

Shaping our Future

Research priorities in Learning Disability

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1. Introduction

The relationship between policy, practice and research is central to an understanding of how our 'past' can influence our 'future'. While policy looks forward to what *should* happen, practice is often rooted in present realities, and research nearly always offers a window on the past, albeit often the recent past. This paper considers an example of engaging with service users and policy stakeholders, in order to help them relate their own present concerns to the need for future research. Funded by the NIHR (SDO) programme, '*Shaping our Future*' was a consultation and review aimed at determining research priorities in Learning Disability over the next ten years in England (Williams et al., 2008). There were four objectives to this work:

- To identify and describe the nature of research in learning disabilities conducted since 2001 in terms of its content and the range of its conceptual and methodological approaches;
- To establish a process by which the research community, practitioners, policy makers, people with learning disabilities and carers can reflect on the current and future research agenda;
- To reach a consensus on the gaps that exist in our knowledge base, which could be rectified through research;
- To determine what kinds of research are most needed by all parties, in order to make research knowledge useful to a range of stakeholders.

The design of the project involved a) listening to primary stakeholders, in four regional workshops, to find out what the main areas of current concern were for them; b) using those findings as the basis of systematic literature searches of Learning Disability research literature between 2001-7; c) discussing the gaps in that research base within a second round of regional workshops. An outcome of this process was thus

that end users of research were directly exposed to the vast range of research evidence that already exists in the field of Learning Disability. This paper will particularly focus on the questions arising from that encounter:

- a) Whose voice counts in setting research priorities?
- b) How can we bridge the gap between research and practice?
- c) What types of research method may lead to policy changes in the future?

2. Methodology

First round of consultation workshops

The goal of the first round of workshops was to reach some consensus on the key areas of concern in the lives of people with learning disabilities, both from their own point of view, and drawing on the perspectives of those around them. People with learning disabilities, family members and professionals were invited to the workshops, by direct mailshots, advertisements on a Learning Disability email forum, and using existing contacts and networking.

Ensuring that all views are listened to in a consultation exercise involves taking account of power relationships (Fairclough, 1995). In common with other social research in this tradition (Oliver, 1992; Barnes and Mercer, 1997) this research methodology would not claim to be 'value neutral'. The aim was to ensure that weight was given to the voices of people with learning disabilities themselves, and so, as in Cole et al. (2006), they were invited to a pre-session in the morning, so that they could discuss their own ideas and agree on how to present back their own priorities in the afternoon. The morning sessions used small group discussions, picture stimuli, and story-telling exercises, in order to allow people to freely explore issues from their own lives. Essentially, this is somewhat like a focus group approach (Fraser and Fraser, 2001). Focus groups offer a good vehicle for the development of ideas, and that is what we hoped for from the present workshops.

The table below gives a breakdown of the composition of the first round of workshops. All participants were invited to represent the views of the organisations, groups or services from which they came, and the people with learning disabilities in particular came with information and ideas from their own groups. In one case participants were in fact representatives of a network of 'Learning Disability partnership boards' and in another case, representatives brought written notes of the issues of importance to their group. Despite common perceptions, therefore, that consultation might be a shallow exercise with this group of participants (e.g. Redley and Weinberg, 2007), the process

of representation was possibly more thorough in the case of people with learning disabilities than with some of the professionals who attended.

Table 1 Participants at first round of workshops

	People with learning disabilities	Family members	Professionals, service providers, managers
South West	12	5	15
Midlands	13	1	19
North East	13	2	17
London and South East	8	4	18
Totals	46	12	69

Literature review

An initial analysis of all data from the four workshops in this first round yielded a long list of matters that had been mentioned. The 29 topics are listed in Appendix A. In order to group these into manageable themes to guide the search terms for the literature review, it was necessary to rationalise and prioritise this long list. This was done by focusing on the main areas that were a) mentioned most frequently at first round workshops, and b) chosen by stakeholders and written up on flipcharts as key points. It was also achieved by summarising many of the 29 issues on the long list and by creating three cross-cutting themes: issues relating to people with high support needs (profound and multiple learning disabilities), to people from minority ethnic groups and to older people with learning disabilities. This exercise resulted in six main themes, which then formed the basis for the literature searches and the subsequent organisation of the report, and details are given in Table 2.

