

## **PUBLISHED ARTICLE:**

**Campbell, M. & Martin, M. (2010) Reducing health inequalities in Scotland: The involvement of people with learning disabilities as NHS reviewers. *British Journal of Learning Disabilities*, 38,1, 49-58.**

*Keywords: health inequalities, expert patient, learning disabilities, Scotland,*

## Summary

People with learning disabilities have more health needs than the general population, and those health needs are different and require more specialised services. There is evidence of poorer outcomes and less effective health interventions for people with learning disabilities in Scotland, and elsewhere.

Reducing health inequalities is currently a key priority for the Scottish Government and NHS policy has encouraged patient involvement in healthcare planning and delivery. This article reports on an NHS initiative to involve people with intellectual disabilities as “expert patients” reviewers in national review teams, looking at the quality of inpatient and community services for people with learning disabilities. All 15 Health Boards in Scotland were reviewed, using a set of quality indicators. Details of the planning and support arrangements are reported. The success of the initiative was evaluated.

This involvement of people with learning disabilities as reviewers of NHS services has tested traditional assumptions and challenged the power imbalance in patient-provider relationships. Recommendations are made for the future success of similar schemes.

## **Abstract**

Reducing health inequalities is a key priority for the Scottish Government. Health authorities are expected to meet quality targets. The involvement of people with learning disabilities in health service review teams has been one of the initiatives used in by NHS Quality Improvement Scotland to empower patients and improve health services. This paper describes this initiative, how it was planned, and an evaluation by health staff, carers and people with learning disabilities.

Recommendations are made to ensure the future success of this type of initiative in Scotland and elsewhere.

This initiative was evaluated positively and tested traditional assumptions, challenging the power imbalance in patient-provider relationships. The theory and the practice of including people with learning disabilities as “expert patient” reviewers are discussed.

## **Introduction**

An NHS QIS initiative to include adults with learning disabilities in a national review of Scottish health services is consistent with principles in the Scottish Executive policy document *The Same As You: A review of services for people with learning disabilities* (2000), which advocates full consultation and involvement in decision making relating to services.

There are approximately 120,000 people with learning disabilities in Scotland, of whom 18-20,000 have severe or profound problems (Scottish Executive 2000). 30,000 people with learning disabilities are in regular contact with health and social work services, and most live at home or in supported accommodation (see Figure 1, which shows the trends in people living at home or in various types of managed care ).

Since 2000, the number of adults with learning disabilities resident in long-stay hospitals or other in-patient accommodation has decreased by more than 80%, from over 1,800 to 364 people in May 2007 (Simpson, Douds and Perera 2008). During the same period there has been a decrease in the number of adults with learning disabilities living in care homes (from approximately 3300 to 2400) and an increase in the number receiving home care services (from 1500 to 3600) (Scottish Government 2008). Around 7,500 adults with learning disabilities now live in their own tenancies.

**[Insert Figure 1 here]**

NHS policy has targeted patient involvement in healthcare planning and delivery as a priority, trying to make best use of patient and carer expertise across all patient groups (SEHD 2005). This has included “expert patient” schemes.

*“The partnership paradigm credits patients with an expertise similar in importance to the expertise of the professional. .... patients are the experts about their own lives”*  
(Bodenheimer, Lorig, Holman and Grumbach 2002: p. 2470)

However the lack of involvement of people with learning disabilities and their carers in their own healthcare has been an area of concern for some years. There is little research on the role of adults with learning disabilities making real decisions about their health and how these decisions are made (e.g. Keywood, Fovargue & Flynn 1999).

Carers and people with learning disabilities report poor understanding and lack of responsiveness by healthcare professionals. For example, some health professionals are more accustomed to dealing with carers and do not see the need to address their patients directly.

- “People don't listen to you”
- “The doctor totally ignored my daughter, she spoke directly to me”
- “The doctor put most of the problems down to my son's learning disability”
- “The doctor spoke in terms that neither I nor my daughter could understand – he was telling us that further surgery was needed”

- “They said she was 'confused'. She's not confused. She's really intelligent and can understand a lot.”

(NHS Ayrshire and Arran 2004).

One of the first “expert patient” programmes was developed by Kate Lorig, Professor of Medicine at Stanford University, who designed an Arthritis Self-Help Course in the 1970s. (Lorig 2002; Lorig, Sobel, Ritter, Laurent and Hobbs 2001). These self-management courses were first introduced in the UK in 1994 by Arthritis Care, as a three-year programme<sup>1</sup>. Pilot schemes for six-week expert patient courses were introduced by 100 Primary Care services in 2001, with a focus on NHS approaches to chronic disease management (BBC Radio 4, 2005).

The most common format for these schemes are disease-specific education packs to support self-management or short, patient education courses to give people information and to equip them with skills and confidence that will help them to be more in control of their lives. (See, for example Diabetes UK/Dept. of Health (2005).

