followed up.

Furthermore only 45% of respondents in the national questionnaire identified that they had undertaken quality audits of the health action plan. Within the focus groups respondents identified that an audit had in fact improved the health action plan and added more information to the plan to support the individual's mental health needs. This audit also demonstrated that there was a variance in the quality of the content between health action plans, so it is reasonable to expect that this would be replicated elsewhere. Since this research was completed the Health Self Assessment has been implemented which asks how health action plans are monitored but again the response rate to this question remains low. (www.improvinghealthandlives.org.uk). Therefore the monitoring and quality aspects of health action plan needs to be reviewed, with the LDPB taking responsibility for this review.

## Summary

Firstly this chapter discussed the findings of the health facilitator questionnaire aspect of the study. It introduced Greig's typology for change which suggested that there are three concepts of change that people respond to by acting as removers, containers or developers and gave examples from the research study to explore these concepts in more detail.

The chapter continued by identifying that the findings demonstrate more positive examples to change utilizing the developer typology which further confirm the ability of the learning disability nurse to adapt their roles to meet change as and when required(Beasley 2006).

The process of health action plan development, health facilitation and primary care involvement were discussed alongside examples of how collaborative practice had improved health aspects for people with learning disabilities. Community nurse opinions regarding their involvement in the health action plan process were identified to demonstrate the varying approaches to health facilitation across England.

This chapter then amalgamated and discussed findings from the three aspects of the research. It has identified several emerging themes discussed commonality of findings between the research subjects. One key issue was that appropriate leadership was required, at all levels, to move the health action plan process forward and examples were given to demonstrate this.

Training regarding health action plans was discussed in some detail. Choice of health facilitators and the nurse's role in this was reviewed. Next the benefits of health action planning were identified and discussed. Whilst health gains were important in the health action plan  process this research had identified that an additional benefit is improved communication with people with learning disabilities, families and carers and health care professionals which can only be of benefit to improving the health of people with learning disabilities both locally and nationally. Finally, it was identified that not all areas have a process to monitor the quality of the health action plan process and this needs to be addressed.

# Chapter Eight

## Concluding Discussion

The previous chapters have given a comprehensive overview of the findings of this research study. This chapter will refer back to the literature review and compare literature to the research findings. In addition it will inform the reader if current literature adds to or detracts from the research findings. Limited information was available about the benefits of hand held records for patients at the start of this study , such as identification of health needs (Lennox *et al* 2006, Smith 2005) and improving communication (Turk and Burchell 2003, Lester *et al* 2003) but these studies were limited in both size and location. This research has reviewed the use of health action plans on both a national level with health facilitators from across England' and on a local level with health facilitators and people with learning disabilities in one locality in the North of England. Throughout the research analysis it became apparent that several themes were interrelated to all three strands of the research process. There were several themes identified within the research study. Firstly, clear leadership is vital to the health action planning process. Next, health screening is vital to the process and provides positive benefits to the individual. There is also a need for adequate training and knowledge for all people involved in supporting people with learning disabilities to access health. In addition work is required by health facilitators to develop the individual's choice of who acts as their health facilitator. It is evident that health action plans have improved communication on many levels. Finally, the completion of the health action plan has identified benefits for the individual. These are now discussed in detail.

## Leadership

Valuing People (2001a) identified that the health of people with learning disabilities was poor and introduced the concept of health action plans as one way to improve this Furthermore it instructed that people with learning disabilities should be offered a health action plan, designed in a person centred way with an identified health facilitator of their choice by June 2005. Limited leadership and guidance was given as to how this should occur, with no additional funding to facilitate health action planning. Nationally services including community teams for learning disabilities (CTLD) were left to decide whether health facilitation would occur as an extension to existing roles or by creating new specialist posts. Several studies (Mobbs *et al*

2002, Boarder 2002, Powell *et al* 2004 and Barr 2006) had identified wide variations and inconsistencies in the way that CTLD function but all concluded that the emphasis was on health related issues. This included health assessment, health promotion, and the development of collaborative partnerships with primary health colleagues to improve access to services. This was reconfirmed by Scott (2011) who in reviewing three community teams for learning disabilities across Sussex confirmed that the emphasis and involvement in health continue to be key factors of the nurse's role.

Repeated criticism given in this study is that there was a lack of national leadership and clear guidance given about the introduction of health action plans. This thesis has demonstrated that the inconsistencies in the way that community teams for learning disabilities function continues. Greig (2003) the then, National Director for Valuing People commented that

> *Change happens where local people want to make it happen.*
> *Governments can issue policy guidance and the Valuing People*
> *Support Team can provide a whole range of development support but*
> *the key issue is whether there is a local belief in the Valuing People*
> *vision and a willingness to do things differently*

This study gives credence to this comment. Indeed evidence identifies that there was a disparity in the way that health action plans were developed and introduced. Feedback from nurses within the study suggests that the successful implementation of health action plans was greater on a local level where clear leadership and direction was provided to develop new ways of working. This democratic leadership style has helped to develop collaborative practice, develop nurse's skills and involvement with primary health care, supported living services and families to promote choice and inclusion.