Table 2 Research literature in Learning Disability retrieved and reviewed

	Number of 'hits'	Number of papers reviewed (UK research 2001-7)
Access to health care	1,629	78
Getting good support	2,473	104
The right to relationships	2,735	54
Housing options	543	44
Work and personal finance	942	42
Inclusion in the community	1,388	38
Totals	9,710	360

The reasons for carrying out the review were to list the research carried out in the areas identified by stakeholders, to summarise the findings, and to thereby identify any major research gaps. Since the review was about English policy-related research, and about current gaps, it was decided to limit the review to research carried out in the UK since 'Valuing People' (DH, 2001), the English Learning Disability policy.

The inclusion criteria were that material should be:

- related to people with learning disabilities
- U.K. based
- written in English
- published in 2001 or afterwards
- about a research study, or a research review, relevant to the social life of people with learning disabilities.

Where appropriate, key literature prior to 2001 in particular areas was also included, at the specific request of NIHR SDO. For a list of databases searched for this literature review, the reader is referred to Appendix B, and for a full list of search terms, Appendix C. The total number of papers retrieved, reviewed and appraised was 360, as detailed in Table 2 above.

Determining research gaps and priorities for the future

Following the literature review, a second round of consultation workshops was held in all four regional areas, to which the same participants were invited. The aim of this second round was to take back findings from the literature review, and to discuss and agree on priorities for future research. The structure of the workshops was similar to the first round, with people with learning disabilities attending a pre-meeting. The table below presents a summary of the composition of the second round of workshops

Table 3: Participants in second round of workshops

	People with learning disabilities	Family members	Professionals, service providers, managers
South West	12	10	16
Midlands	5	1	11
North East	10	2	14
London and South East	5	1	11
Totals	32	14	52

The second-round workshops were challenging, mainly because the consideration of research gaps and priorities is inherently abstract and complex. We felt it was essential to present full summaries of the research reviews we had undertaken, in order to set the scene for identification of gaps and priorities in research. We also felt that we needed to leave space for other matters about research process to be discussed, since these had already been aired during first-round workshops to some extent.

As would be presumed in this type of setting, accessibility was a major issue. People with learning disabilities themselves are generally excluded from research knowledge, since the vast majority of the literature is not accessible to them, despite attempts made by some researchers to provide easy-read accounts of key points from research (Rodgers, 2004; Townsley et al., 2003). Therefore, it was essential to formulate the workshop activities around their needs, and to relate research issues to their own lives and stories. In the 'full' workshop sessions (with family members, professionals and people with learning disabilities), maps of the research summaries were presented, with a focus on the gaps in evidence. In small groups, participants then had a chance

to discuss those gaps and to express views about priorities for the future. These discussions were recorded and analysed thematically for the final report, and it is that analysis on which the current paper draws. Rather than simply present the outcomes of the consultation and scoping review, we will instead concentrate on the issues that arose from this exercise, relating to ownership, process and practice of research. All of these matters have key relevance to the question of how the past can inform the future, not only in the world of Learning Disability policy, but beyond that in other spheres of policy and practice.

3. Findings

3.1 Whose voice counts in setting research priorities?

Social research that is *about* disabled people, or about any socially excluded groups, purports to represent or communicate some evidence or message about their position or their views, and reflect that back to policy makers. However, without the direct input of disabled people themselves, that research endeavour can run counter to the priorities that arise from lived experience. Research has not always served the best interests of disabled people themselves. The movement for emancipatory research, based on a social model of disability, arose from the alienation of disabled people from the research agenda of the 1980s, and is represented in the papers in the 1992 edition of *Disability, Handicap and Society* (Oliver, 1992; Zarb, 1992). Oliver (1992) suggested that disability research shouldn't merely be 'technical objective procedures'. Rather, he suggested, it should be '*part of the struggle by disabled people to challenge the oppression they currently experience in their lives*' (p. 102). One of the key points about disabled people's emancipatory model of research was that they should have a right to *control* both the focus and topic of the research, as well as the process (Barnes et al., 1997). This does not necessarily imply being active in the conduct of research, but has more to do with setting the agenda.