In Scotland, initiatives by Arthritis Care and by the Pain Association are typical examples of professionally led expert patient programmes. There is little evidence however that similar programmes, imparting information to people with learning disabilities, make a real difference to the quality of healthcare they actually receive.

Although the government has stated an intention to involve, “people with learning disabilities in commissioning and reviewing services, in particular through sponsoring PCT commissioning 'exemplar sites'” (Hansard 2008) there are few examples, at national or indeed at international level of this in practice. In Scotland, one notable good practice example is the Mental Welfare Commission<sup>2</sup>, an independent organisation working to safeguard the rights and welfare of everyone with a mental

---

<sup>1</sup> <http://www.arthritiscare.org.uk/>

<sup>2</sup> [http://www.mwscot.org.uk/about\\_us/our\\_commissioners.asp](http://www.mwscot.org.uk/about_us/our_commissioners.asp)

illness, learning disability or other mental disorder, who have appointed a permanent Commissioner with learning disabilities.

People with learning disabilities are not able to exert influence on health services to change, which can render them largely “invisible” and vulnerable to poorer healthcare in this context (e.g. Healthcare Commission 2005; Kerr 2004). On occasions the standard of healthcare has directly resulted in deaths (Parliamentary and Health Service Ombudsman 2009). There is an assumption that people with learning disabilities have no understanding of their health care needs, or the needs of others, because of their learning disability. In the last 5 years however, the traditional assumptions about patient–professional relationships have been challenged by an increase in the involvement of people with learning disabilities, carers and supporters in consultation on health policy and practices, and by the growth of the self advocacy movement and advocacy organisations

Recent Scottish legislation, including the first Act of the devolved Scottish Parliament: The Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003, place a strong onus on clinicians and other professionals to contribute to the development of self advocacy skills. In relation to the Mental Health Act legislation, patients should not be seen as *‘passive recipients of care or treatment, and should be actively encouraged to participate in the decision making procedures under the Act’* (Scottish Government 2003). There is a clear legislative intent to ensure that those with limited capacity should play as significant a part in their treatment as possible, and that professional staff in services should be seeking to maximise and develop capacity.

In this context, how applicable are expert patient initiatives to people with learning disabilities? There is a case to be made for a health-empowering initiative of this kind, based on the evidence to date. People with learning disabilities have more health needs than the general population, and those health needs are different and require more specialised services (e.g. Howells 1986; Langan, Russell & Whitfield 1993; Lindsey 1998; Dept. of Health 1995)

Adequately meeting these complex health needs has proved difficult for health services, especially when people with learning disabilities moved to community settings following the final closure of long stay “learning disability” hospitals between 2000-2007 (Scottish Executive 2003; NHS QIS 2006; Northway, Hutchison, and Kingdon 2006; Campbell 2008; Mencap 1997). In Scotland today, there is evidence of significant health inequalities in mortality, physical illness, mental health and wellbeing, access to and use of health services. Crucially, “*Inequalities are evident according to the presence of disability.*” (Scottish Government 2008) For example, the main cause of death for people with learning disabilities is respiratory disease, linked to pneumonia, swallowing and feeding problems and gastro-oesophageal reflux disorder (NHS Health Scotland 2004). This is followed by coronary heart disease, which is increasing as life expectancy improves and more people live in the community. This is a pattern reflected in the UK as a whole, and internationally. People with learning disabilities have higher than average prevalence of epilepsy, hearing impairments and visual impairments, congenital heart disease, osteoporosis, hypothyroidism, diabetes, respiratory infections, urinary tract infections, and injuries due to falls (Kerr 2004; Horwitz, Kerker, Owens, & Zigler 2000; NHS Health Scotland 2004; Ouellette-Kuntz, Garcin, Lewis, Minnes, Freeman & Holden 2004). They also have higher rates of unrecognised or poorly managed conditions, (Howells 1986; Wilson and Haire 1990), such as hypertension, obesity, some cancers, gastrointestinal disorders, diabetes, oral disease, and thyroid disease (Ouellette-Kuntz 2005; Horwitz et al 2000). There is also evidence of poor outcomes and less effective health interventions for people with learning disabilities in Scotland, and elsewhere, (e.g. Ouellette- Kuntz 2004; Horwitz et al 2000; Lennox, Green, Diggins, & Ugoni 2001; Lennox, Bain, Rey-Conde, Purdie, Bush & Pandeya 2007; NHS Health Scotland 2004; Disability Rights Commission 2004; Hogg 2001; Elliott, Hatton and Emerson 2003; Hatton, Elliott & Emerson 2004; Emerson and Hatton 2008).

