Health Facilitation and Learning Disability

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Introduction

In 2002 the Department of Health launched the Learning Disabilities Research Initiative with the primary aim of informing the implementation and further development of its recently published learning disability strategy, *Valuing People* (Department of Health 2001). The research initiative was directly concerned with examining how the central principles in *Valuing People* are incorporated into services and support systems (Grant and Ramcharan 2002).

Closing the knowledge-action-policy loop was considered a priority by those involved in the initiative. It was seen as a vehicle for creating closer working partnerships between everyone interested in research designed to enhance the rights, independence, choice and inclusion of people with learning disabilities. We very much hope that the findings from this report will help refine policy and practice to further close this gap and lead to more effective implementation of *Valuing People* health targets.

We would like to acknowledge and thank the many different individuals and groups who have contributed both to the research process and to this report. People with learning disabilities, family carers and professionals from a wide range of service sectors in the fieldwork area played a vital role in helping us gather and make sense of information about health facilitation. We are very grateful to them for their time and support. We would also like to thank members of our Advisory Group as well as Fiona Ritchie, Mark Bradley and Lesley Russ for their valuable comments and contributions on sections of the report.
Executive Summary

Introduction

Health inequalities affecting people with learning disabilities and high levels of unmet health needs have been well documented in recent years (Disability Rights Commission 2006; Healthcare Commission 2005). This study explores the implementation of three policy targets outlined in the White Paper, *Valuing People* (Department of Health 2001), which state that every person with a learning disability should:

- be offered a named health facilitator by Spring 2003
- be registered with a GP by June 2004
- have a Health Action Plan by June 2005

Figure 1 on p42 outlines the intended process of health facilitation activity – strategic and operational - envisaged by the accompanying guidance (Department of Health 2002). Attention to the specific needs of people from minority ethnic groups and people with complex needs is emphasised in the guidance document and the study therefore explores their inclusion in both levels of activity.

A combination of qualitative and quantitative methods was used to gather data for the study. The research team used semi-structured interviews, focus groups and shadowing and also looked at primary care records to explore the process and impact of health facilitation (see Methods). The research was carried out in one area but issues raised resonate with those in other areas where health facilitation is being implemented. The report and recommendations have been validated by local stakeholders and used to inform local progress.
Findings: Level 1 or Strategic Health Facilitation

Valuing People health targets were identified in a Local Delivery Plan for the fieldwork area, however significant links between a pilot project and general practices could not be forged, either to support use of a GP toolkit or to collaborate on Health Action Planning. Disincentives included the low priority accorded to learning disability targets within PCTs and the poor monitoring of learning disability services themselves in relation to Valuing People health targets.

There were some good examples of training offered by the Community Learning Disability Team and voluntary sector groups to mainstream services (see Box 2 on p81). Areas commonly identified for training included consent, the definition of learning disability and communication strategies. Training on health facilitation for members of the Community Learning Disability Team and for those acting in a health facilitation role was needed but not available. Family carers defined their own training needs in terms of knowing how to care for the person with learning disabilities and how to access support.

Findings suggest that members of the Community Learning Disability Team would benefit from training on ‘double discrimination’\(^1\) to increase their confidence and equip them to support people from minority ethnic communities more effectively. A helpful model for Partnership Boards to support inclusion is provided on page 93.

Strategic Health Facilitation was needed to improve the quality of care people with complex needs received during hospital admission as well as to support family carers. Strategic change was also needed to reduce delays in prescription changes caused by lengthy communication processes between GPs and hospital consultants.

Level 2 or Operational Health Facilitation

The research team developed and piloted a template that could be combined with practice knowledge to identify people with learning disabilities on GP lists (see Appendix 2). Identification was adversely affected by confusion about the definition of learning disabilities and concerns about labelling people who might not consider themselves to have a learning disability, indicating a need for training. Individuals

\(^1\)i.e. the exclusion from service provision of people from minority ethnic communities on the basis of both ethnicity and learning disability (see Mir et al 2001).
who had moderate or severe learning disabilities or received specialist health services were more likely to be identified in primary care. Findings suggest the most comprehensive city-wide database of people with learning disabilities is likely to be achieved by combining GP lists with records held by other statutory and voluntary sector services for people with learning disabilities. The process of creating such a database was hampered by the absence of information-sharing agreements, along with widespread confusion about the requirements of data protection legislation.

The elements of a good Health Action Plan as defined by the guidance document (Department of Health 2002) are outlined in Box 5 on p109. Findings from the study indicate that family carers and individuals with learning disability did not properly understand the concept of health facilitation and were often not sure what Health Action Plans were. Where support was available to understand the process, and a relationship of trust with the person promoting the Plan existed, take-up was far better than otherwise. Nevertheless, family carers could sometimes consider and refuse a Plan on the basis of their own needs rather than that of the person with learning disabilities. People with learning disabilities themselves felt that determinants of health such as employment, housing and educational opportunities (see Box 6 on p109) were very relevant to their health but these issues were not explored in their Health Action Plans.

**Voluntary Sector Health Action Plans**

Health facilitators in the voluntary sector could recognise that social activity, rather than good health itself, was an important motivation to leading healthy lifestyles for many people with learning disabilities. One organisation used common themes within a number of individual Plans to develop group based activities and provided support provided for people to attend these. People with learning disabilities valued the greater awareness of health that the planning process had enabled them to achieve.

However, links were not usually made with others involved in the health of people for whom Plans were written. Involvement of family members could be especially important to support people with learning disabilities to give up smoking or eat healthy food. Links to other health and social care professionals could be vital to discovering important health issues (see ‘Mary’s Health Action Plan’ on p118). Short-term funding made implementation of Health Action Plans insecure and unlikely to
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continue in the long term. Plans written by a supported living organisation bore many similarities to those carried out by the Community Learning Disability Team (see below).

Children’s Learning Disabilities Team

Health Action Plans carried out by the Children’s Learning Disability Team were extremely detailed documents developed from interviews with family members, school staff and health professionals. The specialist skills of learning disability nurses in the Team were important in picking up health issues that others missed. Team members could promote best practice and suggest new interventions that were unknown to staff in specialist schools or to family carers. 

Whilst valuing the input of the specialist nurses, family carers felt that their priorities could be lost in the very detailed picture provided. An expectation that parents would act as health facilitators to implement Plans, without exploring the support they might need to carry out this role, also meant that Plans could become inactive documents. Parents could also question whether the considerable specialist time invested in preparing the Plan should have focused more on supporting them to resolve priority issues.

Community Learning Disability Team

Health Action Plans facilitated by adult learning disability services helped to explore a range of possible health issues. However, outcomes were adversely influenced by the lack of training for and effective identification of health facilitators once Community Learning Disability Team nurses withdrew. Family carers could be left with a Plan despite evidence that they would not be able or willing to implement health actions identified. Where a Plan was passed on to a capable and willing health facilitator, implementation could be very effective (see “Gordon’s Health Action Plan” on page 129).

Conflicts with paid or family carers that were related to challenging behaviour were not mentioned in any of the above Plans, including those based on a systematic tick-list of physical and mental health conditions. Evidence suggests that such lists need to be combined with person-centred approaches and robust exploration of the wider
determinants of health to effectively support the person with learning disabilities with their health.

The impact of health facilitation was also explored by comparing the medical records of those people with learning disabilities who had been offered health facilitation to those in general practices that had not. There were no significant differences between practices in the quality of care patients received either before or after being identified/offered health facilitation. However, trends were seen, with a rise in medication reviews in practices offering health facilitation and a rise in the proportion of health checks and medication reviews in practices that had identified people with learning disabilities. There were also rises in the proportion of people with a record for blood pressure, body mass index, height and weight for both groups. These trends indicate more attention within these practices to individual lifestyle issues that are likely to affect the health of people with learning disabilities.

**Inclusion in Level 2 Health Facilitation**

One voluntary sector organisation targeted people from a minority ethnic community and included them in the Health Action Planning process. Limited funding, however, meant that other minority ethnic communities could not be targeted in the same way. There was some evidence that ‘double discrimination’ could hamper effective implementation of Plans for people trying to access mainstream services. There was no evidence of work to ensure the inclusion of people from minority ethnic communities by other services producing Health Action Plans.

A number of people with Health Action Plans in the sample had been diagnosed with a mental health condition. The Plans could potentially have provided a person-centred focus on the causes of challenging behaviour displayed by many of these individuals. However, the necessary links to create a ‘circle of support’ (Department of Health 2002) around individuals were not made and so this opportunity was not realised.

Health facilitators who could use longstanding relationships and knowledge of an individual’s communication strategies were able to develop Health Action Plans with individuals who had limited communication. Carers and others who played key roles
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in the individual’s life had an essential role in building up a holistic picture of the person and outlining key issues in relation to health.
Recommendations: Local, Regional and National Action

These recommendations have been developed with the support of local stakeholders involved in the study. Points in bold text and italics indicate key actions that provide a foundation on which recommendations can be carried out.

The local Primary Care Trust should work to:

Provide resources

- Appoint a Strategic Health Facilitator with the skills and authority to develop collaborative work between mainstream services and the Community Learning Disability Team, to take forward the recommendations of this report
- Work with the Community Learning Disability Team to appoint a named health facilitator for each area of the city
- Identify local funding for annual health checks linked to Health Action Plans for people with learning disabilities (a locally enhanced scheme)
- Identify funding to voluntary sector organisations to ensure Health Action Plans can be implemented and reviewed and health promotion activity sustained.

Increase awareness

- Promote the need to improve the health of people with learning disabilities as part of the PCT response to the Disability Discrimination Act 2005
- Promote awareness of the benefits of long term preventative strategies in relation to financial planning
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- Provide accessible information about health services, healthy lifestyles and screening programmes through well informed health service staff
- Ensure that GPs are aware of and use the *Valuing People* definition of learning disabilities to create practice-based registers of people with learning disabilities
- Promote the need to include people with learning disabilities from minority ethnic communities as part of the PCT response to the Race Relation’s (Amendment) Act 2000

Stimulate Action

- Include work on learning disabilities in activity to meet National Service Framework targets and local priority areas
- Ensure all GPs identify people with learning disabilities on their list
- Promote inclusion of Health Action Plans in GP records
- Ensure there are Learning Disability leads in hospital departments to work with the Strategic Health Facilitator
- Ensure that PALS and Public Health leads have targets related to those described in *Valuing People* and related guidance (Department of Health 2001; 2002)

Monitor and Review

- Review and improve communication channels between GPs and hospital consultants with expertise in learning disabilities
- Aggregate evidence from Health Action Plans to inform development of local services

The Partnership Board should work to:

Provide resources

- *Establish the Health Task Group to take forward the recommendations of this report and create an action plan with targets and timescales for implementation.*
- *Ensure that the Partnership Board Executive incorporates work to improve the health of people with learning disabilities in its commissioning plan.*
Increase awareness

• Ensure a training programme for health facilitators is offered and evaluated
• Ensure that training for staff in mainstream health services is expanded and that children’s services are included in this
• Work with the PCT to ensure that all GPs are aware of the GP toolkit and of how to meet the needs of people with learning disabilities.
• Promote Health Action Plans in work relating to Person Centred Plans
• Develop local protocols for information-sharing based on the most recent government guidance (Department of Health/Cabinet Office 2006)
• Work with the PCT to develop a city-wide database of people with learning disabilities that can be used to offer health facilitation and Health Action Plans

Stimulate action

• Identify priority areas for mainstream services and promote collaborative projects between these services and the Learning Disability Teams for adults and children

Monitor and Review

• Ensure the inclusion of people from minority ethnic communities, people with complex needs and family carers in all health-related activity
• Ensure that service users, family carers and groups that represent their interests are involved in decisions about healthcare policy and practice relating to people with learning disabilities
• Monitor needs identified by Health Action Plans and use these to inform planning of local health and social care services
• Ensure that systems are in place for regular audit and review of Health Action Plans

Learning Disability Services should work to:

Provide resources

• Review skills and knowledge within Learning Disability Teams and ensure team members are equipped to carry out health facilitation activity
• Ensure that GPs and other healthcare providers are aware of the support that is available from Learning Disability Teams and can contact a named individual
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Increase awareness

- Work with the Partnership Board and PCT to ensure training for health facilitators. This should promote understanding of the need to create a ‘circle of support’ around individuals and to address determinants of health that may affect them. Training should also provide an overview of health and social care services in the area.
- Continue and expand training to staff in mainstream services to raise awareness about the health needs of people with learning disabilities.
- Train learning disability staff carrying out other forms of assessments (e.g., Person Centred Plans) to ensure these incorporate all elements of a good Health Action Plan.
- Work with relevant colleagues within the PCT to ensure that training covers the needs of people from minority ethnic communities and family carers of people with complex needs (particularly older carers).

Stimulate action

- Collaborate with voluntary sector organisations and their umbrella groups to ensure Health Action Plans will be implemented and reviewed.
- Nominate named people for each area of the city and work with practices to identify people with learning disabilities and carry out health checks and Health Action Plans.
- Promote tools and best practice from other parts of the country that help meet the needs of people with learning disabilities.

Monitor and review

- Ensure that Health Action Plans focus on the priorities of people with learning disabilities and their family carers and that support is provided to implement Plans.
The Strategic Health Authority should work to:

Provide resources and raise awareness:

- **Review and improve input on learning disabilities and health facilitation in professional development courses for healthcare practitioners. Make such courses widely available to primary care staff**
- Ensure that training courses for nursing staff incorporate elements of the curriculum for learning disability nurses and include opportunities for interprofessional learning
- Ensure that all healthcare providers have a named lead for learning disabilities and that these leads report regularly on learning disabilities through their management structures

Take a lead role in:

- **Stimulating activity on learning disabilities and health in PCTs and acute trusts**
- **Monitoring activity on learning disabilities and health in PCTs and acute trusts**

The Department of Health and the Office for Disability Issues should work to:

Provide resources

- **Produce joined-up policies that build Valuing People health targets into other areas of health policy such as National Service Frameworks.**
- **Clarify responsibility for delivering these targets through national guidance**
- **Provide incentives for GPs to offer health facilitation through, for example, National Enhanced Services and the Quality and Outcomes Framework.**
- Clarify ways in which health policies such as Practice-based Commissioning and ‘Choose and Book’ can be used to take forward Valuing People health targets

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2 Since this recommendation was developed the Department of Health has undertaken to provide such guidance (Department of Health 2007)
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Increase awareness

- Promote guidance on information-sharing protocols to Partnership Boards and provide support to areas wishing to develop these
- Strengthen the evidence-base for health facilitation by commissioning research in relation to each step of the process

Stimulate action

Ensure that Valuing People health targets are promoted through work relating to the Disability Discrimination Act 2005.

Monitor and review

- Monitor and report progress on Valuing People health targets
- Review current mechanisms to monitor implementation of generic health policies for inclusion of people with learning disabilities
- Collaborate with the Healthcare Commission to address ethnicity in the improved clinical measures for learning disability (Whitty et al 2006)
- Collaborate with the Commission for Social Care Inspection and the Healthcare Commission to monitor access to health promotion and health checks through the forthcoming performance assessment framework
- Review learning disability components of generic health professional education courses and work with professional bodies to extend these where necessary.

3 http://www.csci.org.uk/care
Chapter 1: Background to this research

The causes of poor health in people with learning disabilities are diverse. A higher biological risk of chronic medical conditions such as thyroid dysfunction, respiratory disease and mental health problems combine with discriminatory structures and practices that act as barriers to accessing appropriate healthcare (Elliott et al 2003; National Patient Safety Agency 2004). Individuals with learning disabilities are less likely to have health checks, use surgical hospital services, have their sight or hearing tested or receive appropriate health promotion advice (Healthcare Commission 2005).

There is an above average death rate among younger people with learning disabilities, however, as life expectancy increases, age-related diseases such as heart disease, chronic respiratory disease and cancer are of particular concern (Elliot et al 2003). Higher mortality rates from coronary heart disease, the second most common cause of death for people with learning disabilities (Hollins et al 1998), highlight an additional factor, relating to the need for support in managing medication and changes to lifestyle (Alborz et al 2003; Lunsky et al 2002).

Inappropriate medication and restraint is a further issue in relation to people with challenging behaviour, who are likely to be treated with psychotropic drugs despite the lack of a psychiatric diagnosis (ARC 2005; National Patient Safety Agency 2004). There is evidence that people with learning disabilities also experience ‘diagnostic overshadowing’, that is, reports of physical ill health being treated as a consequence of learning disability, and so not investigated or treated (Disability Rights Commission
This indicates that current figures for ill-health amongst people with learning disabilities may be even higher than has been estimated (ibid).

Poor access to health services is often a consequence of inadequate professional training; however, raising awareness about the health needs of people with learning disabilities appears, on its own, to have little impact on increasing GP activity with learning disabled patients (Jones and Kerr 1997). From practitioner perspectives, the issue of consent to screening or surgery is fraught with difficulties (Wilkins 2004) and, consequently, often avoided. Women with learning disabilities are, for example, much less likely to be invited to breast or cervical cancer screening than women in the general population (Pearson et al 1998; Stein et al 1999). There is evidence that some forms of screening are less acceptable to many women with moderate to severe learning disabilities (Biswas et al 2005). Studies also demonstrate, however, that discriminatory judgements about the value of people with learning disabilities are implicated in lower referral rates for screening and in higher mortality and morbidity rates for a range of conditions (Pearson et al 1998; Mencap 2004).

In areas that determine health, such as material capital, social integration and support, education and employment (Scambler 2002) there is evidence that people with learning disabilities face considerable disadvantage (Sutherland et al 2002). They are more likely than the general population to live in poverty, to have no educational qualifications, to be economically inactive and to experience problems with housing and hate crime or harassment, particularly if they also have mental health conditions (Krahn et al 2006; Cabinet Office 2005).

The resulting health inequalities mean that many people with learning disabilities have high levels of unmet physical and mental health needs. Within this population, specific groups of people have been shown to be particularly affected. People from minority ethnic communities face both disability discrimination and racism so that the higher rates of mortality and morbidity are even more pronounced (Chaplin et al 1996; Mir et al 2001). Some, particularly Asian, communities suffer higher levels of poverty, social isolation and poorer health than people with learning disabilities as a whole and have higher support needs (Emerson et al 2005). People with profound and multiple disabilities and those discharged from long stay hospitals may also need
specific attention in policy and practice because of the high level of healthcare they generally need (PMLD Network 2002; Chambers et al 1998).

The poor development of practitioner skills in mainstream healthcare has to some extent been sustained by specialist learning disability services. These have often sought to provide all necessary healthcare so that mainstream health services do not see people with learning disabilities as their responsibility. In some areas Community Learning Disability Teams have tried to provide a parallel service to mainstream healthcare (Mencap 2004). The quality of healthcare offered through specialist services has, however, been problematic. Inspection has revealed significant inconsistencies; at best a comprehensive range of accessible health services such as occupational and speech therapy, clinical psychology and psychiatric support can be in place. At worst, one or more of these services may be unavailable, usually because of recruitment difficulties (Cope 2003). Partnership arrangements with mainstream healthcare services are often underdeveloped and links with GPs are considered very good or good by only about 15 per cent of learning disability staff (ibid).

Despite the general evidence that primary care services are not generally making ‘reasonable adjustments’ in accordance with the Disability Equality Duty introduced in December 2006 (HMSO 2005), the Disability Rights Commission’s Formal Inquiry into health inequalities indicated that good practice could also be found. Simple changes to routine procedures could greatly enhance access to healthcare, such as making appointments by email, providing treatment information in alternative formats or sending text or phone appointment reminders (Disability Rights Commission 2006).

The various causes of health inequalities affecting people with learning disabilities make finding solutions to address them complex (Krahn et al 2006). Policy responses to the issues outlined in this section are explored below.
The policy context

Valuing People

The White Paper, *Valuing People*, set out the Government’s strategy in relation to service support for every aspect of a learning disabled person’s life and for family carers (Department of Health 2001). The strategy attempted to stimulate mainstream health service development by setting out a number of key actions relating to known health inequalities affecting people with learning disabilities. These actions included ensuring that mainstream hospital services were accessible and exploring the feasibility of a confidential inquiry into mortality among people with learning disabilities. The development of local specialist services for people with severe challenging behaviour was also identified as a priority for the capital element of the Learning Disability Development Fund. This was intended to reduce the high personal and financial cost of placements for such individuals outside the local area. A promise that discrimination against people with learning disabilities from minority ethnic communities would be addressed was also included in the key actions for health.

The strategy envisaged that National Service Frameworks (NSFs) in the area of coronary heart disease, diabetes, older people and long term health conditions (including epilepsy) would be applied to people with learning disabilities as to anyone else. Specific reference was made to including women with learning disabilities in national screening programmes relating to the National Cancer Plan (NHS 2000).

Similarly, the White Paper made links to the Mental Health National Service Framework, stating that people with learning disability and mental health problems would have their care managed under the Care Programme Approach, used for mental health patients. The four principles of this approach are: assessment, a Care Plan, care co-ordination and review. *Valuing People* specified that care co-ordinators should have expertise in both mental health and learning disabilities and that close collaboration between psychiatrists in each speciality would be required. Specialist staff from learning disability services would, if necessary, provide support in crisis resolution or to enable service users to avoid hospital admission.

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4 A fund set up by the Government to support implementation of *Valuing People* (Department of Health 2001)

5 http://www.cpaa.co.uk/
The White Paper also stated that mental health promotion materials and information about mental health services would be provided in an accessible format for people with learning disabilities, including those from minority ethnic communities. It was anticipated that strategies for improving access to education, housing and employment to promote mental wellbeing would include people with a dual diagnosis of learning disabilities and mental health problems. The White Paper stated that clear local protocols would be in place for collaboration between specialist learning disability services and specialist mental health services.

A new role was identified for specialist learning disability services in the strategy, aimed at making the most effective use of their expertise. This involved supporting people to access mainstream services and ensuring continuity of provision and appropriate partnership between different agencies and professions. Specialist staff were expected to give less time to direct interventions and more time to developing the capacity of staff in mainstream services to support those with complex needs. In addition to their clinical and therapeutic roles specialist staff were instructed to take on:

- a health promotion role; working closely with the local health promotion team;
- a health facilitation role; working with primary care teams, community health professionals and staff involved in delivering secondary health care;
- a teaching role; to enable a wide range of staff, including those who work in social services and the independent sector, to become more familiar with how to support people with learning disabilities to have their health needs met;
- a service development role; contributing their knowledge of health issues to planning processes.

(Department of Health 2001)

Three actions outlined in *Valuing People* had specific time limits for implementation. These stated that every person with a learning disability should:

- be offered a named health facilitator by Spring 2003
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- be registered with a GP by June 2004
- have a Health Action Plan by June 2005

It is these three targets in particular that we explore in this study, although they are linked to other key actions highlighted above. The specific guidance provided in relation to health facilitation and Health Action Plans is outlined below.

Guidance on Health Facilitation and Health Action Plans

The good practice guidance on implementation for Learning Disability Partnership Boards (Department of Health 2002), identifies how a wide range of individuals and organisations might be involved in developing and implementing Health Action Plans. These are listed as:

“the person with learning disabilities, support staff in housing and day service provision, family members, advocates and self advocacy groups, specialist learning disability health professionals, physiotherapists, speech and language therapists, occupational therapists, chiropodists, dieticians, pharmacists, practice nurses, GPs, dentists, optometrists, audiologists and other health professionals, health promotion workers, social care agencies and professionals, including care managers, other agencies and professionals (education, housing, leisure services etc.), Patient Advice and Liaison Services, NHS Direct and voluntary organizations”

(Department of Health 2002)

The role of primary care, however, is identified as being of particular importance. Good practice examples describe Practice Nurses carrying out health assessments and assisting in the production and implementation of Health Action Plans. GPs are presented as identifying people with learning disabilities on their practice lists in order to offer health facilitation, checking plans that have been initiated by family members or advocates, keeping copies of these in patient records and writing in the document itself details of advice they have given to the person with learning disabilities about other health services they can access. The guidance outlines how primary care professionals might collaborate with other services such as health promotion teams
and PCT leads for health facilitation. It is suggested that a pragmatic starting point to the assessment of who should be offered a Health Action Plan is to include people who use, or who have used learning disability services via, for example, special schools, day centers and Community Learning Disability Teams.

General practices are identified as the most appropriate service to take responsibility for ensuring that everyone is offered a Health Action Plan, ‘with help from Health Facilitators if necessary’. Health Facilitators are expected to support GPs to identify people with learning disabilities on their practice lists. The use of Read-codes and record-sharing with Community Learning Disability Teams are suggested as the mechanisms by which people with learning disabilities will be identified and the guidance indicates that ethnic group should also be identified during this process.

The guidance also promotes the idea that people may only need a Health Action Plan during transition periods in their life. Howatson (2005) notes, however, that long periods of time may elapse before a person goes through a stage of transition and views on what constitutes a transition may differ. Adopting this criteria may consequently increase the risk of healthcare needs being overlooked and unmet.

Where plans relating to Transition, the Care Programme Approach or Person Centred Plans exist, the guidance promotes incorporation of Health Action Planning into these existing documents to make them more comprehensive and holistic. In such cases the professional who knows the person with learning disabilities best is presented as the most appropriate person to facilitate the Health Action Planning process. Case studies provided recognise that this individual may need support from a Community Learning Disability Nurse\(^6\) to develop an effective and person-centred document.

At a more strategic level, Primary Care Trusts and Partnership Boards are advised to collaborate in ways that support the writing and implementation of Health Action Plans. The guidance envisages PCTs organising training seminars and collaborating with Partnership Boards to ensure investment in relevant resources and personnel,

\(^6\) or Community Psychiatric Nurse depending on local arrangements
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including a Health Facilitator post in each PCT and a named point of contact for each general practice.

Although a person with learning disabilities and her circle of support is described as initiating the Health Action Plan in one example, professional input to facilitate or at least check the process is described in all cases. Furthermore whilst the term ‘health facilitator’ is recognized as applying to lay roles, it is often used in ways that describe a strategic or support role that is more likely to be adopted by a professional. For example, feeding back knowledge of systems and services to the Partnership Board, becoming involved as part of a protocol around transition and identifying or creating resources when these are difficult to access. Caan et al (2005) note, however, that the specific skills and experience needed for this role are not described.

**Related policy initiatives**

In order to fully understand the impact of policy targets, it is important to take account of other initiatives that might influence implementation (Pawson 2003). These affect not only the climate in which health facilitation is expected to work but also the expectations and motivations of key stakeholders. This section outlines a number of policy initiatives of relevance to health facilitation during the fieldwork period.

**Priorities and Planning Framework**

The Department of Health’s Priorities and Planning Framework for the period 2003-2006 (Department of Health 2002b) set down what the NHS was expected to prioritise and deliver over these years. Strategic Health Authorities were consequently charged with developing ‘Local Delivery Plans’ in line with this framework, based on plans prepared by Primary Care Trusts.

The Framework contained no specific reference to people with learning disabilities. In response to this omission, the implementation team set up following the publication of *Valuing People* circulated an additional document (Valuing People Support Team 2002). This emphasised that the Framework applied to the general population and

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7 For clarity, title case is used to indicate a paid professional acting in this role and lower case for a wider definition of health facilitator.
so should include people with learning disabilities. The document was directed at PCTs, Partnership Boards, Strategic Health Authorities, Learning Disability leads and leads for specific areas prioritised in the Framework. It summarised the health inequalities facing people with learning disabilities and offered suggestions on possible local actions that could ensure these were addressed. In addition a number of resources to aid implementation were placed on the Valuing People Support Team website.

A second Framework for the period to 2008 (Department of Health 2004) similarly omits specific reference to learning disabilities but includes a statement about the need to set local targets alongside the national targets contained in the Framework.

1) National Service Frameworks

As highlighted earlier, *Valuing People* (Department of Health 2001) anticipated that National Service Frameworks (NSFs) in the area of coronary heart disease, diabetes, older people and long term health conditions (including epilepsy) would be applied to people with learning disabilities as to the general population. The White Paper also pointed to specific inclusion in the NSF for Mental Health and of women with learning disabilities in the National Cancer Plan.

However, only a general reference to learning disability is made in these NSFs, for example in relation to Mental Health (NHS 1999) the policy states:

> The needs of minority groups should be carefully considered, including women, young people, people from black and minority ethnic communities, people with substance misuse problems as well as mental illness, personality disorder, or with a combination of learning disability and mental illness.

Implementation guidance on dual diagnosis published a year after *Valuing People* (Department of Health 2002c) deals with substance abuse and mental health and makes no reference to learning disability. Nor does it detail how implementation will address the objectives of *Valuing People* in relation to Health Action Plans,

8 [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)
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collaboration between psychiatrists and staff from learning disability services, accessible health promotion information or strategies to promote mental wellbeing in people with learning disabilities and mental health problems. Given the specific references to this NSF in the Valuing People White Paper, the reason for these omissions is unclear.

A similarly superficial approach to inclusion is echoed in the NSFs for Diabetes and related updates on implementation (Department of Health 2001b; 2003; Roberts 2006) and Coronary Heart Disease (NHS 2003). These refer to the importance of accessible and responsive services but do not address the question of how these will be achieved in practice.

The NHS Cancer Plan includes similar injunctions about appropriate and accessible information but does include a specific action. A working group to draw up national guidance and accessible booklets on screening for women with learning disabilities aimed to publish these by 2001. Accessible booklets were published in 2000 and 2006 and professional guidance was published in 2006 (NHS Cancer Screening Programme 2000; 2006a; 2006b).