Translating these ideas to Learning Disability research has always been problematic (Chappell, 2000; Walmsley, 2001) since people with learning disabilities may not have the necessary intellectual skills to understand research, to advocate for their own and others' needs, or to analyse their own position. Nevertheless, an 'inclusive' research movement has developed, in which people with learning disabilities work alongside other researchers and/or supporters, to take an active role in the generation of knowledge about themselves (Walmsley and Johnson, 2003; Williams, 1999; Williams et al., 2005).

In the current project, people with learning disabilities took on a central role in more

than one way. A small group of advisors, who represented their own organisations, had a role in helping to plan and deliver the workshops. However, at a wider level, the whole project was geared towards foregrounding the perspectives of people with learning disabilities and their allies, through asking them how research could best help them overcome some of the difficulties they faced in their lives. Some may think this an impossible and abstract task. On the contrary, we found that the issues raised by people with learning disabilities drove the discussions in our workshops, simply because they were to do with their own lived experience. The concerns they had were to do with the gaps between a) what they wanted to achieve in life; b) the reality of a restricted and often devalued lifestyle.

One theme in the discussions, for instance, was the wish to go out and join in ordinary community activities. However, workshop participants often spoke of feeling frightened, and were very aware of the risks in the 'wider world'. The overwhelming theme was one of frustration, where people talked about being prevented from doing the things they would like to do, and would like to achieve. People simply wanted to go out – to do ordinary things, such as shopping, cinema, or work. However, there were many barriers which they faced in doing these seemingly simple things, which included physical, as well as attitudinal, barriers:

'Some people with learning difficulties get embarrassed when they are out, particularly if people are staring at them.' [person with learning disabilities in Workshop 1]

Above all, however, people spoke of worries about bullying and hate crime. It was the attitudes of other people (outside the family, and outside the service world) which were of greatest concern.

By contrast with the people with learning disabilities, the family members' concerns were more systemic. There were many issues that they had discussed and analysed many times previously, in what appeared to be a lifetime struggle against the system. They said that interactions with local authorities, care managers, social workers and other professionals were often fraught with problems; the issues they raised were concerned with who controls money and if resources were being used appropriately:

'Who has the money and power and when does this change?' [parent]

Many of the family members who came to workshops felt that they knew perfectly well

what needed to change; they were more concerned about *how* to make changes happen.

The third group of stakeholders at workshops were a mixed group of practitioners and other professionals. They were possibly more aware of the wider picture than the people with learning disabilities or their family members, and much of the discussion turned on strategies for ensuring that the needs of all groups of people with learning disabilities are met. They also frequently mentioned the wider demographic picture, for example raising the issue that more people with high support needs who are living longer. They said that the social and physical barriers faced by people with learning disabilities were also very varied. Practitioners felt that it was important to measure outcomes, and to ensure that the services delivered to people with higher support needs, in particular, are effective. For instance, it was generally agreed that within the modernisation agenda (and indeed within *Valuing People Now*: DH, 2009) there is an emphasis on work but that this is not suitable for everybody and that the needs of all people with learning disabilities must be considered.

'This isn't to say that people with higher support needs can never work – people are generally capable of far more than they are allowed to do.'
[Professional at workshop 1].

People with higher support needs might need some dedicated daytime provision, and this topic provoked a good deal of discussion.

The three different standpoints on a future research agenda, as will be seen from this brief sketch, are not incompatible. People with learning disabilities themselves may be talking about 'what we want', rather than 'what we need to know'. However, an agenda cannot be formulated in isolation from those basic issues about people's life goals. The type of questions that concern people with learning disabilities arise directly from their own experience, and it is those questions which should prompt both research and practice.