Significant problems have been reported in re-shaping and developing appropriate and accessible primary, specialist and continuing health care services, especially for people with significant and complex needs (Dept of Health 1999; Dept of Health 1999a; NHS Scotland 2004; NHSQIS 2006; Campbell 2008).

Prior to 2004, the national review teams for NHS Quality Improvement Scotland consisted of healthcare and social care professionals and academics, who conducted peer review inspection of health services. This paper reports on how people with learning disabilities and carers were included in national health review teams in Scotland, set up to monitor the performance of health authorities and the quality of healthcare being received by people with learning disabilities across Scotland. Planning and support arrangements are reported. The focus of this account is on the role and the experience of people with learning disabilities as in these review teams. This is seen as an innovative, but atypical “expert patients” initiative. The rationale for this study was based on two of the principles from a national overview of services (Scottish Executive 2000):

- People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.
- People with learning disabilities should be valued. They should be asked and encouraged to contribute to the community they live in. They should not be discriminated against, bullied or treated differently from others.

The methodology for collecting data and qualitative analysis at a national level is innovative, but is based on recognised, good research practice for working with people with learning disabilities, using methods which increase trust and rapport (e.g. Simons et al 1989; Atkinson 1993; Fiedler & Twitchin 1992; Stalker & Harris 1998). The evidence base for techniques to support the engagement of people with learning disabilities in the review of health services have been developed in Scotland over the last 10 years (For example, If You Don’t Ask, You Don’t Get -Scottish Executive Central Research Unit



1999; Promoting Health, Supporting Inclusion – Scottish Executive 2002; Changing Lives- Report of the 21<sup>st</sup> Century Social Work Review – Scottish Executive 2006)

The success of the initiative was evaluated following the national review. (The involvement of carers in national review teams was also an innovation, and deserves a separate analysis and report.)

## **Method**

Between June 2004 and August 2005 National Health Service Quality Improvement Scotland (NHSQIS) reviewed health services for children and adults with learning disabilities in Scotland, assessing performance against a set of NHS Quality Indicators (QIs) (NHS QIS 2004). These are:

QI 1 - Involvement of Children and Adults with Learning Disabilities and Their Family Carers through Self-Representation and Independent Advocacy

QI 2 - Promoting Inclusion and Wellbeing

QI 3 - Meeting General Healthcare Needs

QI 4 - Meeting Complex Healthcare Needs

QI 5 - In-patient Services – Daily Life

QI 6 - Planning Services and Partnership Working

For the 2004-5 reviews all 15 NHS area authorities were assessed for performance against QIs 1, 4, 5 and 6 and local reports were published in February 2006, together with a National Overview summarising findings (NHS QIS 2006; Campbell 2007). A second round of reviews, focussing specifically on Quality Indicators 2 and 3 was started in September 2008 and completed by June 2009. The first round of reviews only is covered in this report.

## *Planning*

People with learning disabilities and supporters were recruited as members of the review teams and strategies were developed to support the engagement of people with learning disabilities and carers in all aspects of the review process, and its evaluation.

Two national organisations acted as support agencies in providing people with learning disabilities and carer representatives as reviewers. Both People First (Scotland)<sup>3</sup>, as the organisation that ensured the involvement of people with learning disabilities and PAMIS<sup>4</sup> (Profound and Multiple Impairment Service), as the carer body, were partners in the process.

All teams were led by a team leader who was an experienced NHS QIS reviewer. NHS Quality Improvement Scotland also employed a consultant to support the representatives from PAMIS and People First (Scotland). Two pilot reviews were arranged. Following these pilots, some minor amendments were made to the template for the national review programme to all other health board areas and to the methods used to engage people with learning disabilities in the review process.

People with learning disabilities were involved in all review team activities. This included a series of meetings and interviews with healthcare staff and other stakeholders, visits to health services, and consideration of the evidence and self-assessment documents provided by each of the NHS Boards. People with learning disabilities and carers were in the series of team meetings that took place before and during each review visit, and in evaluating and developing feedback to the NHS Boards at the end of the review. Team meetings were organised to allow people with learning disabilities to contribute early in the process, so that they could have a break if required.

There was one person with learning disabilities, one or more supporters and one person from a care organisation in each of the review teams. There were 15 teams in total, one for each health authority.

---

<sup>3</sup> <http://www.peoplefirstscotland.com/>

<sup>4</sup> <http://www.dundee.ac.uk/pamis/>

The rest of the team, usually 6 people, was made up of a balance of health, social work and voluntary sector staff, and professionals allied to medicine. Review team members participated in a maximum of two reviews, and team leaders participated in four reviews each, on average. The person with learning disabilities was supported at recruitment, training, preparation for the review and on the review itself by the same support worker. Service users and representatives from carer organisations were paid for their work in the same way as other reviewers. More details about the management of support have been published (NHS QIS 2006a).

