Meeting 'Valuing People' health targets: recommendations from a research workshop

Ghazala Mir, Centre for Health and Social Care, University of Leeds, 71-75 Clarendon Road, Leeds LS2 9PL, UK. (E-mail: g.mir@leeds.ac.uk)

Accessible summary

- This paper is about a workshop held by researchers from the University of Leeds.
- The researchers looked at one area to see if people were doing things about health that the Government said they should in *Valuing People*.
- The research found out that there is still a lot of work to do in the area to meet these targets.
  People came to a workshop to talk about this. They thought that:
- Learning disability services should lead the way and draw up a plan about what needs to happen.
- People who run health services should make sure they set targets for GPs and hospitals that fit in with the plan.
- Government should make sure that the targets they set for GPs also fit in with *Valuing People* targets.
- This research is important because it can show what helps health services improve for people with learning disabilities and what gets in the way.

Summary

Research at the University of Leeds has evaluated how well changes to healthcare proposed in the Government White Paper *Valuing People* (Department of Health 2001) were being implemented in one locality and their impact on people with learning disabilities. The project had a developmental aspect and incorporated two workshops over the course of the study to disseminate preliminary findings. These were used to help key stakeholders evaluate progress and to inform discussions about what should happen next in the fieldwork area. This paper discusses recommendations from the first research workshop at which preliminary findings from the study were presented. The workshop involved health and social care providers and managers, people with learning disabilities, voluntary and community organizations. It gives an overview of local issues relevant to the White Paper health targets and highlights those that need to be resolved before these targets can

be achieved. These issues are likely to be replicated in other areas of England and Wales and have implications for leadership, strategy, the allocation of resources and structures of accountability in health and social care agencies.

Introduction

The causes of poor health in people with learning disabilities are diverse. A higher biological risk of medical conditions such as thyroid dysfunction, respiratory disease and mental health problems combine with discriminatory structures and practices that act as barriers to accessing healthcare (Elliott *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).

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 this group of patients (Jones & Kerr 1997). Furthermore, there is evidence that discriminatory judgements about the value of a learning disabled person's life are implicated in higher mortality and morbidity rates for a range of conditions (Mencap 2004). 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 & Allen 1999). However access is not the only issue and some forms of screening are less acceptable to many women with moderate to severe learning disabilities (Biswas *et al.* 2005).

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. 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, hate crime or harassment, particularly if they also have mental health conditions (Cabinet Office 2005).

The resulting health inequalities mean that many people with learning disabilities have high levels of unmet physical and mental health needs. In addition, specific groups of people have been shown to be particularly affected. People from minority ethnic communities face discrimination in relation to both disability and ethnicity so that the higher rates of mortality and morbidity are even more pronounced (Chaplin *et al.* 1996; Mir *et al.* 2001). Some, particularly South 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 require specific attention in policy and practice because of the high level of healthcare they generally need (Chambers *et al.* 1998; PMLD Network 2002).

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 primary care services are often underdeveloped and links with GPs are considered very good or good by only about 15% of learning disability staff (Cope 2003).

The various causes of health inequalities in this population make finding solutions to address them complex. The Government's learning disability strategy (Department of Health 2001) attempted to stimulate mainstream service development by setting three targets aimed at improving access to health services. These 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.

The following section describes the methods used by researchers to engage local stakeholders in a study of health facilitation activity in one locality and the process of facilitating a research workshop to discuss preliminary findings and agree a way forward.

Methods

The research workshop on which this paper is based contributed to data collection for a larger study exploring

the process and outcomes from health facilitation activity in a northern city in England. The research team worked with local stakeholders at various points to ensure their effective participation in the project and use of the study as a local resource. Members of the project Advisory Group included local self-advocacy and service user groups, officers and members of the Partnership Board, staff from the Community Learning Disabilities Team and the heads of Adult and Children's Learning Disability Services. Research team members became involved in local meetings and activity relating to health facilitation, such as a Health Action Zone project and a presentation by the local PRIMIS co-ordinator to GPs about read-coding.

A collaborative relationship was developed through such links; the research team used these to share information about good practice in other parts of the country and to encourage local stakeholders to see the research as a resource for local development. These links were also invaluable in obtaining feedback after the workshop about how inclusive the event had been for people with learning disabilities and strategies that could be used in future to improve their participation.