In the second round of workshops, we asked people with learning disabilities to tell stories about their personal experiences broadly in the topic areas they had defined previously. It was interesting how strong and suggestive these stories were, in terms of leading people's thinking about important research questions.

Adrian was a young man who lived in a supported living house. He had staff caring for him whom he had not chosen, and he lived with others who were not his friends. Although his mother lived nearby, she was not his main 'carer'. Adrian told us a story about his attempts to travel by train. He had previously travelled with others, and wanted to go by himself, to the nearby city in order to visit the shops. The barriers he faced were many and various, and his story hinged on:

- *negative and risk-averse attitudes from his care staff*
- *a lack of friends who would want to travel with Adrian*
- *The need for more flexible solutions, where he could phone people up on his mobile phone if he was lost.*
- *His mother's key role in helping him to achieve what he wanted.*

Following Adrian's story, there was a discussion about the need for research that would help us know better how to balance 'risks' and 'safety'; the need for action projects about personalised living arrangements, so that people would not have to live with others whom they had not chosen; above all, the need to understand and appreciate the continuing role of carers and parents in people's lives, and research that would reflect the important role they play well into the adulthood of their son or daughter with learning disabilities.

In this project, therefore, we found that the most productive way of consulting people about future research needs was to consider not individual nor collective 'voice', but to engage in a dialogue between different interest groups. While service users have a central role in determining what their own priorities are, the translation of that agenda into both policy and research can be done best by listening to many voices, in conversation with each other. The potential problem of following this route, however, is that the voices of people with learning disabilities can be disadvantaged by those who are more powerful or articulate. Therefore, the method of foregrounding their own views, by pre-sessions and summary presentations, was one which we would recommend.

Following the regional workshops, we conducted a focus group of researchers at the Foundation for People with Learning Disabilities, with nine academic and policy-related research representatives from eight centres in the UK concerned with Learning Disability research. A range of methodological interests were represented in this group, as well as a range of theoretical and topic priorities. While there was some discussion about who is best placed to determine what research should be carried out,

and some worries also about the wisdom of relying on people with learning disabilities in this regard, it was notable that there was a high level of agreement with the research agenda we presented. What researchers tended to add to the debate was a wider knowledge and insight into the ways in which research could link with specific policies or legal requirements. For instance, in the wake of the implementation of the Mental Capacity Act in 2007, medical practitioners are now required to explain health choices to all their patients, and to ensure that people with learning disabilities have accessible information, so that they are supported to make decisions about treatments. Monitoring the implementation of the Act will be a major research priority, as one researcher put it:

'There is going to be a sea-change in the way information is provided, as that is required under the Act.' [participant at researchers' focus group]

Researchers also had a more in-depth view of what specific gains could be had from particular types of research, for instance research related to particular syndromes, and advocated for more research that would provide clear evidence to affect policy. More than any of the participants in the workshops, they were very aware of the limitations of research evidence in actually affecting practice.

3.2 How can we bridge the gap between research and practice?

Valuing People Now (DH, 2009) rightly flags up as one of the 'top priorities' the issue of 'making sure that changes happen'. Producing a policy in itself is insufficient to ensure that changes are made in practice. Throughout the 'Shaping our Future' project, there was consideration of the different ways in which research relates to both policy and practice:

One of the remarkable findings in our review was the sheer volume of research, which had seemingly little impact on practice. For instance, an initial question in the first round of workshops related to how we should support people with challenging behaviour, and also people with high support needs or profound and multiple learning disabilities (PMLD). However, the literature search revealed that about a quarter of the 104 research papers reviewed about 'support' (care or workforce issues) were on the topic of challenging behaviour, focusing on staff stress and burnout (Hastings and Horne, 2004; Robertson, Hatton et al., 2005) and the factors that might relieve that stress and promote a more positive work climate (Rose et al., 2006). Methods of 'active support' (Mansell, Beadle-Brown et al., 2003) have been thoroughly