The NSF for Long Term Conditions (Department of Health 2005) identifies learning disabilities as sometimes related to the conditions to which the NSF applies. Again, however, there is no mention of Health Action Plans or health facilitation in the care planning process described, although this appears to be extremely similar to health facilitation for people with learning disabilities:

The care plan needs to be developed and agreed with the person and, subject to their agreement, with their carers and/or an advocate. The care plan is owned by the person, and the relevant multidisciplinary team members review it regularly with them. The professional developing the care plan has a role to help the person navigate their way around the health and social care system (Department of Health 2005)

Evidence based markers of good practice also bear similarities to the expectations of Valuing People that service users with complex needs have a named individual who
is responsible for coordination and will produce a care plan (ibid). Work to produce a care planning guidance document for frontline NHS staff by the end of 2006 is highlighted and the NSF promotes Personal Health Plans developed through “shared decision-making between patients and healthcare professionals in the design of a package that meets the patient’s individual needs” (Department of Health 2005).

The new NHS ‘Life Check’, mentioned in relation to the NSF for Diabetes also bears similarities to the kind of screening mentioned in guidance on Health Action Plans (Department of Health 2002). ‘Life Checks’ are, however, self-assessments and only lead to contact with a ‘Health Trainer’ if they show that an individual is at risk of poor health.

From this sample of the NSFs, it would appear that these have not made significant links to the health facilitation processes outlined in Valuing People, despite their stated focus on addressing health inequalities and the potential for pulling together similar strands of government policy in related areas of health. It is also worth noting that, whereas the White Paper refers to these frameworks as including people from minority ethnic groups who have learning disabilities, the NSFs themselves do not consider the issue of ‘double discrimination’. People with learning disabilities and people from minority ethnic communities are described as two distinct groups, both of which receive marginal attention.

**Public Health White Papers**

Two health-related White Papers were introduced during the period in which this study took place. ‘Choosing Health’ (Department of Health 2004b) sets out action to address inequalities in health that focus particularly on getting information across to people in different groups and securing better access to healthier choices for people in disadvantaged groups or areas. The White Paper acknowledges that the experience of health can be determined by factors such as the environment, social networks, an individual’s sense of security, socioeconomic circumstances and by facilities and resources in the local neighbourhood. It promotes health checks and Health Action Plans, citing a good practice example in which Health Action Plans were received by 92% of people with learning disabilities in one primary care centre. The White Paper further promotes support for cookery clubs and food co-ops to encourage fruit and vegetable consumption to tackle obesity. It also includes a target
to provide practical support for people who lack basic skills to help them use health information, including signposting to programmes tailored to meet these needs (ibid).

‘Our health, Our Care, Our Say’ (Department of Health 2006) includes a number of more specific references to learning disabilities. PCTs are encouraged to improve the ways in which Child and Adolescent Mental Health Services (CAMHS) meet the needs of learning disabled children and to ensure a seamless transfer from CAMHS to adult services. A new role of Practitioner with Special Interest (PwSI) for learning disability and one for adolescent health focusing on disabled children and transition is created and pilots promised, though no dates for when they will be run are given. A Department of Health update on progress in pilot sites since the White Paper was published (Department of Health 2007a) shows that this target was not piloted, but that sites of best practice have been assigned to “Spearhead PCTs”, which are developing PwSI services.

Spearhead PCTs is the term used in the White Paper for the 88 most health deprived Primary Care Trusts which are given extra money to target focused action against health inequalities. Some of these sites will pilot ‘NHS Life Checks’ leading to follow up appointments with ‘health trainers’ or clinicians where necessary. The process described appears very similar to that of health checks leading to Health Action Plans and the involvement of a Health Facilitator (Department of Health 2002).

As in the Department of Health guidance on Health Action Plans, access to services and a focus on prevention is promoted, and health trainers are expected to tackle growing trends in obesity - a significant issue for people with learning disabilities (Disability Rights Commission 2006).

A renewed commitment to regular, comprehensive health checks for learning disabled people and reviewing the best way to deliver on this was also made in this White Paper. New measures for health to be included in the Quality Outcomes Framework (QOF), through which GPs are paid, aim to be established in 2008/09.

A focus of the policy is the significance of support for people with learning disabilities to live in community based housing and a target is set to end NHS residential accommodation by 2010.
More general initiatives contained within the White Paper are also relevant to people with learning disabilities, such as Personal Health and Social Care Plans for those with both social care needs and a long-term condition and pilots to determine how best to join up health and social care information for service users. It remains to be seen how well these will be applied in practice to meeting the needs of people with learning disabilities.

There has been some criticism that the White Paper places too much emphasis on choice rather than on improving services that already exist. There is also a concern that the focus on NHS residential accommodation has resulted in a lack of attention to other areas that determine health and are of wider relevance, such as education, employment and leisure (Allen 2006).

This criticism is to some extent addressed in a resource pack for PCTs and Local Authorities working to improve health in deprived neighbourhoods, produced since the publication of the two White Papers (Department of Health/ Office of the Deputy Prime Minister 2007). The pack emphasizes the need to tackle severe health inequalities through a focus on other forms of disadvantage. The need to specifically include people with learning disabilities is mentioned in relation to Local Authorities making data available to help planning and delivery of services. There are also specific references in relation to access to information, advocacy and screening services. The importance of including people from minority ethnic communities is also highlighted alongside people with learning disabilities in these examples, however, the overlap between disadvantaged groups is not acknowledged.

**The Valuing People Support Team**

As highlighted earlier, an implementation team was set up following *Valuing People* (Department of Health 2001). The team reviewed and consulted on progress in 2005 and confirmed the need to take further action on health inequalities. It pledged to address the inclusion of people with learning disabilities with the National Directors of each NSF and to support the NHS to fulfil its duties under the Disability Discrimination Act (HMSO 2005). It also highlighted the significance of NHS ‘star ratings’ in encouraging senior managers to improve services and the absence of these in relation to learning disabilities. Action to link up with delivery programmes
for other policies, such as mental health and children, in the ‘Care Services Improvement Partnership’, of which the VPST is a part is also promised.

**The Healthcare Commission**

The Healthcare Commission has also stimulated a good deal of activity in relation to services for people with learning disabilities since its appointment of an Advisor for Learning Disabilities in 2005. Following this, a draft three year strategy was produced (Healthcare Commission 2005). This promoted general initiatives to improve the health of people with learning disabilities on which the Commission subsequently consulted widely. A majority of responses indicated that the Commission should check how many Health Action Plans, and health checks have been carried out in England. There was also significant support for asking health services how they are improving services for people with learning disabilities, including people from minority ethnic groups and people who also have mental health problems. A sense of urgency was added to the work planned by the Commission as a result of its investigation of services for people with learning disabilities in Cornwall (Healthcare Commission 2006). The investigation revealed substantial levels of abuse and services that were unregistered and below national standards (ibid). This evidence has prompted a national audit of NHS and independent health care provision for people with learning disabilities. It is intended that an agreed percentage of all action plans from the audit will be examined in detail and that a report on the Commission’s work around learning disabilities will be produced around October 2007.

The Healthcare Commission has also incorporated clinically relevant measures of performance (or ‘metrics’) relating to certain health conditions and population groups into its standards and assessment frameworks. These are used to review service improvements - for example, in relation to mental health, heart failure and diabetes (Whitty et al 2006). The measures for learning disabilities have not yet found their

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9 Information given during a presentation by the Advisory on Learning Disability at a meeting of the Healthcare Commission Advisory Group on Learning Disability
10 Information given during a presentation by the Advisor on Learning disability at a workshop held by the research team
way into the mechanisms for assessing PCTs and allocating resources, apart from one which was included in the Quality Outcomes Framework for 2006:

The practice can produce a register of patients with learning disabilities

(NHS Employers/BMA 2006)

Other measures which have been proposed as indicative of the standard to which Trusts should be providing services to people with learning disabilities include:

- the number of people with learning disabilities with or offered a comprehensive health check prior to a Health Action Plan
- a system for identifying local health facilitators
- a system within each PCT to review the treatment plans of patients in NHS funded hospital beds at least annually by a qualified clinician
- a system and protocols to ensure that people with learning disability and mental health needs are able to swiftly access local mental health services
- screening for dysphagia and a plan that is regularly reviewed
- a regular survey of patient information to ascertain its accessibility to people with learning disability and their family carers
- a system in acute hospitals to ensure patients with learning disabilities are identified and appropriate support provided
- access and take up rates are monitored by the PCT Executive board quarterly for people with learning disabilities to check and promote equal access to benefits in mainstream services, NSFs and plans.

(Whitty et al 2006)

**The Disability Rights Commission**

In 2005 the Disability Rights Commission reported on a formal inquiry into health inequalities affecting people with learning disabilities in England and Wales. The Inquiry confirmed existing evidence about higher rates of mortality and morbidity and found an inadequate response from the health services and governments in England and Wales to the major physical health inequalities identified (Disability Rights Commission 2005). Alongside these findings it documented models of good practice and recommended that governments in England and Wales lead improvements in access to primary care and health checks through the GP contract, commissioning guidance and screening programmes.
The Inquiry’s recommendations to government also included health professional training at key career points and targeting people with learning disabilities in national health inequalities programmes. Commissioners were urged to include people with learning disabilities in local strategic assessments of needs and primary care providers encouraged to offer a range of personalised adjustments such as different appointment times and lengths, text or telephone appointment reminders and accessible appointment cards. Regular health checks for people with learning disabilities along with health promotion activity and partnerships with local disability groups for advice and training were also recommended to primary care teams. The report suggested that health checks be made routine through Health Action Plans when people were first seen by Community Learning Disability Teams.

The report noted that the commitments made in *Valuing People* to addressing health inequalities had not been followed through in other areas of health policy which could provide circular references back to the White Paper rather than setting targets that would achieve its aims. A lack of monitoring activity was also noted and the absence of any mechanism by which to evaluate whether the targets set in *Valuing People* had been met (ibid).

The Department of Health’s response to recommendations by the Disability Rights Commission (Department of Health 2007) refers to recently published guidance for inclusive commissioning. It also indicates that new guidance will be issued to clarify the role of specialist mental health and learning disability providers in enabling access to mainstream primary care. The response exhorts PCTs and Strategic Health Authorities to include person-centred Health Action Plans as part of mainstream health promotion activity and adopt inclusive approaches to screening. GPs are encouraged to ‘engage with the government policy of health action planning for people with learning disabilities’ and complete Health Action Plans to appropriate clinical standards. It is envisaged that the new guidance and the GPs legal duties under the Disability Discrimination Act 2005 will facilitate such engagement.

The response also commits the Department of Health to working with the NHS, the sector skills council for health and social care, regulatory bodies and education commissioners to consider how to address ‘diagnostic overshadowing’ in educational
training. Ways of supporting local self advocacy groups to develop and run local training programmes for NHS staff are also to be explored.

The Department’s response further refers to work commissioned by the NHS Primary Care Contracting Team to help PCTs commission health checks for people with learning disabilities in general practice. A framework for this is expected to be available in 2007/08. Access to regular health checks for people with learning disability is expected to be a future priority for GP contracts. DRC recommendations relating to the needs of specific populations that experience multiple discrimination were not addressed in the Department of Health response, although reference is made to an equality impact assessment of its guidance on commissioning and to PCT commissioning responsibilities.

**Conclusion**

This overview of policy suggests that much of the change outlined in the government’s learning disability strategy and associated guidance is currently likely to occur in pockets rather than at the level of systems. The two White Papers described in this section (Department of Health 2004; 2006) provide support to the health facilitation targets outlined in *Valuing People* by means of promoting best practice in relation to how people with learning disabilities should experience healthcare and other areas that determine health. With the exception of the recent single target included in the Quality Outcomes Framework (BMA/NHS Employers 2006), however, there is a noticeable absence of supportive targets in frameworks through which health and social care services are monitored and held accountable.

Nevertheless, plans to extend the inclusion of measures relating to people with learning disabilities in the QOF (Department of Health 2006) and the comprehensive range of measures developed by the Healthcare Commission are positive signs that the vision of improved health for people with learning disabilities outlined in *Valuing People* may be receiving increasing policy support.

**Addressing multiple exclusion**

The extent to which learning disabled people from minority ethnic communities and those with complex needs are included in the policies outlined in this section is an
important consideration, given the even worse health inequalities they experience (Mir et al 2001; PMLD Network 2002).

Valuing People makes a significant number of references to the unmet needs of minority ethnic groups and the legal obligation of public bodies to ensure these are addressed (Department of Health 2001). However, in terms of its own targets, the White Paper set only one that was directly relevant to addressing the inequalities experienced by these communities:

Proposed Performance Indicator: the proportion of people with learning disabilities from minority ethnic communities who are receiving services divided by the proportion of all people in the local population from minority ethnic communities

(Department of Health 2001)

Information has been received from less than half of Partnership Boards in relation to this target, indicating that less than a quarter of the expected population of people with learning disabilities from minority ethnic communities are known to services\textsuperscript{11}.

The significance of the Race Relations (Amendment) Act 2000 is highlighted in the guidance document on health facilitation (Department of Health 2002) in relation to people with learning disabilities and family carers from minority ethnic groups. The guidance points out that the Act places a general duty to promote race equality on public bodies, and that they should set out their arrangements for ensuring ethnic minorities have access to information and to the services they provide. Partnership Boards are therefore advised to set specific additional targets to avoid inequality in service delivery and outcomes.

The guidance suggests that local delivery of Health Action Plans needs to address the higher level of health inequalities affecting minority ethnic communities from the start of its implementation programme. There is recognition that disability and ethnicity have traditionally run as separate strands through policy and practice rather than being brought together as related issues. A change in the climate of traditional

\textsuperscript{11} See www.valuingpeople.gov.uk/ethnicity
practice is therefore encouraged to achieve inclusion and the need for clarity about who has responsibility for the different aspects of service provision is underlined (Department of Health 2002).

Examples of appropriate actions that Partnership Boards can take include gathering local demographic information and using population data that is broken down by ethnicity during the planning and review of health facilitation activity. Recruiting a diverse range of health facilitators, translating Health Action Plan material into community languages, allocating specific responsibility for this area of work at a high level and establishing structures of accountability are also encouraged. The need for Partnership Boards to have adequate mechanisms to consult and represent people from minority ethnic communities is highlighted.

In relation to people with complex needs, the guidance suggests that specialist health professionals are likely to be needed to develop Health Action Plans and ensure multi-disciplinary and multi-agency co-ordination. Individual Health Action Plans may need to be supplemented by joint professional records, and efforts should be made to avoid multiple forms of planning through a shared assessment framework where possible (Department of Health 2002).

A particular emphasis is placed on communication, both between those involved in health facilitation and with the service user, through communication equipment and sign language or other methods. The need to make environments more accessible to people with complex needs is also highlighted. Information, training and support for primary health care providers and the Patient Advice and Liaison Service is described as essential to ensuring equality of access and outcome. Partnership Boards are advised to ensure that budgets are in place for all these areas of development and for the proper representation of this group of service users in decision-making and consultation bodies.

The standards set by the guidance on health facilitation (Department of Health 2002), have not, however, been consistently echoed in national activity relating to implementation. For example, there is no reference to ethnicity in the improved clinical measures promoted for learning disability (Whitney et al 2006), though measures for other conditions are inclusive (for example in relation to heart disease,
diabetes and mental health and in results from patient satisfaction surveys). People with complex needs are included to some extent; as highlighted earlier, measures refer to protocols for those with mental health needs and specific plans for dysphagia.

Opportunities to address multiple exclusion have also been missed in the National Service Frameworks (see above) and in the revised Quality Outcomes Framework. Although the latter promotes identification of all people with learning disabilities, only new patients are required to be included in the ethnic breakdown of practice lists. It will not therefore be possible to identify people with learning disabilities from minority ethnic communities in most cases. This inconsistency in addressing multiple exclusion suggest that inclusion needs to be taken seriously in terms of national implementation as well as local activity. Otherwise health facilitation activity has the potential to widen health inequalities already experienced by people from minority ethnic communities and people with complex needs.

Existing evidence on health facilitation, Health Action Plans and health screening

Health Facilitation

The Valuing People Support Team review (2005) noted a number of mechanisms through which health inequalities amongst people with learning disabilities are more likely to be addressed, many of which relate to strategic health facilitation activity. These include mainstream health plans that are inclusive and collaboration between learning disability leads in Primary Care Trusts, Strategic Health Authorities and other agencies, although the review notes that this is rare. Allocation of financial resources also help progress, from government spending on the NHS and from funds to implement Valuing People. The review promotes local plans led by Primary Care Trusts and developed through Partnership Boards as well as dedicated time to develop knowledge as additional and vital mechanisms for change.

There is evidence that dedicated posts for health facilitation have made a positive contribution to addressing gaps in current services and made a noticeable impact on quality and efficiency of care. Caan et al (2005) describes the appointment of a Health Facilitator to improve transition planning for school leavers with learning disabilities, which had been identified as a local need. Developing 'signposting' and appropriate referral systems for young people led to improved access to adult
services but required a high level of skill both in terms of providing continuity across a wide range of services and linking with other skilled professionals. An evaluation of the service has led to developments within local services and shaped future workforce planning (Caan et al. 2005). Recommendations from the study include shared central records of care for people with learning disabilities and that common health needs from these are audited and used to develop service provision further (Caan et al. 2005).

In terms of individual health facilitation, Matthews (2003) suggests that carers are in the best position to recognize changes in behaviour and that, in partnership with a specialist learning disabilities nurse and with appropriate training, a person’s key worker would be the ideal health facilitator. Corbett et al. (2003) suggest that all mainstream health professionals should be responsible for addressing the health needs of people with learning disabilities. The views of people with learning disabilities themselves indicate that choice is important and a wide range of individuals, including family members and voluntary sector staff could potentially act as health facilitators (Smith et al. 2004). This wider approach is endorsed by Valuing People (Department of Health 2001), which states that staff, relatives and carers who live and work with people with a learning disability on a day-to-day basis are in an ideal position to influence their health, and have a responsibility to do so.

Training and education of carers is seen as essential for those taking on this role to improve awareness of, and attitudes towards, all aspects of health (Matthews 2005) and there is evidence that ongoing support from community learning disabilities services is also needed (Corbett et al. 2003; Davis 2005). Training requested by health professionals has focused on communication issues (Marsden et al. 2006; Powrie 2003) and dealing with health needs related to independent living skills, such as diet and budgeting, which primary care teams may feel are outside their remit (Powrie 2003). Kerr (1996) suggests that carer education is more likely to affect service uptake and, ultimately, the quality of life experienced by people with learning disabilities.

There is evidence that collaboration between community learning disability staff and other health professionals may not, however, be straightforward. Hames and
Carlson (2006) demonstrate that primary health care staff lack knowledge of the role of community learning disability teams and are confused about which professionals are within the team. In particular there is poor awareness of their role in relation to health facilitation and health promotion. The authors also point to a large body of evidence that indicates GPs (as opposed to primary health care staff) are reluctant to undertake further training on learning disabilities. They would, however, like more information about specialist services and key contacts that would make advice and support easily accessible (Hames and Carlson 2006).

**Identifying people with learning disabilities**

There are a number of ethical and practical problems associated with identifying people with learning disabilities in an area (Whitaker 2004). There is also evidence that general practices may be concerned about labelling individuals and unclear about the definition of learning disability (Kippax 2006). However, the creation of a ‘register’ of patients with learning disabilities may also be seen by practice staff as a first step to enhancing their own awareness of the needs of people with learning disabilities (Alborz 2005). In one study of over 40 women with learning disabilities it was felt acceptable to have a label of a learning disability in health care notes, to indicate that individuals may need support (Levi et al 2004). There is evidence that, once the process has been completed, practice staff consider maintaining a register to be relatively straightforward (Alborz 2005).

Current work to identify the numbers of people with learning disabilities in general practices indicates wide variations, from between 0.001% and 2% of list size (ibid; Westminster PCT 2006). However, Whitaker’s (2004) review of prevalence studies notes wide variations in estimated prevalence, relating to the definition of learning disabilities and data sources used. Where data is taken only from existing users of learning disability services, studies report between 0.23% and 0.29% of the population are registered as having a learning disability. Where the dual criteria of intellectual and adaptive functioning is adopted – as in the White Paper – the best evidence suggests prevalence is likely to be around 1% of the population (ibid). Using IQ tests alone brings prevalence rates closer to 2.5%. Confusingly, the White Paper quotes this higher prevalence rate alongside the dual criteria definition (Department of Health 2001).
Health Action Plans

Matthews (2005; 2006a 2006b) argues that the engagement of GPs and PCTs is not a necessary prerequisite of developing Health Action Plans. He is critical of health and social care professionals who insist on the principle that GPs and PCTs should take prime responsibility for implementing *Valuing People* targets, regardless of the best interests of people with learning disabilities. Training for care staff in residential and day care settings is again seen as a vital first step, so that they can draw up, deliver and review Health Action Plans covering four key areas: a thorough health check; personal hygiene; regular daily activity and diet:

In this model the Health Facilitator is the central individual responsible for ensuring that every client is assessed by direct carers, and providing teaching and support to undertake the role. The Health Facilitator is responsible for developing the Health Action Plan and implementing it, ensuring that those issues that need to be referred to the GP are followed up, whilst those issues that can be dealt with in-house are also attended to. The Health Facilitator is a specific role of an individual covering a specific caseload, service or section of a service.

Basic day-to-day health assessment is carried out by the people who know the individual intimately, and who are in the best position to notice changes.

GP provides the same medical care as is provided to the rest of the community, including screening.

(Matthews 2006a; 2006)

The role of family carers and their relationship with day care staff and Health Facilitators in this model is less clear, however, as is the means by which people with learning disabilities themselves might be involved in deciding what goes in their Health Action Plan.

Howatson (2005) points out that Health Action Plans are not new. As early as 1994, Fitton highlighted the importance of individual plans and care record books as valuable tools for communicating information, acting as a reminder, reference and
guidance document for carers. He recommends that the areas of health identified in the *OK Health Check* for people with learning disabilities (Matthews 1997) should be used alongside more widely applicable *Essence of Care* benchmarks (Department of Health 2003b) to produce a Health Action Plan.

*Essence of Care* mirrors many of the principles outlined in guidance about health facilitation (Department of Health 2002), for example, in relation to communication the benchmark refers to the need for care co-ordination and a comprehensive care plan which is regularly updated and evaluated. Indicators for this benchmark include a named professional who ensures that individuals or their carers can identify both the care co-ordinator and the key agencies providing care. The standards also state that risk groups should be identified locally and highlight the need for vulnerable groups such as people with a learning disability and people from minority ethnic communities to be included. Howatson (2005) suggests that this would ensure policies were being used in conjunction with each other, and that health facilitators are following the most current best practice guidance.

The Valuing People Support Team review of progress on *Valuing People* (VPST 2005) recommended that Health Action Planning be linked to Person Centred Planning (PCP). However, Robertson et al (2005) note that in practice both types of planning are usually regarded as separate processes by health and social care professionals. Integration is more likely to be considered when PCP is undertaken rather than vice versa.

**Health screening and health checks**

Regular health checks have been shown to identify significant unmet health needs amongst people with learning disabilities and there is evidence that subsequent health checks a year later may uncover further, sometime serious needs (Disability Rights Commission 2006; Martin 2003). Although there is evidence that some GPs do offer regular health checks for people with learning disabilities (ibid), Kerr (1996) describes GP opposition to a health promotion role. More recent studies invariably involve considerable support from the community learning disability team and this may be a key factor enabling practice staff to accept and adopt such a role (Alborz 2005; Powrie 2003). It has also been suggested that clinics offering health checks
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should be nurse-led in view of Kerr’s findings and the relatively few individuals who require referral to a GP (Alborz 2005; Martin 2003).

Interventions noted in Alborz’s (2005) study comprised of preventative healthcare, and/or health education and advice and were not felt to add too much to the workload of practice staff. The evidence points to repeated identification of health need and diagnosis of significant health conditions over successive health checks. This indicates a need for regular health checks, rather than the episodic checks at key life stages envisaged by Department of Health guidance (2002). Annual checks were preferred by nurses and family carers involved in the study in view of these findings (Alborz 2005).

Once begun, practices involved in such studies have been positive about continuing a programme of health checks, either in collaboration with the learning disability service or through generic well-person clinics after an initial health check (ibid). Matthews (2005) points out that well-person clinics will not provide the level of screening required by people with learning disabilities. This suggests that collaboration between learning disability services and general practices may need to be resourced for some time, particularly in the absence of directives or incentives for practices to do such work (Alborz 2005). Martin’s (2003) study over a five-year period, however, suggests that reliance on community learning disability nurses may decrease after two years as patients’ health is better managed.
In order to evaluate the effectiveness of the health facilitation policy outlined earlier, it is important to have a clear understanding of what the policy intends to achieve. Pawson (2002) suggests that policies are, in fact, programme theories and evaluating policy initiatives is a process of testing these theories. Using a ‘theory of change’ strategy, researchers may examine each stage of policy implementation and make process observations to test how closely the theory accords to reality. The first important step in this approach is to reconstruct the intended stepping stones of the policy initiative and the sequence in which they must be achieved in order to get the intended outcome. In the case of Valuing People health targets this may be conceptualised as in Figure 1 overleaf.

The figure highlights both levels of health facilitation and the connections between them. Deconstructing the policy in this way reveals the ‘true and awesome complexity’ (Pawson 2003) of an initiative such as health facilitation by making explicit the numerous and varied processes involved and the hypotheses that are implicit within the policy.

In this report we use this conceptual model of health facilitation policy to explore its elements and their intended relationships to each other. We compare this with findings from fieldwork data in order to arrive at an informed judgement on whether the theory behind the policy is effective in practice.
Health Facilitation and Learning Disability

Figure 1: The intended process of Health Facilitation

**LEVEL ONE** (Strategic)

1. **STEP 1**
   - *Lead Health Facilitation post in each PCT and named contact for each general practice*
   - Supports mainstream service development

2. **STEP 2**
   - *PCTs/Partnership Boards provide training and investment*
   - so that health staff, service users and facilitators can gain knowledge, skills and support

3. **STEP 3**
   - *Mainstream service development*
   - more appropriate and accessible services

**LEVEL TWO** (Operational)

1. **STEP 1a**
   - *Identify people with learning disabilities*
   - Lead Health Facilitators work with GPs using read codes and record-sharing

2. **STEP 2a**
   - *GPs offer health facilitation*
   - to all those identified. (Health Screening & Health Action Planning)

3. **STEP 3a**
   - *Health Action Plans produced*
   - in collaboration with service user, health facilitator, carer and involved professionals

4. **STEP 4a**
   - *Service users health needs identified and met*
   - Better health outcomes

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12 Through identifying people with learning disabilities, supporting those involved in developing Health Action Plans, feeding back knowledge of systems and services to the Partnership Board, becoming involved as part of a protocol around transition and identifying or creating resources when these are difficult to access (Department of Health 2002). The term Strategic Health Facilitator is used to differentiate this role from general health facilitation (see next footnote).

13 Responsibility for this is accorded to a wide range of individuals including the person with learning disabilities, family and paid carers, professionals in primary care, specialist learning disability services, social care, specialist health services, education, housing and leisure services. Practice nurses and GPs are described carrying out health assessments prior to developing Health Action Plans where these health needs have not recently been assessed (Department of Health 2002).
The framework also provides a means of integrating qualitative and quantitative findings so that they are able to complement and validate each other (Bryman 2006). Using mixed methods enabled the research team to look both at the impact on outcomes of *Valuing People* health targets as well as at processes that could help explain these outcomes (Becker et al 2006).

Leeds, the fieldwork area for the study, is similar in many ways to the demographic profile for England and Wales as a whole. The age, structure, ethnic origin, economic and health profile of the population is of similar proportions, as is percentage of the population that provides unpaid care to someone with a chronic illness or disability (The Leeds Initiative 2001). The five Primary Care Trusts which operated in the city during the fieldwork period covered a range of socio-economic groups and were of varying size. In one respect the fieldwork area was not typical of others where *Valuing People* may be implemented: the Community Learning Disability Team consisted of around 30 nurses, a much larger team than in most other localities. This difference did, however, enable the research team to explore the significance of this resource to implementation of the White Paper health targets.

**Qualitative study methods**

**Semi-structured interviews**

Qualitative samples for the study were purposive to include all key health and social care stakeholders affected by the introduction of health facilitation. We conducted individual semi-structured interviews with 25 health and social professionals from the fieldwork area. These individuals were drawn from statutory and voluntary provision and included individuals acting as strategic and individual health facilitators, primary and secondary healthcare practitioners and managers, advocates and support workers and policymakers.

Professional interviews explored: understanding of the role of health facilitator; the mainstream healthcare experience of people with learning disabilities and their broader experience of health facilitation; methods through which this role of the role of health facilitators was expected to work; the role of Health Action Plans, existing

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14 see www.healthcareworkforce.nhs.uk.
15 Information from personal communications with members of the National Health Facilitation Network
and planned contacts with other professionals and service users; perceived problems and opportunities, examples of early health gains and inclusion of people from minority ethnic communities and people with complex needs.

In addition to individual interviews, the research team kept track of and attended local events and policy initiatives related to health facilitation. Literature and informal fieldwork in connection with these events contributed to analysis of the context within which health facilitation in the fieldwork area took place. National e-lists for professionals working in the field of learning disability and health were also included as a data source to monitor activity elsewhere and note trends in the implementation of the policy.

We intended to conduct in-depth interviews with 30 people with learning disabilities who had a Health Action Plan. However, delays in the implementation of *Valuing People* health targets made this impossible and only 15 people could be interviewed. The sample included children and adults, males and females and people with mild, moderate and severe learning disabilities, people living in different settings, people with different health problems as well as individuals from minority ethnic communities. This helped ensure that we addressed diversity in the experience of people with learning disability. Individuals were identified through a voluntary sector organisation, the Community Learning Disability Team and the Childrens Learning Disability Team, all of whom had worked on health action planning.

For each person with learning disabilities, we interviewed a family member or health facilitator most involved in supporting their health, a total of 17 people. In addition we interviewed two family carers who had discontinued the process of a Health Action Plan for their relative with learning disabilities to explore reasons why this had happened.