### *Training*

All reviewers received a one-day training session. Learning disabled reviewers received training in their own sessions that ran parallel to those attended by other reviewers, thus allowing for more time to be spent on the specific areas that they were going to review, and less on the wider focus of the general reviewer training. The training focused on explaining the style of review, introducing reviewers to the format of the evidence and the Quality Indicators for Learning Disabilities (NHSQIS 2004, NHSQIS 2004a – accessible version) providing examples of questions to ask during meetings with healthcare staff and other stakeholders, and evaluating how well the performance indicators had been met.

### *Preparation for the review*

Preparation for the 3-day reviews varied slightly for people with learning disabilities. Whilst the package of self-assessment and evidence documents from NHS Boards was sent out to *all* reviewers at the same time, it was recognised that people with learning disabilities and carers needed more time and support to prepare.

Typically, people with learning disabilities spent 1–2 days going through the NHS Boards' evidence and self-assessment documents with a supporter from People First (Scotland), setting this in context of the review programme, and developing a list of questions and/or areas for exploration.

People First (Scotland) supporters prepared a workbook as a tool for guiding people through the process. This provided a framework based on the key points from the Quality Indicators for Learning Disabilities. Specific questions, to be asked during the review, were then developed from the workbook. (See Appendix 1 for an extract from the workbook.). The template worked well in providing an approach for all reviews, and could be supplemented to suit local circumstances or issues

### *Sub-teams*

During the 3-day reviews several sub-teams worked on their own or came together preparing for the larger meetings. Sub-teams were also involved in comparing experiences after the meetings with NHS staff, carers and service users, amending questions, reviewing overall findings, developing a consensus on scoring, and preparing verbal and written feedback to the NHS Board. People with learning disabilities were allocated to a sub-team which focused on specific Quality Indicators, examining the following:

- *‘Inpatient services – daily life’* (Quality Indicator 5) This was relevant to a number of reviewers, who had previously lived in old-style learning disability hospitals or other forms of inpatient care, and were able to use their experience to focus attention on determinants of good quality care during interviews with service users and staff.
- *‘Involvement of children and adults with learning disabilities and their family carers through self-representation and independent advocacy’* (Quality Indicator 1) This indicator was chosen as being of particular relevance to people with learning disabilities receiving healthcare, e.g. *“Another factor that can worsen experiences of people with learning disabilities is a lack of advocacy services to enable them to make choices about healthcare.”* (Healthcare Commission 2005)

These two quality indicators were selected as the ones where “peer” review would be most effective.

*Evaluation by those who took part in the national reviews of NHS services for people with learning disabilities*

Full details about the evaluation of the reviews, describing the methodology have been published (NHSQIS 2006a). For reasons of space, a summary only is produced here.

This is an extract from the easy-read summary of the final evaluation that was produced (NHS QIS 2006a).

*“After the review visits, PAMIS and People First (Scotland) representatives and supporters went to workshops. At these workshops they talked about how well the visits had gone, and wrote down things that were good and things that could have been better. They also filled in questionnaires, and so did the people who led the NHS QIS teams and the NHS QIS staff.”*

An evaluation was carried out by consulting separately with:

- PAMIS representatives and staff
- People First (Scotland) representatives and supporters
- review team leaders
- sub-team leaders
- NHS Quality Improvement staff.

Questionnaires in accessible form were designed to examine responses to all parts of the programme were circulated to all parties. This included questions on understanding the written evidence, meeting the review team, carrying out the review, evaluating the NHS Board, commenting on the draft report, and looking at arrangements for travel, food and accommodation (each review lasted 3 days and involved 3-4 overnight stays for all review team members). A series of four consultant-led workshops

was then held with PAMIS representatives and staff, and People First (Scotland) representatives and the supporters who had been on the reviews to discuss the responses to the questionnaires. The workshops took the form of focussed discussions, using the accessible questionnaires as a guide and trying to reach a consensus on each of the questions. The consultant who led the workshops recorded the range of views expressed (NHS QIS 2006a). Service users who were reviewers were involved in these workshops and in the subsequent production and national launch of the report (NHSQIS 2006a). The written responses to the questionnaires and the notes recorded in subsequent discussions were analysed manually, rather than coding responses and entering it on a qualitative data analysis computer package. This summarising was done by the consultant, who identified common themes and patterns in responses and brought these together in the writing of the evaluation report (NHS QIS 2006a).

## **Results**

The evaluation response of PAMIS and People First (Scotland) representatives is summarised below in a combined form, with some examples to illustrate the points made. This is a summary of the full evaluation (NHS QIS 2006a) Responses were gathered qualitatively, as described in the Methods section. There was general agreement on the majority of points. Where there were points particular to an organisation these are indicated.