Conversely, where there has been lack of direction and a more laissez-faire type of leadership (Lewin 1951) it resulted in limited progress. Respondents cited feeling isolated with a lack of support by their manager, their colleagues (in integrated teams), the PCT and the LDPB (learning disability partnership board). Indeed there was a lack of joined up working .with

areas developing health action plans independently of each other. This aspect mirrors Mir *et al* (2007) findings of a study in Leeds whereby services developed health action plans independently of each other. However the local research study contradicts Mir as due to robust leadership health action plans were developed as a collaborative piece of work across supported living services providers. The negative aspect of this development compared to the national results is that work was in the early stages of development to deliver health action plans to the wider learning disabled community.

This may prove problematic as the current thinking is to devolve accountability down to the local level. It is evident that this has not worked for this initiative. The government may want to move away from an autocratic style of leadership to allow more democratic local leadership but it is evident that effective leaders need to be in place at the local level to achieve this. This study had shown that where leaders act as motivators and developers the most progress has been made. However, not all leaders have worked in this way and it is clear that in those areas that have not had the leadership that an autocratic approach, instructing services of exactly what is required is needed. More importantly a "lesson learnt approach" should be taken to share the good practice, so that areas that are struggling can be assisted to improve.

Finally, several respondents suggested that issues with implementation arose as there was no appropriate strategic health facilitation lead in their area. They often felt that there was an increase to their workload with no additional time to undertake health action plans. Health facilitators suggested that again these issues were due to a lack of leadership and guidance on either a local or national level. Furthermore, the concept of health facilitation and health action plans (Valuing People 2001a) was introduced with no additional funding and the expectation was that community learning disability teams would adjust and adapt their roles.

Grieg argued that where there was a local belief and willingness for things to happen differently change can happen. This research has give examples where this was proven to be the case and health action plans were introduced successfully, alongside the development of the health facilitators' skills. However, there were also examples where change was slower or did not occur if there was a clear lack of leadership. For the policy to be successful therefore both national leadership and clear lines of accountability and monitoring need to be in place.

These findings mirror that of Mir (2007) who concluded that "Leadership is needed at national, regional and local levels if the pockets of good practice that have been developed in various parts of England are to be replicated elsewhere". This need for leadership continues to be an issue for learning disability nurses in general which was reiterated in Learning from the Past: Setting Out the Future (RCN 2011) which confirms that there needs to be "strategic leadership for all learning disability nurses in the mixed care economy".

During this study Equal Treatment: Closing the Gap (DRC 2006) reported on the continuing health inequalities faced by people with learning disabilities. The report Promoting Equality (DOH 2007) responded with a number of recommendations including a firm commitment to publish additional guidance on health action planning. The findings of this research, including the need for leadership and further guidance were shared with the report author. This additional guidance; Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance was published in 2009. This report reiterated the need for clear leadership, across and within organisations to take the health agenda for people with learning disabilities, including health action plans forward.

## Health screening

The next key theme identified was that health screening is instrumental to the implementation of health action plans. Much had been written about the benefits of health screening for people with learning disabilities (Cooper *et al* 2006, Kerr *et al* 2005, Martin 2005, Valuing People 2001a, Allan 1997). All these studies identified unmet health needs when undertaking various health screening projects with people with learning disabilities. What was unknown at the start of this research was if health screening was being implemented as part of the health action plan, who was involved in completing this screening and if indeed there were any benefits to it. Locally, health screening did not inform the health action plan but some health benefits were still identified. This research study identified that in 72% of cases health screening did take place to inform the health action plan. Furthermore there were more health needs identified where screening took place.

However, the research identified that not all screening was undertaken by primary care staff, with some learning disability nurses undertaking the health screen due to issues engaging primary care in the process. Valuing People (2001a) suggests that "learning disability nurses are specialists in their field and should be a point of reference to others". This way of working, with learning disability nurses carrying out health screening by themselves will not assist to develop collaborative practice and improve the knowledge of primary care staff (Michael 2008, Barr *et al* 1999). This again demonstrated that clear leadership is required to ensure that learning disability nurses work to engage primary health care staff to complete these health checks so that access to health and primary care support in this becomes normal, usual practice. This was reiterated by McGrath (2010) who during a local study identified that generic services can undertake these health checks independently if training is given first and support is offered by the community team for learning disabilities.