The interviews with people with learning disabilities and family carers explored recent experience of healthcare, the broad experience of health facilitation and who was important in this, experience of the Health Action Plan and views on its role, the impact of the initiative on general health and involvement in healthcare decision-making and planning. Interviews with health facilitators focused on the Health Action
Plan, the process of drawing this up and collaboration with others involved in the individual’s health.

A booklet was designed to support the engagement of people with learning disabilities in semi-structured interviews. This used images and accessible language to ensure the concept of health was understood and to ask questions and provide prompts for each area covered. Participatory research methods were also adopted to facilitate the engagement of people with learning disabilities with the research process (Johnston and Webster 2000). A ‘health line’ was used to ask individuals about their current health, what helped them become more healthy and to prompt discussion about a time when they needed support with health. In addition, a set of cards relating to the determinants of health and to aspects of healthcare were used to explore how these were prioritised by people with learning disabilities and what support they received in relation to them through the health action planning process.

The booklet and cards were piloted by a local service user support group established by the Partnership Board and feedback was also provided by the Department of Health Learning Difficulties Research Team set up to evaluate all the projects carried out under the Learning Disabilities Research Initiative (see Introduction).

**Focus groups**

Focus groups were used to allow exploration of issues relating to people from ethnic minority communities and family carers of people with complex needs, who are traditionally marginalized within service provision. The focus groups enabled the research to explore issues previously raised with service practitioners, people with learning disability and family carers, thus building on the data collected during face-to-face interviews (see Bowling, 1999). As a result of the low numbers of people with learning disabilities who had Health Action Plans and the delays in fieldwork this caused, the number of focus groups held was reduced from our original plan of five to two groups. We used these discussions to explore other kinds of assessments and plans and how well these fit the criteria for good Health Action Plans (see Findings: Step 3a). Six other types of health assessment were obtained from focus group members. These included four Care Plans, one Individual Learning Plan and one medical assessment from a school.
Shadowing and review of health action planning

Towards the end of the fieldwork period we focused on the day-to-day role of health facilitators in the process of health action planning. We spent some time shadowing two members of the Community Learning Disability Team who were involved in the strategic and individual health facilitation process.

Shadowing allowed us to examine the social and organisational context in which these individuals had to work and how they managed the different expectations of their role from the perspectives of various stakeholders. Shadowing also enabled exploration of the inter-relationships between this role and that of other professionals as well as how relationships among different service agencies were negotiated. In relation to individual health facilitation, we observed the process through which Health Action Plans were drawn up as well as relationships with and involvement of service users and family carers.

Primary Care Records

Consent was obtained from 13 of the people with learning disabilities included in our research to look at their primary care records. This provided an invaluable opportunity to triangulate information from interviews and Health Action Plans. Records could often reveal a range of professionals involved in supporting the health of individuals and also provided an overview of the individual’s health needs. It was possible to develop a detailed picture of the support people received with their health by combining information from semi-structured interviews, GP records and Health Action Plans.

Data analysis and writing up

The qualitative stage of research generated considerable in-depth material from a variety of different sources. For each person with a Health Action Plan we analysed at the role played by their health facilitator, family members, GP, specialist learning disability professionals and others who might be mentioned in any of these data sources. We also looked at the level of collaboration between different people involved in the individual’s health.

The aim of data analysis and write-up was to reflect the perspectives of different stakeholders and to ensure that evaluation of the role of health facilitators took
account of the views of service agencies as well as services users and their carers. Different accounts were integrated according to specific themes, identified as relevant from the literature, respondent interviews, focus groups and shadowing (see Silverman, 2001). The model of health facilitation policy (see Figure 1 p24) provided a framework in which these could be presented.

Informed consent from participants was obtained for all parts of the work. With permission, individual and focus group discussions were recorded and fully transcribed. Initial analysis, as outlined above, was an ongoing element of our work and fed into service development. A complete analysis of research material, however, was conducted at the end of the fieldwork period. The material from the face-to-face interviews, focus groups and shadowing were treated as one data source and coded into themes using NUD*IST software. Relevant extracts from messages posted on elists relating to health and learning disability were also coded during this process to provide a national context to the findings from our local research.

These themes were used to explore the extent to which the intended outcomes of health facilitation policy had been fulfilled in the fieldwork area. We also explored the impact of Health Action Plans by comparing individual Plans with data from semi-structured interviews and with the primary healthcare records of people with learning disabilities for whom Plans had been drawn up. To reflect the complexities of the process, case studies, incorporating the views of service professionals, service users and carers, were also used to synthesise information from these various sources and to supplement the insights provided by thematic analysis of the research material (see Mason, 1996; Yin 1994).

We used the five-stage ‘framework approach’ as the basis of a clear and transparent approach to the analysis of data from each stage of the project (Ritchie and Spencer, 1994). These stages are:

- Familiarisation: a full review of transcripts and notes.
- Identification of key themes around which the data can be organised: the framework).
- Indexing: application of themes to text.
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- Charting: use of headings and sub headings to build up a picture of the data as a whole.
- Mapping and Interpretation: in which associations are clarified and explanations worked towards.

During the analysis, regular meetings were held between the researchers to discuss the emergent themes from the data. To ensure a degree of reliability and consistency, a second team member coded ten *per cent* of all the transcripts and discrepancies between coding were resolved through mutual agreement.

The generalisability of the qualitative data was addressed in ways specific to this methodology (Strauss and Corbin 1998, Schofield 1994). Within the analytical framework outlined above, we explored the range and frequency of the responses on particular issues and this formed the basis of generalising the respondent’s experience. Our approach to analysis aimed to contribute to and engage with current debates about learning disability, service development, ethnicity and family caregiving and so help ensure the wider relevance of the research findings.

Throughout the analysis, instances in which the needs of service users and carers and Government targets were not met as well as examples of good practice were identified. This formed the basis of the key findings, which were presented in draft form for validation by members of the Advisory Group for the project, made up of local stakeholders. The Group was asked to consider recommendations that should follow from these findings. These recommendations were combined with those from the two research workshops and the analysis by the research team to provide a final set of recommendations to be promoted during the dissemination stage.

**Quantitative methods**

The *Valuing People* health targets are quantitative in nature and the study therefore explored whether or not these had been met using quantitative methods. In addition, we used such methods alongside qualitative exploration to explore the impact of health facilitation. There were three stages to the quantitative phase of the project.
Phase 1
The first phase was to create a register of all people in Leeds who have a learning disability. This was achieved by drawing on the information held by organisations with which people with learning disabilities are known to have contact. This included voluntary organisations, health services, education and social services.

Phase 2
In the second phase a template was developed to identify patients from general practice lists, and all practices in Leeds were invited to apply the template to their practice list, thereby creating practice based registers of patients who have a learning disability. This list was then cross referenced with the names on the Leeds-wide register described above.

Phase 3
The third phase was to determine whether or not health facilitation had changed the nature of contact with general practice/primary care. This was based on an analysis of data extracted from the GP records of each patient contact with the practice one year pre and one year post health facilitation

**Phase 1: Creation of the Leeds-wide Database**
All organizations that were known to have contact with people with a learning disability were contacted. The following section will outline the process of obtaining the list of patients from each organisation. For each organisation, the following information was requested for each individual: surname, date of birth, gender and postcode. This information was felt to be sufficient to uniquely identify individuals and allow us to cross check with other lists.

**Local voluntary sector organisations and day centres**
In May 2004, 131 organisations that were listed in ‘Through the Maze’ (Leeds Social Services & Leeds People First 2004) were contacted. All organisations were requested to provide details of individuals known to them who had learning disability. Initially, 19 organisations replied, but only 9 sent lists: New Horizons; PHAB; St Anne’s Supported Living: Community Integrated Care: West Ardsley Adult Training Centre; Moordend Day Centre; Wetherby Day Centre; Ramshead Wood Day Services; and Horsforth Day Services. The remainder were either concerned about
confidentiality, or felt that the majority of people known to them would be known to the bigger organisations, such as Education and Social Services.

**Education**

In May 2004 a list of children with learning disability was requested from the Special Education Needs & Inclusion Support Services. Due to illness and holidays, it was September before a meeting was arranged to discuss in detail the access to education lists. Research governance and access forms were signed and returned. The list was sent in November 2004 but due to data errors the final list was not received until January 2005.

**Social services**

In May 2004 a list was requested from the Data Protection Development Manager. In June a formal application for access to data was submitted, and in September, Social Services Research Governance Group approved the research. The data was not received until January 2005.

**Leeds Mental Health Trust**

Lists were requested from seven services within the Trust after obtaining Leeds Mental Health Trust governance approval in September 2004. A month later, no replies had been received and contact with the Trust revealed that the Leeds Learning Disability Clinical Governance Forum and Strategy Group [LDRF] had decided not to provide the data. In November there was a meeting between researchers and Research Support and Effectiveness Managers in the Trust to discuss the way forward. Following this, the research team attended a meeting of the Learning Disability Research Forum, which agreed to provide data once approval was obtained. The Forum identified the Director of Nursing and Clinical Governance/Caldicott Guardian as the key person required to formally approve the research. The Clinical Nurse Advisor for Learning Disabilities approached the Director and in late November written approval to disclose information was received. The data was not received until February 2005. Two lists were supplied one from consultant contact and another from nursing.
Learning Disability Services

In June 2004 letters were sent to 20 PCT based Learning Disability Community Services. Of the 10 replies five lists were received. Podiatry (December 2004) and community dental services (December 2004) sent the research team complete lists. For the Learning Disability Physiotherapy Services the research team had to manually extract data from the physiotherapy records at 5 locations (2006). This was also the case for Speech and Language Therapy Service (January 2006), and Occupational Therapy Services (January 2006).

General issues
There was wide variation in the detail and quality of data sent: some of the written lists were illegible; no postcodes were provided by some of the organisations and others had missing or incorrect dates of birth and incorrect spellings. There are several possible reasons for inaccurate data including incorrect/inconsistent information provided to organisations by carers/patient, and mistakes in capturing this information at different points along the data pathway. Only Leeds Social Services, Leeds Mental Health Trust and Education Leeds sent us the information electronically; data from other sources had to be input manually.

Phase II: Working with General Practices and Creation of the Template

Development of Template
The template was initially developed in five GP practices. This process started in March 2004 through to May 2004. The practices were asked to identify patients with learning disabilities; no guidance was given other than to also consider patients living in group homes or hostels for people with learning disabilities. There was a variable response to this initial exercise which highlighted several problems with data collection and data quality in primary care, both generally and more specifically relating to learning disability: not all practices could identify all their patients. The extent of transfer from paper to electronic patient medical records and summarizing/coding of the patient data varied greatly between practices and no standard definition of learning disability had been used. These factors influenced the development of the template, reinforcing the need for a multi-targeted approach to identifying patients with a learning disability.
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The first step in the development of the template was to refer to the electronic medical record of those patients identified by the practice; the problem page was used as the key source in the record that held the codes related to the person’s learning disability. This list of codes was supplemented by advice and information about coding for learning disability obtained from authoritative sources, such as the Read formulary, Department of Health documents and Primary Care Information Services (PRIMIS). This process led us to capture other learning disability specific codes.

E3 (Mental Retardation) was the first code searched as this was informally recommended by the Department of Health (see Appendix 3). The first practice had intentionally coded people with learning disability with an E3 code, retaining the original diagnoses/codes in the problem section of the patients’ electronic medical record: From this it was possible to capture and categorise three broad categories of codes that were ‘ascribed’ to people with learning disabilities before the E3 was added:

- codes that relate to diagnoses
- codes that relate to functional ability, which may be a description of a level of intelligence or of social functioning.
- codes relating to appropriate referrals or learning disability assessment

Though E3 was not routinely used in the remaining practices more codes within these three categories were found by doing searches on codes used and identified in the previous practice and on addresses (small group homes/hostels for people with learning disability). This iterative approach resulted in a substantial number of codes that could be used in searches of practice computer systems for people with learning disability. The number was reduced by a process of identifying a higher code where possible: we sought advice on this from the local primary care data quality service.

The three categories of codes included many clinical terms that did not necessarily indicate a learning disability. We had to strike a balance between including all those codes that might encompass a learning disability, with the concurrent resources required to verify the list, against leaving out codes and the risk of ‘missing’ some patients with learning disabilities. A balance was struck between including syndromes
that do not necessarily cause learning disabilities yet affect <1:15,000 and excluding rarer conditions that have a definite association with learning disability. Disorders specifically listed in a pilot guide to health facilitation for GP practices, created by a local PCT (Leeds Mental Health Trust 2006), were also included on the template.

In September 2004, two practices were involved in piloting the template. This involved the practices running computer searches, and then validating the list. The searches in the two practices also highlighted codes where the numbers of possible patients identified were so high that verification would have been too time consuming. For example codes that denote difficulties, problems or general delays in respect of learning ability, behaviour, specific and general development can include many people who do not have learning disability. E2F (specific delays in development) and ZV2 ([V] Reproduction/development problems) were omitted from the template for this reason. Due to the preferred terminology of ‘learning difficulty’ the code 13z4E was retained despite the potential for including many patients who do not have learning disability. The code for learning disability - Eu81z-1, was omitted because some computer systems can only search on the higher code Eu81z ([X] developmental disorder of scholastic skills unspecified), which is not learning disability specific. A similar problem emerged with the use of the code for global delay E2F5-1, hence its exclusion despite its widespread use in past medical records. As a result of this process, the template was revised further.

In addition, in August 2004, 395 questionnaires were sent by e-mail to PRIMIS facilitators in Primary Care Trusts in England to see what codes they used/recommended. There were 68 replies, 23 of which gave detailed responses to the questionnaire. Replies were also sought from Debra Moore and Alison Giraud Saunders, from the ‘Valuing People Support Team’, a national implementation team established by the White Paper (Department of Health 2001). The final template was agreed by the research team in January 2005 (see Appendix 2) and includes:

- a list of codes that give a definite indication of a learning disability
- a list of codes that give a possible indication of a learning disability AND need to be verified by the patients’ GP
- Patients who live in a group home specifically for people with a learning disability, identified by searching by group home address
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- Recollection from memory by GPs of patients with a learning disability that may be known to the practice.
- the White Paper definition of learning disability (Department of Health 2001)

It is worth noting that the template identifies adults and children with learning disabilities on practice registers, although GP practices are only required to report the number of patients aged 18 years and over (NHS Employers/BMA 2006). Limitations of the template are that it will, of course, only identify patients for whom relevant codes have been entered. Codes are also more likely to identify people with moderate or severe learning disabilities or those already using specialist learning disability services. Practice knowledge and awareness of learning disability will consequently be important for identifying people with mild learning disabilities.

Postal contact with practices
In January 2005 practice list sizes were received for the whole of Leeds. This was in order that we could determine the proportion of people in each practice list that had a learning disability.

In January 2005, 19 of the 22 practices in one PCT were contacted by letter, inviting them to take part in the study. They were asked to run the template in their practice and feed back the findings to the research team. (Three practices in this PCT had already sent lists in 2004 as part of the pilot study)

Of the 19 practices:
- 1 sent a list
- 2 refused
- 1 asked if there was payment for participation in the research
- 2 requested the research team to search the practice computer system on the codes (one practice subsequently closed and did not validate its list, the second practice could not accommodate the researchers due to ‘problems’ at the practice
- 13 did not reply

A second letter in March 2005, sent to the 13 practices that had not replied, elicited three lists, three refusals and seven non-responses.
At the end of April 2005, 96 practices in the other four Leeds PCTs were contacted:

- 10 sent lists. (5 of these practices asked the research team to search the database).
- 3 requested searches but did not validate the lists, 2 citing lack of resources
- 2 were equivocal, having concerns over confidentiality and requesting more information
- 11 refused, 3 citing lack of resources and concerns over confidentiality
- 70 did not reply

Due to the low response rate, a further letter, with a shortened version of the template, was sent in June 2006 to practices that had either not replied or declined to send lists. The shortened template included only the codes that give a definite indication of a learning disability. This was because it was easy to run off the computer systems and did not require the validation by the practice that the ‘possible codes’ involve. It was thought that this would increase the response rate.

Of the 90 letters sent, 12 sent lists based on the shorter template and 8 declined to take part in the research. Seven of the 12 practices that provided lists asked for the research team to come into the practice to search on the codes.

Altogether, we gathered data from 30 (25%) practices: 17 practices applied the full template, and 13 applied a shortened version of the template, which included only the codes that give a definite indication of a learning disability.

Appendix 4 outlines this process for each practice.

**GP registration as at June 2004**

In June 2004 West Yorkshire Central Services Agency (WYCSA) were contacted about the proposed cross checking of our Leeds-wide database with their GP registration data. This was so that we could determine whether or not people on the Leeds-wide database were registered with a GP at June 2004. On providing the required evidence of research ethics approval, research governance, and honorary contracts with PCTs, approval was granted in late June 2004. It was then necessary
to apply for access to the system from the NHS Information Authority and obtain a user name and password. This was obtaining in September 2004. For each person identified on the Leeds-wide database, their details were checked with WYCSA for the details of GP registration. The code of the practice was recorded for each person who was registered. Notes were made if the patient had moved, had died, or was registered with a practice outside the Leeds PCTs.

This process enabled us to record the GP practice code for each person identified from each source, and allowed us to verify the findings from individual practices by creating practice based lists from the database, and cross referencing with the lists developed by the GP practices. Three groups of patients could be identified:

1. Identified by the practice only
2. Identified by other sources and not by the practices
3. Identified by both sources.

Capture-recapture analysis was undertaken to estimate the prevalence in Leeds of people with a learning disability (La Porte 1994).

**Methodological issues**

Not all the people on the Leeds-wide register were found on the WYCSA search. However it is not possible to conclude from this that these people were not registered with a GP on 30/6/04. There are several reasons, other than non-registration, why they may not appear on WYCSA:

1. Organisations’ datasets are not up to date. There may be no system in place for on-going updating of the lists. Therefore there are people on the LD list who moved or died before June 2004.
2. People who live outside or near the Leeds boundary may be registered with a GP in a non-Leeds PCT and not feature in WYCSA. A crude estimate may be made by the simple measure of calculating the number of non-Leeds postcodes; however it should be noted that a proportion of people with non-Leeds postcodes are registered with Leeds GPs. It could be argued that people with inner Leeds postcodes are unlikely to be registered with a non-Leeds GP practice. The non-appearance of these people in WYCSA is
therefore more likely to reflect non-registration. A proportion of the population is mobile and it is possible that postcode data provided to the organisations was seen as temporary, with main residence and GP registration being elsewhere. It is of course impossible to quantify this. We do not know the length of contact between the person with learning disability and the organisation. If it was just a brief contact it is feasible that the person was only in the area a short time and remained registered with a non Leeds GP during this time.

3. The organisations’ datasets are incomplete. Although they were asked to provide name, date of birth, postcode and sex, the information supplied was very variable. Several voluntary sector organisations, and even some statutory services, provided only the initial of the first name, and only the year of the date of birth. In all the lists there were the occasional omissions of the date of birth, which is a key factor when searching on WYCSA.

4. The organisations’ datasets contain inaccuracies, which may lead to non-identification in WYCSA. There is no way of knowing how many of those ‘non-identifications’ are due to non-registration with a GP and how many are due to inaccurate data. There are several possible reasons for inaccuracies: mistakes may be made at different stages of data collection, recording and retrieval. The organisation may be given ‘wrong’ information and details may be misheard and misspelt. Names may be inverted e.g. Paul Gregory, instead of Gregory Paul; this may be more commonly found when recorded by people unfamiliar with diverse cultural naming customs. There were instances where the inaccuracies are due to particular writing styles or illegibility of the lists sent to us. When organisations gathered the information to send to us there were inaccuracies such as phonetic spellings, misreading of entries and inversion of numbers.

Phase III: Evaluating the Impact of Health Facilitation

Data extraction from primary care records

In September 2004 letters were sent to patients in one of the two pilot practices used to develop the Template that also offered Health Facilitation (HF), asking them to take part in the research study. Of the 23 patients, two patients returned signed consent forms. In November 2004, letters were sent to all the patients in the other pilot practice, and two patients returned signed consent forms. A practice that had
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agreed to take part in this part of the research also sent letters to the patients, and no patients returned consent forms. It was then realized that obtaining patient consent to gain access the patient records would be problematic. We contacted the ethics committee to explore options and were advised to apply for PIAG approval, allowing us to review records without patient consent. Permission was granted in January 2006, and data extraction commenced in February 2006 and was completed in May 2006.

The data extraction from primary care records was originally planned to be carried out for 400 patients selected from the Leeds-wide register. However given the delay in implementing health facilitation in Leeds this was not possible within the time restraints of the study and data was instead extracted for all adult patients’ records (116 Patients) from four practices; two had offered health facilitation to their patients and two had created practice based registers based on the full template for identifying people with learning disability in GP practices. The aim was to describe and compare the impact on the nature of contact with primary care one year pre and one year post intervention between patients at practices who:

1. created a register and offered Health Facilitation (HF) to their adult patients,
2. created a register of patients only.
3. were identified by other sources, but not by the GP when creating the practice based registers

Data extracted

The data extracted included:

- Active health problems
- Date, type and value of: Weight; Height; BP; Smoking; Alcohol; BMI; Cervical Smear; Mammogram; Lifestyle advice given.
- Date and type of referral
- Date and nature of each contact with primary care

Data was entered directly onto an Access database on a laptop computer at the practice. The computer had encryption software installed to safeguard the data. Data was exported on to SPSS for analysis.
Leeds Mental Health Trust were also contacted in June 2006 to determine which patients had received a Health Action Plan at that time. Data was also obtained from the Children’s Learning Disability Team. In both cases routine audit systems were not in place and the number of Plans for children was estimated based on the monthly average of Health Action Plans since these were first developed in 2004.

**Ethical issues**

All research requires an ethical strategy and this particular project raised several important ethical issues. Some individuals involved in this project came from social groups which are often exploited by research (Barnes 1996). In line with best practice guidelines for involving service users in research (Consumers in NHS Research Support Unit 2002), payments were made to family carers and people with learning disabilities for transport and attendance at the research workshops as well as at focus groups and for time spent in individual interviews.

The quantitative stage of the research, with its use of GP records and databases, required particular sensitivity. The White Paper indicates that every person with a learning disability is covered by the health-related targets. Without baseline information about the number of people with learning disabilities in an area, it is impossible to assess whether every eligible person has been included in work carried out to meet these targets. However, the difficulties associated with setting up a database of people with learning disabilities have been documented (Whitaker 2004) and include ethical, cost-benefit and practical considerations.

Despite research exemptions in the Data Protection Act 1998 and the rigorous process of gaining Ethics Committee, Research Governance and PIAG approval, this process raised many concerns, particularly within the voluntary sector but also from statutory services. There was considerable confusion about whether or not records could be released and concerns about providing access to records without individual consent. This led to significant delays in our ability to gather relevant data from local stakeholders. Our experience of obtaining records confirms the need for local protocols and clarification for practitioners (Department of Health/Cabinet Office 2006).
Confidentiality

The need to respect and maintain confidentially was considered during both the quantitative and qualitative phases of the research. During the qualitative stage of the research, we provided information according to the communication needs of people with learning disabilities and, where necessary, in relevant languages, to ensure all participants understood our aims fully, according to the principles of informed consent. In setting up the interviews, we were sensitive to the involvement of family dynamics, the relationship between users and service providers and the relationship between different professionals. Respecting confidentiality between all the different stakeholders was also essential. This applied to people with learning disability and their family carers or health professionals if we felt there was the potential to harm relationships. Similarly we were sensitive to the confidentiality of different professionals involved in the study, especially if they were critical of their own or other institutions’ policies and procedures.

Carrying out research in an identifiable area with a fairly specific group of individuals raises challenges in relation to confidentiality. Although we have identified the city in which the research took place in order to address the issue of generalisability, we have adopted various strategies to protect the identity of people who spoke to us. In relation to people with learning disabilities we have often changed details relating to personal characteristics and family members to mask identity. Where professionals are concerned we have described individuals as members of groups so that their precise identity can not be pinned down. The final report has been validated with members of our Advisory Group, which includes key local stakeholders, and the issue of confidentiality in relation to individuals involved in the study has been checked with them.

Engaging local stakeholders

The research team for the project included, apart from academic researchers, the Patient and Public Involvement Manager for the Leeds PCTs and the Joint Commissioning Manager for Learning Disabilities. Their inclusion in the planning of the study aimed to ensure the policy and practice focus of the research and a focus on user involvement. As members of the Advisory Group, they also facilitated access to key stakeholders and provided valuable insights into the organisational
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aspects of policy implementation. Other members of the Advisory Group provided links to local service users and staff in voluntary sector organisations, learning disability services for adults and children, PCT management structures, the Partnership Board and to other research studies on health and learning disabilities.

Throughout the course of the study members of the research team held a number of strategic meetings with those involved in implementing health facilitation in Leeds. Key stakeholders were interviewed as part of the research process. The research team also became involved in the Partnership Board Health Task Group which was overseeing a Health Action Planning project and was able to feed into this group. Contact was also made with the PRIMIS coordinator and with local voluntary sector groups in which health facilitation and health action planning had taken place. Close relationships were developed with all these individuals and groups.

Members of the Advisory Group provided invaluable feedback on drafts of this report, which helped ensure its accuracy and a balance between the different interests and perspectives of different stakeholders.

Research Workshops

An important feature of the project was to act as a resource to local stakeholders and inform the emerging role of health facilitators. To ensure the research could maximise its impact on the development of this role, and take into account the views of those with learning disability and family carers, it was important to feed back the preliminary findings of both quantitative and qualitative research. At the end of the first year of data collection the presentation of initial findings formed the basis for a service development workshop to which service users, carers and professionals were invited. The national lead for health on the Valuing People Support Team and key local actors took a lead role in the presentations and facilitation of the event. Those attending were invited to discuss the findings in small mixed groups and to suggest ways in which the service should develop (see Appendix 1 and Mir 2005).

A similar format was used for the second event with the Learning Disabilities lead from the Healthcare Commission giving a keynote presentation, followed by presentation of findings relating to Health Action Plans and primary care records of people with learning disabilities. However, some important improvements were
made. One of the presentations was given by the Rainbow Group, a local self advocacy group, who performed a drama about the importance of accessible information. Secondly, a pre-meeting for people with learning disabilities was held to prepare them for the workshop.

Feedback from the previous workshop had indicated that some of the discussion in mixed groups was difficult for service users to follow. The pre-meeting was held a week before the second workshop and the presentations were given at this event. Small group discussions enabled people with learning disabilities to think about what they felt were the most important issues to raise on the day of the research workshop. A discussion group specifically for people with learning disabilities was also arranged at the second workshop as an optional alternative to the mixed discussion groups. Almost every person with learning disabilities who attended chose to take part in this group rather than the mixed discussions.

The research team also used the workshop to highlight which recommendations had been achieved and which were still outstanding from the previous workshop. In discussion groups, people were asked whether the research findings reflected what they knew about health facilitation in Leeds, what needed to happen next, how this could happen and who should be responsible for particular actions. The priorities of service users for local development were identified by the discussion group in which they took part (see Findings: Local Development).

Following the first workshop a meeting was held to discuss its recommendations with representatives from the Partnership Board, Community Learning Disability Team, PCTs, service user groups and Strategic Health Authority. This meeting aimed to bring key stakeholders to a common understanding of action that should follow the workshop recommendations.

The research team were also invited to follow-up meetings held to discuss a draft strategic plan for learning disabilities and stimulated by the research workshops.
Reflections on the research process

This was not an easy piece of research to carry out. Gathering information to answer our research questions revealed the fragmented nature and poor quality of the data available on people with learning disabilities. The task of accurately identifying how many people with learning disabilities there were within the fieldwork area became a complex exercise in drawing together separate databases and registers, the precise number of which was unknown. Qualitative fieldwork revealed inconsistent definitions of learning disability across different agencies and between individual primary care practitioners. This meant that our estimate of the number of people who should benefit from the Valuing People health targets is necessarily hedged with caveats.

Added to this, the complex framework within which we and Caldicott Guardians who could provide access to data needed to operate led to further confusion and long delays. For example, Guardians within the same Trust could have conflicting views about what data could be released so that permission might be given and then retracted or given by some Guardians and not by others. Some procedures seemed entirely unnecessary, such as members of the research team requiring three separate checks by the Criminal Records Bureau to cover each Trust included in the study.

The process of obtaining quantitative information for the study was extremely time-consuming and often frustrating. Even after the rigorous procedures we went through to ensure ethical approval, most voluntary sector agencies would not release information without consent. Our research questions were necessarily revised to accommodate the difficulties we encountered and the fact that very few people with learning disabilities were receiving the kind of health facilitation envisaged by the White Paper. We were fortunate in having the support of our Advisory Group and funders, who guided our decisions on how to adapt the study.

The study had been designed to capture diverse perspectives and to support the development of health facilitation in the fieldwork area. This meant we relied on local participants to engage with the research process and each other and come to a shared understanding of the way forward. Local stakeholders were positive about the potential of the study to act as a resource, however, there was clearly a tension
Health Facilitation and Learning Disability

between the slow progress on meeting Valuing People targets and the evaluation we were tasked to carry out.

There were conflicting views amongst local stakeholders about who was responsible for the slow progress on health facilitation, which we sought to synthesise in the final report. Validation of the report with these stakeholders required a fine balancing of various perspectives and numerous refinements to the final report in response to the feedback we received on drafts. This process was, at times, difficult but we feel the report is more robust and comprehensive as a result.
Findings

Chapter 3: Level 1 or Strategic Health Facilitation

As described earlier, health facilitation is defined within the Department of Health guidance (Department of Health 2002) as two levels of activity: work to develop services (Level 1) and work with individuals (Level 2). Figure 1 on page 42 indicates the various elements outlined in the guidance document for each of these levels and how they are expected to relate to each other. The various actions highlighted by the guidance are placed in a logical order and arrows indicate the influence each action is intended to have on others. Findings from the study about each step in this process of health facilitation are outlined below, following a description of the local policy context in which this activity took place.