Invitations to the workshop were sent to all individuals who had taken part in the research, either through qualitative interviews or through links the research team had developed to create a city-wide database of people with learning disabilities. The workshop was intended to provide an effective opportunity for people to share relevant experience, discuss the preliminary research findings and suggest ways of making progress in the fieldwork area across diverse stakeholder boundaries.

A total of 50 people attended the workshop, 17 months into the project (see Table 1). By this time 25 health and social care professionals had been interviewed for the project and arrangements to interview people with learning disabilities and their health facilitators were underway. Local advocacy groups that were already in contact with people with learning disabilities attending the workshop were asked to support their involvement. Payments were offered for time, transport and support costs to people with learning disabilities and family carers.

The workshop began with a keynote presentation by the Valuing People Support Team health lead, highlighting the importance of health facilitation. Two members of the research team then presented preliminary qualitative and quantitative findings from the study.[1] Following this, four discussion groups were facilitated by members of the

Table 1 Research workshop delegates

1	Children's learning disability services
10	Community learning disability team
1	GP
1	Manager: Social Services
3	Managers: Adult Learning Disability Services
6	Primary Care Trust (including Director of Public Health, Service Development Manager, Learning disability lead and PRIMIS Coordinator)
5	Research team
7	Service Users from advocacy/self-advocacy, BME, leisure/activity and supported living voluntary sector groups
1	Sure Start
1	Unknown organization
1	Valuing People Support Team lead
12	Voluntary sector learning disability staff – person-centred planning, advocacy/self-advocacy, minority ethnic leisure/activity, supported living and umbrella groups
1	Voluntary sector staff: One-stop advice centre
50	Total

research team but led by input from key individuals involved in health facilitation activity at local and national level:

- 'Good practice around England' was led by the Valuing People Support Team lead and provided an overview of effective approaches to implementing health facilitation targets.
- 'Working with GPs to improve services' was led by a local self-advocate, a GP and a manager of the Community Learning Disability Team, and discussed the challenges of working across professional disciplines.
- The local PRIMIS co-ordinator led a workshop on 'Finding People With Learning Disabilities on GP Registers' and GP involvement in Health Action Plans.
- The Head of Learning Disability services and a PCT Director of Public Health led a discussion group on 'Meeting *Valuing People* Health Targets: local opportunities and barriers'.

Each group was asked to discuss the preliminary findings and recommend ways in which health facilitation and health action planning could move forward in the area. Specific ideas about what needed to be in place to turn these recommendations into practice and who should be responsible for taking them forward were requested by the research team. The discussion and recommendations agreed in each group, along with ideas about who was responsible to take each recommendation forward, was recorded by the researchers on flipchart paper and typed up along with preliminary findings from the study into a workshop report (Mir 2005). Discussion group leaders were asked to validate the sections of the report relating to their group. Recommendations from each group were collated into similar categories and synthesized to produce overall recommendations from the workshop. A follow-up meeting was held with key stakeholders at the workshop to validate the report

---

[1]The framework approach to qualitative analysis (Ritchie & Spencer 1994) and the NUD*IST software package were used to analyse professional interviews on which preliminary findings were based. Development of the template and methods used for quantitative fieldwork are described in the full report of the project report (Mir *et al.* 2007).

and overall recommendations. The report was disseminated to all who attended as well as being sent to inform the Disability Rights Commission's Informal Inquiry into Health Inequalities and to two national elists relating to health and learning disabilities.[2]

The sections below outline research findings about local health facilitation activity alongside recommendations in response to these from the research workshop. Lessons learnt by the research team from facilitating the workshop are also considered.

Findings

Establishing baseline information

The White Paper indicates that every person with a learning disability is covered by the health-related targets. However, 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 to meet these targets. 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. Within the fieldwork area different service providers had their own service-based registers, but the absence of information-sharing agreements and concerns about data protection legislation acted as barriers to the development of a comprehensive and up-to-date record. The development of such a database had, nevertheless, been identified by local service planners as an important and necessary piece of work for the strategic planning of future services.