Whilst writing up this research and following on from the recommendations of the Michael Report (2008) a national Direct Enhanced Service (DES) was introduced for people with learning disabilities to access an annual health check. The DES has now been extended until 2012. However, the success of the DES is limited as it is not a mandatory process. The need to inform health action plans with health checks is confirmed and reiterated in Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance

> *"Health checks will only have their full impact if they encompass health action planning and if people with learning disabilities can then access the services they need to maintain and improve their health. This requires good communication and partnership working across a range of services, including primary care, local government, public health, mental health services, acute care and specialist services"* (DOH 2009b)

Guidance was issued as part of the DES regarding which health issues should be monitored and this guidance included the development of a health action plan as a result of the health check. It is evident that this is not happening for all on a national level. Regionally only three of twenty four PCT's are monitoring the quality of these health checks (Smith 2010).

Effective partnership working is demonstrated by Hull and Humberside who developed the annual Health Self Assessment for people with learning disabilities in 2008. The Health Self

Assessment was adopted nationally and in 2010 all ten Strategic Health Authorities completed the assessment. The Health Self Assessment reviewed many aspects of access to health care, including GPs offering annual health checks. It also incorporated the criteria that health action plans generated health checks, health checks were initiated by primary health care and that health action plans were monitored by LDPB. Evidence suggests that areas are not meeting these targets (IHAL 2011). However, the national uptake for health checks April 2010 to March 2011 is only 49%, although there is debate as to the accuracy of figures (Copeland 2011). Following the Health Self Assessment each area completed an action plan to address issues and these are being monitored on a local level and will be reviewed as part of the 2011 Health Self Assessment process. Therefore the findings of this research remain current and valid as it is still necessary to ensure that health screening does inform the health action plan and that this is completed by primary health care.

## Choice of facilitator

Valuing People (2001a) says that people with learning disabilities will be offered a health action plan by a health facilitator of their choice by 2005. There was no literature recorded at the start of this study to suggest if this was happening. This thesis has identified that people were not always offered a choice of health facilitator. Evidence identified that implementing the health action plan was generally a service led process whereby the key worker would act as the health facilitator. The local model mirrored this as it was service led and during the SUFG interviews participants identified ways that this could change thus making the plan more person centred and accessible. Furthermore, nationally, 47% of people acting as health facilitators were paid staff of various descriptions. Examples were provided where a member of the community team nurse would act as health facilitator for people with complex needs only handing over the responsibility to carers or family members once the plan was in place. This service led approach contradicts the person centred approach (Sanderson 1997) and concept behind health action planning (DOH 2002). Indeed one participant in the focus group commented that they were given a plan even though they did not want one. Finally the evidence suggests that there was limited involvement of the individual's circle of friends being involved in the plan which again detracts from the concept of being person centred.

However, it is acknowledged that not all health action plans followed a standardised format nationally and instances of good person centred plans were given. Health facilitators gave examples where plans had been adapted and presented in alternative formats and yet the majority of plans developed were in a written format. As identified, limited guidance was available (DOH 2002) and this research shows that this resulted in a wide range of formats being developed that ranged in size from 13 to over 50 pages, with a variety of topics covered in the plan. Harrison and Berry (2005a) suggest that the plan should include the needs of the carer, yet only 14% respondents suggested that these were included in the health action plan. This could be because the plans were service led therefore a carers needs were less relevant as they were not supporting the individual. However a valuable opportunity has been missed to make sure that the carer needs are identified.

In addition this thesis has identified that the quality of the health action plan was not consistently monitored.  This continues to an issue and is one requisite of the Health Self Assessment (IHAL 2011).However, data presented nationally suggests that monitoring the quality of health action plans continues to be an issue.

As the literature regarding health action plans was relatively new there was no data available to indicate the number of plans completed. This thesis demonstrates that most of the health facilitators who responded were experienced in their role and had been involved in completing multiple health action plans. Nationally the mean number of plans completed was 24 compared to 4.7 locally where health facilitators tended to focus on one or two supported living services. Nationally health facilitators appeared to have larger caseloads working across more people. Some health facilitators were in specific strategic roles with one health facilitator having completed 300 health action plans. However, health facilitators indentified that there were contradictions in their roles due to lack of guidance and leadership and there was a suggestion that this role should be included in their job description. Matthews (2005) reports that health action plans were slow in getting established. This study demonstrates that whilst some areas have tackled the challenge of health action planning head on and made good in roads to supporting their development. Others lag some way behind, and cite lack of support in developing health action plans and issues relating to lack of time and capacity to develop the process. Respondents were not all aware of the number of people with learning disabilities in

their locality and the details provided show that even where they knew the numbers a huge amount of work was still required.

## Training

Knowledge or a lack of it was a key theme identified in the literature. This related to knowledge across the board in supporting people with learning disabilities to access health. There were issues relating to knowledge of learning disability by GPs (Michael 2008, Marshall *et al* 1996) and primary care staff (Melville *et al* 2006, Melville et al 2005, Ross *et al* 1994).Lack of knowledge about health by carers ( Iacono and Sutherland 2006, Matthews 2005,Lewis and Porter 2004) and people with learning disabilities themselves( Ramessur-Marsden *et al* 2008,Beange *et al* 1995).