researched and there is evidence to show that they are effective, particularly with people who have more complex needs. Nevertheless, these findings were not widely known about amongst the stakeholders in our workshops. Similarly, there were major concerns about health, and an assumption that there would be large research gaps in this area. Family members were particularly worried that the people they cared for had poor levels of care when admitted to hospital, and said that we needed more research about the systems for hospital admission. However, our literature review revealed a wide range of research in this area, detailing many of the barriers and starting to suggest solutions (Lennox, Nadkarni, Moffat and Robertson, 2003; Cumella and Martin, 2004; Hannon, 2004).

Within our study, we attempted to examine not only the quality of research, but also its impact. The relationship between research, policy and practice is not always straightforward, but that complex web of interrelations can be an advantage in making changes happen.

1) Research can be triggered by policy or by law (for example the current research interest in the Mental Capacity Act), and can also inform future policy development by providing evidence of what is happening in the practical implementation of policy. An example of this is the research by MENCAP (2007) *Death by Indifference* which underpins the focus on tackling health inequalities in *Valuing People Now* (DH, 2009).

2) Research can also help to make or evaluate practical changes, and can impact directly onto service provision or the lives of people with learning disabilities. These changes, in turn, can be reflected up to policy-makers. Grassroots experiences, changes and actions can make a difference to policy. An example of this would be the research by Cole and Williams (2006) which highlighted good examples of community-based provision for adults with learning disabilities. These examples are being used in some areas to make changes to local authority policies about day services. Research has an important role in helping to synthesize and disseminate the messages from development work, such as that which is currently being undertaken by the British Institute for Learning Disability (BILD) about workforce development.

3) Research can directly consider the gap between policy and practice, and help us to understand how changes will happen.

This third way of relating to policy/practice is the one which is perhaps most lacking in the current research about Learning Disability. There are some indicative examples. For instance, the body of research about workforce issues is concerned to examine

how we move from the policy rhetoric about 'choice and control' into actually making a difference to support workers' practices. Forbat (2006) pointed out that the policy goals of 'Valuing People' were seldom part of the discourse used by local senior managers. However, it is very important that research can help us all understand how to make the shifts which we know need to happen.

3.3 What type of research methods will lead to policy change in the future?

One of the major outcomes of the current project was that it is not sufficient to consider the research agenda as simply a series of gaps in knowledge. The *process* of research is as important as the *topic*. When asked to prioritise the ideas for research gaps that had been discussed at the workshops, most participants hesitated and gave much consideration to what would really be the first step, and where the funding should go. In the end, they nearly all decided on practical ideas, which were aimed at finding out how to make change happen. One workshop prioritised questions about new models of housing, in order to spread the word about new housing options. Another workshop group prioritised health research that would take examples of good interventions in GP practices, and analyse what made them work well, so that others could learn from them. In all these cases, workshop participants focused on:

- practical action
- learning the lessons from one example, and spreading to others
- research that is about 'how' questions.

It was also noted that we need to move outside the field of Learning Disability research, to learn the lessons from other fields – for instance, from research about management, which could help us understand the ingredients for successful change and implementation of policy.

So how effective can inclusive research be in bringing about changes in policy or practice? As Bloor (1997:222) pointed out, policy is seldom based directly on research evidence, but there are recent examples in disability policy where accumulated research evidence has had a direct effect, often in combination with the demands of service users themselves. An example from the 1990s was the accumulation of research evidence led by disabled people (for instance Zarb and Nadash, 1994) which culminated in 1996 with the Community Care (Direct Payments) Act. A current example of influence on policy is the research carried out for Carers UK (Buckner and

Yeandle, 2007) calculating the savings to the public purse represented by carers' work, at £87 billion. This research coincided with new Government announcements of support for carers.