In order to evaluate progress on meeting the targets, the research team contacted statutory and voluntary agencies as well as GP practices to set up a database of all people with a learning disability in the fieldwork area. The research team had followed a rigorous process of gaining Ethics Committee and Research Governance approval as well as site-specific research governance approval from each PCT and further approval from the Patient Information Advisory Group. The whole process took a total of around 13 months. Even so, the research team encountered many concerns, particularly within the voluntary sector and also from statutory services. These concerns mostly focused on the ethics of providing access to records without individual consent, although there was recognition that relying on such consent was not feasible if the database was to be comprehensive. Further difficulties were caused by the fact that

some service user lists were not computerized and involved time-consuming work with manual records.

There was considerable confusion and inconsistency amongst practitioners and Caldicott Guardians[3] about whether information could be shared or not. Only one of five guardians in the fieldwork area understood the correct procedure to follow before information could be released to the research team. Messages posted on national health facilitation elists[2] suggested similar confusion elsewhere – in one area GPs were sharing information about whether people registered with Community Learning Disability Teams were on practice lists; in other areas guidance from PCT Caldicott Guardians blocked this process. In such cases the perceived requirement to obtain individual consent appeared to be having an adverse influence on collaboration between GPs and Community Learning Disability Teams to offer health facilitation to known service users. Although information sharing protocols that enable such collaboration do exist in some areas,[4] the level of inconsistency and uncertainty suggests that national guidance on information sharing between agencies and in relation to medical research will serve an important function (Cabinet Office/ Department of Health 2006).

In primary care, identifying people on GP practice registers highlighted different problems; there was little consistency in the use of Read-codes[5] in relation to people with learning disabilities. Work with five practices showed that no fewer than nine Read-Codes indicated a definite diagnosis of learning disability and 19 codes indicated a possible diagnosis. From these five practices, members of the research team developed a template which practice staff could use in the process of identifying people with learning disabilities on their registers.[6]

Individual GP-based registers, combined with health screening, have been shown to be effective in highlighting the health needs of learning disabled patients (Martin & Martin 2000). Most GPs, however, were not motivated to use the Read-code template either to contribute to the database or in order to offer health action planning in collaboration with the Community Learning Disability Team. Running the read-code template itself took little time and support

---

[2]The National Health Facilitation Network (mark.bradley@ oxleas.nhs.uk) and the Learning Disability and Health Network (ldhealthnetwork@ldhealthnetwork.org.uk).

[3]Senior health professionals who have a strategic role in the management of patient information, including agreeing and reviewing protocols governing the protection, use and disclosure of patient information (Department of Health 1997).

[4]See, for example, the Royal Borough of Kensington and Chelsea's protocol (http://www.rbkc.gov.uk/partnerships/infoshareassess).

[5]Computer codes used in GP practices to classify specific health-related conditions.

[6]The template may be accessed at Appendix 3 of a GP Toolkit developed by Leeds Mental Health Trust. http://www. leedsmentalhealth.nhs.uk/siteDownloads/0511_GPtoolkit_8.pdf.

was offered by the research team to carry out the search, however the request to generate a list of patient with learning disability received a poor response from most of the 22 general practices approached. Fieldwork data indicated concerns in some general practices about 'labelling' patients who might not perceive themselves as learning disabled and about inconsistent definitions of learning disabilities that might have historically been used. However, most professionals interviewed felt the poor response was because *Valuing People* targets were seen as 'aspirational' within both Primary Care Trusts (PCTs) and learning disability services and far less likely to be met than the targets for which PCTs were more accountable and GPs received payment, such as those relating to National Service Frameworks.

> I think that what National Service Frameworks have done with other groups is that it's provided more must-do's which have been right in… right at the heart of the health system …both commissioners and providers have had standards that they have to meet. It's been a much softer target in relation to Health Facilitation. (PCT lead on learning disabilities)

> Nobody has any problem with the ideas and philosophy. Usually it's been well thought out, they've consulted, you know, clinicians and professionals and carers and users have been involved. …At the end of the day it comes down to where are the resources to do it, or the people to do it? (Chair, PCT Professional Executive Committee)

Unlike conditions such as diabetes or cancer, learning disability had not, at that time, been included in the Quality and Outcomes Framework (through which GPs are monitored and paid). Consequently, there were no financial incentives for GPs to identify people with learning disabilities and no penalties for failing to identify this population.[7] Named leads within the PCTs and Strategic Health Authority appeared, as a result, to be doing little to promote the health goals in the White Paper or to ensure that deadlines were met.