However, studies available at the time of commencing this thesis and others published during the research process have shown that training and increasing knowledge can improve access to health. Melville et al (2006) delivered training to practice nurses resulting in improved access to services. This thesis has identified that through the use of health action plans, in some areas, collaborative working has developed. This has helped to improve the knowledge of all involved. Indeed some areas reported that primary care had taken over the health screening themselves and this was happening prior to the introduction of the DES. Locally, one supported living service reported that health staff actually wrote in the health action plan. Furthermore one health facilitator nationally, identified that it had improved working relationships with primary care as it allowed them "to liaise with generic health professionals to inform them of specific health problems that can occur with certain syndromes" (respondent 32).

Valuing People (Department of Health 2001a) suggests that social care staff and carers need to gain; "Competence in basic health issues and implementing health promotion initiatives". However, practice and treatment room nurses in Scotland implied that unqualified carers did not have the knowledge to provide adequate health care for people with learning disabilities (Powrie 2003). They identified that carers changed regularly and did not appear to communicate with each other with the result that medical investigations were often delayed, or that patients did not attend for appointments.

At the time of this study, there was little published information available to demonstrate whether the introduction of health action plans had made a difference to improving people's knowledge about the individual's health requirements. Corbett (2007) evaluated the use of hand held records and suggested that they could assist with communication between carers and health professionals. This study has identified that the use of health action plans had indeed aided communication and knowledge for all involved. On a national level of 99 responses 91% (88) agreed that the health action plan aided communication and that it helped by having all information in one place. This had helped to challenge professionals and review previous medical history. This was evidenced on a local level with several examples where staff had used to the plan to refer to previous health information. Locally, examples were also given where the plan helped with sharing information so that even if unfamiliar staff were supporting the individual all information was in one place and therefore they did not waste valuable GP appointment time. If this was replicated nationally it would supersede Powrie's(2003) theory as all information would be available, regardless of the individual carers' knowledge.

Furthermore the health action plans had helped paid carers to learn things about the person they supported that they had not previously known, and develop improved relationships with the individual's family. Additionally both groups of health facilitators identified that the health action plan had helped carers to challenge primary health care thus ensuring that routine health checks were now offered and received. However some respondents nationally identified that there were still on going issues with carer knowledge about the individual's health.

Both groups of health facilitators identified that carers and supported living services needed training in delivering health action plans and more knowledge regarding supporting peoples health needs in general. Several examples were presented by national respondents where they had developed training for health facilitators from supported living services and other carers. Some included various health aspects as part of the process. Interestingly several nurse health facilitators identified that they could have used training themselves as the concept was also new to them and they were left to get on with it. Whilst this approach fits with the concept that learning disability nurses are flexible and adaptable (Tait and Turner 2001) it demonstrates a

lack of foresight and leadership as a valuable opportunity has been lost to develop new skills more effectively.

The need for increased knowledge was reiterated in Valuing People Now (2009a) which confirmed that " the workforce across public services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the Valuing People Now priorities". Gates (2011) completed the Valued People Project to review and identify the longer term commissioning of education requirements for the learning disability health workforce in one strategic health authority area. In addition a UK wide evaluation is currently underway to ensure that a professional framework for learning disability nursing is developed in line with Modernising Nursing Careers (Devine 2011). This is commendable as both projects reiterate that the learning disability nurses skills are still required, but that consideration needs to be given into how these skills are developed and used. This work however, does not address both the national and local issues confirmed by this research thesis that carers (paid and unpaid), also need to have better understanding and awareness of health issues for people with learning disabilities and how they can support people to both identify and address these health needs via health care services.

Evidence suggests that people with learning disabilities often do not have knowledge about their own health and therefore may not access service (DRC 2006, Robertson *et al* 2000). However, with appropriate support and by developing appropriate ways to give information they can access preventative services (Ramessur-Marsden *et al* 2008). Examples were given where with appropriate support people with learning disabilities have improved their own health thorough the use of health action plans. One respondent identified that the benefit of the health action plan was that the individual could now attend hospital on their own with no support from staff. However Codling and MacDonald (2011) have identified that whilst health promotion activities did improve people with learning disabilities knowledge, this did not result in them retaining that information to actually change their health practices. They completed health promotion activities with 38 people and by using questionnaires before and after the sessions confirmed that the individual's knowledge had improved. In follow up interviews three months later they concluded that participants had not been able to transfer this knowledge across to their everyday lives. Codling and MacDonald (2011)have suggested that

this is because people with learning disabilities rely on the support of others and that " to improve the health of people with learning disabilities nurses may need to include the circle of support they receive from others so that knowledge gained from health education can be sustained" (page 46).Whilst it is acknowledged that this is a small study it reiterates one of the thesis findings that carers and family members supporting people with learning disabilities need awareness of health to support change to happen. This includes knowledge by the carer in general, and knowledge of how to support the individual to change and improve their own health practice.