Research findings are often most influential when there is joint working between research organisations and development and campaigning groups. A review carried out for the Social Care Institute for Excellence (Carr, 2003) about user-involvement in change found that actions were more likely to have an effect when policy trends, research and direct action came together. This happened, for instance, during research about the support needed by direct payments users with learning disabilities, carried out by Swindon People First (Gramlich et al., 2002), which was followed by the production of accessible information about direct payments, as well as information campaigns including training and drama presentations. A current example would be the Learning Disability Coalition (of leading development organisations), whose goal is to campaign for better funded provision in Learning Disability. This coalition urgently wants hard evidence from research findings, to back up their demands for better provision. One of their published aims is to:

'Achieve an evidence-based assessment of the long-term resource requirements for people with learning disabilities', (Learning Disability Coalition, 2007).

Within our second round of workshops, we conducted small group discussions based on particular research questions, to ask participants how they would approach those questions. These discussions on the whole focused on practical solutions, and research as a vehicle for presenting, analysing and promoting solutions to problems that work. For instance, in considering how people with learning disabilities in residential homes can have better access to community life, one group suggested targeting a few residential homes and actually introducing particular residents to community activities. This type of endeavour was considered very much as an 'action research' cycle (Stringer, 1999) in which practical action would be undertaken, evaluated and reviewed.

Practitioners, as well as policy-makers, are urged to be 'evidence based' and to base their decisions and actions on the outcomes of robust and validated research studies. However, as the researcher group itself acknowledged, decisions about local and national strategy, as well as practitioner actions, are very seldom based on rational research evidence. Political, economic and cultural issues will have a far greater influence on decisions made at any particular point. However above all, our workshops highlighted the value of direct involvement in research – by service users and by

those who are closest to them. Participants said that research that is owned by disabled people, their families, and frontline practitioners, will be more likely to make a difference, since it generates knowledge that both 'empowers' people to understand their own position, and to have a stronger voice in telling policy makers what is needed.

4. Discussion

This paper has outlined some of the practical and process issues that were highlighted by Williams et al. (2008) in a consultation and review about research priorities. The actual research agenda that emerged from this project was very much in line with other contemporary policy-related work in Learning Disability, in particular the consultation that was held for *Valuing People Now* (DH, 2009) and which was reported on at the same time as the research consultation. There should be no surprise in this similarity, since both consultations started from the goals and aspirations of people with learning disabilities themselves, to have a valued life. Both research and policy have to tackle the gaps and hurdles that still exist, when people with learning disabilities set out to achieve ordinary life goals that most people would take for granted. These goals are represented in the six main topics that guided our literature review and our final report, and two examples will suffice here to illustrate these gaps.

Access to health care

People with learning disabilities and their family members have a right to be healthy, and to access the same health services as everyone else in the community. Despite the large volume of research into health issues of people with learning disabilities, however, there are still major gaps. Access to generic, ordinary health services was a topic of great concern during this consultation. It was felt that there was considerable variation across the country:

'People with learning disabilities are often discriminated against and people may also be discriminated against because of their age or where they live; services do vary according to where you live.' [People with learning disabilities]

There were therefore some generic, as well as specific, questions that were felt to be priorities for future research, including:

- What is the variation in the experience of people with learning disabilities of health services in different geographical areas?

- What are the mortality rates of people with learning disabilities, compared with the non-disabled population?
- What are the mechanisms which explain unequal health outcomes?
- Are there NHS services which are being denied to people with learning disabilities (e.g. certain treatments, operations etc.)?

Housing options

People with learning disabilities at our workshops said that they very seldom had the chance to choose the individuals they lived with. This is something that most people in the community would take for granted, yet we still do not appear to know how to deliver this basic right to people with learning disabilities. Therefore, despite the large volume of research about housing models, there was still felt to be a need to answer questions such as the following:

- How much home ownership is there by people with learning disabilities (compared with non learning disabled people)?
- How many people with learning disabilities move area? What are the patterns and the obstacles?
- What experiences do people with learning disabilities have of living in certain neighbourhoods (comparing rough areas with better areas, for instance)?
- What have local authority housing departments done, to include the needs of people with learning disabilities?