Resources and opportunities

In the context of poor accountability at local and national levels to deliver the health targets outlined, local champions were vital to providing opportunities and accountability for progress. The Director of Public Health in one PCT used Health Action Zone (HAZ) funding to run a 3-year pilot project within his own Trust, aiming to provide a model for

delivering *Valuing People* targets to other PCTs in the city. The project was led by members of the Community Learning Disability Team and produced a toolkit to help GPs provide appropriate care to patients with a learning disability. The team also developed some links with hospital services and with dentists to improve awareness of the needs of individuals in this population group. The named PCT lead for learning disability work was not, however, involved in this initiative and worked in a different PCT.

Despite the use of HAZ resources and the existence of an unusually large learning disability nursing team, the project failed to forge significant links between this team and GP practices, either to support use of the toolkit or to collaborate on health action planning. As already highlighted this was partly due to lack of interest from GPs but other issues were also significant. Many people in the team did not feel confident about approaching or collaborating with GP practices. Even senior members of the team felt they had poor understanding of the structures within which primary care teams worked and how to initiate collaboration. Furthermore, there appeared to be anxieties within the team about being overwhelmed by requests for health facilitation and not being able to support or monitor the process properly. Existing working arrangements allowed the provision of high quality support to a small number of people with learning disabilities and this was seen as preferable by some people within the team to larger scale involvement with a wider caseload of people.

There was also evidence that professional ideas about health action plans and who should receive health facilitation could be different from the ideas promoted in *Valuing People* (Department of Health 2001). For example, the White Paper includes all people with learning disability whereas most service providers were clear that they did not have the capacity to be this inclusive and that resources could only be targeted at those with a severe learning disability. Furthermore, Government guidance states that health action plans should be person-centred whereas some learning disability professionals could assume that anyone they were already supporting 'already had their health needs met' and did not need a Health Action Plan.

Despite the numerous references in *Valuing People* to compliance with the Race Relations (Amendment) Act 2000, there was no clear action to make sure people from minority ethnic communities were included in work relating to the health of people with learning disabilities. Written documents about health action planning and health facilitation in the fieldwork area made no mention of people from minority ethnic communities, although a subgroup of the Learning Disability Partnership Board had been newly formed to formulate a strategy on ethnicity and learning disability. The lead role taken by a voluntary sector organization and the inclusion of ethnicity as a priority area for the Learning Disability Development Fund

---

[7]In April 2006 four QOF points were introduced to the new General Medical Services contract for general practices to produce a register of people with learning disabilities.

appeared to be key factors in helping to address this issue at a general level. However, the importance of paying specific attention to minority ethnic communities in health facilitation activity was highlighted.

Further opportunities for progress were evident within the voluntary sector. Three voluntary groups had initiated work related to health facilitation. One had organized a residential weekend and worked with nine service users to produce Health Action Plans. This was the only example of person-to-person or 'Level 2' health facilitation (Department of Health 2002) found at this point during fieldwork. Another group offered training to PCTs and medical students. The third had worked with local hospitals to make signage more accessible to people with learning disabilities.

There is evidence of substantial progress on meeting *Valuing People* health targets in some areas of the country (Valuing People Support Team 2004), demonstrating that progress is possible and can be achieved. Initiatives that have contributed to progress have included incentive payments to GPs to identify people with learning disabilities on their registers and the appointment of strategic and clinical leads for health facilitation and health action planning. However, preliminary findings from this study showed that progress towards achieving these targets had been minimal in the fieldwork area. There were indications that this scenario may be typical of many other parts of England. For example, researchers contacted a total of 395 PRIMIS facilitators in PCTs 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. Membership of a national health facilitation network at the time of the workshop comprised 67 individuals representing 53 PCT or learning disability services in England.[8] If the network 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).

These findings highlight issues affecting the ability and motivation of relevant stakeholders to achieve the White Paper goals. The research workshop was held within the fieldwork area to discuss these findings and agree a way forward. Shared ideas emerged about how to make progress in the locality and these are outlined below.

Workshop recommendations

Leadership and strategy

Clear ideas were highlighted by workshop participants about the areas in which different social actors had

___
[8]By February 2006 membership had increased to 74 individuals, representing 67 PCT or learning disability services.

responsibility. The Head of Learning Disability Services – a jointly commissioned post that straddled health and social care services – was perceived as responsible for developing a strategy and driving the work forward. The model used within mental health services, which employed a dedicated team working across all PCTs on mental health issues, was suggested as appropriate. Detailed targets and outcomes were felt to be necessary in relation to support for people with learning disabilities, collaboration between different sectors and clinical outcomes (see Table 2).

There was considerable consensus about what should happen although priorities were perceived differently by different stakeholders. Voluntary sector professionals and people with learning disabilities, for example, emphasized support for individuals with learning disabilities whereas members of the Community Learning Disabilities Team felt training for mainstream healthcare staff was most important.

Workshop participants recognized that a local strategy was unlikely to succeed unless the Strategic Health Authority gave its backing and set related targets for PCTs. This might involve agreeing a 'locally enhanced service', or financial incentive, for GPs to identify patients with learning disability in their practice populations and offer health screening. Resources would also need to be allocated in order to train service users and professionals with the necessary skills and knowledge. The need for incentives and rewards to be built into a local strategy as well as penalties for those who disregarded it was highlighted.

Recommendations from the workshop indicate that the collaborative partnerships needed to deliver *Valuing People* health targets are complex. They require the involvement of the learning disability nursing team to support and deliver health facilitation activity, PCTs to ensure the inclusion of people with learning disabilities in local health services, and the Learning Disability Partnership Board (with the involvement of service users, family carers and voluntary

Table 2 Workshop recommendations: elements of a local plan

Education and guidance about *Valuing People* rights and responsibilities – for people with learning disabilities and for health and social care professionals

Guidance for GPs on using read codes to find people with learning disabilities on their registers

People in each hospital department who will take responsibility for learning disability work

Better communication and links between voluntary organizations, carers, people with learning disabilities, GPs and the Learning Disability Nursing Team. These links should help trigger requests for health facilitation

Establishment of a Partnership Board Health Subgroup to include people from all these groups

Annual health checks for people with learning disabilities linked to Health Action Plans

Support for people with learning disabilities to look after their health and make choices

organizations) to commission and monitor work related to a local strategy. The Department of Health's role was also emphasized: the White Paper was seen as unlikely to change most people's lives unless accountability for work on learning disability was built into the structures through which the Department monitors local health services, such as the Quality and Outcomes Framework and National Service Framework targets.

Workshop follow-up

Analysis of the composition of delegates indicated that researchers had successfully engaged with stakeholders across a number of relevant areas. At least 10 of the workshop participants were members of the local Partnership Board, or regularly attended meetings, and included the Co-Chair. However, important gaps in engagement remained. A number of PCT professionals attended but only one GP, from 22 who had been invited. This may have been a reflection of the low priority GPs generally accorded to health facilitation activity, as reflected in our research findings, as well as fact that the template had not yet been offered to all general practices in the area. In addition, no delegates identified themselves as family carers; this may have partly been because fieldwork in relation to this group had only just begun. However, some feedback also indicated that workshop timings, which had been organized primarily to facilitate professional attendance, made it difficult for family carers to return home in time to receive relatives attending day care.

In terms of the involvement of people with learning disabilities at the event, feedback from the project Advisory Group indicated that, although physically present and in one case leading the discussion group, individuals had sometimes found it difficult to follow or contribute to the dialogue, which was not always accessible. It was decided that at the next research workshop to be held 18 months later a pre-meeting to present workshop findings should be organized. This would allow more time for people with learning disabilities to give feedback on how findings were presented and think about what they would like to contribute to the workshop.

A further meeting was held for key stakeholders after the first workshop to validate the report and discuss follow-up action. Participants in this meeting agreed that the recommendations should be used as a benchmark for progress at the second workshop to be held towards the end of the study. The Head of Learning Disability Services requested a further meeting to discuss a strategy for health facilitation in the area, which he was drafting to incorporate recommendations from the workshop. An element of this was the establishment of a Partnership Board Steering Group involving all relevant stakeholders. The Clinical Lead for the Community Learning Disabilities Team told people who

attended the meeting that since the workshop the team had devoted more time to health facilitation activity and recognized the need to prioritize this work.