Local health and social care provision

Specialist learning disability services in the fieldwork area were delivered through the Mental Health Trust, where the Adult Community Learning Disability Team and specialist psychiatry and supported living services were based. The Children’s Learning Disability Nursing Team and a specialist physiotherapy service for people with learning disabilities were based within the Primary Care Trusts and had a citywide remit. A range of services for people with learning disabilities, from small group living schemes to day services and from respite care to sheltered employment were also offered through the Local Authority Social Services.
Mainstream primary healthcare services were delivered through five Primary Care Trusts (PCTs)\textsuperscript{16}, one of which was nominated as a city-wide lead for work relating to learning disability. Acute sector provision was delivered through six local hospitals.

Voluntary sector services for people with learning disabilities included advocacy and self-advocacy groups, supported living homes and organisations offering social activities. Many of these were affiliated to an umbrella organisation for voluntary sector learning disability groups.

\textbf{Local policy on health facilitation}

The three \textit{Valuing People} targets relating to GP registration, health facilitators and Health Action Plans were identified in the Local Delivery Plan\textsuperscript{17} for 2003 to 2006. Objective 5 of the Plan stated that PCTs would be working on awareness raising and securing GP registration in 2001/02. A pilot project to develop the role of Health Facilitator and a framework for Health Action Plans was planned for 2002/2003 along with activity to develop a Theatre Project involving service users. Responsibility for ensuring these were delivered was allocated to a Partnership Board Task Group and PCTs. Risks to delivery of the targets were identified as:

- Inadequate investment
- Inability to recruit appropriate staff
- Inability to identify all people with learning disabilities
- Capacity within primary care

Actions identified to manage these risks included:

- Robust project management arrangements
- Robust workforce strategy.
- Close involvement of the Partnership Board throughout the process.
- A review of existing registers by the Partnership Board to ensure completeness and inclusiveness.

\textsuperscript{16} These merged to form a single Primary Care Trust on 1 October 2006.

\textsuperscript{17} http://www.wysha.nhs.uk/Library/reports_and_publications
Outcomes identified in relation to these targets in 2002/2003 were that health facilitators would be in place and Health Action Zone funding for a pilot project would be secured.

**STEP 1: Lead Health Facilitator post in each PCT and named contact for each general practice to support mainstream service development**\(^{18}\).

Following the closure of a long stay hospital in the fieldwork area some years earlier, learning disability nurses at the hospital had been redeployed to expand the Community Learning Disability Team and facilitate the integration of hospital residents into local communities. The team was consequently unusually large, with 30 nurses\(^{19}\). It was envisaged that this would be a significant resource in supporting mainstream service development:

The role of the community nurse is changing and expanding… we will have specialist learning disability nurses integrated into GP practices and integrated into mainstream hospital provision, supporting people accessing mainstream services…. We need to have a learning disability nurse associated with each practice. The reason for that is that the nurses are going to be the people who facilitate and roll out the health action planning process, so that’s their role. So we need to have a link with the GP practices, because they are there now but they’re fairly tenuous, but we would like to have a stronger link.

*Learning Disability Service Manager*

In April 2003 one of the five PCTs commissioned a post in order to develop the role of Lead Health Facilitator and support the implementation of Health Action Plans. This work was resourced with Health Action Zone funds and aimed to develop a

\(^{18}\) Through identifying people with learning disabilities, supporting those involved in developing Health Action Plans, feeding back knowledge of systems and services to the Partnership Board, becoming involved as part of a protocol around transition and identifying or creating resources when these are difficult to access (Department of Health 2002). The term Strategic Health Facilitator is used to differentiate this role from general health facilitation, which may be carried out by a range of people, including family members.

\(^{19}\) This number is taken from interviews with managers in Learning Disability and Joint Commissioning services. The number identified varied between 25 and 40 posts and 30 was most commonly cited.
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model in one PCT that could be used to deliver Valuing People targets in the remaining PCTs in the city.

The post was filled by two members of the Community Learning Disability Team, one of whom was employed for one year at half-time and another who took on the role for six months on top of his existing responsibilities. A steering group made up of the PCT Director of Public Health who had funded the project, Learning Disability Service managers and members of the Community Learning Disability Team oversaw the project and received progress reports from the Lead Health Facilitators appointed.

The project established a reference group of service users and also attempted to establish a reference group of GPs. However, the robustness of the health facilitation process and the evidence base for Health Action Plans as a tool were questioned by GPs and this group did not materialise. Attempts to liaise with primary care nurses highlighted assumptions that people with learning disabilities should be cared for by the Community Learning Disability Team. The ‘awareness raising’ in primary care that had been mentioned in the Local Delivery Plan did not appear to have taken place:

"It became apparent that prior to any pilot taking place that a system needed to be in place to back the implementation process. The systems needed to incorporate expectations, practical support and some teaching and training."

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It was recognised that these issues threatened implementation timescales for health action planning. In order to address them it was decided to develop a toolkit for GPs that would include a flowchart of the health action planning process, details about expected standards of care, resources to facilitate communication between GPs and people with learning disabilities, common questions and answers and a service user's guide to health action planning (Leeds Mental Health Trust 2006). The toolkit was completed within the first year of the project with support from staff in Joint Commissioning Services.

20 Although this report is described as a draft, this was the only report for the period in question
Within PCTs, it was argued that learning disability was not a priority and even the Diversity and Learning Disability leads felt that aspirations within the White Paper were unrealistic. Consequently, there was no sense of ownership within PCTs and no evidence of work to promote *Valuing People* health targets throughout the five Trusts:

To be totally frank, nobody in government in the Department of Health has asked me anything about Health Facilitators, I get asked every month about waiting lists for operations, I get asked every month about access to Primary Care to see a GP for the population as a whole etcetera, etcetera. The Department of Health make very clear in what they ask you to report about, what their priorities are… nobody’s ever asked me about people with a learning disability.

*PCT Manager*

the honest answer is that learning disabilities is not as high a priority, and I would say in any Trust as .. coronary heart disease, cancers, you know … diabetes, teenage pregnancy, all the things that the Government… you see Government ministers talking about every day on telly and, you know, the things that are costing the NHS the biggest amount of money.

*PCT Manager*

Despite the investment of Health Action Zone (HAZ) resources and the unusually large learning disability nursing team, the Health Action Planning project consequently failed to forge significant links between the Community Learning Disability Team and general practices, either to support use of a GP toolkit or to collaborate on Health Action Planning.

Ironically, a similar dynamic was reflected within learning disability services. Fieldwork during 2004 revealed a feeling that the *Valuing People* targets were ‘aspirational’ and ‘not real targets’. Staff in learning disability services felt that these goals were not prioritised and were poorly supported by those who had responsibility
to promote them in other service areas. This was demoralising for people within the team:

The lead for learning disabilities in the Health Authority seems to change like the wind. I can certainly think of, in the last year there’s been three different people… I know who the name of the person is but they’ve never said “Well I’m the new person, I’m taking over.”

Nobody actually comes along and says “What’s your activity in terms of, from a learning disabilities point of view.” … in terms of, you know, *Valuing People*, it has got some targets in there, you know, and I would like somebody to come along and say “What you doing about them?”

If there are some targets, at the end of the day in a document like *Valuing People*, if we can’t value it, then how do I expect other people to?

*Learning Disability Services managers*

The work involved in health facilitation was also seen as additional work rather than as a new way of working (Department of Health 2002) and members of the Community Learning Disability Team did not perceive themselves to be employed as Health Facilitators. The Team was involved with a range of existing work that extended beyond GP practices, which was monitored more closely and therefore more likely to be delivered:

our core business isn’t just with PCTs, it’s with forensic services and psychiatry … it’s with all the, the psychology services that are still part of the Mental Health Trust, so we are not working just with one group of people. We’re actually, in terms of accountability as well, I’m accountable to, from a governance point of view, the Commission for Health Improvement [sic] audit and improvement. But I’m also

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21 In fact there were five changes to the Strategic Health Authority lead over the three-year period of the research.
accountable to the Commission for Social Care Improvement [sic] as well, so different parts of our service are accountable to different bodies for different reasons. So the links are not just with the PCT

*Learning Disabilities Service Manager*

Despite these perceptions, some attempts to engage PCTs and primary care practitioners continued, through meetings with PCT Professional Executive Committees and offers to provide training. In general, there was a poor response to these and there appeared to be little wish to collaborate.

Nevertheless, there were a few exceptions - a primary care team within one PCT contacted the Community Learning Disability Team requesting awareness raising sessions; another PCT had facilitated the Health Action Planning project and there was substantial collaboration from two GP practices within this Trust.

In some areas of healthcare provision, the Community Learning Disability Team had been able to develop strategic initiatives:

> opticians seem to be quite interested actually and I think one of the things that we did in the health service was we did the RNIB training which was around sensory impairment and a lot of work with visual impairment. So all the people that went on the courses had to do a project and some of that was accessing local services. So certainly from optometry there has been some successes.

*Learning Disability Service Manager*

The Community Learning Disability Team had also supported service user involvement in health services through consultation events on the White Paper ‘Our Health, Our Care, Our Say’ (Department of Health 2006) in partnership with a local service user reference group. In addition, the team had facilitated consultation on the Choose and Book schemes in collaboration with the Patient Advice and Liaison Service and the Partnership Board’s Learning Disability Reference Group. Members
of the Community Learning Disability Team and student nurses had themselves also been trained by service users\textsuperscript{22}.

Poor engagement with general practices was not simply a result of poor response from PCTs and general practices, however. The skills of some nurses within the Community Learning Disability Team were generally not as highly developed as has been found necessary in areas where this role has been established (Caan et al 2005)\textsuperscript{23}. Those who had moved into the Team from group homes established after the closure of the long stay hospital were new to their roles and did not feel confident about approaching individual GP practices or working across professional disciplines.

\ldots it’s demanding and so it goes hand-in-hand with the whole thing of upping the education and making sure that much more qualified staff are about……much more educated workforce

\textit{Community Learning Disability Team}

Professional ideas about who should receive health facilitation could also be different from the ideas promoted in \textit{Valuing People}. The White Paper (Department of Health 2001) stipulates that all people with learning disability should be offered a Health Action Plan. This was felt to conflict with local criteria for service eligibility and managers often stated that they did not have the capacity to deal with all people with learning disabilities in the city. Government guidance also states that Health Action Plans should be person-centred (Department of Health 2002), whereas some learning disability professionals could assume that anyone they were already supporting ‘already have their needs met’\textsuperscript{24} and did not need a Health Action Plan.

The guidance on health facilitation (Department of Health 2002) indicates that Community Learning Disability Team should not deal with individual health action planning except in the most complex cases. However, there were anxieties within the team about being overwhelmed by subsequent requests for Level 2 (ie individual) health facilitation and not being able to support or monitor the process properly.

\textsuperscript{22} Information on the Mental Health Trust website during Learning Disability Awareness week
\textsuperscript{23} Information from preliminary findings on a study of Health Facilitators indicate that most are qualified to degree or postgraduate level (Whitehead 2006)
\textsuperscript{24} Information from interviews and a HAP Project progress meeting in December 2004
Existing working arrangements allowed the provision of high quality support to around 300 people with learning disabilities and there was concern that the larger scale involvement entailed in providing support for individual health facilitation would threaten this and be difficult to sustain.

As a result members of the Community Learning Disability Team appeared to emphasise the role of other agencies and individuals in providing individual (Level 2) health facilitation rather than on their own role in supporting the process of mainstream service development (Level 1 health facilitation). The role of the Community Learning Disability Team was presented within the GP toolkit and publicity materials as that of a support for health facilitators once the process of Health Action Planning had already begun. The preparatory work needed to equip mainstream services to respond effectively to requests for Health Action Plans or to train different groups of people to initiate Health Action Plans was not mentioned in these documents.

Information provided at a HAP Project progress meeting in December 2004
Box 1: Responsibility for health facilitation: perspective of the Community Learning Disability Team.

Question:
How can we make health action plans and health facilitation happen?

Points to consider:
• Who else should take responsibility and initiate a health action plan with the person?
• What other ‘entry points’ need to be considered, to ensure everyone can have a health action plan.
• What practical things can be done as an organisation, carer, friend, etc
• List different individuals and agencies that you think might be involved in implementing health facilitation/health action plans

Exercise given out by Community Learning Disability Team to Partnership Board meeting December 2004

People with learning disabilities need to opt in to mainstream healthcare arrangements and then take responsibility for those actions identified that will maintain and improve their health.

What is Health Facilitation?
A health facilitator is an individual chosen by a person with learning disabilities to enable them to find out what they need to do to say healthy and use the right services. They can help the individual create their health action plan.

Plans can be supported by the person, a family carer, primary care staff or support services. The facilitator helps to monitor progress and helps to speak up when the individual is not getting the right help or service.

Mental Health Trust learning disability website

The toolkit will …provide a reference point for those individuals in your practice area who can work in partnership with you to meet the health needs of people with learning disabilities.

A Health Action Plan is a person-centred tool that is developed to enable a person with learning disabilities to facilitate their own health care. Where an individual needs extra help to do this, they will need the help of a health facilitator.

A health facilitator … could be a carer, key worker, friend or practice nurse. In some circumstances it might be a learning disability nurse.

GP Toolkit produced by the Health Action Planning Project
STEP 2: PCTs/Partnership Boards provide training and investment

A number of initiatives funded by PCTs and the Partnership Board relating to the health of people with learning disabilities were found in the fieldwork area. These were aimed at raising general awareness of health needs and suggesting effective communication strategies. However, there was very little support for individuals acting as health facilitators.

Training professionals

In line with the Local Delivery Plan, PCT funding was provided to the Rainbow Group, a local self-advocacy project, to develop a drama production that could be used to train health professionals. The group encountered a poor response from primary care professionals to the offer of training and consequently focused on delivering the production to university medical students and at national conferences, where demand was greater (see Box 2).

The Partnership Board also provided resources to establish ‘Asking You’, a service user reference group, which aimed to give people with learning disabilities a greater voice in how services were run. The group was asked to develop an accessible leaflet about Health Action Plans to be included in the GP toolkit. It also worked with the local Hospital Trust to improve signage within the hospitals and make these more accessible to people with learning disabilities.

The Community Learning Disability Team developed a training package for mainstream health professionals in 2003 and began piloting this in 2004. The training had some success in the Hospital Trust and was offered to health professionals through collaboration with the Head of Patient and Public Support Services for the Trust. Feedback during the sessions indicated that levels of awareness amongst participants were low and that training provided them with valuable information. However, the training events were taken up by relatively small numbers of staff.

The Team also successfully collaborated with a manager in one PCT to provide awareness-raising sessions for primary care and administrative staff (see Box 2).
However, approaches to other PCTs to deliver training received a poor response. Two workshops were organised by the research team and a Community Learning Disability Team manager to provide information at GP conferences about the Health Action Planning pilot and how to identify people with learning disabilities on practice lists. These failed to attract any participation at the first event and at the second, workshop attendance was limited to practice nurses.

In Children’s Learning Disability Services, there had been involvement with health visitors to raise awareness about how to recognise children with learning disabilities and how to support parents:

[to] talk about ways that they may recognise that children have got severe learning disability or autism, for example, you know, and look at how they might recognise that within their home visiting ….and look at giving them information about basic advice around eating, sleeping, behaviour management, so that they’re able to take on that little bit extra of specialism to advise families

Childrens Learning Disability Service

It was recognized by all stakeholder groups that there was inadequate training for health professionals in the area of learning disability:

I was the lucky parent that was invited to go and speak to the third year medical students, and they had an hour training And I don’t know if it was something like six weeks around probably psychiatric wards. But it sounded as though, unless they decided to specialise in that field, it’s very basic training that they get

Focus Group: carer of people with complex needs

The Health Action Planning pilot had gathered feedback from surgeries and practice nurses about the kind of information they needed. Issues of consent, the definition of learning disability and communication strategies were common concerns. There was also a feeling in primary care that poor responses to people with learning disabilities

were a result of practitioners lacking confidence and feeling ‘worried that they might do the wrong thing’\(^\text{27}\). It was recognized by those promoting health facilitation that training would be important not only in improving awareness but in changing attitudes and that this process would take time:

> it does involve a change of mindset and attitude towards what people with learning disabilities are capable [of] and what their carers and supporters can help them with. I certainly think it’s going to take time and it’s actually allowing that time to the process which is where it comes into conflict with the very clear and the very blunt deadlines that are set for health action planning and health facilitation in Valuing People

**Member of Health Action Planning pilot**

There was resistance from some mainstream health professionals, however, to the idea that they should be trained for these roles or should be developing an additional caseload of people with learning disabilities. Even when this was accepted, the need for this new work to be legitimized and for people to be released from already overstretched workloads in order to receive training was made by a number of professionals in and out of learning disabilities provision:

> There needs to be huge amounts of extra training. And there is, coming on-stream more training, but yeah, I can’t see how I can say GPs aren’t reluctant. They will be cos there’s just.. there’s no.. where’s the time?

**Chair of Professional Executive Committee**

But it is a culture, what they’re doing should be ingrained in the whole way of doing things and that’s why it’s got to get into the training of future generations of medical professionals

**Member of voluntary sector organisation**

\(^{27}\) PCT professional
Very little training was organized for children’s services that promoted *Valuing People* targets amongst learning disability professionals. The need for training was seen as particularly important within the special school system where school nurses had had no specific training on learning disabilities\(^{28}\). Consequently school nurses often referred issues to the specialist children’s team that the team felt they should have been able to deal with themselves. A training pack in response to the volume of referrals around sexual health issues was consequently developed by the team, for which it won a national award\(^{29}\).

\(^{28}\) Information from member of Children’s Learning Disability Team  
\(^{29}\) [www.leedspct.nhs.uk/latest news](http://www.leedspct.nhs.uk/latest news)
Box 2: Good ideas about training

A manager from the Community Learning Disability Team worked with a Primary Care Trust manager to run training workshops for around 35 people working in a Primary Health Care Team. The training tells people about the needs and rights of people with learning disabilities. It covers how to communicate well with people and information about Health Action Plans. Next year, both Teams hope the training will also be run in a new health centre and offered to more people who work there. The local police force has said they would like similar training.

‘The Great Big Health Check’ was an event for people with learning disabilities to help them find out more about healthy lifestyle information and health action planning. 215 people came to the event including 134 Service Users. People especially liked the stalls about diet and exercise. Lots of people with learning disabilities asked for a Health Action Plan (although a lot also said they did not want one).

The Community Learning Disability Team gave out copies of a booklet called ‘My health record’. This could help people and their carers or supporters to make a Health Action Plan. They will also get training to help them. Lots of people wanted the event to happen again. ‘My Health Record’ has now been translated into different languages.

The Rainbow Group is a group of people with learning disabilities who run workshops about health at conferences. The workshop games and exercises they use work very well with a mixed audience. Professionals get to hear what people with learning disabilities themselves have to say about health and this has a powerful effect. People with learning disabilities feel involved in what is going on and feel they can say what they think too. The Rainbow Group feels that having the workshop run by a group of people with learning disabilities and getting people involved in it is a good way of making everyone feel they are at the same level.
Training on health facilitation

Specific training for health facilitators was even less common than awareness-raising activity. A module on health facilitation and health action planning had been developed by the School of Healthcare Studies at the University of Leeds. However, no staff from either mainstream services of the Community Learning Disability Team had been supported to access the module, either by PCTs or the Partnership Board, despite discussions between the University and the Health Facilitator initially leading the Health Action Planning pilot. The module was run for three years and then discontinued\(^\text{30}\).

The reference group of service users established by the Health Action Planning Project confirmed Department of Health guidelines that people with learning disabilities wanted to choose their health facilitator. This was seen to raise a number of dilemmas for learning disabilities nurses and fears that health facilitation could lead to health problems, which would need to be addressed through training:

> I think one of the biggest barriers to implementing [health facilitation] is fear and that goes with teaching and training and handing those skills over to other people because if you’ve got somebody with a learning disability that’s not self-reporting an issue it takes a lot of skill to know what to look for and so we know that’s the sort of challenge that we’ve got.

*Community Learning Disability Team*

Training for specialist learning disability staff was also needed to facilitate new ways of working. As already highlighted, many members of the Community Learning Disability Team were new to their roles and needed to develop the skills and knowledge that would equip them to facilitate collaboration with others and link together different planning processes.

Family carers also felt that in relation to consent and choice, a sophisticated understanding that balanced these concepts against health outcomes was needed amongst health professionals:

\(^{30}\) Information from the course co-ordinator
This is all “No, you’ve got to have a choice and you’ve got to be able to consent to things.” I mean how can you when it’s for their own good. If you stand around asking for a consent, they’re going to do themselves more harm. You know, there’s some people like that that know, maybe it’s the training.

**Focus group: minority ethnic carers**

As mentioned earlier, Matthews (2005) notes that these two concepts may be used by learning disability staff in ways that have adverse effects for people with learning disabilities and highlights a similar need for balance.

It was recognized that there was a need for different kinds of training in relation to different kinds of health facilitator. Some baseline characteristics were considered central to carrying out the role effectively:

if it was a nurse I wouldn’t suddenly expect to start giving them lots of information about health, however, if it was a carer for the person it might be very appropriate to give them all kinds of information so I think that in itself would be an issue. What would be absolutely critical is that that person had a good understanding, sort of a good base line in current thinking about learning disabilities and inclusion and about working in person centred ways and possibly some information about what kind of tools you could use to give people more control of their life.

**Community Learning Disability Team**

you don’t need to have a great technical knowledge of the issue but you have to have a knowledge of the process and you have to be presented as a warm and friendly and open to the person that you are with and be able to argue with the others otherwise everything closes down around you, so yes, there has to be training and there has to be some sort of resource … and also an understanding of what the expectations [are]

**Voluntary sector organisation**
Attempting to raise awareness amongst people with learning disabilities and training a range of individuals to become health facilitators was also seen as a problem in the context of poor expectations of support from primary care providers:

I mean the way that it looks to me is that if you say to somebody “You should be able to have a Health Action Plan. Go to your doctor and get them to sort it out for you or your practice nurse or whatever.” When they go there, they’re likely to be met with blank amazement I suspect.

Voluntary sector organisation

Only one PCT has demonstrated commitment to the process and ... most PCTs and individual GP practices are unaware of their obligations towards introducing Health Action Plans.

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Furthermore, it was recognised that there was a need to link training into implementation of health action planning and not to see it as an end in itself:

there are lots of people training to do Person Centred Planning in Leeds but if you actually measured how many Person Centred Plans are actually done, there’s not very many.

Member of Community Learning Disability Team

Training for family carers/supporters

Managers and staff involved in the Community Learning Disability Team felt that people with learning disabilities, their carers and supporters also needed to be empowered through training to ask for health facilitation and to complain and ask for support if they did not get it. A very successful event was held in 2006 to raise awareness amongst these groups about health and Health Action Plans (see Box 2).

Professional views of what training on health facilitation family carers or supporters should receive focused on ensuring they knew the boundaries and expectations of the role and were equipped to carry it out:
I think the distinction between facilitation and health advice needs to be drawn out. So there needs to be training for people who are going to act in this role so that they don’t overstep the mark, but they actually enable people to access advice rather than providing it themselves.

*Learning Disability Service Manager*

No training of this kind was available to family members who were already acting as health facilitators for their relatives. However, staff from voluntary sector supported living organisations were invited to an event promoting Health Action Plans in 2006 and this was facilitated by managers of the Community Learning Disability Team and Joint Commissioning Service. The event was attended by 20 people from 12 organisations. Following the ‘Great Big Health Check’ (see Box 2), the Community Learning Disability Team also planned to deliver training on health facilitation to staff and support workers working with people who had requested a Health Action Plan.

Family carers themselves defined their training needs in terms of knowing how to care for the person with learning disabilities and how to access support. Many of those we spoke to from minority ethnic communities had been trying to access this help for years and felt they were ‘just left to get on with it’:

I needed to be taught how to manage their behaviour … I mean I wanted to know a little bit more and I didn’t just want to be left… I mean I’m getting older and I’m saying “Look, I can manage it now, but in another couple of years down the line, if I become ill, how am I going to manage?” You know I don’t want my brothers to go to a home, I don’t want them to lash out at me or my children and I cannot have that control over them.

the language is still an issue and I’m still working towards finding someone to help me. Well, I need to go out and learn, to go and learn sign language so I can communicate a little bit more. …. Because I think that got missed out when they were at school.

*Focus Group: minority ethnic carers*
STEP 3: Mainstream service development

Implementation of health facilitation across the fieldwork area was delayed as a result of the Health Action Planning pilot and, before this, waiting for the Department of Health guidance on Health Action Planning (Department of Health 2002). Whilst the pilot was being conducted, managers described a vision in which the learning from the pilot would facilitate wider engagement with primary care practices:

“Within six to twelve months we would do a review of the process and then we would roll it out across all the PCTs fairly quickly. So we weren’t going to drag our feet, but we were going to go to them with some factual information about, ‘In this area we identified there were this number of people, we found this level of healthcare, these were the types of issues that were found, this is where we got the facilitators from, this is the training that we gave them’, so we’ve answered all the questions before we actually get to the main GP body”.

Community Learning Disability Team manager

For reasons outlined earlier in this chapter, this wider engagement with primary care did not happen following the conclusion of the Health Action Planning pilot and by the end of the research project the evidence of mainstream service development was sparse. Plans to invite GPs to an event launching the GP toolkit and highlighting the newly introduced incentives to GPs in the Quality and Outcomes Framework31 did not materialise, despite agreement by local stakeholders that such an event would be extremely important and valuable (see Local Development below).

Changes were more apparent within learning disability provision itself. For example, there was evidence of more engagement with the health facilitation agenda by the Community Learning Disability Team. Wherever possible, members of the Team carried out Health Action Planning with individuals who had been referred to them for other reasons, before discharging them from the service. The very successful ‘Great Big Health Check’ event (see Box 2) was also held at the end of the research period.

31 Financial incentives to identify people with learning disabilities on practice registers were introduced in April 2006 (NHS Employers/BMA 2006)
A new Strategic Plan for learning disability services in Leeds was also in the process of being developed and this was linked in to the establishment of a Healthy Lives Steering Group to oversee the Plan (see Local Development below)\(^{32}\).

The Strategic Plan envisaged that the Healthy Lives Steering Group would draw its membership from the PCT, Mental Health Trust, Teaching Hospitals Trust, Joint Commissioning Service, people with learning disabilities, carers and voluntary sector organisations. However, the latter three groups of stakeholders were not involved in the initial meetings of the group and it was suggested that the involvement of service users needed more thought\(^ {33}\). A decision was later made, however, to establish a Partnership Board Health Task Group and it was envisaged that this would take over the remit of the Healthy Lives Steering Group\(^ {34}\).

The Strategic Plan aimed to cover all aspects of learning disabilities services over a 5-year period. It described the setting of ‘specific targets for learning disability in modernisation plans’ relating to diabetes, obesity, heart disease and cancer.

The Steering Group was informed that a 5-year funding plan was also being produced alongside the strategy and that plans to review both therapy services and the interface between mental health and learning disabilities were also forthcoming. The model for redesigned services would be based on the idea of a ‘Ladder of Inclusion’ so that the involvement of the Community Learning Disability Team and other specialist learning disability services would be most focused on those who could not be dealt with by mainstream services (See box 3). Additional plans to develop an interagency database of people with learning disabilities were also mentioned at various times during the fieldwork period, as described in the Local Delivery Plan. However, for reasons outlined later (see Step 1a below), this service-held database did not materialise.

\(^{32}\) The previous Partnership Board group set up to work on health had in effect been a steering group for the Health Action Planning Project. Once this project came to an end in December 2004, the group also ceased to meet.

\(^{33}\) Information from meeting of the Healthy Lives Steering Group, July 2006

\(^{34}\) Information from local stakeholders at the final Advisory Group meeting of the project
Certain reasons for the patchy implementation of the policy at a strategic level can be ruled out – in terms of resources, the Community Learning Disability Team was physically far larger than most other similar teams across the country. In relation to the team for children’s services, it was approximately six times bigger. There was also a ‘healthcare champion’ in the form of the Director of Public Health who provided funding for the Health Action Planning pilot, and dedicated time had been given to a member of the Community Learning Disability Team to work on policy implementation.

However, the skills and knowledge necessary to act as Lead Health Facilitators did not appear to be a strength of the Team and during the period of the pilot from 2003-4 even senior members felt that ‘PCT land’ was unknown territory. Confusion about the role of the Health Facilitator and the purpose of Health Action Plans combined with a poor response from PCTs acted as disincentives to pursue strategic implementation vigorously, although some valuable engagement did take place with people with learning disabilities, family carers, supporters and professionals.

Accountability of the pilot project may also have been a factor. The PCT champion was not involved in the Partnership Board and the progress of the pilot did not appear to be properly monitored by the Board. Progress reports were provided only to the Steering Group for the pilot and presentations at the Partnership Board about health facilitation did not provide regular feedback from the pilot project.

Further disincentives to strategic development would appear to include the poor monitoring of learning disability services themselves in relation to Valuing People health targets. Although the low priority accorded to these targets in other areas of healthcare are clearly a barrier to implementation, the fact remains that little attempt has been made to capitalise on the inclusion of learning disability in the revised Quality and Outcomes Framework in April 2006.
Box 3: The Ladder of Inclusion service model

| Those services that can be accessed without support |
| Services where adaptations to the service required to make them accessible |
| Services where additional support required to access |
| Specialist services for people with learning disabilities |

Inclusion in Level One health facilitation

*People from minority ethnic communities*

A progress report for the first year of the Health Action Planning project identified the lack of attention to people from minority ethnic communities and the need to prioritise this work in the coming year. However, this recommendation received no further attention in subsequent progress reports, highlighting the fragile nature of attention to diversity and the need to embed such work within existing structures so that they could not be neglected.

There was evidence that members of the Community Learning Disability Team themselves required greater confidence and knowledge of how to include people from minority ethnic communities in their work effectively. Family carers of people from these communities complained of low contact with specialist services, being ‘left to get on with it’ and extreme difficulty in trying to get specialist support:

thinking back I think I were left to it most, you know mostly. And if I did come across a problem it was like running around thinking who
can help....I didn't have no dealings with nobody, apart from this review that they did every year. I don't think, I don't there was any input from anywhere you know. You’re just more or less left to yourself

Focus group: minority ethnic carers

The gap in professional knowledge about how to engage with people from minority ethnic backgrounds also led to poor practice being reinforced with other professionals during a training session for hospital staff. A participant in the event stated that interpreters could not be used for people who did not speak English because of the cost implications. Although interpreting is generally accepted as vital to effective communication with people who have limited English (Nothard 1993; Mir et al 2001), the statement was not challenged and was accepted as valid by the trainer. Within the limited time allocated by the hospital for training it would not have been possible to cover the needs of people from minority ethnic communities in any depth. However, the needs of traditionally marginalized groups are emphasised in the guidance on health facilitation (Department of Health 2002) suggesting that acknowledging these needs and being equipped to deal with issues relating to these is essential to effective delivery of health facilitation activity.

A further area for Level 1 health facilitation related to negative assumptions about people from minority ethnic communities amongst professionals. Family carers complained about the quality of healthcare they received in hospital, the need for advocacy and the fact that they could be subjected to stereotypes by healthcare staff relating to violence and poor parenting:

then we’ve got the stereotypes. I mean, you know big, powerful, violent black male so I’m sure that he gets… I mean that was actually a nurse used that when he was thirteen, he was actually very tiny for his age but he described him and I thought “Yeah, that’s how you see it.”

I had a nurse telling me, I shouldn’t go up to my daughter and cuddle her because I’m making her cry. She went down to X-ray with us, she
says “Stop going up to her.” Well, she can’t see, if I’m not going to touch her, she’s not going to know I’m there

…

We were waiting for porters and this and that and she [the carer’s younger daughter] was there and like “She should be in bed.” I says “She should … I know she should but we weren’t expecting to stay this long.” “Alright, stop, don’t keep going up to her.” I said “I know my daughter; you know, well enough, if I don’t go up to her and don’t cuddle her, she won’t even know I’m here.”

**Focus group: minority ethnic carers**

The need to address this kind of discrimination has been well documented and is mentioned numerous time in *Valuing People*:

all services for carers should be responsive to the needs of people from minority ethnic communities

staff who understand the values and concerns of minority ethnic communities and who can communicate effectively with them have an important role to play

the Government will ensure that our new initiatives are responsive to their needs

**Department of Health 2001**

Findings suggest that members of the Community Learning Disability Team would benefit from training on issues relating to ‘double discrimination’ to increase their confidence in this area and equip them to support people from minority ethnic communities more effectively. This would also enable them to challenge other professionals who may not be working in ways that are culturally competent (Aspinall and Jackson 2004).

A subgroup of the Learning Disability Partnership Board had been formed to address the issue of inclusion for people from minority ethnic groups. In 2004, the subgroup invited a Partnership Board team from Bolton to learn from their model of inclusion.
Minutes of the meeting indicate that the factors outlined in Box 4 were important features of the model. The Ethnicity Subgroup developed a proposal for a post which was agreed by the Partnership Board. Following delays in the tendering process, an appointment was made towards the end of September 2006. The postholder was, however, located in a voluntary sector organisation and it is unclear what mechanisms will enable him to achieve the level of influence outlined in the Bolton model (see Box 4). It also remains to be seen whether and how this post will influence work on health facilitation in the fieldwork area.

**Family carers and people with complex needs**

The experience of family carers of people with complex needs in hospital indicated that on some occasions care had been of a high quality and one carer described a very helpful hospital book that provided a comprehensive record of her relative in case of future admissions. However, findings suggest that acute sector professionals often lacked the skills to care for people with learning disabilities and did not have appropriate facilities either to care for the person or to support carers, on whom they relied to provide basic care:

I did everything for her. … and they said “Oh we can feed her”… So I went and left them for an hour, [they] couldn’t feed her. … she won’t open her mouth. You know, they couldn’t force it in. They didn’t know what to do you see.

they just don’t, they haven’t got a clue with her. They don’t know what’s wrong with her, she’s left in a, you know, hanging on….We just don’t let her go in hospital.

it’s adult wards, and I don’t, it’s like mixed wards. You’ve got this tiny little person who sleeps on all fours with baby toys, put in a ward where there’s drunks at one side and a man at this side, a woman over there. It’s quite you know, awful.

*Focus group: carers of people with complex needs*
“Participants experience of people with learning disabilities – facilities very poor for carers and no provision for them to have a break. [Carers] felt had to provide all aspects of care”

Notes from hospital training event

Problems could also occur during extended periods of respite care when carers were themselves in hospital. One carer described the condition of his daughter after seven months respite whilst his wife was terminally ill in hospital:

she lost thirty pound in weight, she, her bed sore took... it were tracking right up. They thought she’d have to be operated on. And district nurses were out every day for her, took nearly eighteen month. ... And both her legs are permanently bent, she were on and off antibiotics. ... just come back in a right state.

With all the expertise that family carers had developed over years of caring, they often knew more about their relative’s health than professionals. Findings confirm that family carers could detect symptoms of deterioration much sooner than professionals involved with the individual (NPCRDC 2000). Nevertheless, carers felt their views and concerns were often dismissed unless they managed to secure the support of another professional. Staff who reinforced their observations could therefore perform an important function:

when [person with learning disabilities] went through this bad period, the staff here in special care and the nurses and up at [respite care], were brilliant. And they were noting things down. I wouldn’t say they noticed anything any different to me, but they reinforced what I was saying. And I did sometimes think other authority figures, i.e. doctors, consultants or whatever, were ignoring me. But because care staff were saying the same thing, all of a sudden something happened.

Focus group: carers of people with complex needs

None of these issues was raised during training with hospital staff, although the potential role of people known to the person with learning disabilities to facilitate communication between professionals and patients with a learning disability was
Health Facilitation and Learning Disability

touched on during discussions. Findings suggest that the role of family carers in helping to diagnose and treat people with learning disabilities, particularly those with complex needs, should be specifically addressed during training for healthcare professionals.

Another area in which Level 1 health facilitation would have been helpful to family carers of people with complex needs related to communication between GPs and hospital consultants. Carers felt that GPs lacked the confidence to prescribe or change medicine without involving consultants and the process of making a decision could consequently lead to long delays:

You could be waiting six, seven months. And if you’re going through a bad period when they’re fitting constantly, or they’re having severe ones and they’re stopping breathing, you want that dealing with straightaway.

*Focus group: carers of people with complex needs*

This finding indicates a specific area in which the Community Learning Disability Team could work to support family carers, GPs and hospital consultants to develop more effective protocols and ensure treatment is made available as early as possible.
Box 4 – how to include people from minority ethnic communities in learning disabilities work

- Get people to realise how important it is to make this someone’s job - a small amount of money can achieve great results and get you ‘star ratings’ for good work.

- Make sure the job lasts for a long time. Use money from Social Services, the Primary Care Trust and the Learning Disabilities Development fund.

- Choose a powerful manager for the job – in Bolton this is the person in charge of the money (‘the lead commissioner’).

- The person who gets the job should talk to people from minority ethnic communities about what they need and support people working in services to deliver these things.

- He or she can also support staff from minority ethnic communities who are having problems at work.

- He or she should be asked to work with people writing plans for the Partnership Board, PCT or Social Services. Working together will help make sure the plans include people from minority ethnic communities.

- Set up an Ethnicity Subgroup on the Partnership Board. Members of this group should go to all the other sub groups of the Partnership to influence its work.

- Talk to the Ethnicity Subgroup before you make agreements to buy services from other organisations.

- Groups that have agreements to provide services should include people from minority ethnic communities and their work should be checked regularly.
Chapter 4: Level 2 or Operational Health Facilitation

STEP 1a: Identify people with learning disabilities.

The Department of Health guidance (Department of Health 2002) anticipates Lead Health Facilitators working with GPs using read codes and record-sharing to identify individuals with learning disabilities on practice registers.

As described earlier, the Health Action Planning Project had developed a toolkit for GPs and this identified some common syndromes associated with learning disabilities. However, by June 2004 no work had been done to identify people with learning disabilities in general practice. Members of the research team had independently developed and piloted a template for this purpose in order to evaluate how many people with learning disabilities in the city were registered with a GP (see Appendix 2). Contact was made with the PCT lead for the Health Action Planning Project, and it was decided to work together to identify people with learning disabilities on practice lists in one PCT, prior to rolling this out to the rest of the city.

The process of identification

The method for developing a template that could be used to identify people with learning disabilities on practice registers has been described earlier (see Methods). Issues relating to the definition of learning disabilities were raised during the process of identification. Professionals working in primary care and PCTs suggested that individuals who were accessing services and had obvious learning disabilities were more likely to be identified in primary care. Those who did not fit these categories could be excluded in order to avoid labelling people who might not consider themselves to require social support in their everyday lives:
I sort of looked at a few of them and thought you know, I don’t think you can send a letter out to that person, because I know they’ll be offended. Or I know that, you know, I don’t think that’s appropriate for those sort of people.

... you see lots of these people when I look on the list are very, very regular people, you know that are coming in, and really making use of the sort of health facilities. You know, when I … I was surprised when it brought up that they were all kind of familiar people.

*Member of general practice staff*

Other people who might not appear on final practice lists included those living in bail hostels in the area, which had a very high turnover of residents. It was reported that a significant number of these residents could have learning disabilities and were likely to have unmet health needs. Some respondents also pointed to areas popular with students as ones in which individuals with learning disabilities were also likely to be missed because of the high rate of movement from the area.

Individual GP-based registers have been shown to be an effective tool in helping to highlight the health needs of learning disabled patients (Martin and Martin 2000). The pilot project had struggled to find more than two GPs; outside the pilot most were not motivated to use this template either to contribute to the database35 or in order to offer Health Action Planning in collaboration with the Community Learning Disability Team. Running the read-code template did not take a long time and support was offered by the research team to carry out the search. However, going through the list generated to produce a final register did take longer and generating this was not considered a priority by most practices.

This appeared to reflect the priority accorded to identification of people with learning disabilities in PCTs across England. As part of the process of developing the template, researchers contacted a total of 395 PRIMIS facilitators in Primary Care

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35 Only 30 of 120 GP practices responded to requests by the research team to run the template on their lists, despite three reminders and the offer of support to generate the list of patients with learning disabilities.
Trusts in England to find out which codes they were using or recommending to GP practices in relation to learning disabilities. Of the 68 replies only 23 could give details of such activity.

Unlike conditions such as diabetes or cancer, which are linked to National Service Frameworks, identification of learning disability was not included in the Quality and Outcomes Framework (through which GPs are monitored and paid) until April 2006 (NHS Employers/BMA 2006). Consequently, there were no financial incentives for GPs to identify people with learning disabilities when fieldwork for the study took place. Named leads within the PCTs and Strategic Health Authority appeared, as a result, to be doing nothing to promote the Valuing People goal of GP registration for every person with learning disability or to ensure that the related target was met.

Creating the Leeds-Wide database

In order to assess how many people with learning disabilities were registered with a GP it was necessary to construct a city-wide database. However, there were no protocols for different service providers to share their own service-based registers. Findings suggest that the absence of information-sharing agreements, along with widespread confusion about what was and was not allowed by data protection legislation, acted as barriers to the development of a comprehensive and up-to-date database for the city. The development of such a database had, however, been identified within the Local Delivery Plan as an important and necessary piece of work for the strategic planning of future services.

The research team had received approval to construct such a database (see Methods). From all sources listed in Table 1, the database included the details of 8111 people.

36 http://www.wysha.nhs.uk/Library/reports_and_publications
Table 1: Number from each source

<table>
<thead>
<tr>
<th>Source</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental</td>
<td>593</td>
</tr>
<tr>
<td>Education</td>
<td>712</td>
</tr>
<tr>
<td>LMHT^37 Consultant</td>
<td>469</td>
</tr>
<tr>
<td>LMHT^37 Nursing</td>
<td>482</td>
</tr>
<tr>
<td>Social Services</td>
<td>2536</td>
</tr>
<tr>
<td>Voluntary Organisations</td>
<td>858</td>
</tr>
<tr>
<td>Therapy Services</td>
<td>2461</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>8111</strong></td>
</tr>
</tbody>
</table>

As expected many people were represented on more than one database. The database was then searched for duplicates (people on more than one list), giving a total of 4222 individuals on the Leeds-wide database. The numbers from different sources are presented in Table 2; of the 593 people on the dental list, 11% were also on the education list, 16% were known to LMHT consultants, 23% to LMHT nursing, 62% were known to Social Services, 26% to organisations listed in ‘Through the Maze’ (Leeds Social Services& Leeds People First 2004 – see Methods). and 56% to therapy services.

^37 Leeds Mental Health Trust
Table 2: Crossover between sources

<table>
<thead>
<tr>
<th></th>
<th>Dental</th>
<th>Education</th>
<th>LMHT Consultant</th>
<th>LMHT Nursing</th>
<th>Social Services</th>
<th>Voluntary Organisations</th>
<th>Therapy</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental</td>
<td>X</td>
<td>68</td>
<td>93</td>
<td>134</td>
<td>365</td>
<td>157</td>
<td>330</td>
<td>593</td>
</tr>
<tr>
<td>Education</td>
<td>68</td>
<td>X</td>
<td>4</td>
<td>7</td>
<td>4</td>
<td>1</td>
<td>249</td>
<td>712</td>
</tr>
<tr>
<td>LMHT Consultant</td>
<td>93</td>
<td>4</td>
<td>X</td>
<td>145</td>
<td>342</td>
<td>140</td>
<td>287</td>
<td>469</td>
</tr>
<tr>
<td>LMHT Nursing</td>
<td>134</td>
<td>7</td>
<td>145</td>
<td>X</td>
<td>380</td>
<td>224</td>
<td>329</td>
<td>482</td>
</tr>
<tr>
<td>Social Services</td>
<td>365</td>
<td>4</td>
<td>342</td>
<td>380</td>
<td>X</td>
<td>652</td>
<td>913</td>
<td>2536</td>
</tr>
<tr>
<td>Voluntary Organisations</td>
<td>157</td>
<td>1</td>
<td>140</td>
<td>224</td>
<td>652</td>
<td>X</td>
<td>402</td>
<td>858</td>
</tr>
<tr>
<td>Therapy</td>
<td>330</td>
<td>249</td>
<td>287</td>
<td>329</td>
<td>913</td>
<td>402</td>
<td>X</td>
<td>2461</td>
</tr>
<tr>
<td>Total</td>
<td>593</td>
<td>712</td>
<td>469</td>
<td>482</td>
<td>2536</td>
<td>858</td>
<td>2461</td>
<td>8111</td>
</tr>
</tbody>
</table>

**GP registration**

Of the 4222 people on the database, GP registration was ascertained for 89%. Of the remainder 2% had died, 5% had moved, 2% had a non Leeds postcode, and for 2% there was insufficient information. Of those for whom registration was ascertained (3751), 88% were registered with a GP as at June 2004, and 12% were not.

Table 3: GP registration

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered</td>
<td>3282</td>
<td>78%</td>
</tr>
<tr>
<td>Not Registered</td>
<td>469</td>
<td>11%</td>
</tr>
<tr>
<td>Died</td>
<td>92</td>
<td>2%</td>
</tr>
<tr>
<td>Insufficient information</td>
<td>92</td>
<td>2%</td>
</tr>
<tr>
<td>Moved</td>
<td>200</td>
<td>5%</td>
</tr>
<tr>
<td>Non Leeds Postcode</td>
<td>87</td>
<td>2%</td>
</tr>
<tr>
<td>Total</td>
<td>4222</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Number identified by the GP practices**

All practices across the city (120), from the five PCTs were asked to apply the template to their practice population (see Appendix 2). Altogether 30 (25%) practices, replied: 17 practices applied the full template. the remaining 13 applied a shortened version of the template, which included only the codes that give a definite indication of a learning disability. This was because it was simple to run on GP computer
systems and did not require the time consuming validation by practice staff that the ‘possible codes’ involved.

Each person on the Leeds-wide database of people with a learning disability was searched for on West Yorkshire Central Services Agency, to establish their registered GP. This provided validation of the GP template list. Table 4 shows the number of patients identified from the Leeds-wide database, and then cross-matched with the lists created by the individual practices using the template. A total of 852 patients were identified from the 30 practices using the template. Of these 488 (57%) were also identified on the Leeds-wide database. There were variations between practices ranging from 0% to 100%. For the practices that applied the full template, the average proportion was 46%, compared to 57% for those who applied the short template. This was not a significant difference.

On the Leeds-wide database, 1056 (23%) were identified as being registered with one of the 30 practices. Of these, 46% were also identified by the practices. There were variations between practices ranging from 0% to 85%. For the practices that applied the full template, the average proportion was 41%, compared to 34% for those who applied the short template. This was not a significant difference. As highlighted earlier, findings from qualitative interviews suggest that the low overlap between GP registers and the city-wide database may be a result of practice staff omitting people with mild learning disabilities from the list through concerns about ‘labelling’. The existence of bail hostels and student accommodation in a practice area can also adversely affect identification. Further research is needed to ascertain other reasons for exclusion and to explore how many excluded individuals may nevertheless fit the dual criteria of learning disability and need for health and social care support described in the White Paper, *Valuing People* (Department of Health 2001). Further evidence is also needed to understand whether those who require support are a static or changing group within the population of people with learning disabilities ie whether some people will fit the dual criteria at particular times and in relation to particular issues.
Estimate of prevalence

As can be seen from Table 4, the proportion of the practice population identified by the template alone was 0.4%. This varied from 0.3% to 1.0% and, where practices used the full template, included corroboration of patients identified on the lists generated from read-codes. When combined with those patients identified from the Leeds-wide register this increased to 0.7%.

Capture-recapture techniques can be used as a quick and cheap alternative to population surveys for estimating prevalence rates (LaPorte, 1994) Table 5 shows the findings from the capture-recapture technique. The capture-recapture gave an estimated total population size of 1843, 95% CI (1765, 1921), with an estimated 420 missed by both sources (Chapman, 1951). This represents a prevalence of 0.8% of the total practice population. Capture-recapture was also undertaken for each individual practice. As can be seen from Table 5, the capture-recapture by practice gave an estimated prevalence of between 0.2% and 3.7%. For the practices that applied the full template, the average proportion was 1.07%, compared to 0.76% for those who applied the short template. This was not a significant difference.

All practices across the city (120), from the five PCTs were asked to apply the template to their practice population. Altogether 30 (25%) practices, replied ie 17 practices.
Table 4: Number identified from the GP Template and overlap with Leeds-wide database

<table>
<thead>
<tr>
<th>Practice</th>
<th>Type of template applied</th>
<th>Leeds-wide database</th>
<th>Practice template</th>
<th>Total number from both lists</th>
<th>Cross reference Leeds-wide database and practice template</th>
<th>Practice list size</th>
<th>Total by practice list size</th>
<th>Template by practice list size</th>
<th>Leeds-wide by practice list size</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Practice only</td>
<td>Both lists</td>
<td>Leeds wide database only</td>
<td>Practice list size</td>
<td>Total by practice list size</td>
</tr>
<tr>
<td>P1</td>
<td>Long</td>
<td>79 62%</td>
<td>75 59%</td>
<td>128</td>
<td>49 37%</td>
<td>26 20%</td>
<td>53 43%</td>
<td>13435</td>
<td>0.95%</td>
</tr>
<tr>
<td>P2</td>
<td>Long</td>
<td>20 56%</td>
<td>20 56%</td>
<td>36</td>
<td>16 42%</td>
<td>4 11%</td>
<td>16 47%</td>
<td>5053</td>
<td>0.71%</td>
</tr>
<tr>
<td>P3</td>
<td>Long</td>
<td>48 80%</td>
<td>31 52%</td>
<td>60</td>
<td>12 20%</td>
<td>19 32%</td>
<td>29 48%</td>
<td>9562</td>
<td>0.63%</td>
</tr>
<tr>
<td>P4</td>
<td>Long</td>
<td>74 78%</td>
<td>48 51%</td>
<td>95</td>
<td>21 22%</td>
<td>27 28%</td>
<td>47 49%</td>
<td>12212</td>
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* Estimated by capture-re-capture technique (La Porte 1994)

**STEP 2a: GPs offer health facilitation to all those identified**

The GP toolkit developed by the Health Action Planning Project suggested that the process by which general practices offered health facilitation should be through a letter or GP visit to people with learning disabilities. It was anticipated that this would then be followed by requests for Health Action Plans by individuals, who would then be referred to a learning disability nurse. The pilot had not involved collaboration with Children’s Learning Disability Services and so this process only covered adults with learning disabilities.
Concerns were expressed at an early progress meeting for the project about information sharing between the Community Learning Disability Team and GP practices. As already highlighted, there was no local protocol for different health service providers in the area to share information (see Caldicott Committee 1997 and Cabinet Office/Department of Health 2006).

The Community Learning Disability Team was also concerned about the time that would be involved in facilitating this process. Members of the team felt they could not be responsible for the health facilitation of around 2,500 people with learning disabilities, as well as training GPs and identifying people with learning disabilities in GP practices. There were also questions about how far learning disability nurses would stay involved, and who would carry out evaluation and review of Health Action Plans. At the same time, a report on the pilot project stated that the team was reluctant to limit health action planning to existing people on their caseload, on the grounds that "a valuable opportunity to contribute to the education of members of the GP practice may be missed, with many failing to understand the concept of health action planning."  

The pilot had resulted in two practices identifying a total of 63 patients with learning disabilities, 47 of whom were adults. A letter was sent out from the practice offering a Health Action Plan, from which only two enquiries resulted. As no stamped addressed envelope had been sent with the initial letter, the Steering Group advised the Lead Health Facilitator to resend the letters and to follow this up with a telephone call to ascertain that the letter had arrived and that people understood what was being offered. Of the 47 patients, 24 lived in hostel accommodation and health facilitation was refused on their behalf by a member of hostel staff. Feedback to the Community Learning Disability Team indicated that hostel staff intended Health Action Plans to be incorporated into Person Centred Plans, however no collaboration with the Community Learning Disability Team was requested.

In the end, six requests for a Health Action Plan resulted from the pilot. Of these, the Lead Health Facilitator decided only three needed to be followed up as the other

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38 This was the number of people with learning disabilities known to Social Services.
39 Health Action Planning progress report September 2004
Health Facilitation and Learning Disability

three were known to the Community Learning Disability Team and had agreed after discussion that ‘their health needs were being met’\(^\text{40}\). This approach appeared to conflict with Department of Health guidance, which indicates that Health Action Plans should be person-centred and cover a wider range of issues than nursing assessments that might already be in place (Department of Health 2002).

The remaining three individuals were visited by staff from the Community Learning Disability Team to discuss health facilitation. In each case, the family carers or individuals who requested Health Action Plans had been encouraged by their GPs to request a Plan, however, it was clear that they did not properly understand the concept of health facilitation and were not sure what the role of the health facilitator was:

I don't know what I expect really. I think what, what I would like, and, and my sort of view would be that this person whoever it be, would be able to come and see [person with learning disabilities] and give me suggestions how to keep her healthy, to improve her health, to give her better quality in life and maybe suggest things that I hadn't thought of. Because you, you do get into a terrible rut. You get into this routine, and you sort of think, “Oh, you know, I could have done that”, well when you hear about other people doing things.

…. 

I think, to be honest, I think she [the Community Learning Disability Team nurse] was at a bit of a loss to know what I, my expectation was. I think we were in a way sort of crossed, we sort of got our wires crossed. ‘Cos I thought she was coming to tell me.

*Family carer*

The reason for this referral by the GP had been prompted by parents’ concerns about their increasing age and what would happen to their daughter in the future. Transition for people with learning disabilities in the care of older family carers are identified as a priority group for Health Action Plans by the Department of Health guidance.

\(^{40}\) Feedback at a meeting to discuss second progress report
Health Facilitation and Learning Disability

(Department of Health 2002), however, the confusion about what was being offered meant that no Plan resulted in this case. This indicates that professionals may need to be clearer about the benefits of Health Action Plans and provide practical examples about how the process can work.

Some family carers could also feel that health needs were already being met and consequently refuse a Health Action Plan. Carers could sometimes consider the need for a Plan from their own point of view in terms of whether they needed more support in caring for the person with learning disabilities, rather than whether this person should have more say on issues relating to their health, such as housing and independence:

A2: I suppose I didn’t really feel as though I really needed it, with having him [the GP] close at hand, I didn’t feel as though we needed it really…. We’ve no problems. I don’t have, I don’t feel to have any problems, put it that way.

... 
A: I’m moving out 40….40, mum?
Q: Is that a plan?
A2: So he says.

Family carer and person with learning disabilities

Where support was available to understand what the process involved, however, and where a relationship of trust with the person promoting the Plan existed, it was clear that takeup was far better, despite confusion and some apprehension about what was involved:

He [the GP] just says that you’re gonna get a facilitator, a facilitator and then [two nurses from the Community Learning Disability Team] which then [the GP] knows very well and I didn’t know them from Adam and it got bit, got bit frightening and then after a while we got on all right after that

Person with learning disabilities
This is likely to be the reason for the more positive response to the offer of health facilitation by an advocacy group that had secured funding to produce Health Action Plans for nine existing service users. These and other Health Action Plans which were produced during the period of the study are described in detail in the next section.

**STEP 3a: Health Action Plans produced**

Eleven Health Action Plans had been identified by the research team by the time fieldwork for this aspect of the study began. A further three were carried out by the Community Learning Disability Team as a result of the Health Action Planning Project, one of which was led by the GP practice. Two from the Children’s Learning Disability Team were also included in the study.

General issues arising from Health Action Plans produced in each of these service areas are explored below. The quality of the Plans produced is measured against the characteristics of a good Health Action Plan identified in the Department of Health guidance (Department of Health 2002). These characteristics combine Level 2 health facilitation with strategic action to ensure that Health Action Plans are adequately supported and implemented (see Box 5).

**Voluntary Sector Health Action Plans**

Ten of the eleven Health Action Plans produced in the voluntary sector were facilitated in one organisation with an existing group of services users. The organisation had taken the group on a residential weekend to focus on thinking about health and producing the Plans. The process allowed people to express and develop their views about health in a group situation and to develop the plan individually with a trusted person. The approach was person-centred but in the context of the individual as part of a group.
Box 5: What makes a good Health Action Plan?

- The plan is individual for the person.
- Takes into account any relevant broader determinants of health
- Pays due attention to individual lifestyle, culture and health care issues.
- Supports the White Paper values of rights, independence, choice and inclusion
- Involves primary care, and other generic health service staff
- Is done with (not to) the person with learning disabilities
- Where appropriate involves people close to him/her
- The person concerned (and/or those close to them) knows what is in the plan and is actively involved in implementing it
- The plan fits in with other assessment and planning mechanisms in the person’s life
- There is clarity and co-ordination, not confusion and duplication
- Is ‘live’ with the focus on the action, not just the plan
- The role and responsibilities of everyone involved in the plan are clear
- Everyone involved knows the part they have to play
- Implementation of the plan is monitored
- The plan feeds into service development
- There is an identified date for review
- Backed by broader initiatives that make implementation more likely
- Reflect any relevant national or local initiatives aimed at improving health, including actions to reduce health inequalities and National Service Frameworks

(Adapted from Department of Health guidance (Department of Health 2002))

Box 6: The Determinants of Health

Source: Dahlgren and Whitehead (1991)
Health facilitators in the organisation recognised that social activity was an important motivation for many people with learning disabilities. It was clear from interviews for this study that interactions with a group or with supporters was often the only social contact many people with learning disabilities had outside their own families. Whilst some people were active and independent outside the home, many did not feel safe to go out on their own and had had previous experiences which discouraged them from doing so:

he had a mishap in the shop when he used to go out, and that really put him off from going into a shop on his own.

*Family carer*

[Person with learning disabilities] said she had had a bad experience. I asked her if she could tell me what it was and she said no. I asked her if it was very bad and she said yes it was very bad. She didn’t feel like she wanted to be out of the house without her mother.

*Notes from interview: person with learning disabilities*

The social aspects of activities identified in the Plans were often a major reason that people with learning disabilities wanted to be involved in them and motives for exercise and health activities could sometimes have nothing to do with wanting to improve physical health:

[His] understanding of fitness, I don’t think it’s … I don’t think he’s concerned about his health, I think he just enjoys football … I encourage him to come and be a part of the group but if it’s stretching or if it’s, if it’s gym or if it’s things like that he’ll definitely be there cos he likes it, he thinks he’s gonna get some muscles.

*Voluntary sector health facilitator*

The Health Action Plans facilitated in this organisation focused very narrowly on health promotion issues such as healthy eating, smoking cessation and exercise. Social interaction was indirectly addressed, as described above, and other determinants of health such as employment, housing and educational opportunities were not identified during the process of Health Action Planning (see Box 6).
Individual interviews with the people with learning disabilities involved indicated that these wider issues were very relevant to health:

everything’s boring except for, I need something interesting in my life it’s not a computer course. I used to do two years at college. I love college.

*Person with learning disabilities*

A2: he’s interested in car valeting, he’s got, he’s got a big interest with cars…. Whether he gets paid for it, or it’s, valeting, I haven’t put, you know, he can work two or three hours in a day or just three hours in a week. You know, it’s up to you, which you are willing to do, aren’t you?
A: Yeah.
Q: You look quite excited about that.
A: Yeah… in the very near future.

*Supporter and person with learning disabilities*

When I’m at home now it’s just so hard for me now, I wish I was (out myself?) Wish I lived by myself but they…I’m always thinking that I wish I was by myself… But then again I… don’t know which way to go like.

*Person with learning disabilities*

It was also clear from these interviews and from speaking to the health facilitators themselves that the voluntary organisation was supporting some of the individuals in relation to employment, friendships and volunteering. However, this kind of activity had not been identified by supporters as related to health and so those who wanted support were not prompted to include these issues.

Staff within the organisation had applied for Health Action Zone funding to carry out the Plans and began to develop them with service users immediately this was received. This had advantages and disadvantages; it meant that the delays experienced by the Community Learning Disability Team (through waiting for Department of Health guidance and the results of the Health Action Planning pilot)
were avoided. The disadvantage was that staff members did not use the criteria in the Department of Health guidance in their development of the Health Action Plans produced.

As a result no attempt was made to create links with others who were involved in the health of people for whom Health Action Plans were written. Family members, who were often well known to the organisation, were, at best, sent a copy of the Plan. They often did not realise they had been expected to carry out some of the actions identified and had not been consulted about these:

>I’ve never, I never seen this If she’d have showed me. If she’d have shown me, I’d have said, “What’s this? Why have I got, why am I on it?”

*Family carer*

Links with family members were particularly important in relation to some health actions on which they had a major influence. For example, people with learning disabilities who wanted to give up smoking or learn to cook healthy food found it hard to do so when others around them were not involved in supporting them:

>A: Yeah, I think what would help is if both mum and my boyfriend quit [smoking] then I’ll probably be able to focus on quitting.

*Person with learning disabilities*

>A: I don’t let him, [cook]

Q: You don’t let him? It’s down here [on the Health Action Plan] that you help him do that.

>A: By the time he comes home I’ve done all the cooking, because he’s out all day

*Family carer*

This meant that the work done by the voluntary sector group in relation to health promotion was undermined in other contexts because people with learning disabilities did not get the support they needed from others close to them outside the group.
There was no link either to other health and social care professionals who were supporting the individual with health issues and consequently the Plans did not pay attention to important issues. Health Facilitators had no awareness of physical and mental health conditions which the people with learning disabilities they were working with had, such as diabetes, asthma, depression and hypertension, unless specifically mentioned by individuals themselves (this only happened in one case). Six of the ten Health Action Plans in the voluntary sector were for people who had significant physical or mental health conditions but no links were made to activity in other organisations or other health–related Plans concerning the person (see ‘Mary’s Health Action Plan’ on p117).

Most surprisingly, even though one health facilitator was employed by two separate voluntary sector organisations to support a person with learning disabilities, he did not consider combining the information from the Health Action Plan with his work to support the individual with medication for depression. Through his other post he was involved with the Community Learning Disability Team outreach nurses who supported psychiatry services but had never told them or his line manager in the second organisation about the Plan:

[I could have] possibly added to it so we could identify then who the main people were in his life at that time would have been useful, yeah….
I noticed since I started with [second organisation].. I’ve never mentioned it with my Line Manager through my supervisions and updates…, I’ve never mentioned that he’s got a Health Action Plan and I should be looking to implement or help him with that. … No again it wasn’t mentioned at the review. They did mention stuff on his health and activities wanting to do but it was never mentioned that he’s got, have an Action Plan and we should follow it up or whatever

Voluntary sector health facilitator

Similarly, when a copy of the Health Action Plan for another person was sent to the managers of her supported living home, there was little attempt to incorporate this into the Health Action Plan they already held for her. In fact, the person in question had two Health Action Plans. The plan held at the supported living home was far
more detailed and contained a systematic list of issues such as hearing, sight, mobility, communication and continence, reasoning and mental health, dental care and eyesight, that might affect health. The supported living home was visited by a podiatrist, chiropodist and nurse who came regularly and staff at the home accompanied the individual to appointments for epilepsy and psychiatry.

This plan noted that the individual had a poor diet and ate very little, and that she needed to be encouraged to eat high calorie foods. Her epilepsy and medication were also noted as issues for which she needed support, for example in attending appointments and taking medicine. Information about exercise and what the individual liked to do as well as relevant family history were also included. The Health Action Plan appeared to have been drawn up in a range of predetermined areas in order to inform other professionals. It contained a great deal of useful information that would be helpful in terms of supporting the individual but there was little evidence of her perspective being the prime focus of the Plan.

A sheet with the Plan contained notes in preparation for a psychiatric appointment and noted that issues relating to diet might be a symptom of a depressive illness. The notes complain about a reluctance to take this issue seriously by psychiatrists and question whether the individual would be treated differently if she was not learning disabled. The document appears to show that a great deal of thought was given before appointments to the issues that needed to be raised and that members of staff at the centre appeared to act in ways that protected the individual’s health within the supported living home and also as advocates for her health in relation to other professionals.

However, using information from the individual’s own interview for the study and her primary care record it became clear that significant issues had not been mentioned within this Plan and the accompanying notes which were of importance to the person with learning disabilities. Neither Health Action Plan for this person mentioned the individual’s conflict with supporters, which featured strongly in medical notes and was related by psychiatrists to challenging behaviour and anorexia:

There is nothing to suggest that there is an underlying mental illness influencing [her] behaviour. She describes ongoing interpersonal
issues with some other residents, which again had been picked up during the Outreach nursing assessment, but are outstanding... the input required is environmental

... About three months ago her behaviour deteriorated. This change appears to have been precipitated by staff changes in her home and the move of her sister into a house in the community.

... One of her care workers suggested that she does have some control over her jerks but certainly during her attendance today she was quite unconscious of marked jerking

... she tells me that she was feeling generally frustrated with her life and the fact that she wants a boyfriend, but does not meet many new people.... [following an incident of challenging behaviour, she] describes herself as being ‘scared and angry’

Extracts from letters in primary care medical records

The disturbing details these extracts add to the picture of this individual’s health indicate that systematic tick-lists of physical and mental health conditions are inadequate tools to develop Health Action Plans to the standard set out in the Department of Health guidance document. These need to be combined with person-centred approaches and robust exploration of the wider determinants of health to properly support the person with learning disabilities with their health and wellbeing.

Potentially, the first Health Action Plan could have provided a neutral means of allowing the individual to talk about the conflict she experienced with supporters and how this related to her behaviour and diet. This was particularly important because of the conflict of interest that appeared to prevent supporters in the residential home from acknowledging this link. GP records for the individual indicated that supporters had asked doctors to prescribe medication for challenging behaviour. Specialist learning disability nurses involved, however, felt that the behaviour was caused by the reactions of supporters in the residential home to demands for more control by the person with learning disabilities.
A Care Programme approach was suggested by the Community Learning Disability Team nurse involved in this person’s healthcare. There was no indication from any of the data sources obtained that this would be linked to existing Health Action Plans.

The ten Health Action Plans produced within the first voluntary organisation were person-centred but presented a limited picture of the person from a single point of view. They were not ‘live’ documents at the individual level and most people with learning disabilities and family carers did not remember the Plan at all a year later when interviewed. There was also no review of these individual Health Action Plans.

However, at the level of the group, the Plans had been used to organise a number of activities. Swimming, football and healthy eating classes were taken up over the following months as common themes and the Plans helped develop the service provided by the organisation. In this sense, within the organisation itself, the Plans fulfilled an important strategic function that was anticipated by the Department of Health guidance on Health Action Planning (Department of Health 2002).

The organisation included a group for African Caribbean people with learning disabilities and the sample of people with Health Action Plans was consequently over representative of people from minority ethnic communities. However, culture was not specifically addressed during the health action planning process. Staff members acting as health facilitators in this organisation were from the same community and it may be that such issues were taken for granted and so not explicitly addressed in Health Action Plans. Issues relating to double discrimination may have been an issue, however, in relation to the discrimination they faced with certain service providers. Support to access leisure centres, where discrimination could often be very blatant, was an important aspect of the activity carried out by the group in the context of many members feeling intimidated by the idea of going to these centres on their own:

especially the gyms, I found them very difficult to deal with…and I found some problems in the swimming baths as well ..we tried to keep our group in a tight group but I think a bunch of people with disabilities, to some gym owners doesn’t look attractive in their gym possibly.. we’d got there this particular time and they said “Well
you’ve got to become a full member, it’s gonna cost this amount.”… so they had shooed us outside and [the people with learning disabilities] were very upset because they’d been to that gym before, it didn’t seem a problem. … I went actually back just, just off hand two weeks ago and … I asked somebody coming out are they a member. They said “No we just paid at the door”.

Voluntary sector health facilitator

It is difficult to disentangle race discrimination in the above context from the discrimination that people with learning disabilities generally face in relation to accessing sports activities (Hawkins 2000; Devas 2003). However, the perception of people with learning disabilities within this group and their supporters was that both types of discrimination played a part in the exclusion they experienced.

The focus on health promotion activity in these Plans reflected an approach based on prevention of illness rather than dealing with existing medical conditions. People with learning disabilities felt that the process of writing Health Action Plans raised their awareness about health and helped them learn about how to keep healthy. They also felt they had benefited in terms of their own confidence and skills. They valued this process and the social experiences incorporated into Health Action Planning, even though their individual goals were not always subsequently met:

[Person with learning disabilities] said she didn’t remember doing the Health Action Plan at all. She did remember the pictures on the front of the plan but not what had been written inside or how it had got written. She said though, that the good thing about having the Health Action Plan was the residential, that during the residential they had played football and had various activities and that they had eaten healthy food.

Notes of interview with person with learning disability

They sort of made me think about ways I could lose weight, what I could do and what I wanted to do and I’ve managed to do it.

Person with learning disability
Mary lives with her parents and goes regularly to a training centre and to a voluntary group for people with learning disabilities. She has diabetes and blood pressure. Her Health Action Plan was written with her by a supporter in the voluntary sector group she attends (her health facilitator). Good things about the Plan are it gives Mary the chance to say that she would like to play football and lose weight and that she would like to try cooking healthy meals. Her family had not thought about asking her these things.

The group she did the Plan with organised football sessions and healthy cooking lessons and Mary has taken part in these. Things that are not so good about the Health Action Plan are that no-one else was involved in writing it, and it does not mention her diabetes or hypertension. Medical records for Mary show that her GP has said she should lose weight but the GP doesn’t know about the Plan.

Mary has not been for a review of her diabetes even though she has had three letters from her GP. Her mother normally goes with her but she is finding it difficult to take Mary to the doctor’s sometimes as she is looking after a disabled relative too. If the health facilitator had spoken to Mary’s mother about her health he might have found out that Mary needed help to see the doctor.

Mary’s training centre was sent a copy of the Health Action Plan but staff there also don’t know that Mary is diabetic. The Health Action Plan could have made sure everyone helped Mary with this or at least that the problem got some attention.

Mary has never been to see an optician as her mum thinks her eyesight seems OK. Mary’s mum does not remember getting a copy of the Health Action Plan and says she does not think Mary needs to get involved in cooking at home as she would make too much mess.
The focus on group health promotion was partly a reflection of the lack of medical knowledge and primary care links within the organisation and partly because staff resources to work at an individual level were not available. Even at the level of the group, however, the link between Health Action Planning and short-term funding made implementation of Health Action Plans insecure and unlikely to continue in the long term:

there was no management time connected to it so [staff] were more or less left to themselves …to follow it up obviously because there was no concrete time to like do supervisions or for that, it was difficult really to keep up to, up to date on what was happening so probably going on the residential helped a bit but then when the, when the funding came to an end it was difficult, even though we did try and seek extra funding to continue it was difficult to continue or to help some people.

Voluntary sector health facilitator

Managers within the organisation were well aware that the Health Action Plans that had been produced were incomplete and only partially fulfilled the requirements of a good Health Action Plan. They were keen to collaborate with service providers who could complement the valuable activities they had been able to generate however:

if there was a referral made to us by the Facilitators, then I think it’s around these areas, elements of a sort of whole Health Action Plan, we would be able to fulfil some of those elements. So I think that’s how the partnership working could work, is identify organisations, statutory and voluntary sector who are delivering services.

Voluntary sector organisation

Children’s Learning Disabilities Services

Health Action Plans carried out by Children’s Learning Disability Team were extremely detailed documents developed from interviews with family members, school staff and health professionals. They were the result of a referral to the Team by professionals involved with the child in relation to a specific issue. Despite the guidance on health facilitation (Department of Health 2002) distinguishing Health
Action Plans from traditional nursing assessments, members of the Children’s Learning Disabilities Team felt that all assessments were comprehensive enough to be renamed Health Action Plans after *Valuing People* was published:

what we did when *Valuing People* came out was change what we were actually calling our nursing assessment, because really the nursing assessment wasn’t representing entirely what it was, cos it wasn’t just purely an assessment. There was a set of recommendations after every section, there was actions identified about who would refer to where and when and who would do that. There was a description of the role of the specialist nurse within, and a statement about what they would do. So in a way it was wrong to call it just a nursing assessment ‘cos it included the assessment, but there was a lot more there as well. And the Health Action Plan, when that came through, that just described it beautifully really, that that’s what it was.

*Children Learning Disabilities Team*

Evidence from members of the Team and parents showed that the specialist skills of learning disability nurses in the Team were important in picking up health issues that others missed. Team members could promote best practice such as dealing with challenging behaviour in ways that did not involve medication (Unwin and Deb 2006). They could also suggest new assessments or interventions that were unknown to staff in specialist schools or to family carers. The Team regularly came across very low levels of awareness about how to care for children with learning disabilities as well as ‘diagnostic overshadowing’ - professionals viewing a child’s medical condition as though this was part of the learning disability and so failing to investigate or treat this (Disability Right Commission 2006):

even when you’ve got like a child that’s got a clear diagnosis with a set of clear clinical characteristics of their health needs, even then, you know, there’s been, we could get a referral for a fourteen year old...

This child should be having PH testing of the oesophagus to make sure that the antacid medicine that’s he’s having is being effective as
Health Facilitation and Learning Disability

a matter of good healthcare anyway. But he’s probably not even having the antacid medication, you know.

Children Learning Disabilities Team

Whilst valuing the input of the specialist nurses, however, parents felt that much of the Health Action Plan described what they already knew. The reason why a child had been referred for the Plan could also be lost in terms of a priority in the very detailed picture provided. The length of time it took to complete the Health Action Plan, which involved a number of visits over a period of months, also worked against the need to address this issue as a matter of urgency:

…there’s only one small section of it that is really of interest to me which was the issue that, that we got, you know that [the learning disability nurse] got involved about in the first place

…it just seems to take a while, do you know what I mean? … it’s just the, you know, how busy everybody is and fitting it all in, I suppose really.

Family carers

Links were developed by the specialist nurse with the different individuals who could contribute to the health of the child or young person with learning disabilities. However, these did not appear to be for the purpose of ensuring co-ordination and a common framework for review; their purpose seemed to lie in developing a holistic picture of the child in the mind of the learning disability nurse.

Once the Health Action Plan was completed and recommendations for action were made to each party involved, it was left to parents to ensure the Plan was implemented. Members of the Children’s Learning Disability Team considered the Plan to be an empowering tool in this respect, however, there were mixed reactions to this view of the Plan and it was clear that parents felt some support was needed to review and implement the actions:
You know she gives helpful advice but it’s kind of obvious and if you could do it you’d be doing it, you know ...it’s all very well giving advice but how do you put it into action?

**Family carer**

It was interesting to note that whilst parents could be seen as ‘too stressed’ to communicate effectively with healthcare professionals around diagnosis, they could nevertheless be seen as entirely competent in terms of implementing the Health Action Plan:

ninety five percent of parents are stressed, it’s chaos, it’s, you know, they’re not the most reliable.. they’re not in the most reliable situations to give good evidence to medics about the health of children.

**Children’s Learning Disability Service**

As with the Health Action Plans in the voluntary organisation described earlier, these Plans were seen as a one-off exercise. Parents were given the option to telephone the specialist nurse who wrote the Plan for further advice, however, this required them to take the lead themselves rather than be followed up by the nurse. Family carers felt it would be more helpful to support them to implement actions in relation to the priority for which they were first referred:

perhaps certain practices ...other than the standard response then, you know if [the nurse] could put those into action for us then that might be useful cos obviously we have tried the standard responses and they’re not working either at home or at school ... I mean the problem is with health professionals, all health professionals I’m sure, is that once they switch off from you, once your case is closed you’re forgotten, that’s it, you’re out, you’re off their books, you don’t exist any more, you know until you pick up the phone and, and chase them again, you know it’s not ongoing.

**Family carer**
A further issue in relation to Health Action Plans for children raised by family carers related to transition. Guidance on the National Service Framework for Children states that:

in school the formal transition planning process starts at age 14 (year 9) and it is helpful to embed medical transition within the broader context of growing up and moving on, incorporating Health Action Plans where appropriate.

*(Department for Education and Skills/Department of Health 2006)*

This had not been the experience of many parents people involved in the study who felt that almost all the support they received with healthcare disappeared once children became adults. No discussion appeared to have taken place with the Transition Service in relation to incorporating Health Action Plans into the planning process:

Well we need to get clear information from adult services, and agree what documentation they’re going to use. And I think anybody you know that’s coming through the service should be asked if they want to complete one. And there’s no reason from 14 why that couldn’t happen. It’s just agreeing in the middle the sort of common ground really. I don’t see it as an issue; it’s just that we’ve not been consulted or involved in it, in developing the paperwork even.

*Transition team*

**Community Learning Disability Team led Health Action Plans**

Of three plans carried out by the Community Learning Disability Team, two had been initiated as a result of the Health Action Planning pilot. One of these was left with the individual and a family carer and the other with a receptionist at the individual’s GP practice (see ‘Gordon’s Health Action Plan’ below). A third had been developed outside the pilot as a by-product of an individual’s referral to the Community Learning Disability Team by specialist psychiatry services.
The format of the Health Action Plan used by the Community Learning Disability Team was similar to that used by the voluntary sector organisation and based on one of the examples in the Department of Health guidance document (Department of Health 2002). Main headings identified the health issue, the action that followed and the person responsible for performing the action. The involvement of a learning disability nurse in helping to write the Plan ensured that a wide range of potential health issues were covered, however this process did not appear to be very person centred in relation to the actions included:

[I] wouldn’t have said that many of them came from [person with learning disabilities]. It was mainly us thinking of yeah, health needs. I wouldn’t have said any … [she] really came up with those.

**Health facilitator**

Members of the Community Learning Disability Team perceived their role in terms of supporting the creation of Health Action Plans either during a period of clinical intervention with a person with learning disability or at discharge. This was a secondary role to the intervention itself and the Health Action Plan was passed on to another individual after discharge with no monitoring of the Plan by the Team or other person afterwards. Two of the Plans were left with parents, though evidence suggested that they would not support implementation of the Plan. Reasons for this included mistrust of professionals and poor knowledge of how to support access to healthcare by the parents themselves.

Mistrust in one case was related back to an incident of sexual abuse whilst the person with learning disabilities was at a training centre which led to the parent ‘keeping away’ from professionals unless this was unavoidable. In both cases, whilst the parents supported their relative to access healthcare their capacity to act as advocates in these settings was limited (for example, one spoke little English), and they did not always support the priorities of the people with learning disabilities themselves.

The nurse’s involvement with one of these individuals was a result of referral from psychiatry services relating to suspected epilepsy. During the time in which she was involved in helping to determine a diagnosis, she supported the individual to attend a
gym on a weekly basis and also accompanied him to see his GP and a neurologist. This helped raise his awareness about the benefits of losing weight and increased his confidence to speak to professionals about his health. A Care Plan was drawn up for epilepsy medication but this was a completely separate document from the Health Action Plan and no links were made between the two Plans.

As with the instance described earlier in the voluntary sector, medical records for this person indicated that conflicts within the household were linked to requests for medication by family members to deal with challenging behaviour by the person with learning disabilities. When asked to prescribe anti-depressants the GP did so ‘reluctantly’ and also referred him to psychiatry services. Later records indicate that the GP suggested attending a day centre or respite care as a means of addressing the challenging behaviour. The Health Action Plan makes no mention of anti-depressant medication and it appears that conversations between the GP and learning disability nurse were limited to the issue of epilepsy, without reference to other issues that might have been addressed by the Health Action Plan.

The nurse was aware of conflicts between the individual and family members, some of which upset the person with learning disabilities greatly, and she had made attempts to get him involved in regular daily activities outside his home. However, these issues were again not mentioned in the Health Action Plan and the nurse felt worried about discussing them with the family, who were not supportive of outside activities for the individual, in case this caused offence. Findings suggest a strong possibility that this person’s problems with conflict at home and the reason for his initial referral to psychiatry could resurface after the nurse’s withdrawal. As already highlighted, the role of health facilitator had been passed on to members of the individual’s family after discharge by the Community Learning Disability Team. However, without appropriate support to involve people with learning disabilities in decisions about their own health, some respondents recognised that carers might not be the best health facilitators:

I think that the health facilitator can be certainly the carer, it can be a relative, it can be a health professional, can be whatever but there are certain times when... like in life when you’ve got to be able to recognise that perhaps you’ve got your own prejudice, perhaps
you’ve got your own interest in a particular thing and that maybe isn’t the same as the individual i.e. what a mother or father may think is best for the child is not always what’s best for the child as the person becomes an adult, and they may want to do their own thing and branch out and mum or dad being the advocate may not always be the best person.

*PCT professional*

A similar situation has been described in relation to the Health Action Plan carried out by carers in a supported living home. These findings indicate that paid carers in residential settings may also need to pay attention to conflicts of interest with people for whom they may act as health facilitators. In such cases it would be appropriate to provide independent support to enable people with learning disabilities to have a central voice in the health action planning process and to help support implementation of the Plan once it has been created.

In the case of the third Health Action Plan led by the Community Learning Disability Team, a far more constructive situation was developed, mainly because the health facilitator involved was more able and willing to play an active role in supporting the individual’s Plan (see “Gordon’s Health Action Plan” below). The health facilitator’s position within the GP practice gave her easy access to both the person with learning disabilities, Gordon, who came to see her “several times a week”, and to the GP and practice nurse. Through the GP she was also linked to psychiatry services, who had contact with the voluntary organisation that supported Gordon. Although the ‘circle of support’ (Department of Health 2002) around Gordon was not completely formed, there were strong links in important places. More direct links between the health facilitator, the voluntary sector organisation and with social workers involved with Gordon would have helped to improve the process and create a circle of support around Gordon in relation to his health.

*Other plans and assessments*

A range of other health-related plans and assessments were in use and identified during the course of the study and many professional respondents felt these significantly overlapped with, or were identical to Health Action Plans:
I think Health Action Plans are fine things, they’re new names for care plans, coordinated plans, person-centred planning, integrated care plans, I mean I’ve been involved in care for twenty odd years and they’re all the same and they’re a jolly good idea ….New forms, slightly different format, slightly different way of doing it, it’s all trying to tackle the same problem; you need integrated, holistic, joined-up, in one place, at one time plan that somebody owns that’s about their needs, that everybody feeds into and that’s what we’ve been trying to struggle with around learning disability, mental health, older people’s planning for years and it’s another way of doing it, in my view!

Senior PCT Manager

Every person in the Mental Health Trust’s supported living houses had a support package based on one such assessment document. The document contained detailed exploration of the person’s health needs and actions identified during the process of assessing these required would be linked to specific support plans to meet the health requirements. Descriptions of these plans by the Trust’s Service Manager indicated that the individual and support staff would have access to the document and associated support plans. The level of GP or consultant input to the plans would vary according to the extent of the individual’s health needs. An internal quality audit checked outcomes and completion of documentation was also audited externally by the Commission for Social Care Inspection.
Gordon lives with his son. He has some physical health problems and is seeing a consultant about them.

Sometimes a friend from the local church or a supporter comes with him as he can’t understand the consultant. But this doesn’t always happen as they don’t always have time to come to the appointments.

Gordon also has some mental health problems and is seeing a psychiatrist. He is taking medicines for depression after he lost a relative.

He gets very bored at home and would like to do a college course. A Social Worker comes regularly to check up on his son and Gordon feels she ‘causes me stress every, every, every week’.

Gordon’s GP sent him a letter about having a Health Action Plan and said Gordon should get one. Gordon agreed but didn’t really know what it was.

He had a visit by two learning disability nurses which he felt was ‘a bit frightening’. They wrote the Plan with Gordon and Diane. Diane is a receptionist at the surgery who knows Gordon well and already supports him to understand the GPs.
The practice nurse was Gordon’s first choice but she said she didn’t have time to be Gordon’s health facilitator.

The good things about the Health Action Plan are that it includes things about Gordon’s physical health. It says that he needs to see a dentist and optician and that he can’t understand the hospital consultant.

Diane is in touch with lots of places that are important to Gordon’s health. She speaks to his GP and the practice nurse regularly and has helped him get liquid medicine instead of tablets, which he finds easier to take. The practice nurses will keep checking Gordon’s blood pressure and support him to lose weight.

Diane has also worked with the learning disability nurses to help him find out about opticians who know how to work with people with learning disabilities.

She has also asked the consultant to write to her so that she can explain things to Gordon after his appointments. Diane has supported him to stop drinking and Gordon thinks he wouldn’t have done this without the Plan.

Things that could be improved are that Diane feels she needs training and is unsure about exactly what her role is supposed to be. She doesn’t know how often she should look at the Plan with Gordon and what to do if she feels stuck. She would like to meet other people who are health facilitators and have more guidance and support.

The Plan mentions that Gordon wants to do a course but has no action point about this. Also, it doesn’t mention the problems Gordon is having with Social Services about looking after his son, which gives him a lot of stress. Diane is not linked up to people in Social Services or the voluntary organisation that is also involved with Gordon.

One of the action points on the Plan is that the voluntary group will help Gordon get access to counselling. But they have not agreed to do this and Gordon hasn’t mentioned it to them. He says he ‘wants someone to talk to’.

Gordon feels having the Plan and Diane to help him is a good thing. He does feel people at the practice can get bossy about it sometimes but he says he doesn’t really mind this because he feels he sometimes needs it.
The research team had the opportunity of looking at a number of plans held by one day centre in relation to four people with complex needs whose carers were invited to a focus group discussion for the study. These were very detailed documents giving precise details of the kind of care an individual needed. It was clear that they were regularly updated and that family carers were involved in the reviews. The plans were almost exclusively focused on physical health needs and aspects of nursing care related to these, however, with no space for other issues relating to healthcare outside the centre. The plans did not specifically link together different people involved in the health of the individual or explore health needs that were unmet elsewhere. Although carers appeared to have been consulted about nursing care, the plans were not seen as a mechanism for addressing their more general concerns about health, such as problems in support received from GPs or consultants or a lack of resources to meet the care needs of an individual during short breaks away from home. These findings suggest that although plans carried out by staff in some parts of learning disabilities services fulfilled many of the criteria outlined in Department of Health guidance (see Box 5), some further development was needed before these could be understood as Health Action Plans. In particular, a greater focus on doing the Plan ‘with’ rather than ‘to’ the person was needed. A more holistic picture of how to improve the health of the individual would require more involvement of those close to the individual and supporting them to have these needs met:

A1: …half the time you just do not know what is wrong with her. But I can sense that there is something …. Or you can see by the look in her eyes that there is something wrong. I can’t say what, but I’m as close to her as anybody’s going to get

A2: Sixth sense.

Family carers of people with complex needs

Valuing People target on HAP

There was no routine mechanism for auditing the number of Health Action Plans carried out in the fieldwork area, however the Community Learning Disability Team were contacted to determine how many people with learning disabilities had had a Health Action Plan. A decision had been made within the team following completion of the Health Action Planning pilot to prepare Health Action Plans before nurses
Health Facilitation and Learning Disability

withdrew from involvement with any service user, if possible. A Health Action Plan pathway was developed to help determine the point at which Plans should be developed between initial referral, clinical interventions and case closure.

Feedback from the Community Learning Disability Team indicated that up to June 2006, the Team had helped to complete 79 Health Action Plans. This number did not include service users and family carers who did not take up the offer to have a Plan. Members of the Team reported that refusal could be linked to having an existing plan which individuals felt had met their needs.

In addition an estimated 240 children with learning disabilities involved with the Children’s Learning Disability Team also had a Health Action Plan. Taking into account the 11 voluntary sector Plans described earlier, the total number of Health Action Plans known to have been completed by November 2006 stood at around 330. This number does not include Health Action Plans in other voluntary and statutory organisations that were not discovered by the research team during the fieldwork period.

**STEP 4a: Service users health needs identified and met/better health outcomes**

We explored this expectation of the health facilitation policy in two separate and complementary ways. Using qualitative research methods, we spoke to people with learning disabilities, their family carers and health facilitators about the process of developing Health Action Plans and what effects they felt these had had on their health (see Step 3a). We also obtained consent from the people with learning disabilities (or their carers if necessary) to compare primary care records with the Plan so that we could assess how well it tied in with other work on health involving the person’s GP and a range of other professionals. Evaluation of the outcomes was based on triangulating and synthesising data from all these sources (Pawson 2003; Yin 1994).

Some Health Action Plans appeared to be better at identifying health needs than others (see Step 3a). There were also improved outcomes for some people with learning disabilities and family carers. However in all cases there appeared to be problems with implementation which affected whether or not Plans led to better health outcomes.
In relation to those carried out in the voluntary sector, the process of health action planning was valued by people with learning disabilities both for its social benefits and the increased knowledge and confidence it provided. The absence of attention to existing medical conditions, however, meant that unmet need in relation to these were not identified and so could not be met. Health actions relating to lifestyle, such as diet and exercise, were met to some extent at group level. However, as already highlighted, the input available to support group members was affected by the lack of funding available to continue the process once Health Action Plans had been completed.

Health Action Plans facilitated by adult learning disability services helped to explore a range of possible health issues and in two cases led to individuals being supported to have these met. However, outcomes were adversely influenced by the lack of training for and effective identification of health facilitators once Community Learning Disability Team nurses withdrew.

In relation to Health Action Plans for children, the time devoted to preparing the Plan was considerable. However, the expectation that parents would act as health facilitators to implement Plans, without exploring the support they might need to carry out this role, meant that the Health Action Plan could become an inactive document. Parents could also question whether the specialist time involved should have focused more on supporting them to resolve the priority issue:

Who is it for? Because most of it is only telling me what I already know… I think it would have been just helpful to just deal with this [priority] issue really, you know… And to continue dealing with it, you know, not, not to just write a report and then just leave us to it, you know cos this is, there’s a lot of work gone into this, you know, it’s fantastic, hours, you know but those hours, you know, maybe they could have been spread over a longer period of time more effectively really.

Family carer
Similar dynamics relating to resources and adequate follow-up appeared to be paralleled in other assessments and reviews that identified actions to support the person with learning disabilities:

the reviews that I've had at training centres I mean I put all these issues and ideas to them and “Oh, yes we'll do this” but then when I've gone back and said “Has it been implemented?” “No.” “Why?” “No staff.” So I mean how can our children and the people we care for come on when and they do all these reviews and things, when they have no staff to do it with?

Focus Group: minority ethnic carers

A further way of exploring the impact of health facilitation was to compare the medical records of those people with learning disabilities who had been offered health facilitation to those in general practices that had not. Originally, our plan had been to compare the records of people who had Health Action Plans for a year before and a year after the Plan had been created (see Methods). However, because of the low numbers of people who had a Health Action Plan during the fieldwork period, it was not possible to make a statistical comparison. It was, however, possible to explore whether the offer of health facilitation, after identifying people with learning disabilities on general practice registers, triggered any dynamic that had an effect on the overall quality of primary care for people with learning disabilities.

Analysis of patients identified and/or offered Health Facilitation

The number of patients' notes reviewed for this analysis was 103, broken down by practice as follows and summarised in Table 6:

Register and offered HF – Practices A and B: 46 adult patients were identified by the two practices that had a register and had offered their patients health facilitation (HF).

Register only – Practices C and D: 57 adult patients were identified by the two practices that had a register, but had not offered their patients HF.
Table 6: Numbers from GP data extraction

<table>
<thead>
<tr>
<th>Practice</th>
<th>Identified by practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>32</td>
</tr>
<tr>
<td>B</td>
<td>14</td>
</tr>
<tr>
<td>C</td>
<td>43</td>
</tr>
<tr>
<td>D</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>103</td>
</tr>
</tbody>
</table>

In total data was extracted for 46 patients who were on the practiced-based register and were offered HF (Register and HF) and 57 patients who were on the practiced based register only (Register only).

**Demographics**

Table 7 shows the demographic characteristics of the patients. There was no difference between age or place of residence. There was a significant difference (p<0.001) between gender, with a higher proportion of males in the register only group.

Table 7: Demographic characteristics

<table>
<thead>
<tr>
<th></th>
<th>Register and HF</th>
<th>Register only</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age - Mean (standard deviation)</strong></td>
<td>43.7 (12.1)</td>
<td>48.3 (14.4)</td>
</tr>
<tr>
<td><strong>Gender (% male)</strong></td>
<td>27/46 (59%)</td>
<td>43/57 (75%)</td>
</tr>
<tr>
<td><strong>Place of residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group home</td>
<td>30 (65%)</td>
<td>38 (67%)</td>
</tr>
<tr>
<td>Own home</td>
<td>4 (9%)</td>
<td>9 (16%)</td>
</tr>
<tr>
<td>With parents</td>
<td>9 (20%)</td>
<td>6 (11%)</td>
</tr>
<tr>
<td>Not known</td>
<td>3 (6)</td>
<td>4 (6%)</td>
</tr>
</tbody>
</table>

**Active health problems**

The active health problems screen on the GP system lists all the active health problems that the patient has. For patients in the sample there was a wide range of health problems. The key finding from looking at the active health problems was that of the 103 patients, 5 (5%) did not have a code for Learning Disability/Mental retardation in the active health problems list.
A maximum of 8 active health problems could be recorded, resulting in 824 (103 x 8) possible codes. 345 active problems were recorded across the sample, which represents an average of 3.34 active health problems per patient. Due to the range of different health problems (with small numbers in each sub-group), for analysis we identified a number of chronic diseases. Table 8 shows the number of patients with any one of these conditions.

Mental Health was the main active health problem with 28% in the register and HF group and 32% in the register only group. This was followed by epilepsy, with 17% in the register and HF group and 21% in the register only group. Diabetes was more common in the register only practices (14% vs 7%), as was hypertension (9% vs 12%).

**Table 8 Number with active health problem on main disease groups**

<table>
<thead>
<tr>
<th>Active Health problems</th>
<th>Register and HF group (46)</th>
<th>Register only (57)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>3 (7%)</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>3 (7%)</td>
<td>8 (14%)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>8 (17%)</td>
<td>12 (21%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>4 (9%)</td>
<td>7 (12%)</td>
</tr>
<tr>
<td>Chronic Disease (at least one of the above)</td>
<td>16 (35%)</td>
<td>23 (40%)</td>
</tr>
<tr>
<td>Mental Health</td>
<td>13 (28%)</td>
<td>18 (32%)</td>
</tr>
</tbody>
</table>

In the data extraction we made a note of whether or not in the year pre and post intervention (creation of a register or creation of a register and offer of HF) the patient had had a chronic disease review for the above diagnostic groups. It became apparent that for a small number of patients, although they may have had a review for, say, asthma, this was not listed as one of their active health problems (3 patients). It is assumed that where there was evidence of a review, the patient had an active health problem.

Table 9 shows the number of patients who had a chronic disease specific review pre and post intervention. Grouping those who had asthma, diabetes, hypertension or epilepsy listed as an active problem: in the register and offered HF group, there were 16 patients of whom 8 (50%) had a review pre, and 11 (67%) post. In the register
only group, there were 23 patients, of whom 14 (60%) had a review pre, and 16 (69%) post.

**Table 9 Chronic disease review undertaken.**

<table>
<thead>
<tr>
<th></th>
<th>Pre/post</th>
<th>Register and offered HF</th>
<th>Register only</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Asthma</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre</td>
<td>1/3</td>
<td></td>
<td>4/5</td>
</tr>
<tr>
<td>Post</td>
<td>2/3</td>
<td></td>
<td>1/5</td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre</td>
<td>1/3</td>
<td></td>
<td>5/8</td>
</tr>
<tr>
<td>Post</td>
<td>2/3</td>
<td></td>
<td>8/8</td>
</tr>
<tr>
<td><strong>Hypertension</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre</td>
<td>¾</td>
<td></td>
<td>0/8</td>
</tr>
<tr>
<td>Post</td>
<td>¾</td>
<td></td>
<td>1/8</td>
</tr>
<tr>
<td><strong>Epilepsy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre</td>
<td>4/8</td>
<td></td>
<td>8/13</td>
</tr>
<tr>
<td>Post</td>
<td>4/8</td>
<td></td>
<td>9/13</td>
</tr>
<tr>
<td><strong>At least one chronic disease</strong></td>
<td>Pre</td>
<td>8/16</td>
<td>14/23</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>11/16</td>
<td>16/23</td>
</tr>
</tbody>
</table>

**Number of contacts**

Table 10 shows a summary of the number of contacts patients had pre and post the intervention. The overall average number of contacts pre-intervention for the register and HF group was 7.35, and for the register only group it was 7.86. This was not a significant difference. The mean number of contact post intervention for the register and HF group was 7.89, and for the register only group it was 8.54. This was not a significant difference.

There were no significant differences in the type of contact (drugs only, GP contact and nurse contact) pre and post intervention.
Table 10: Number of contacts (Pre and post intervention)\(^{41}\)

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>No.</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Register and offered HF</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre</td>
<td>7.35</td>
<td>7.80</td>
<td>46</td>
<td>0</td>
<td>39</td>
</tr>
<tr>
<td>Post</td>
<td>7.89</td>
<td>11.76</td>
<td>46</td>
<td>0</td>
<td>74</td>
</tr>
<tr>
<td>Drugs only pre</td>
<td>.00</td>
<td>.00</td>
<td>46</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Drugs only post</td>
<td>.07</td>
<td>.33</td>
<td>46</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>GP contact pre</td>
<td>5.22</td>
<td>5.21</td>
<td>46</td>
<td>0</td>
<td>25</td>
</tr>
<tr>
<td>GP contact post</td>
<td>4.96</td>
<td>5.85</td>
<td>46</td>
<td>0</td>
<td>34</td>
</tr>
<tr>
<td>Nurse contact pre</td>
<td>2.13</td>
<td>3.48</td>
<td>46</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Nurse contact post</td>
<td>2.87</td>
<td>6.01</td>
<td>46</td>
<td>0</td>
<td>38</td>
</tr>
<tr>
<td>Register</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre</td>
<td>7.86</td>
<td>12.74</td>
<td>57</td>
<td>0</td>
<td>77</td>
</tr>
<tr>
<td>Post</td>
<td>8.54</td>
<td>11.02</td>
<td>57</td>
<td>0</td>
<td>72</td>
</tr>
<tr>
<td>Drugs only pre</td>
<td>.00</td>
<td>.00</td>
<td>57</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Drugs only post</td>
<td>.00</td>
<td>.00</td>
<td>57</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>GP contact pre</td>
<td>4.25</td>
<td>4.45</td>
<td>57</td>
<td>0</td>
<td>26</td>
</tr>
<tr>
<td>GP contact post</td>
<td>5.05</td>
<td>5.40</td>
<td>57</td>
<td>0</td>
<td>31</td>
</tr>
<tr>
<td>Nurse contact pre</td>
<td>3.61</td>
<td>9.82</td>
<td>57</td>
<td>0</td>
<td>51</td>
</tr>
<tr>
<td>Nurse contact post</td>
<td>3.49</td>
<td>7.28</td>
<td>57</td>
<td>0</td>
<td>41</td>
</tr>
</tbody>
</table>

Nature of consultations

Table 11 shows a summary of the mean number of different types of consultations. There was no difference between the mean different types of contact between the register and offered HF group, and the register only patients. There was also no difference between pre and post the intervention.

\(^{41}\) Mean and standard deviance
### Table 11: Nature of consultations

<table>
<thead>
<tr>
<th>Register and offered HF</th>
<th>Valid N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>New problem Pre HF</td>
<td>N=46</td>
<td>2.07</td>
<td>1.88</td>
</tr>
<tr>
<td>New problem Post HF</td>
<td>N=46</td>
<td>2.00</td>
<td>1.75</td>
</tr>
<tr>
<td>Follow up of existing Pre HF</td>
<td>N=46</td>
<td>4.15</td>
<td>5.68</td>
</tr>
<tr>
<td>Follow up of existing Post HF</td>
<td>N=46</td>
<td>4.09</td>
<td>9.44</td>
</tr>
<tr>
<td>OCP Review Pre HF</td>
<td>N=46</td>
<td>.22</td>
<td>.89</td>
</tr>
<tr>
<td>OCP Review Post HF</td>
<td>N=46</td>
<td>.22</td>
<td>.84</td>
</tr>
<tr>
<td>Immunisation Pre HF</td>
<td>N=46</td>
<td>.15</td>
<td>.42</td>
</tr>
<tr>
<td>Immunisation Post HF</td>
<td>N=46</td>
<td>.80</td>
<td>.75</td>
</tr>
<tr>
<td>Health check Pre HF</td>
<td>N=46</td>
<td>.13</td>
<td>.34</td>
</tr>
<tr>
<td>Health check Post HF</td>
<td>N=46</td>
<td>.09</td>
<td>.28</td>
</tr>
<tr>
<td>Medication review Pre HF</td>
<td>N=46</td>
<td>.09</td>
<td>.28</td>
</tr>
<tr>
<td>Medication review Post HF</td>
<td>N=46</td>
<td>.20</td>
<td>.78</td>
</tr>
<tr>
<td>New problem Pre HF</td>
<td>N=57</td>
<td>2.19</td>
<td>2.57</td>
</tr>
<tr>
<td>New problem Post HF</td>
<td>N=57</td>
<td>2.30</td>
<td>2.75</td>
</tr>
<tr>
<td>Follow up of existing Pre HF</td>
<td>N=57</td>
<td>4.51</td>
<td>11.21</td>
</tr>
<tr>
<td>Follow up of existing Post HF</td>
<td>N=57</td>
<td>4.86</td>
<td>8.72</td>
</tr>
<tr>
<td>OCP Review Pre HF</td>
<td>N=57</td>
<td>.00</td>
<td>.00</td>
</tr>
<tr>
<td>OCP Review Post HF</td>
<td>N=57</td>
<td>.04</td>
<td>.19</td>
</tr>
<tr>
<td>Immunisation Pre HF</td>
<td>N=57</td>
<td>.47</td>
<td>.50</td>
</tr>
<tr>
<td>Immunisation Post HF</td>
<td>N=57</td>
<td>.39</td>
<td>.49</td>
</tr>
<tr>
<td>Health check Pre HF</td>
<td>N=57</td>
<td>.05</td>
<td>.23</td>
</tr>
<tr>
<td>Health check Post HF</td>
<td>N=57</td>
<td>.11</td>
<td>.31</td>
</tr>
<tr>
<td>Medication review Pre HF</td>
<td>N=57</td>
<td>.14</td>
<td>.40</td>
</tr>
<tr>
<td>Medication review Post HF</td>
<td>N=57</td>
<td>.19</td>
<td>.48</td>
</tr>
</tbody>
</table>

Table 12 shows the proportion of patients who had a health check or medication review, pre and post HF. There was no difference between the proportion of patients having a health check or medication review between the register and offered HF group, and the register only patients, pre or post intervention. There was also no significant difference between pre and post the intervention, within either group. However, trends were seen, with a fall in health check, but a rise in medication reviews for the register and HF group. There was rise in the proportion of health check medication reviews for the register only group.
### Table 12: Health checks and medication reviews

<table>
<thead>
<tr>
<th>GROUP</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>%</td>
</tr>
<tr>
<td>Health check Pre HF</td>
<td>40</td>
<td>87.0%</td>
</tr>
<tr>
<td>Health check Post HF</td>
<td>42</td>
<td>91.3%</td>
</tr>
<tr>
<td>Medication review Pre HF</td>
<td>42</td>
<td>91.3%</td>
</tr>
<tr>
<td>Medication review Post HF</td>
<td>41</td>
<td>89.1%</td>
</tr>
<tr>
<td>Health check Pre HF</td>
<td>54</td>
<td>94.7%</td>
</tr>
<tr>
<td>Health check Post HF</td>
<td>51</td>
<td>89.5%</td>
</tr>
<tr>
<td>Medication review Pre HF</td>
<td>50</td>
<td>87.7%</td>
</tr>
<tr>
<td>Medication review Post HF</td>
<td>48</td>
<td>84.2%</td>
</tr>
</tbody>
</table>

**Values: BP, Alcohol, BMI, height, lifestyle, weight and smoking**

Table 13 represents the proportion of the sample who in the year before, and the year after each intervention, had at least one record with a value for Blood Pressure (BP), Alcohol, Body Mass Index (BMI), Height, Weight, and smoking status. There were rises in the proportion of people with a record for BP, BMI, height and weight for both groups. Records about alcohol, lifestyle and smoking increased for the register only group, but not for the register and HF group. This links to an increase in health checks for the register only group, whereas there was a fall for the register and HF group.
Table 13: Values

<table>
<thead>
<tr>
<th></th>
<th>Register and offered HF</th>
<th>Register</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>PRE BP</td>
<td>25</td>
<td>54%</td>
</tr>
<tr>
<td>POST BP</td>
<td>32</td>
<td>70%</td>
</tr>
<tr>
<td>PRE ALCOHOL</td>
<td>16</td>
<td>35%</td>
</tr>
<tr>
<td>POST ALCOHOL</td>
<td>10</td>
<td>22%</td>
</tr>
<tr>
<td>PRE BMI</td>
<td>16</td>
<td>35%</td>
</tr>
<tr>
<td>POST BMI</td>
<td>26</td>
<td>57%</td>
</tr>
<tr>
<td>PRE HEIGHT</td>
<td>10</td>
<td>22%</td>
</tr>
<tr>
<td>POST HEIGHT</td>
<td>22</td>
<td>48%</td>
</tr>
<tr>
<td>PRE LIFE</td>
<td>8</td>
<td>17%</td>
</tr>
<tr>
<td>POST LIFE</td>
<td>3</td>
<td>7%</td>
</tr>
<tr>
<td>PRE WEIGHT</td>
<td>16</td>
<td>35%</td>
</tr>
<tr>
<td>POST WEIGHT</td>
<td>25</td>
<td>54%</td>
</tr>
<tr>
<td>PERSMOKEING</td>
<td>18</td>
<td>39%</td>
</tr>
<tr>
<td>POSTSMOKING</td>
<td>16</td>
<td>35%</td>
</tr>
</tbody>
</table>

**Screening**

There were 41 women altogether in the sample: 9 had a record for cervical smear before and 11 after the interventions. Of these 41 women, 17 were aged over 50; 12 had a record for mammogram before and 11 after the interventions.

**Summary**

These findings do not show statistical differences in the impact on primary healthcare of identifying or offering health facilitation and the small numbers involved mean that such differences would have to be very large to be statistically significant. However, certain trends towards increased medication reviews and health checks in practices that identify people with learning disabilities on their registers is suggested by our findings. In practices where health facilitation was also offered, health checks were reduced but medication reviews increased. There were rises in the proportion of people with a record for blood pressure, body mass index (a measure for obesity), height and weight for both kinds of practice. Records about alcohol, lifestyle and smoking increased for the ‘register only’ group, but not for the ‘register and health facilitation group’. These trends indicate more attention within these practices to individual lifestyle issues that are likely to affect the health of people with learning disabilities.
Inclusion in Level 2 health facilitation

Despite the lack of attention to inclusion in Level 1 health facilitation, people with learning disabilities from one minority ethnic community were over-represented in the sample of people who had a Health Action Plan. This was primarily because the voluntary sector organisation in which 10 Health Action Plans had been carried out targeted a group of African Caribbean service users in its health facilitation work. Limited funding meant, however, that other minority ethnic communities could not be targeted in the same way. There was little evidence of work to ensure the inclusion of people from minority ethnic communities by other services producing Health Action Plans. There was also some evidence that ‘double discrimination’ could be an issue in terms of trying to implement the Plans (see Voluntary Sector Health Action Plans).

People with complex needs were also well represented within the sample. A number of people with Health Action Plans had been diagnosed with a mental health condition. The Plans could potentially have provided a person-centred focus on the causes of challenging behaviour displayed by many of these individuals. However, the necessary links to create a ‘circle of support’ (Department of Health 2002) around all the different people involved in their health were not made and so this opportunity was not realised.

Four people in the sample had very limited communication. In two cases, health facilitators who had longstanding relationships with these individuals were able to use their knowledge of the individual’s likes and dislikes and use communication strategies they had developed over the years to communicate about Health Action Plans. In the remaining two cases, both children, carers and others who played key roles in the individual’s life had an essential role in building up a holistic picture of the child and outlining key issues in relation to health.
Chapter 5: Local Development Activity

An important aim of the study was to contribute to development of local services through a dual process of a) identifying barriers to implementation and examples of good practice and b) providing opportunities for stakeholders to make joint decisions about service development. It was intended that this approach to evaluation would give policymakers and practitioners the opportunity to implement recommendations as the research progressed. Adjustments made to provision as a result of this process were themselves evaluated in order to contribute to a more refined an understanding of health facilitation.

Two workshops for all participants in the study were conducted during the research period to discuss the preliminary findings of quantitative and qualitative data. In this respect, the study’s research communication strategy was meant to ensure that the dissemination and development arms of research were not simply a tag-on to the research itself (Grant and Ramcharan 2002).

Research workshops

Bringing together services users, carers and health and social care professionals offered an important opportunity to negotiate ways of building on good practice and addressing barriers to effective service delivery. The workshops provided a forum in which plans for developing the health facilitation role, that took account of all relevant perspectives, could be formulated. In addition the workshops helped us to validate our work and ensure that the recommendations in this report were realistic, based within the context of service delivery and adequately grounded in the perspectives of service users and carers.
Recommendations from the first research workshop, which discussed preliminary findings on Level 1 health facilitation, are included in Appendix 1 (see also Mir 2007). Feedback from local stakeholders indicated that people had found the event very useful and informative and a good basis to develop partnership work between different interested groups. One evaluation form indicated that the event had given local services a necessary “kick up the backside”. The issues raised by the research were, however, felt to be complex and evaluations indicated that more time was needed to absorb the findings and discuss their implications.

The second workshop presented preliminary findings on Level 2 health facilitation as well as highlighting movement, or lack of movement, using the previous recommendations and Department of Health guidance as a benchmark. There was general agreement that the research reflected the local situation accurately. Recommendations from each of the discussion groups in this second event fell into the following themes:

**Collaboration** was needed to provide local leadership –

- To create a specific role of Strategic Health Facilitator located within the PCT to raise the profile of health facilitation and influence the way mainstream resources were used. This post would have key responsibility to link mainstream work with the Community Learning Disability Team, the Partnership Board and the voluntary sector. IT support within the PCT would also need to be developed. Links to other relevant mainstream services such as leisure centres would also be needed and services should have a named person for people with learning disabilities.
- Between voluntary and statutory service providers to ensure that no-one was reinventing the wheel. Better resourcing of the voluntary sector was needed to enable this.
- With GPs and practice nurses, focusing on policy areas where targets already exist such as obesity and National Service Frameworks
- With other areas where health facilitation is actively being implemented. Tools and strategies for best practice needed to be explored and adopted.
Using a range of approaches - having a range of tools that are co-ordinated and accessible and allowing a range of models of health facilitation. People with learning disabilities felt that health promotion activity and information about screening was needed along with support for treating existing illnesses.

Better communication – was needed to raise awareness about health facilitation and Health Action Plans amongst different stakeholders and to signpost people with learning disabilities and carers to access these. People with learning disabilities felt this was a particularly important recommendation. Better communication between different services was also needed to avoid duplicate assessments. Clarity and guidance was needed by primary care practitioners on how practice based commissioning and other NHS policies, such as ‘Choose and Book’ or ‘Payment by Results’, could be linked to the Valuing People targets.

Training and raising awareness – for health facilitators and people with learning disabilities about Health Action Plans. For doctors and other healthcare professionals to understand how to meet the needs of people with learning disabilities and to ensure they are not using unhelpful criteria to exclude people from practice registers. Better awareness was also needed amongst other mainstream service providers such as leisure centres. People with learning disabilities felt this area was a particular priority.

Annual Health Checks – were seen as a logical next step from registers of people with learning disabilities and a bridge to Health Action Plans. Audit systems to monitor these which involved the Healthy Lives Steering Group and were linked to the Partnership Board were recommended. Performance indicators in the Quality and Outcomes Framework were recognised as an important influence on change and should therefore be incremental. It was also recognised that services would need to be able to respond to health needs identified during health checks. Current gaps in service, for example audiology waiting lists, needed to be filled and priority accorded to people with learning disabilities.

A number of groups and individuals were assigned specific responsibilities by one discussion group: the Healthy Lives Steering Group and Head of Learning Disability Services were asked to ensure a letter was sent out to all GPs offering support with
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health facilitation and to ensure consistency and good practice in the use of health facilitation tools. The Steering Group was also asked to ensure the association between Community Learning Disability Team nurses and GP practices was made explicit to the practices and taken forward. The Partnership Board was asked to ensure that service users health needs were met and to oversee the work of the Steering Group. At a national level it was felt that audit information about local PCTs could help inform local practice and that forthcoming activity by the Healthcare Commission could provide this.

Evaluations of the second event were mostly very positive and presentations by the Rainbow theatre group of people with learning disabilities were particularly well received. Feedback indicated that the event had usefully filled gaps in people’s knowledge. There were a number of comments indicating that action was needed to follow on from the workshop and that the pace of change needed to be quicker.

The themes from both workshops have been explored in our findings; workshop recommendations inform the conclusion and future action advocated by this report.

Engaging with local stakeholders

The research team made attempts from the beginning of the study to involve local stakeholders in its Advisory Group and to develop links that would help local services use findings from the study as a resource. Links with the local PRIMIS co-ordinator were also helpful to researchers in developing the template for identifying people with learning disabilities on practice registers and promoting this to PCTs.

The Advisory Group was extended over the course of the research to include important actors in the fieldwork area. This group has been an invaluable resource to the research team, contributing both to the focus of the study and its influence on local development. We have worked with the Advisory Group to ensure a balanced approach in the presentation of our findings and to produce a ‘no surprises’ report on which further local development can be built.

Another important means of engaging after the first research workshop was a follow-up meeting held to discuss its recommendations and the local action that might follow them. The third Strategic Health Authority (SHA) lead to be appointed since the
beginning of the study had just begun her post and attended this meeting as an induction to what was happening in the area. The PCT lead for Learning Disability, members of the Community Learning Disability Team and Joint Commissioning Service as well as representatives of local voluntary sector organisations were also invited.

It was agreed that the recommendations should be used as a benchmark for progress up to the time of the next workshop 18 months later. Disappointingly, however, the SHA lead felt that little support could be offered to improve the engagement of PCTs. Although the Valuing People health targets were written into Local Delivery Plans these were not monitored by the Department of Health in the same way as other targets relating to National Service Frameworks and so would not be prioritised by the SHA.

A second follow-up meeting was facilitated by the research team in January 2006 (almost a year after the first workshop) at the request of the Head of Learning Disability Services. This was used to discuss the Health Action Planning section of a draft strategic plan for learning disability services which had been developed using the workshop recommendations. The strategy promoted a ‘Ladder of Inclusion’ model to reorganise specialist learning disability services (see Box 3). The model aimed to target resources to those in most need of specialist support and to provide varying levels of support to others to help them access mainstream healthcare.

The model bears similarities to the thinking of Lead Health Facilitators in other parts of the country, and a suggestion that there should be different levels of person-to-person contact with health facilitators, including:

(a) Standard Individual Level - performed by most unpaid carers/family members (supporting appointments and assisting person to understand what health professionals are suggesting etc)
(b) Complex Individual Level - perhaps Community Learning Disability Nurses looking at people with complex health needs requiring specialist individualised support to meet their health needs beyond what primary care can provide in an annual health check
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(c) Primary Care Level - what practice nurses or other primary health care professionals can provide within their remit to support health action planning, annual health checks/reviews and any related appointments - with a view to linking all of these to the Health Action Plans.

National Health Facilitation elist

Those present at the follow-up meeting noted that there was a need to target minority ethnic communities within the plan as a whole if they were to be included in health related activity and agreed that annual health checks and individual health action planning would be addressed within the strategic plan. The strategy also proposed the establishment of a Healthy Lives Steering Group (referred to in the second workshop) to ‘promote and protect the health of people with learning disabilities’ in the city.

The group agreed that the creation of a Strategy Implementation Manager post based within PCTs would allow focused time to take the plan forward. It was also suggested that a meeting be arranged with representatives from the five PCTs to discuss the implications of incentives to be introduced in April 2006 for GPs to create registers of people with learning disabilities. It was suggested that this should be linked into other relevant work on learning disabilities such as the template to create practice registers (see Appendix 2) and the GP toolkit produced by the Community Learning Disability Team. The group felt that tying in this work with current policy initiatives such as ‘health literacy’ and engaging with ‘hard to reach’ groups would make it more attractive to PCTs. The research team was invited to take part in this meeting once it had been arranged.

The meeting with PCTs had not happened by the time of the second research workshop approximately six months later. Although a letter had apparently been sent to every GP by the Joint Commissioning Service about health facilitation, GPs at the workshop said that they had not received this and asked that it be resent. The Strategic Plan was presented to the Partnership Board at the end of 2006 and a
decision made to establish a Partnership Board Health Task Group on which all stakeholders would be represented

**Creating links between good practice and local stakeholders**

During the course of the study, researchers developed links that helped them understand approaches to health facilitation being used outside the fieldwork area. We used our links with local stakeholders to inform them of these approaches and to promote best practice. This included a Strategic Health Authority framework for learning disabilities developed in the West Midlands, improved measures for assessing the quality of primary care for people with learning disabilities developed by the Healthcare Commission (Whitty et al 2006), the National Health Facilitation Network for professionals working on the ground and information about incentives for GPs introduced in other areas. National leads from the Valuing People Support Team and the Healthcare Commission were invited to give keynote presentations and lead workshop discussions at each of the research workshops.

Despite the potential threat our evaluation of local work could pose, stakeholders were very positive about the role research could play in local development throughout the course of the study. Over this time developments within the Community Learning Disability Team and its management have been apparent (see Level 1, Step 3 above). The research appeared to provide a catalyst for some increased activity on health facilitation, particularly in relation to identifying people with learning disabilities on practice registers. It is to the credit of local stakeholders that responsibility for taking forward findings from the study was owned and clearly stated after the first research workshop:

> We are in a fortunate position, to have this research project going on in our city. [The Director of Public Health] and I are committed to ensuring the findings inform current practice…. Ownership is important and we need to get the various agencies to accept responsibility for Health Facilitation. It is up to us to make sure it remains on the agenda and is not allowed to be forgotten, in the light of other priorities.

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42 Information from Partnership Board minutes
Leadership and capacity are required, in particular from the Primary Care Trusts, on a sustainable basis if we are going to make significant progress.

As has been mentioned, there is much we cannot control. Nonetheless, [the Head of Learning Disabilities] and I are going to meet up to see how we can take these issues forward and move these debates on, in ways that reminds the NHS and Local Authority that they have many responsibilities to people with learning disabilities and they cannot just forget about them.