## Benefits for the individual

Finally, respondents identified that there were additional benefits to the health action plan than those already discussed. There was no literature available at the time of this study that identified any additional benefits from completing a health action plan. Therefore, this study has contributed to the evidence about the benefits of health action plans. Many respondents identified measurable health gains ranging from the opportunity to participate in routine screening, not missing appointments, identifying and treating problems that may have previously been missed or ignored due to the individual's learning disability and it was useful in aiding communication with acute services.

What is evident from the findings is that there have been many benefits from introducing health action plans for people with learning disabilities across England but there has been a disparity in the way that this has been achieved. Dependant upon the level of leadership and support offered services have developed and adapted along the way. Some areas, including locally, had identified specific strategic health facilitators to take the role forward. Some areas have adapted their work load so that health action planning has become integral to the way that community team for learning disabilities function and other areas are still working to develop health action plans seeing them as a hindrance to their already busy work loads.

In addition various formats and methods of health action plans have developed with a variety of training given to those undertaking the role of health facilitator. Some areas developed robust training that included a general overview of health and the determinants of health

alongside the concept of health action planning. This was not mirrored locally, where training in the implementing health action plan was only given to supported living services managers. However local practice is different to national practice in that the majority of health action plan development was not undertaken or developed by community team for learning disabilities but by supported living service providers.

## Limitations to the study

There were several limitations to this study that are recognised and these are discussed below. Firstly there was no national data base of health facilitators and so this data is only presented in relation to those that responded and not as a percentage of all health facilitators nationally. In addition, as the research governance approval process was under going considerable change when this research process began not all Primary Care Trusts across England responded with approval and so this research only represents responses from all nine Valuing People regions and not all PCT's.

Secondly, whilst questionnaires were the most appropriate method, it was not possible for the researcher to follow up any comments which may have resulted in some rich additional data being lost. If this study was repeated I would include the option for a follow up telephone interview so that any additional comments could be discussed. I would also consider the use of local researchers so that a regional and national perspective could be obtained.

Whilst the health facilitator focus groups were conducted with representatives from all supported living service providers, some services had more representation than others and it may have proven useful to hold additional focus groups to obtain a wider perspective. In addition, this study did not include family carers as the health action plan process with families was in the early stages of implementation at this time.

The focus group with people with learning disabilities had several limitations and these have been acknowledged previously. Firstly, the group consisted of four participants. Whilst these participants were from all service providers they could not be representative of all people receiving a service. Secondly the selection criteria were specific in that participants had to be

able to be unsupported and able to verbally communicate. It is acknowledged that this excluded people with more complex needs, and those that may have needed support to attend a meeting. Were this process to be repeated I would use different methods, such as focused workshops to obtain baseline information, and then follow these up with focus groups and individual interviews. In addition I would look to include people living independently, or with families as part of the research.

## Implications for practice

### Nationally

As this research was multi faceted it has identified implications for practice on both a macro (national) and micro (local) level. The following areas were identified as actions key actions that need to happen to move the health action plan process forward. National training needs to be developed for carers who support people with learning disabilities. A mandatory health module should be developed for support workers to enable them to understand the health aspects for people with learning disabilities in order for them to undertake their supporting role adequately. There needs to be an adequate training/awareness raising programme regarding health action plans and health related issues for all people, regardless of qualifications, supporting people with learning disabilities. Some areas within the research have given excellent examples of how training has been developed in their locale but guidance needs to be developed at a national level. The context and depth of this training requires further examination, but it is evident from the findings of this research that nurses require training as well as carers and their families and health care providers. Furthermore, the importance of health screening or a health check to inform the health action plan needs to be an integral part of this training.

Clear guidance and leadership needs to be developed on a national and local level to ensure that the health agenda for people with learning disabilities is developed and that learning disability nurses get the same equitable levels of support to develop the health agenda within their practice.

Health screening for people with learning disabilities needs to be delivered by primary care staff in order for a transfer of skills, knowledge and improved practice to happen. A national review of the DES process should be completed to identify:

1. Who undertook the health screening
2. If this increased their knowledge
3. What health outcomes were identified
4. If health action plans were instigated  and monitored as a result

Ownership for monitoring the introduction of health action plans, the monitoring of outcomes and implications for practice should lie with the Learning Disability Partnership Board, via inclusion within the new area Health and Well Being Boards. Specific outcome measures should be included in all service level contracts that offer support to people with learning disabilities to access health (community team for learning disabilities, supported living services, primary health care and secondary health care services). This contract should include a review process and penalties for non compliance and data on who is acting as health facilitators in the area.

The concept of issuing national guidance to be interpreted and developed on a local level fits with the current government's concept of the big society and the reorganisation of the NHS to develop and implement practice on a local level alongside consultation with service users. However there are valuable lessons to be learnt from the health action plan process to inform this concept. Namely that clear guidance, including robust lines of accountability and monitoring of processes must be developed to ensure that the quality and equity of services is maintained. In this instance that is to ensure that all people with learning disabilities are offered an equitable service that is not dependant upon the enthusiasm and leadership skills of the individual PCT or community team for learning disabilities. Not ensuring this will result in disparity of services provided and a return to the post code lottery. Thus resulting in a disparity in the way that health action plans are provided, how training is given and how health outcomes are identified and acted upon.

## Local Implications

This research thesis has identified that whilst the introduction of health action plans was a national instruction (Valuing People 2001a) limited guidance in how this was to be achieved was provided. The way that health action plans were introduced on a local level did make a difference to both the health experiences and health benefits for people with learning disabilities. The research has proven that local practice mirrors certain aspects' of national

practice in that a nominated lead was identified. Training was given to health facilitators and people with learning disabilities were offered the option of a health action plan.

However lessons were learnt following analysis of the health facilitator's questionnaires and local focus groups as to how practice could be improved and this is presented in table 8.1 below. Due to the reconfiguration of supported living services not all recommendations were achieved. Furthermore it would be useful to repeat this research to include people who do not verbally communicate, carers and people living independently, to gain a wider perspective on how health action plans were now working. This could be done using a variety of engagement methods, e.g. themed meetings, focus groups, individual interviews using the person chosen communication method. The findings and requirements could then be included as quality measures within the existing contracts with providers.

*Table 8.1 Recommendations from the local research findings*

| Recommendation | Action taken |
|---|---|
| Person centred planning process including health action plans to be included within provider contracts by Learning Disability Partnership Board. | All providers deliver person centred training and these aspects are covered in the supported living services contracts |
| Community learning disability team to raise awareness within primary care regarding health action plans as part of DES | Training provided but not all GPs undertaking DES |
| Changes to current health action plan documents to be addressed including named person responsible for actions on the health action plan | All areas identified addressed and amended |
| Working group to develop more accessible health action plans | This group was set up, but due to service reconfiguration services are now working independently |
| Supported living services to remind staff that people can choose to opt out if they do not require one | Feedback was given from the study and supported living services were asked to share this information with staff. |
| Training to be developed for support staff re health action plans | Due to reconfiguration this has not happened |
| Health action plan to be developed for non supported living services that is more accessible to use | Plan developed and is offered as part of community team for learning disabilities contact |
| An example of an aide memoire health action plan to be developed and shared | This was shared with supported living services |
| People with learning disabilities should be included in training to professionals | There are plans by CTLD to do more training with people as partners |

## Conclusion

This research informed the health action plan guidance that was developed in 2009. It is clear from this research that despite lack of national leadership and guidance health action plans have improved the heath of some people with learning disabilities living in England. The use of health checks and clear supportive leadership have resulted in health facilitators feeling valued, in identifying more unmet health needs, and in developing improved communication with primary care, families and the individual themselves. Where there was a disparity in services with a clear lack of leadership health facilitators felt less empowered and saw health action planning as an add on to their job.

It is also clear that training in delivering the health action plans has increased the knowledge of health facilitators. To improve this on a national level health related training needs to be made mandatory for all care staff including where necessary, nurses, to ensure that they have a basic knowledge and understanding in order to support people with learning disabilities to achieve good health. Furthermore systems need to be developed to ensure that health action plans are delivered in a person centred way, with the quality and outcomes monitored robustly.

Finally good effective, supportive leadership, more informed guidance, training and support is required for some areas to maximise these benefits. There needs to be a clear line of accountability for delivery and monitoring of the health action plan and this should be delivered via service contracts.

This thesis is the culmination of five years work. It began with a quest to improve practice in the area in which I work. Having worked with people with learning disabilities for twenty four years; the last four of which were in the role of strategic health facilitator, I was delighted when I found out that health action plans were to be introduced. I was soon surprised at the lack of attention given to the new policy. My intention in this thesis was to address this neglect and I am delighted that I have been able to map the development of health action plans across the country. The overall task, to help people with learning disabilities to lead healthier lives, continues and remains my most important professional objective. The research that is presented in this thesis has formed part of this task, and I very much hope will it make a positive difference to the lives of people with learning disabilities.