These issues will continue to be discussed and developed, and so there will continue to be a need for research to underpin new developments in thinking and in services. Above all, research evidence is vital if people with learning disabilities are to obtain proper supports, so that they can enjoy the human rights that they were discussing in this study. For all these reasons, the setting of a research agenda can never be a closed book, and this project has demonstrated how it can best be based on a continued dialogue with all the major stakeholders centrally involved.

If research is going to include people with learning disabilities in a more systematic way, as our consultation suggested, and to work with families and practitioners as equal partners in research, then the infrastructure to support these developments needs to be in place. We will therefore conclude this paper with the final

recommendations from our project.

- The main research priority areas flagged up in this study should be used to inform the funding decisions of major research funders in a more co-ordinated way than at present.
- Further reviews should be funded, to cover specific areas of research which this study was unable to cover (such as medical research about specific syndromes; neurological research; mental health needs).
- Action research in partnership with a range of stakeholders (people with learning disabilities, family members and practitioners) should be funded. These studies should be well-designed and robust, in order to help us understand how changes can happen, and how we can bridge the gap between policy and practice.
- There should be funding for targeted research which gives us evidence to argue for particular resources and commitments from government.
- Local research and demonstration projects should be funded, which can both develop key areas of good practice and also serve as flagships and learning points for other areas, and for national policy.
- Funders need to commission research which moves outside the 'Learning Disability box', and views the issues for people with learning disabilities in the context of the lives of other, non-disabled people.

References

Barnes, C. and Mercer, G. (1997). *Breaking the mould? An introduction to doing disability research*. In: C Barnes, G. M. (ed). Leeds, The Disability Press.

Bloor, M. (1997). Addressing social problems through qualitative research. In: Silverman, D. (ed) *Qualitative Research: theory, method and practice*: 221-239.

Buckner, L. and S. Yeandle (2007). *Valuing Carers - calculating the value of unpaid care*. London, Carers UK.

Chappell, A. (2000) Emergence of participatory methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities* **28**: 38-43.

Cole, A. and V. Williams (2006). *Having a good day? Report of a survey of community based day opportunities for adults with learning disabilities*, SCIE.

Cumella, S. and D. Martin (2004). "Secondary healthcare and learning disability: results of consensus development conferences." *Journal of Learning Disabilities*, 8(1), March 2004, pp.30-40.

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

Department of Health (2009). *Valuing People Now: From Progress to transformation*. London, Department of Health.

Fairclough, N. (1995). *Critical Discourse Analysis: the critical study of language*. London and New York, Longman.

Forbat, L. (2006). "An analysis of key principles in *Valuing people*: implications for supporting people with learning disabilities." *Journal of Intellectual Disabilities* 10(3): 249-260.

Fraser, M. and A. Fraser "Are people with learning disabilities able to contribute to focus groups on health promotion?" *Journal of Advanced Nursing* 2001 Jan; 33(2): 225-33 (42 ref).

Gramlich, S., G. McBride, *et al* (2002). *Journey to Independence: What self-advocates tell us about direct payments*. Kidderminster, BILD.

Hannon, L. (2004). "Better preadmission assessment improves learning disability care." *Nursing Times* 2004 Jun 22-28; 100(25): 44-7

Hastings, R. and S. Horne (2004). "Positive perceptions held by support staff in community mental retardation services." *American Journal on Mental Retardation* 109(1): 53-62.

Learning Disability Coalition (2007) *Our Aims*
<http://www.learningdisabilitycoalition.org.uk/ouraims.asp>

Lennox, T. N., J. Nadkarni, *et al* (2003). "Access to services and meeting the needs of people with learning disabilities." *Journal of Learning Disabilities (London)* 2003 Mar; 7(1): 34-50.

Mansell, J., Beadle-Brown, J., Macdonald, S. and Ashman, B. (2003). "Resident involvement in activity in small community homes for people with learning disabilities." *Journal of Applied Research in Intellectual Disabilities* 16(1): 63-74.

Mencap (2007). *Death by Indifference*. London, