Executive Summary
INTRODUCTION

Health inequalities affecting people with learning disabilities and high levels of unmet health needs have been well documented in recent years. This study explores the implementation of three policy targets outlined in the White Paper, *Valuing People*, 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 overleaf outlines the intended process of health facilitation activity – strategic and operational - envisaged by the accompanying Department of Health guidance. 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. 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 full report page 79). 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
Executive Summary

Health Facilitation and Learning Disability

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 of the full report.

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\(^2\). 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 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.

---

\(^1\)i.e. the exclusion from service provision of people from minority ethnic communities on the basis of both ethnicity and learning disability.

\(^2\) see www.leedsmentalhealth.nhs.uk/siteDownloads/0511_GPtoolkit_8.pdf
**Figure 1 - The Intended Process of Health Facilitation**

**LEVEL ONE (Strategic)**

- **STEP 1**
  - **Lead Health Facilitation**
  - *Post in each PCT and Named contact for each general practice*
  - Supports mainstream service development

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

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

**LEVEL TWO (Operational)**

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

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

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

**STEP 4a**

- **Service users health needs identified and met**
- **Better health outcomes**

---

3 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. The term Strategic Health Facilitator is used to differentiate this role from general health facilitation (see next footnote).

4 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).
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 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. Short-term funding made implementation of Health Action Plans insecure and unlikely to 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.

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’ 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 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

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 and 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 ownership of the need to improve the health of people with learning disabilities as part of the PCT’s response to the Disability Discrimination Act 2005
- Promote awareness of the benefits of long term preventative strategies in relation to financial planning
- 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 ownership of the need to include people with learning disabilities from minority ethnic communities as part of the PCT’s response to the Race Relations (Amendment) Act 2000
Executive Summary

Health Facilitation and Learning Disability

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

Monitor and Review

- Review and improve communication channels between GPs and hospital consultants with expertise in learning disabilities
- Aggregate evidence of need from Health Action Plans to inform the 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 guidance from the Department of Health and Cabinet Office
- 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

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 that can be accessed in the area.
- Continue and expand training to staff in mainstream services to raise awareness about the health needs of people with learning disabilities
- Provide training to learning disability staff carrying out other forms of assessments to ensure they 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 professional development 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 within PCTs and acute trusts
- Monitoring activity on learning disabilities within 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
Executive Summary

Health Facilitation and Learning Disability

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 Commission for Social Care Inspection and the Healthcare Commission to monitor access to health promotion and health checks through the forthcoming performance assessment framework
- Collaborate with the Healthcare Commission to address ethnicity in the improved clinical measures for learning disability
- Review learning disability components of generic health professional education courses and work with professional bodies to extend these where necessary

http://www.csci.org.uk/care
For further information contact
Ghazala Mir
Senior Research Fellow
Centre for Health and Social Care
Leeds Institute of Health Sciences
University of Leeds
71-75 Clarendon Road
LEEDS LS2 9PL
Tel: 0113 343 6905
Fax: 0113 343 6880
www.leeds.ac.uk/hsp/hr/hsc