# Appendices

1. Health facilitators questionnaire

2. Health facilitator focus group questionnaire

3. Health facilitator focus group interview schedule

4. People with learning disabilities focus group interview schedule

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┌─────────────────────────────────────────────────────────┐
│ ┌─────────────────────────────────────────────────────┐ │
│ │              Questionnaire regarding                  │ │
│ │ Health Action Plans and Health Facilitation for      │ │
│ │        People with Learning Disabilities              │ │
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# Questionnaire regarding
# Health Action Plans and Health Facilitation for People with Learning Disabilities

Please complete the following questionnaire by ticking all relevant boxes, and answering questions where appropriate

*1. In which Valuing People region are you based?*

| | |
|---|---|
| *North East* | |
| *Yorkshire & Humber* | |
| *East Midlands* | |
| *Eastern* | |
| *South East* | |
| *London* | |
| *South West* | |
| *North West* | |
| *Midlands* | |

2. *What is your role in supporting people who have a learning disability?* (**please choose one option**)

| | |
|---|---|
| *NURSE     Residential Service Based* | |
| *Community Nurse* | |
| *Health Facilitator role* | |
| *Social Worker* | |
| *Care Manager* | |
| *Line Manager in residential services* | |
| *Support Worker in residential services* | |
| *Unpaid carer* | |
| *Family member* | |
| *Friend* | |
| *Advocate* | |
| *Transition Worker* | |
| *Ethnicity Worker* | |
| *Other please list* | |

**3   If employed, who do you work for?**

| | |
|---|---|
| *Primary Care Trust* | |
| *Mental Health Services* | |
| *Social Services* | |
| *Mencap* | |
| *Independent Provider* | |
| *Charity Organisation* | |
| *Voluntary Organisation* | |
| *Other:* | |

**4.  Is your role**                                   **(please tick)**

*Strategic*

*Operational (hands on)*

*Both*

**6.   How many Health Action Plans (HAPs) have you facilitated?**
**Please comment:**

**6. How many people with learning disabilities live in your town or city?**

**Please estimate:**

*7. How many people have HAP?*

*Don't know or* [    ]

*8.How long have you worked with people with learning disabilities?*
   **(Please tick the appropriate box)**

| Under 1 year | 1 – 5 years | 6 – 10 years | 11 – 15 years | Over 16 years |
|---|---|---|---|---|
|  |  |  |  |  |

*9. Who took the lead in introducing HAP in your locality?* **(please tick)**

| | |
|---|---|
| *Learning Disability Partnership Board* | |
| *Primary Care Trust* | |
| *Community Team for Learning Disabilities* | |
| *Designated Health Facilitation Lead* | |
| *Other:* please comment: | |

*11. Was the design of the HAP led by the learning disability services?*

*Yes* [    ]
*No* [    ]

*11. Who was involved in the design of the HAP?* **(Please tick all that apply)**

| | |
|---|---|
| *People with a Learning Disability* | |
| *You* | |
| *Residential Service Provider* | |
| *Mencap* | |
| *Social Services* | |
| *Private Providers* | |
| *Voluntary Services* | |
| *Advocacy Services* | |
| *Primary Healthcare Services* | |
| *Other:* please list | |

*12. Was the HAP piloted after design?*

| | |
|---|---|
| *Yes* | |
| *No* | |
| *Don't Know* | |

*If No go to Question 14*

*13.    Were any changes to the format made as a result of the pilot?*

| | |
|---|---|
| *Yes* | |
| *No* | |
| *Don't Know* | |

*14. Does the HAP contain the following?*  **(Please tick all that apply)**

| | |
|---|---|
| Consent Form | |
| Best Interest discussion | |
| Refusal form | |
| Information on the carer's needs | |

*15. What other information is included in the HAP?*  **(Please tick all that apply)**

| | |
|---|---|
| General Health | |
| Family Health history | |
| Medication | |
| Syndrome specific information | |
| Mental Health & Well being | |
| Women & Men's Health | |
| Lifestyle / Healthy Living | |
| Death & Dying | |
| Epilepsy | |
| Diabetes | |
| Screening histories | |
| Records / outcomes of appointments | |
| Admissions to Hospital | |
| Communication | |
| How to recognise if I am in pain | |
| HAP Goals | |
| Any other information:  (please list) | |

*16. Who funds the printing of the HAP?*

| | |
|---|---|
| *Primary Care Trust (PCT)* | |
| *Community Team for Learning Disabilities* | |
| *Residential Service Providers* | |
| *Person who plan belongs to* | |
| *External funding (*please identify) | |
| *Other* (please comment) | |

*17.  In what formats is the plan available?*

| | |
|---|---|
| *Written* | |
| *Written & Pictorial* | |
| *Braille* | |
| *CD Rom* | |
| *Taped* | |
| *Video* | |
| *Translated* | |
| *Other*  (please list) | |

*18.  How many pages are in the plan?*  **(Please tick)**

| *1 – 10* | *11 – 20* | *21 – 30* | *31 – 40* | *41 – 50* | *51+* |
|---|---|---|---|---|---|
| | | | | | |

*19.* **Who acts as Health Facilitators in your region? (Please tick all that apply)**

| | |
|---|---|
| *Learning Disability Nurses* | |
| *Paid Carers* | |
| *Unpaid Carers* | |
| *Family* | |
| *Friends* | |
| *Advocates* | |
| *Primary Care Staff* | |
| *Others* (please list) | |

*20.* **Was training offered to Health Facilitators prior to commencing HAP?**

| | |
|---|---|
| *Yes* | |
| *No* | |

*Comments:*

*21.*     ***In what format was training being delivered?***

| | |
|---|---|
| *Day Courses* | |
| *Booklet* | |
| *Word of Mouth* | |
| <u>Other</u> (please state) | |

*22.* **Was it useful?**

*Yes*

*No*

*23.* **How are Health Facilitators chosen?  (please tick all relevant answers)**

| | |
|---|---|
| *By the person with a learning disability* | |
| *Service led / directed* | |
| *Health Facilitator supports person in residential services* | |
| *Via referral to the Community Team* | |
| *Unpaid carer/parent* | |
| *With support of Advocacy services* | |
| *Other* (please list) | |

*Comments:*

**24. Who has been involved in the completion of HAP?  (Tick all relevant answers)**

| | |
|---|---|
| *People with learning disabilities* | |
| *Family members* | |
| *Friends* | |
| *Paid carers* | |
| *GP* | |
| *Practice Nurse* | |
| *Optician* | |
| *Dentist* | |
| *Advocacy Services* | |
| *Acute Services* | |
| *Other* (please list) | |

**25. Did health screening take place to inform the HAP?**

*Yes*  

*No*  

*Comments:*

*26. **Have current health needs been identified as a result of HAP?***

*Yes* ☐

*No* ☐

*If No go to Question 28*

*27. **How have these been addressed?*** (Please tick all that apply)

| | | |
|---|---|---|
| *Referral to* | *Primary Care* | |
| | *Acute Hospital Services* | |
| | *Social Worker* | |
| | *Advocacy* | |
| | *Community Team for Learning Disabilities* | |
| | *Health Promotion advice for individual* | |
| | *Health Promotion advice for carers* | |
| *Reports to* | *Professional Executive Committee of the PCT* | |
| | *Partnership Board* | |
| | *Other* (please list) | |

*28. **Have health gains been identified as a result of HAP?***

*Yes* ☐

*No* ☐

*Comments:*

*29. How are these reported?*  (Please comment)

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*30. Who is responsible for monitoring HAPs* (please comment)

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*31. How are HAPs monitored and reviewed?  ?*  (please comment)

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*32.  Has an audit of HAPs been done?*

| | |
|---|---|
| *Yes* | |
| *No* | |
| *Don't Know* | |

*33.  How is the quality/standard of HAP monitored?*  (please comment)

```



```

*34.  Did the HAP aid communication with health professionals about the individual's needs?*

| | |
|---|---|
| *Yes* | |
| *No* | |

*Comment:*

```



```

**35.  Do you feel that the introduction of HAP has resulted in measurable health gains for people with learning disabilities?**

| | |
|---|---|
| *Yes* | |
| *No* | |

*Please comment how:*

```



```

## 36. *Do you feel supported in your role?*

*Yes* ☐

*No* ☐

*Comment:*

 

## 37. *Do you have any other comments?*

 

**THANK YOU FOR YOUR TIME AND SUPPORT IN COMPLETING THE QUESTIONNAIRE**

Please return to Mrs Sue Smith – Health Facilitation Lead

*Heywood & Middleton Primary Care Trust Learning Disabilities Service*
Ralph Williams Clinic. Stevenson Square, Smallbridge, ROCHDALE, OL12 9SA

Fax: 01706 702118

Email:  sue.smith@hmrpct.mhs.uk

## Health Facilitator Focus Group Interview
**Pre interview questionnaire**

| | |
|---|---|
| 1) What is your job role | |
| 2) How long have you been in the service | |
| 3) How were you chosen to be a health facilitator | |
| 4) How many haps done | |

7) Who was involved in completing health action plan –list

| | |
|---|---|
| *People with learning disabilities* | |
| *Family members* | |
| *Friends* | |
| *Paid carers* | |
| *GP* | |
| *Practice Nurse* | |
| *Optician* | |
| *Dentist* | |
| *Advocacy Services* | |
| *Acute Services* | |
| *Other- please list* | |

# Health Facilitator Focus Group Interview

1) Did you have any training regarding health action plans?

2) Would training have been useful? And if so how?

3) How did you find completing the health action plan (too long/short/ok?)

4) Was the health action plan  useful- why/why not

5) Would you change anything?

6) Did it make a difference? How

7) How do you monitor plans? Who is involved?

8) Did service users/families get involved/ give any feedback regarding health action plans?

9) Do you feel supported in your role as a health facilitator? If not how could this be done?

10) Any other comments

# People with learning disabilities focus group questions

1) How long have you had a Health Action Plan?

2) Did staff involve you in completing your health action plan?

3) Did staff listen to what you had to say?

4) Who else was involved in completing your health action plan?

5) Are you happy with your plan?

6) What do you like about your plan?

7) What do you dislike about your plan?

8) Has your plan been useful to you? How?

9) Where do you keep your health action plan?

10) Would you like any changes to your health action plan? If so what?

11) Have you any other comments?

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