Less commitment was given by the PCT and Strategic Health Authority leads for learning disabilities who felt that 'hard targets', i.e. those for which they were more accountable, would necessarily be prioritized. Both leads felt that a cultural shift was needed to facilitate the engagement of GPs, using incentives and nationally led performance management.

The workshop report contributed to national activity by the Valuing People Support Team, the Healthcare Commission and the Disability Rights Commission for incentives to be provided to GPs through the Quality Outcomes Framework. The workshop recommendation about this was implemented in April 2006.[7] A further recommendation that people with learning disabilities receive annual health checks was not included in the QOF but would appear to be a logical next step once general practice registers have been established.

Conclusion

The lack of accurate baseline information about the numbers of people with learning disabilities in an area means that professionals are unable to verify they are currently reaching all those who are potentially included in the *Valuing People* health targets. Preliminary findings from the study indicate that, in practice, service providers may not be motivated to do this anyway. In the context of limited resources, only those with severe or complex needs may be targeted by health and social care services. Practitioner's anxieties about being inundated with requests for help may act as a disincentive in the process, preventing attempts to even offer health facilitation to the general population of people with learning disabilities.

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. Specialist staff were given key roles to facilitate capacity development in mainstream services: through partnerships with healthcare providers and contributing their specialist knowledge to planning processes. Findings from the research and feedback from the workshop indicate that many of these roles were not adopted in the fieldwork area and more robust mechanisms were needed to facilitate the process of role change. Nevertheless, developments after the workshop indicate that the research project and the workshop itself created a focus on health facilitation in the fieldwork area, generating a forum for local stakeholders and a momentum that became a catalyst for local activity.

Inclusion of *Valuing People* health targets in the outcomes for which GPs and PCTs are held accountable at national level would appear to be a clear way to stimulate the necessary level of local action. Within this, specific targets relating to minority ethnic communities and people with profound and multiple learning disabilities are indicated to ensure compliance with the legal framework on race equality and inclusion of groups that experience most health needs. At present work to develop improved clinically relevant performance measures pays little attention to minority ethnic communities or people with profound and multiple learning disabilities (Whitty *et al.* 2006).

The complex partnerships needed to deliver improved health services to people with learning disabilities have significant potential to fail because of the number of links between different actors that they involve (Harrison 1994). In this context, leadership and strategy to effect joint working within and between different service sectors appear to be key to achieving progress. Recommendations from the research workshop indicate that this leadership is needed at national, regional and local levels if the pockets of good practice that have been developed in various parts of England are to be replicated elsewhere.

Good Practice Statement

The research workshop for this study included people with learning disabilities. An accessible version of a report from the workshop is available and has been distributed to everyone who has taken part in the study as well as to local and national practitioners. Members of the research team have presented preliminary findings and workshop recommendations at numerous events to professionals involved in health facilitation activity. A paper on the development of the template to identify people on general practice registers was written for a practitioner-focused learning disability journal (Evans *et al.* 2005) and the template is available on the web.

A second research workshop took place in June 2006 and 'pre-meetings' for people with learning disabilities were held beforehand to ensure they could contribute their views easily. The workshop was also organized to make sure family carers could attend alongside caring commitments. Final reports from the study will be made available in a variety of accessible formats. Dissemination activity aims to influence policy and practice in relation to the health of people with learning disabilities.

References

Alborz A., McNally R., Swallow A. & Glendinning C. (2003) *From the Cradle to the Grave: a literature review of access to health care for people with learning disabilities across the lifespan*. Manchester, National Primary Care Research & Development Centre.

Biswas M., Whalley H., Foster J., Friedman E. & Deacon R. (2005) Women with learning disability and uptake of screening: audit of screening uptake before and after one to one counselling. *J Public Health*, **27**: 344–7.

Cabinet Office (2005) *Improving life chances for disabled people*. London, Prime Minister's Strategy Unit.

Cabinet Office/Department of Health (2006) Making a difference: safe and secure data sharing between health and adult social care staff. http://www.cabinetoffice.gov.uk/regulation/documents/mad/data_sharing.pdf (Accessed August 2006).

Chambers R., Milsom G., Evans N., Lucking A. & Campbell I. (1998) The primary care workload and prescribing costs associated with patients with learning disability discharged from long stay care to the community. *Br J Learn Disabil*, **26**: 9–12.

Chaplin R.H., Thorp C., Ismail I.A., Collacott R.A. & Bhaumik S. (1996) Psychiatric disorder in Asian adults with learning disabilities: patterns of service use. *J Intellect Disabil Res*, **40**: 298–304.

Cope C. (2003) *Fulfilling lives: inspection of social care services for people with LD*. London, Social Services Inspectorate/Department of Health.

Department of Health (1997) *The Caldicott Committee: report on the review of patient-identifiable information*. London, Department of Health.

Department of Health (2001) *Valuing People: a new strategy for learning disability for the 21st century*. London, The Stationery Office.

Department of Health (2002) *Action for health, health action plans and health facilitation detailed good practice guidance on implementation for learning disability partnership boards*. London, Department of Health.

Elliott J., Hatton C. & Emerson E. (2003) The health of people with learning disabilities in the UK: evidence and implications for the NHS. *J Integr Care*, **11**: 9–17.

Emerson E., Mallam S., Davies I. & Spencer K. (2005) *National survey of adults with learning disabilities in England 2003/4*. Rotherham, NHS Health and Social Care Information Centre/Office for National Statistics.

Evans J., Mir G., Atkin K., Marshall J. & Allgar V. (2005) Identifying people with learning disabilities in general practice. *Living Well*, **5**: 18–22.

Harrison S. (1994) Knowledge into practice: what's the problem? *J Manage Med*, **8**: 9–16.

Hollins S., Attard M.T., von Fraunhofer N., McGuigan S. & Sedgwick P. (1998) Mortality in people with learning disability: risks, causes, and death certification findings in London. *Dev Med Child Neurol*, **40**: 50–6.

Jones R.G. & Kerr M.P. (1997) A randomised control trial of an opportunistic health screening tool in primary care for people with intellectual disability. *J Intellect Disabil Res*, **41**: 409–15.

Lunsky Y., Emery C.F. & Benson B.A. (2002) Staff and self-reports of health behaviours, somatic complaints, and medications among adults with mild intellectual disability. *J Intellect Dev Disabil*, **27**: 125–35.

Martin G.H.B. & Martin D.M. (2000) A register for patients with learning disabilities in general practice: workload implications of ex-hospital patients. *J Intellect Disabil*, **4**: 37–48.

Mencap (2004) *Treat me right! Better healthcare for people with a learning disability*. London, Mencap.

Mir G. (2005) *Valuing Health: report of a learning disability research workshop*. University of Leeds, Centre for Research in Primary Care.

Mir G., Nocon A., Ahmad W. & Jones L. (2001) *Learning difficulties and ethnicity*. London, Department of Health.

Mir G., Allgar V., Cottrell D., Heywood P., Evans J. & Marshall J. (2001) *Health facilitation and learning disability*. University of Leeds, Institute of Health Sciences.

NHS (2006) Authorities and trusts in England. http://www.nhs.uk/England/AuthoritiesTrusts (Accessed September 2006).

Pearson V., Davis C., Ruoff C. & Dyer J. (1998) Only one quarter of women with learning disability in Exeter have cervical screening. *BMJ*, **316**: 1979.

PMLD Network (2002) *Valuing people with profound and multiple disabilities*. London, PMLD Network.

Ritchie J. & Spencer L. (1994) Qualitative data analysis for applied policy research. In Bryman A., Burgess R., editors. *Analysing qualitative data*. London, Routledge: 173–94.

Scambler G. (2002) *The new inequality and health. Health and social change*. Buckingham, Philadelphia, Open University Press.

Stein K. & Allen N. (1999) Cross sectional survey of cervical cancer screening in women with learning disability. *BMJ*, **318**: 641.

Valuing People Support Team. 2004. Newsletter June 2004: all about health. http://www.valuingpeople.gov.uk.

Whitaker S. (2004) *Mental health and learning disabilities research and practice*, Vol. 1:1. South West Yorkshire Mental Health NHS Trust and University of Huddersfield. http://www.hud.ac.uk/hhs/research/mhrg/journal/issue1.pdf.

Whitty P., Richardo M., Boyle R., Shribman S., Roberts S. et al. (2006) *The better metrics project: Version 7*. http://www.healthcare commission.org.uk.

Wilkins J. (2004) Making a difference. *Learn Disabil Pract*, **7**: 8–10.