### *Training*

Taking part in a review was evaluated as providing the best training. Those who were involved in more than one review felt that their confidence grew as they became more familiar with the process. A single day of training at the beginning of a year-long programme was not considered effective. Some people received training a number of months before taking part in a review and responses in the evaluation indicated that a training session immediately before a review, or attending more than one

training session would be preferable. Role playing exercises were seen as providing a more realistic and enjoyable way of developing and testing out interview skills, than simply being told or given information.

#### *Preparation for the review*

Receiving the evidence and self-assessment material from NHS Boards as early as possible was evaluated as being very helpful. Some people would like to have received it about a month before the review. Both organisations (PAMIS and People First) suggested that suitably anonymised ‘mock’ evidence items could be used to assist NHS Boards in preparing their evidence for review teams to maximise accessibility. Reviewers were emphatic in the evaluation workshops that the review programme for each NHS Board should be made available in good time before the review, in order that reviewers know where they are going and who they will meet. This allows them to prepare questions appropriate to the circumstances.

#### *The review – meeting people and visiting NHS services*

Representatives had mixed experiences in relation to whether they met the “right” people during the reviews, and how well prepared they were to tell them about their experiences. Reviewers felt that sound guidance from People First could be sent to NHS Boards, advising on how to go about involving people with learning disabilities and carers in the meetings they set up for the review. It was considered important that NHS Boards identify appropriate agencies to support attendance, to make it clear what the purpose of the exercise is, and to suggest that those taking part in meeting with reviewers should be encouraged to prepare.

People who were involved in more than one review found that the second or subsequent review was significantly easier than the first. Feedback indicated that it would be beneficial to develop a panel of experienced reviewers with learning disabilities who could be drawn on for additional reviews.

Last minute changes to visit programmes, and sessions where the expected people did not arrive, presented a particular challenge to people with learning disabilities. Efforts were made to limit this as far as possible.

#### *The review – working with other team members*

Reviewers with learning disabilities involved in providing feedback to the NHS Board on strengths and areas for improvement felt that it had been important that they were seen to be “expert patients”, with a contribution to make.

Early contact with the sub-team leader was appreciated by both people with learning disabilities and carers, though it was not felt to be essential. End of review verbal feedback sessions to the Health Board being reviewed were experienced by all as fairly tough. Where reviewers with learning disabilities were involved in feeding back to the NHS Board it was recommended that they have the opportunity to speak first, as this allowed them to prepare and deliver a point, rather than having to do so in the middle of a discussion. The final session of the review – the evaluation and grading of the Health Board performance - was experienced by all as very pressured and difficult.

#### *Feedback from team leaders, sub-team leaders and NHS QIS project officers working with people with learning disabilities and carers*

Other reviewers and support staff reported that they found people with learning disabilities very well prepared, although there was some variability. Integration of people with learning disabilities and carers with other team members worked very well, at both task related and social levels. The roles of team leader and sub-team leader in setting the tone of the whole review, and in modelling the approach to involving and engaging with people with learning disabilities and carers, was seen as very important.



The positive impact on professionals who were having a rare opportunity to work alongside people with learning disabilities and carers was commented on by several respondents.

There was some anxiety about challenging people with learning disabilities and carers where other team members disagreed with points. It was suggested that this could form a useful focus for everyone in future training. It was felt that the views of the whole team are and should be valued, but that it is wrong to hold back from disagreement if that is warranted.

Feedback sessions went well from the team leader and sub-team leader perspectives. Sub-team leaders found this worked best if they took a strong line in focusing on the Quality Indicators for Learning Disabilities, steering people towards the main issues

## **Recommendations**

Overall, the process of including people with learning disabilities as and review team members who were seen as “expert patients” worked very well. NHS staff being reviewed and other review team members commented favourably. People with learning disabilities indicated their enthusiasm for, and enjoyment of, the process. There is clear evidence of the general effectiveness of the process through the quality of the reports following the reviews (NHSQIS 2006). People with learning disabilities and carers have taken lead responsibility for evaluating one area of the Quality Indicators for Learning Disabilities, and have played a major role in another area. Their contribution to the process was significant.

From the evaluation, the following recommendations are made for future reviews, which will include people with learning disabilities as review team members:

- NHS QIS should continue to use specialist organisations, such as PAMIS and People First (Scotland) to recruit and support appropriate reviewers from their area of interest.
- NHS QIS should develop a pool of experienced people with learning disabilities and carers who can be called on periodically to take part in review.
- People First (Scotland) should develop training materials on a CD Rom.
- PAMIS and People First (Scotland) should further develop and refine tools and approaches to assist NHS Boards in supporting greater engagement with local people with learning disabilities and carers.
- PAMIS and People First (Scotland) should develop a format for recording notes during or immediately after meetings.
- NHS QIS should adopt, as standard practice in feedback meetings, a practice of people with learning disabilities making their contribution at the start of the meeting.