_PCT Director of Public Health_

There was clear interest in following this commitment through at the meeting held after the workshop despite the lack of support from the Strategic Health Authority lead. Between the two workshops some important work was done, however findings indicate that there are still significant gaps in the process of strategic Health Facilitation that must be filled if improved access to mainstream services is to become a reality for people with learning disabilities in the city. This was recognised in formal and informal feedback after the event:

Despite a number of positive ideas and potential developments, I think it’s disappointing that the issues of 12 months ago still remain

_Anonymous evaluation comment_
Chapter 6: Conclusions

Our approach to exploring the effectiveness health facilitation policy has been based on examining the different elements of this policy and analysing our findings in relation to each element (see Figure 1 on p42). Investigating the effectiveness of these mechanisms has the potential to aid understanding of whether health facilitation policy achieves its intended outcomes and may also have implications for other government initiatives which are based on similar theories about cause and effect (Pawson 2003). This approach is particularly relevant to the wide range of initiatives introduced in recent years to tackle social exclusion and health inequalities (Judge and Bauld 2006; Stronks et al 2006).

Relatively modest resources, accompanied by guidance that is often more about vision rather than practicalities, have not resulted in the speedy resolution of the deep-seated social problems that these initiatives set out to address (Judge and Bauld 2006). However, it is useful to see these programmes in political terms too – as a means of placing public health high on the political agenda and creating relationships that increase awareness and create new ways of working (Stronks et al 2006). In this context, evaluators who work closely with policymakers are more likely to influence policy change (ibid)

Responses to the more recent White Paper Our Health, Our Care, Our Say (Department of Health 2006) amongst learning disability advocates have been revealing in this respect. There are indications that people anticipate a disparity between policy and implementation. Additional responsibilities and financial costs are felt to be a barrier to achieving the vision outlined in the policy, particularly in the existing context of reduced social care budgets and family carers ‘fighting for
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resources’ both personally and at the level of Partnership Boards. There are also concerns that existing service models and the proactiveness expected of people with learning disabilities and family carers to access services are unrealistic\textsuperscript{43}. Nevertheless, there is recognition that prior to \textit{Valuing People}, specific references to learning disability would not have been made in a White Paper on health and social care. The bringing together of health and social needs as well as targets aimed at people with learning disabilities are also valued\textsuperscript{43}.

The current policy context is likely to be further influenced by the introduction of a new duty to promote equality of opportunity for people with disabilities through the Disability Discrimination Act in December 2006. The Disability Rights Commission gives the examples of accessible information, training and responding to known service barriers as issues that are included in this duty (Disability Rights Commission 2005). As highlighted by the recommendations of the second research workshop, further developments in relation to health facilitation need to take account of this context and plan for collaboration in areas where mainstream services will be prioritising their activities.

Findings from the study indicate particular issues that need to be resolved at both levels of health facilitation implementation. These resonate with issues raised in other studies on health facilitation and on national health facilitation elists, and are considered in more detail below.

**Level 1: Strategic Health Facilitation**

The intention of the \textit{Valuing People} health targets is that Community Learning Disability Teams collaborate with mainstream health professionals to create better access to health services for people with learning disabilities. However, findings show considerable disincentives exist that prevent widespread collaboration and that a substantial amount of strategic work is aimed at trying to resolve these barriers.

Some of the risks identified in the Local Delivery Plan for the area (see Local Policy on Health Facilitation) for the fieldwork area either did not materialise or were addressed – there was substantial investment in the form of Health Action Zone

\textsuperscript{43} Comments taken from messages on the Choice Forum elist 2006
funds to begin the process of health facilitation and a large team of learning disability nurses to support implementation. A GP toolkit was produced and, with the support of the research team for this study, GP practices involved in the pilot were able to identify people with learning disabilities on their registers.

However, other anticipated risks were not robustly addressed and led to the failure of the pilot to stimulate widespread local action on health facilitation. Capacity within primary care was clearly an issue that did not receive adequate attention and Lead Health Facilitators appointed to the Health Action Planning pilot faced resistance and apathy to their attempts to engage. Furthermore, some primary care practitioners questioned the evidence base of the policy and were unwilling to collaborate without a clearer justification for resources being directed to health action planning. There was little evidence of the ‘robust workforce strategy’ mentioned in the Local Delivery Plan to raise awareness of health facilitation amongst GPs and a Theatre Project appears to have been the only related initiative that preceded the Health Action Planning pilot.

Furthermore, capacity within the Community Learning Disability Team itself had not been anticipated as an issue. There was confusion and misunderstanding about the nature and goals of health facilitation within the Team and many learning disability nurses did not have the skills needed to adopt a strategic and collaborative relationship with PCTs. Indeed, it is questionable whether the pilot should have been led by members of the Community Learning Disability Team rather than by a PCT-based Strategic Health Facilitator. Not only did learning disabilities nurses themselves face a steep learning curve in relation to how GP practices and PCTs worked, they also had no authority or influence within these sites and ownership of the White Paper goals consequently remained external to most areas of primary care provision. The PCT approach of commissioning out work on health facilitation to the Community Learning Disability Team and voluntary sector organisations appears to have worked against the need to develop its own capacity.

A further action to manage risk that was anticipated in the Local Delivery Plan but not addressed during implementation was the close involvement of the Partnership Board throughout the process of implementation. Findings suggest that the steering group that supervised the Health Action Planning pilot did not have adequate links to
the Board and was not representative of all local stakeholders, particularly people with learning disabilities, family carers or voluntary sector groups that represented their interests. The service user reference group set up as part of the Health Action Planning pilot was not involved in decision-making and acted as a consultation body. Consequently, the White Paper principle of ‘Nothing About Us Without Us’ (National Service Users Advisory Group 2001), promoted to GPs through the toolkit, did not adequately influence the Health Action Planning pilot or meetings of the Healthy Lives Steering Group, established after the pilot had been completed. Findings elsewhere confirm that the input of people with learning disabilities can help to sustain the effort needed to implement what is a complex and necessarily long term policy (Foundation for People with Learning Disabilities 2006).

Within the fieldwork area, a number of initiatives have successfully addressed strategic health facilitation. Considerably more strategic work is required, however, much of which does not necessitate collaboration with GPs. Accessible information about Health Action Plans and mainstream health services, training programmes for individuals acting as health facilitators, targeted work with people from minority ethnic communities and people with complex needs and collaboration with organisations that can support people with learning disabilities to implement Plans are all areas highlighted for future work by our findings and identified by the guidance on Health Action Plans for strategic action (Department of Health 2002).

More work is needed with GPs to identify people with learning disabilities on their practice lists. At present around a quarter of practices in the fieldwork area have used the template developed by the research team (see Appendix 2). The introduction of incentives to produce a register in the Quality and Outcomes Framework (NHS Employers/BMA 2006) needs to be exploited and supported by those leading on health facilitation. The issue of inclusion on GP lists also requires further attention. Although some reasons why people with learning disabilities might be excluded from these lists have been highlighted in this study, further research is needed to understand how GP lists can be more inclusive and why only 41% of service users were captured in final lists. A city-wide database that can be combined with GP lists and training for primary care staff is also needed to identify a higher proportion of people who both have learning disabilities and also require support.
GP responses to QOF points indicate that these are an effective mechanism to improve the quality of primary care (Cole 2005; Kmielowicz 2006). This suggests that, nationally, moving beyond identification of people with learning disabilities on practice registers and focusing on interventions that will lead to improved health outcomes is also needed.

The level of activity in the fieldwork area may be typical of many other parts of England. Responses by PRIMIS co-ordinators (see Methods) indicate that a small number of PCTs are working to systematically identify people with learning disabilities. In addition, membership of the National Health Facilitation Network in February 2006 was 74 individuals, representing 67 PCT or learning disability services. If the Network’s membership is any guide to national activity, then this represents a fairly small proportion of over 300 PCTs and 76 Mental Health Trusts in England (NHS 2006). In terms of the number of Health Action Plans completed, even in areas actively implementing both levels of health facilitation, these are clearly not reaching large numbers of people with learning disabilities (Westminster PCT 2006; Medway and Swale Health Partnership 2006; Alborz 2005).

It would, therefore, not be surprising to find many other places where progress on Valuing People health targets has been patchy or minimal. At the same time, there are sites in which considerable strategic progress has been made (ibid; Caan et al 2005). Highly skilled individuals who can bring together different service sectors to achieve progress are providing strategies and good practice examples for others to adopt. This shows that progress is possible and can be achieved with the right strategy and leadership. In order for such models to be developed more widely, however, national leadership to remove current barriers and provide incentives for implementation appears to be needed.

Various roles and responsibilities were outlined as necessary in Valuing People (Department of Health 2001) to deliver its key health actions. Amongst these was a governmental responsibility to include people with learning disabilities in health-related policies and a role for the Department of Health to monitor progress on Valuing People health targets. Findings from the review of relevant policies and from

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44 Information from the National Health Facilitation network
the research study indicate that more robust mechanisms are needed to ensure that this happens. These mechanisms are particularly important given that deficits in NHS budgets are causing Primary Care Trusts to prioritise financial balance over plans to deliver services with adverse implications for policy implementation (Commission for Social Care Inspection 2006).

**Level 2: Operational Health Facilitation**

Delays in the implementation of *Valuing People* targets inevitably affected the extent to which we could explore individual health facilitation and the impact of the policy on people with learning disabilities. In terms of using primary care records to evaluate changes in the quality of healthcare, sample figures are too small to indicate statistical differences. However, as already highlighted, a trend towards increased medication reviews and health checks in general practices that identify people with learning disabilities on their registers is suggested by our findings. In practices where health facilitation was also offered, health checks were reduced but medication reviews increased. In both types of practice these trends indicate more attention to individual lifestyle issues, such as smoking and body mass index, that are likely to significantly affect the health of people with learning disabilities.

These findings suggest the process of identifying people with learning disabilities and offering health facilitation may itself increase awareness amongst primary care staff and improve the quality of care offered. Practices involved in the study had no financial incentive to take part as fieldwork was carried out before revision of the Quality and Outcomes Framework (NHS Employers/ BMA 2006). This suggests an existing positive attitude towards meeting the healthcare needs of people with learning disabilities. In practices where financial incentives are needed to stimulate such activity, greater attention to health checks and medication reviews for people with learning disabilities may be even more necessary and may require additional incentives.

Evidence from the study suggests that the most effective way of identifying people with learning disabilities in an area is through combining general practice lists of people with learning disabilities with records from other sources. Practice identification is, however, adversely influenced by concerns about labelling and confusion about the definition of learning disability. Training in both these areas is
consequently needed to improve the accuracy of this process so that all people with
learning disabilities are identified and offered health facilitation.

The findings in relation to Health Action Plans are, similarly, based on a relatively
small number of Plans and so indicate trends in the fieldwork area rather than
providing a comprehensive overview. This is particularly the case with Health Action
Plans for children. However, the issues raised may be considered as potential areas
in which good practice and a need for improvement may be identified.

In the case of each person with a learning disability included in this study, it was clear
that a range of people were playing a part in relation to health. Family members,
GPs, supporters in voluntary sector organisations, general practice staff and hospital
consultants as well as learning disability nurses, specialist psychiatry staff, social
workers and sometimes (though rarely) friends, were all mentioned by people with
learning disabilities as providing this kind of support. However, in most cases the
person who helped create a Health Action Plan for the individual failed to use this
process to bring all these individuals together and create a 'circle of support', to
ensure that everyone knew what the individual's health priorities were and the part
each person would play in relation to these. Where those involved with the individual
were expected to help implement the Health Action Plan, there was a clear need to
negotiate this and not assume compliance with the Plan.

There were, nevertheless, some promising approaches to Health Action Planning
that indicated particular strengths in the services described. Person-centred
approaches and a substantial time commitment were apparent in the voluntary sector
and children’s services. In adult learning disability services, where the Plan had been
produced in collaboration with primary care and passed on to an active health
facilitator, there appeared to be a strong foundation for continued support after
specialist learning disability nurses withdrew.

The support offered was in all cases valued by people with learning disabilities, who
often felt unsafe or timid about accessing services on their own, sometimes because
they had suffered abuse in the past. Some people with learning disabilities also
valued the social aspect of health-related activities rather than the health benefits,
which may on their own not have provided adequate motivation.
There is clearly, however, much room for improvement in current models of Health Action Plans. Some were more like assessments than person-centred plans and findings indicate that neither systematic ‘tick-lists’ nor open-ended ‘wish-lists’ adequately incorporate the elements of a good Health Action Plan as defined by the guidance (Department of Health 2002). GPs were often completely absent from the process and no copies of Health Action Plans were found in any of the GP records for people with these Plans, even when the GP himself had referred the person involved. There was no evidence of related training for any of the people acting as individual health facilitators. This could mean they were unsure about their role or did not facilitate Plans in accordance with Department of Health guidelines.

Findings suggest that addressing the determinants of health is a particularly important part of the health action planning process that is often overlooked. Social relationships and daily activity outside the home are important aspects of health which affect people with learning disabilities as much as other social groups. The wider literature on health inequalities offers important direction on the focus that health facilitation should adopt in practice. A range of areas have been shown to affect health status, including education, employment and the ability to participate fully in society (Marmot et al 1998). This suggests that action to deal with inequity in healthcare needs to run alongside strategies that improve health status and involve all determinants of health (Exworthy et al 2003; Hofrichter 2004). Health promotion activities and screening, which were considered a priority by people with learning disabilities themselves, also play a vital part in addressing health inequalities and should not be considered secondary to dealing with existing health issues (ibid).

Evidence suggests that family dynamics and relationships in supported living homes which may have a major impact on a person with learning disabilities are rarely discussed in the process of drawing up Health Action Plans for adults. These issues are more likely to be raised in relation to Person Centred Plans and findings suggest that combining both types of Plan is more likely to address the determinants of health.

In the voluntary sector, support to carry out the Plans and review them depends on continued funding and all sectors need to consider Health Action Plans as a long
term process rather than a one-off exercise. Collaboration between voluntary sector organisations and statutory services to bring together different areas of expertise is indicated by the findings. The former can contribute to implementation of Plans through opportunities for friendships, volunteering and employment and can bring strong person-centred approaches to health facilitation; the latter can help close the circle of support around an individual by providing links to the health and social care professionals needed to improve their access to services.

As in other areas of the country, Health Action Plans were being offered to a very small proportion of people with learning disabilities in the city (Westminster PCT 2006; Medway and Swale Health Partnership 2006). Approaches that make these more widely available and accessible to people with learning disabilities are related to Level 1 or Strategic Health Facilitation and the issues for national and local action outlined in the previous section.

**Inclusion**

When *Valuing People* was published in 2001, three additional reports were commissioned in relation to specific groups that have been consistently excluded during implementation of learning disability policy. These reports were distributed alongside the White Paper and focused on people with learning disabilities, people from minority ethnic communities and family carers (National Service Users Advisory Group 2001; Mir et al 2001; Ward 2001).

Despite this specific focus and strong message, findings from this study indicate that people from these three groups continue to be excluded in strategic work relating to Health Facilitation. Although people with learning disabilities were consulted during the Health Action Planning pilot, they had little control over decision-making. People from minority ethnic communities were identified early on as a priority group for future attention but this priority disappeared and no actual work was done to strategically target minority ethnic groups. Engagement with family carers did not appear to have received any attention during the pilot study.

Evidence suggests that Strategic Health Facilitation needs to consistently ensure inclusion of people from these three groups and that their perspectives should inform the decision-making process. There is also a particular need to raise awareness
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about the needs of people from these priority groups in professional development programmes and to highlight how these needs can be met.

In relation to individual health action planning the inclusion of people from minority ethnic communities was almost entirely due to the activity of a voluntary sector group that specifically targeted people from African Caribbean communities. Cultural background as well as learning disability appeared to be relevant to the discrimination they faced from some service providers and findings also indicate a need to train health facilitators to increase their confidence in this area.

If health facilitation is to address inequalities effectively, it is vital that inclusion informs the foundation on which work at both levels of activity is carried out. In order to avoid mirroring the exclusion practised within mainstream services, it will be important to specifically target these three groups and ensure that the standards set by the Department of Health guidance are achieved (Department of Health 2002).
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Health Facilitation and Learning Disability


Appendix 1: Research workshop
February 2005

DISCUSSION GROUPS

GROUP 1: Working with GPs

This group was led by members of the voluntary organisation, CHANGE, a local GP and members of the learning disability nursing team. The group was facilitated by Professor Phil Heywood and Dr Ghazala Mir from the Centre for Research in Primary Care

What needs to happen?

• Health professionals need to work across boundaries so that GPs can contribute to better health outcomes for people with learning disabilities. Links between services are needed to trigger GP referrals.
• The right balance is needed between specialist learning disability services and general GP services
• There needs to be consistency between the way different GPs treat people with learning disabilities
• Resources for training in PCTs should be allocated in accordance with the proportion of patients with learning disabilities. Courses for undergraduate medical students are a way of changing the culture in mainstream services. PCTs and GPs need to be more receptive to training.
• People with learning disabilities need support to look after their health. The level of support needed is currently high because services aren’t accessible.
• More accessible information to raise awareness amongst people with learning disabilities about their right to a Health Action Plan

How can this happen?

• Mapping the current roles of health professionals would help in decision-making about what needs to change
• Organisational targets that are monitored rather than relying on individuals to carry this forward
• A Health Check List tied to Health Action Plans offered every year (recommended) or at least every three years. This would pick up conditions and have a knock-on effect on other healthcare systems.
• Every hospital department should have a person responsible for working on learning disability issues.
• Including targets in the Quality and Outcomes Framework by which GPs are monitored/paid
• Every area of work in each PCT should be asked to report within 14 days on how it is including people with learning disabilities
• Work by GPs should be commissioned as a locally enhanced service and specialist practices should be developed
Health Facilitation and Learning Disability

Who should do it?
- The Learning Disability Partnership Board should commission work to take these actions forward
- The Head of Learning Disability Services should drive this work forward and clarify the process.

GROUP 2: Finding people with learning disabilities on GP registers

This group was led by the Informatics Manager from a local Primary Care Trust. It was facilitated by Victoria Allgar and Joyce Evans from the Centre for Research in Primary Care

What needs to happen?
Guidance on coding - so that GPs can identify people with learning disability on their registers.
Better communication between organisations - voluntary organisations, carers, people with learning disabilities and the Learning Disability Nursing Team need to communicate with GPs to trigger referrals for Health Action Plans

How can this happen?
Financial incentives to meet targets

Who should do it?
Community learning disability nurses should initiate contact with GPs and GPs should identify people and refer them to the community learning disability nurses for Health Action Plans

GROUP 3: Good practice around England

This group was led by Debra Moore of the Valuing People Support Team and members of the local learning disability nursing team.

What needs to happen?
- Better use of information technology - Use of the CRPC template so that GPs can identify people with learning disabilities on their registers
- Information and education for individuals and families. People with learning disability should be involved in planning services
- Support staff in residential settings need to be educated
- There is a need for clear leadership.
- Health action planning should be given the same importance as other targets

How can this happen?
- Health involvement – consultation with key stakeholders
- An Action for Health Plan for the city is urgently needed
- Easy access to easy documentation

Who should do this?
Action for Health Plan could be drawn up by Head of Learning Disability Services.
GROUP 4: Meeting Valuing People health targets - opportunities and barriers for services

This group was led by the Director of Public Health in a local PCT and the Head of Learning Disability Services in the area. It was facilitated by Dr Karl Atkin of the Centre for Research in Primary Care.

What needs to happen?

- Health professionals need to understand the health targets that are being promoted for people with learning disabilities. Most don’t understand what these are or see them as optional extras.
- There should also be a bottom-up approach – the health of people with learning disabilities should be seen as part of their whole life and not just about what services can offer - person centred planning that draws out health issues and allows people control of their lives. It is important to make people aware of their entitlement to health facilitation so that they can ask for this. There is a need to build on the information about health that people with learning disability may already have and not to underestimate them. At the same time developing trust is an important part of improving access eg to screening programmes.
- The experience and resources of voluntary sector organisations need to be used.
- Leadership is needed – to make sure the ground work happens and to give guidance about how service providers can carry out their responsibilities. There needs to be a proactive approach.
- The work should use incentives not goodwill.
- The aim should be equal outcomes not just equal access.

How can this happen?

- Leadership and capacity is needed.
- A more structured plan should be drawn up to:
  - Educate people in Primary Care Trusts and increase capacity for inclusive ways of working.
  - Make sure people with learning disabilities have more support to make choices. This is labour intensive and a lot of ground work is needed.
  - Introduce a local enhanced service payment but not a specialist service. Approach needs to include carrot AND stick.
  - Use existing targets that should include people with learning disabilities eg diabetes, coronary heart disease, screening. Cross referencing data to see if people with learning disabilities are being included. ‘Naming and shaming’ practices that are not inclusive.
  - Improve communication between different stakeholders.
  - Co-ordinate this work in PCTs (in a similar way to mental health work).
  - Share responsibility by different health professionals/teams.

Who should do this?
The Strategic Health Authority, PCTs, the Learning Disability Partnership Board and the Mental Health Trust all need to take responsibility for educating PCTs and guiding them. The SHA and Department of Health should take a more proactive role to ensure PCTs meet their responsibilities. The Partnership Board should monitor what is happening.
RECOMMENDATIONS

Some shared ideas about what needs to happen if things are to move forward in the city came out of the discussion groups. These are:

LEADERSHIP!
- The Head of Learning Disability Services - to make clear what needs to happen through a well thought-out plan and drive the work forward.
- The Strategic Health Authority - to set targets for PCTs
- PCTs - to make sure people with learning disabilities are included in all its areas of work and to pay GPs to meet these targets.
- The Learning Disability Nursing Team - to contact and work with GP practices.
- The Partnership Board - to ask for (commission) work to be done and make sure it gets done.
- The Department of Health - to include learning disability in the Quality and Outcomes Framework and to actively make sure PCTs meet targets.

A PLAN!
This could be based on the model for mental health and should have detailed targets and outcomes in the following areas:
- Support for people with learning disabilities to know about their rights, look after their health, make choices
- Education and guidance about Valuing People rights and responsibilities – for people with learning disabilities and support staff in residential places. GPs need guidance on using read codes to find people with learning disabilities on their registers.
- Better communication and links between voluntary organisations, carers, people with learning disabilities, GPs and the Learning Disability Nursing Team. These links should help trigger requests for health facilitation. The Health Task Group should include people from all these groups.
- Annual health checks for people with learning disabilities linked to Health Action Plans.
- People in each hospital department who will take responsibility for learning disability work

RESOURCES!
- A special payment (‘locally enhanced service’) for GPs to find people with learning disabilities on their registers
- Money for training

REWARDS AND PENALTIES!
An award or beacon status for PCTs and GPs that take a lead and do these things well. ‘Naming and shaming’ the ones that don’t.
Appendix 2: University of Leeds GP template

Template for identifying patients with a learning disability in primary care: practice based registers

The definition of Learning Disability used is that in the Department of Health White Paper 2001: Valuing People: A New Strategy for Learning Disability for the 21st Century:

“A person with learning disabilities has a significantly reduced ability to understand new or complex information and a reduced capacity to cope independently. This condition is present from childhood and has a lasting effect on development.”

READ CODE SEARCHES

KEY: 0 = zero and % = include all sub-codes. (If you are using different codes, please contact us)

Codes that give a definite indication of a learning disability

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
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<tr>
<td>E3%</td>
<td>Mental Retardation</td>
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<tr>
<td>Eu7%</td>
<td>[X] Mental Retardation</td>
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<tr>
<td>PJ0%</td>
<td>Mental handicap problem</td>
</tr>
<tr>
<td>PJyy2</td>
<td>Fragile X chromosome</td>
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<td>Eu842</td>
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<td>PKy93</td>
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<td>Noonan syndrome</td>
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<td>9HB%</td>
<td>Learning Disability Status</td>
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Codes that give a possible indication of a learning disability AND need to be verified by the patients’ GP

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
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<td>Eu8lz</td>
<td>[X] Dev Dis Scholas Skills unsp</td>
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<tr>
<td>13Z4E</td>
<td>Learning difficulties</td>
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<td>PK5</td>
<td>Tuberous Sclerosis</td>
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<tr>
<td>PK61</td>
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<td>Problems with learning</td>
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<td>13Z3</td>
<td>Low IQ</td>
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GROUP HOME  Patients who live in a group home specifically for people with a learning disability, identified by searching by group home address.

GP IDENTIFICATION In the pilot study, the GPs identified some patients who were not found using the above READ code searches OR group home address searches. Please include any additional patients with a learning disability that may be known to the practice.
Appendix 3: Read Codes in primary care

An explanation from Connecting for Health of the representation of Learning Disability and Mental Retardation terms in the Read Codes

Three main versions of the Read Codes are released bi-annually by NHS Connecting for Health:

Four byte set - dating from the mid 1980s and used primarily by General Practitioners

Version 2 - dating from 1990 for use in the acute sector and later used by General Practitioners Clinical Terms

Version 3 - dating from 1994 and used in the acute sector with some GP systems available

Version 2 of the Read Codes is based on The International Statistical Classification of Diseases and Related Health Problems, published by the World Health Organisation (WHO). The acute sector is required to submit statistical returns to the Department of Health using codes from this classification and as a member state of WHO, are also committed to returning statistics for international purposes in the same format. The Read Codes were originally created reflecting the 9th revision of the classification, (ICD-9) with the 10th Revision (ICD-10) mandated for use in England and Wales from 1 April 1995.

WHO classify ‘mental retardation’ and ‘learning disability’ as separate entities reflecting their international meaning and use.

In ICD-10, learning disability is classified to category F81 Specific developmental disorders of scholastic skills (which is mirrored by the Version 2 Read Code hierarchy of Eu81-). In ICD-9, the original basis for the Read Codes, these conditions were classified to 315-, Read code hierarchy E2F.

ICD-10 also contains categories F70-F79 Mental Retardation. These are reflected by the Read Code hierarchy Eu7.. In ICD-9 these conditions were classified to 317-to 319-, Read Code hierarchy E3…

In April 1995, on the implementation of ICD-10, advice was issued from the NHS Centre for Coding and Classification to V2 users that V2 Read codes prefixed E0-E3 reflecting ICD-9, should no longer be used and that they had been replaced by Eu…codes.

However, the issue remains that the term mental retardation is present in the ICD, and although it is mainly viewed as obsolete within the UK, General Practitioners are advised by various groups to use Read code E3.

Once released, Read concepts cannot be deleted due to the fact that they may have previously been used in a patient's record, and this history needs to be retained.

Any other actions that we may take unilaterally to resolve this issue will impact one or other of the terminology and classification user groups. There could also be a knock on effect to both national and international statistics.

Therefore, in order to resolve this we will seek formal advice from The Royal College of Psychiatrists via the UK Coding Review Panel.

45 www.connectingforhealth.nhs.uk Accessed August 2005
Once we have obtained this advice we can agree a way forward based on firm advice. Depending on the advice from the College it may be that we need to refer to the WHO Update Reference Committee for consideration of changes to the ICD.
Dear Practice Manager

**Practice Register of Patients with a Learning Disability**

We are writing to you in relation to a research study that we have been commissioned to undertake by the Department of Health.

The research project is a result of the White paper ‘Valuing People’ (2001), which outlined a strategy for improving healthcare for patients with learning disabilities. More recently the Department of Health published the ‘Better Metrics project’ (Nov, 2004) that has outlined clinical performance indicators for people with a learning disability. One of these is that all GP practices have a system for identifying patients with a learning disability.

The research team has been working in conjunction with the Director of Public Health, North West Leeds PCT, chair of a group responsible for implementing Health Facilitation in Leeds.

The first phase in the research project has involved developing a **Leeds-wide database** of people with learning disabilities. We have obtained patient lists from social services, voluntary agencies, PCT led learning disability services, Leeds Mental Health Trust, and education departments. One of the aims of the Leeds-wide database is to establish whether all people within this patient group are registered with a GP. We have verified GP registration through WYCSA. From the database we have identified [number of patients] patients with a learning disability who are registered with your practice.

We are now combining this database with individual general practice generated lists. This will enable us to create a comprehensive **Leeds-wide database** of people with learning disabilities. We have already gathered these lists from practices in NW Leeds PCT and are extending it to the rest of Leeds.

To help you develop your practice register of the patients who have a learning disability, we have developed a template: ‘**Leeds University Template**’ (see attached). This includes a list of READ codes that you could use to identify patients using your practice computer system. This combined with practice staffs’ knowledge, should enable you to identify the majority of your patients who have a learning disability. One of the research team can come to your practice to apply the template and leave you the list of patients to validate. The Health Informatics Service support the project and are advising practices to use the template to improve their data quality around this group of patients. This process will be in line with the data quality targets in the new GMS Contract.

All we ask is for you to send us your list of your patients to include on the **Leeds-wide database**. We would require the patient’s: name, date of birth, sex and postcode. We have enclosed a data collection form and a self addressed envelope for you to return the practice register to us. If you prefer, one of the research team could come to your practice to collect the list, or input it directly onto the database using a laptop. The database is password protected, and is only accessible to the research team.

The second phase of the research is an audit of patient’s medical records. We are looking for practices that would allow us to extract data from patients’ medical records.

We have obtained Research Ethics Committee Approval (04/Q1107/1) and Research Governance Approval (Ref 631), covering the 5 Leeds PCTs. We also hold honorary contacts with Leeds PCTs. We will conform to the Data Protection Act 1998. All data will be collected, stored and processed in accordance with this. Once your practice patients have been cross checked against the other data sources, all personal information will be deleted,
and patients will only be identified by a project ID number. The information on the database will not be shared with any other organisations.

If you are not willing to give the research team a list of patients with a learning disability, could you please indicate this by ticking the box on the form and returning in the enclosed envelope, so we can keep our records up to date.

If you have any queries, or require more information about the project, do not hesitate to contact me.

Yours sincerely
## Appendix 5: Process of GP lists

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