## Discussion

People with learning disabilities have been marginalised because of inequalities in accessing both information and health resources. Some efforts have been made in Scotland to address this by making available more support, to allow them to participate in decisions about how services are organised and run. (SCLD 2008; Scottish Government 2008).

The NHS QIS initiative reported here, to train and involve people with learning disabilities in national review teams as “expert patients”, was an atypical approach to existing “expert patient” schemes. Reviewers looked at the quality of inpatient and community services for people with learning disabilities across Scotland, and the success of the initiative was subsequently evaluated.

The “self agency” model by Koch Jenkin and Kralik (2004) in the context of chronic illness self-management, proposes a therapeutic relationship in which there is *shared* power, rather than the

traditional medical model, where power rests with the professional. In this “partnership paradigm” a responsive approach to empowering the patient is the focus. The process of empowering people with learning disabilities to have a say in local and national health services is not simple or easy, as was evidenced by the amount of time and resources that were needed to make this initiative possible. The very detailed planning over a period of two years, and the substantial commitment of resources by NHS QIS should be carefully considered in similar initiatives.

The inclusion of people with learning disabilities in NHS QIS review teams in Scotland was an innovative step, and the evaluative feedback from everyone involved was generally very positive. The make up of review teams also had a positive impact on how health services viewed these “expert patients”, and how their health needs can be met in a more inclusive way. The innovation also resulted in a number of unforeseen consequences, during and after reviews, which challenged traditional assumptions about the balance of power between professionals and people with learning disabilities.

The “peer review” model of inclusion did have limitations and the process could be enhanced. There was, for example, variability in how well reviewers with learning disabilities were able to apply their training in practice on the reviews. Of course, this was also the case for reviewers without learning disabilities. The role of the review team leader here was key, in monitoring and providing appropriate support. There was also a need for “critical support”. Few people with learning disabilities have had the chance to develop the skill of self-evaluation; they had difficulty assessing what they have done well and where they needed to improve their skills. There is a tendency, unfortunately, to see things in absolutes, where an individual’s performance on a review was either ‘great’ or ‘a total disaster’. There is a need during and after reviews for honesty and *constructive* feedback.

Analysing specific aspects of a person’s performance is difficult, partly because the focus tends to be on regular, positive reinforcement. Whilst positive reinforcement is essential and creates a conducive

environment for learning, it should be honest and based on reasonably high expectations. For example, if someone with or without learning disabilities says something inappropriate or is off-topic in a meeting or during an interview, they should be told. Contributions that are unrelated or too personal can often be treated as an “embarrassing mistakes” by other non disabled participants, and lead to uncomfortable silences, without anything being said to make the same mistake less likely in the future. This ultimately does a disservice to people with learning disabilities because they are not being treated them as equal, or capable of developing their skills. That is the most likely explanation of why we don’t challenge and encourage more effective ways of participating.

In considering how the role of people with learning disabilities can best be taken forward, it is important to differentiate between poorer health and poorer healthcare *services*. People with learning disabilities have more, and different, health needs than the general population. Initiatives such as this one will not change that; a different type of public health initiative is needed. However, the quality of inpatient and community services, access to those services and the timely diagnosis and treatment of health problems *can* be improved through empowering initiatives such as this. Similarly, it has been shown that higher expectations of what health services a person *should* receive can be encouraged through this kind of “expert patient” initiative. (NHS Health Scotland 2004; Jeste, Gladsjo, Lindamer, & Lacro 1996; Keywood et al 1999; Alborz, McNally, Swallow & Glendinning 2003; Horwitz et al 2000).

None of this can be achieved without a belief in, and a commitment to the process by both the organisation leading the review of services and the organisations being reviewed. The next steps will be to establish the value of including people with learning disabilities in all health and multi-agency reviews as standard good practice. Despite the evidence presented in this paper and elsewhere, there is a move towards streamlined or “light touch” inspection of services, which do not include people with learning disabilities. Frameworks for co-operation between services and inspection agencies or

“concordats” may result in more effective self-evaluation by services, but does a chat with triangular sandwiches around a boardroom table really constitute an inspection?

The creation of a multi-agency inspection post, at national level, for a person with learning disabilities would both acknowledge the value of people with learning disabilities as reviewers and establish a good practice process for future reviews. In research terms, comparative evaluation of annual national reviews, with people with learning disabilities as researchers, would produce recommendations and learning points that are needed for continuous improvement of the peer review process.

## **INSERT APPENDIX 1**

## **References**

1. Alborz, A., McNally, R., Swallow, A. and 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*. London: National Co-ordinating Centre for NHS Service Delivery and Organisation.

2. Atkinson, D. (1993) *Relating*. In P. Shakespeare, D. Atkinson & S. French (Eds.) *Reflecting on Research Practice*. Open University Press, Buckingham.
3. BBC Radio 4 (2005) *The Expert Patient*. Trisha MacNair investigates the new NHS Expert Patient Programme. Thursdays 4 & 11 August 2005, 8.00-8.30pm
4. Bodenheimer, T., Lorig, K., Holman, H. and Grumbach, K. (2002) Patient self-management of chronic disease in primary care. *Journal of the American Medical Association*, 288, 2469-2475.
5. Campbell M (2008) The importance of good quality services for people with complex health needs. *British Journal of Learning Disabilities*, 36, 1, 32-37(6).
6. Campbell, M., Whoriskey, M., Davidson, A., McCue, M. and Lyall, R. (2007) A National Review of health services for people with learning disabilities in Scotland. *British Journal of Developmental Disabilities*, 53, 1, 104, 25-36.
7. Dept. of Health (1995) *The Health of a Nation: A Strategy for People with Learning Disabilities*. HMSO London.
8. Dept. of Health (1999) *Facing the Facts: Services for People with Learning Disabilities, a Policy Impact Study of Social Care and Health Services*. Department of Health, London.
9. Dept. of Health (1999a) *Once a day, one or more people with learning difficulties are likely to be in contact with your primary healthcare team. How can you help them?* Dept of Health Publications (Authors Dr Mary Lindsey and Dr Oliver Russell: Catalogue number 98C114/173B) Department of Health, London.
10. Diabetes UK/Dept. of Health (2005) *Structured Patient Education in Diabetes - Report from the Patient Education Working Group*. Department of Health Publications, London.
11. Disability Rights Commission (2004) *Closing the Gap: Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities or mental health problems*. Paper prepared by Andrew Nocon- DRC Senior Research Officer Publication date: 10th December 2004 Disability Rights Commission. London.
12. Elliott, J., Hatton, C. and Emerson, E. (2003) The health of people with learning disabilities in the UK: evidence and implications for the NHS. *Journal of Integrated Care*, 11, 3: 9-17.
13. Emerson, E. & Hatton, C. (2008) *People with Learning Disabilities in England*. CeDR Research Report:1 May 2008. Mencap/Learning Disability Coalition. Centre for Disability Research (Lancaster).

14. Fiedler, B. & Twitchin, D. (1992) *Achieving User Participation. Living Options in Practice*, Project Paper No.3, Kings Fund, London
15. Hansard (2008) Written question by Mike Hancock (Portsmouth South, Liberal Democrat) "What plans he has to reduce the health inequalities experienced by people with a learning disability; and if he will make a statement." Reply by Ivan Lewis (Parliamentary Under-Secretary (Care Services), Department of Health; 12 May 2008 . House of Commons Official Report website <http://www.hansardwestminster.co.uk/> House of Commons London SW1A 2TT
16. Hatton, C., Elliott, J. and Emerson, E. (2004) *Key Highlights of research evidence on the health of people with learning disabilities*. Institute for Health Research, Lancaster University.
17. Healthcare Commission (2005) *Draft three-year strategic plan for assessing and encouraging improvement in the health and healthcare of adults with learning disabilities*. Consultation November 2005. Healthcare Commission, London.
18. Hogg, J. (2001) Essential healthcare for people with intellectual disabilities: barriers and opportunities. *Journal of the Royal Society of Medicine*, 94, 333-336.
19. Horwitz, S.M., Kerker, B.D., Owens, P.L., and Zigler, E. (2000). *The health status and needs of individuals with mental retardation*. New Haven, CT: Yale University.
20. Howells, G. (1986) Are the medical needs of mentally handicapped adults being met? *Journal of the Royal College of General Practitioners*, 36, 444-456.
21. Jeste, D.V., Gladsjo, J.A., Lindamer, L.A. and Lacro, J.P. (1996) Medical comorbidity in schizophrenia. *Schizophrenia Bulletin*, 22, 3: 413-430.
22. Kerr, M. (2004) Improving the general health of people with learning disabilities. *Advances in Psychiatric Treatment*. 10, 200–206.
23. Keywood, K., Fovargue, S. and Flynn, M. (1999) *Best practice?: health care decision making by, with and for adults with learning disability*. Joseph Rowntree Foundation Ref JRF 1999 029; Liverpool: National Development Team and University of Liverpool.
24. Koch, T., Jenkin, P. and Kralik, D. (2004): Chronic illness self-management: locating the "self". *Journal of Advanced Nursing* 48, 484-492.
25. Langan, J., Russell, O. and Whitfield, M. (1993) *Community Care and the General Practitioner: Primary Health Care for People with Learning Disabilities*. Norah Fry Research Centre, Bristol.
26. Lennox, N., Bain, C., Rey-Conde, T., Purdie, D., Bush, R. and Pandeya, N. (2007) Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial International. *Journal of Epidemiology*, 36 1, 139-146.

27. Lennox, N.G., Green, M., Diggins, J. and Ugoni, A. (2001) Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. *Journal of Intellectual Disability Research*, 45, 3, 226-232.
28. Lindsey, M. (1998) *Signposts for Success in Commissioning and Providing Health Services for People with Learning Disabilities*. Health Services Executive, London.
29. MENCAP (1997) *Left in the Dark*. Mencap Publications, London
30. Lorig, K. (2002) Partnerships between expert patients and physicians. *Lancet*, 359, 9309, 814-5.
31. Lorig, K..R., Sobel, D.S., Ritter, P.L., Laurent, D. and Hobbs, M. (2001) Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice* 4, 6, 256-262.
32. NHS Ayrshire and Arran (2004) *The Health Champions Project*. Development Supported Limited, Ayrshire and Arran Health Board.
33. NHS Health Scotland (2004) *People with learning disabilities in Scotland: health needs assessment report*. NHS Health Scotland, Glasgow.
34. NHS Quality Improvement Scotland (NHS QIS) (2004). *Learning Disability Quality Indicators*. NHS QIS, Edinburgh
35. NHS QIS (2004a) Learning Disability Quality Indicators. *Service user version with symbols (Questions Booklet)*. NHS QIS/ GPCT Speech and Language Services for People with Learning Disabilities. Edinburgh.
36. NHS QIS (2006) *National Overview of Learning Disability Services*. NHS Quality Improvement Scotland, Edinburgh.
37. NHS QIS (2006a) 2004–2005 *Learning Disabilities Review Programme: Involving people with learning disabilities, carers and supporters. Evaluation Report*. Produced by Mike Martin Associates for NHS Quality Improvement Scotland.
38. Northway, R., Hutchison, C., Kingdon, A. (Editors) (2006) *Shaping the Future: A Vision for Learning Disability Nursing*. UK Learning Disability Consultant Nurse Network.
39. Ouellette-Kuntz, H. (2005). Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disability*, 18, 2, 113-121 (9).
40. Ouellette-Kuntz, H., Garcin, N., Lewis, S., Minnes, P., Freeman, C. and Holden, J. (2005). Addressing Health Disparities through Promoting Equity for Individuals with Intellectual Disabilities. *Canadian Journal of Public Health*, 96(2), S8-S22. (CIHR commissioned paper).



41. Parliamentary and Health Service Ombudsman (2009) *Six lives: the provision of public services to people with learning disabilities*. Parliamentary and Health Service Ombudsman/ Local Government Ombudsman. London.
42. SCLD (2008) *Scottish Consortium for Learning Disabilities Health Working Group Reports*. SCLD, Glasgow.
43. Scottish Executive (2000) Working Group - Review of Services for People with a Learning Disability. *The Same as You? A Review of Services for People with Learning Disabilities*. Scottish Executive, Edinburgh.
44. Scottish Executive (2002) *Promoting Health, Supporting Inclusion*. Scottish Executive, Edinburgh.
45. Scottish Executive (2003) *Home at Last? A Report on Progress with the Closure of Learning Disability Hospitals in Scotland*. Scottish Executive, Edinburgh.
46. Scottish Executive (2006) *Changing Lives- Report of the 21<sup>st</sup> Century Social Work Review*. Scottish Executive, Edinburgh.
47. Scottish Executive Central Research Unit (1999) *If You Don't Ask, You Don't Get. Review of Services for people with learning disabilities: the views of people who use services and their carers*. Scottish Executive, Edinburgh.
48. Scottish Executive Health Department (2005) *From National Framework for Service Change in the NHS in Scotland, Self care, carers, volunteering and the voluntary sector: towards a more a collaborative approach*. SEHD, Edinburgh
49. Scottish Government (2003) *The Mental Health (Care and Treatment) (Scotland) Act 2003*. The Scottish Government, Edinburgh.
50. Scottish Government (2008) *Equally Well: Report of the Ministerial Task Force on Health Inequalities - Volume 2* (2008) The Scottish Government, Edinburgh.
51. Simons K., Booth T. & Booth W. (1989) *Speaking out: user studies and people with learning difficulties*. *Research, Policy and Planning* 7,1, 9-17.
52. Simpson, N., Douds, F.. and Perera, C. (2008) *Survey of Learning Disability Inpatients Services in Scotland*. Conference presentation to Royal College of Psychiatrists (Scottish Division), Learning Disability Section Meeting, 28<sup>th</sup> March 2008

53. The Scottish Government (2008a) *High Level Summary of Statistics Health and Community Care*. Scottish Government, Edinburgh.
54. Wilson, D.N. and Haire, A. (1990) Health care screening for people with mental handicap living in the community. *British Medical Journal*, 301, 1379–1381.



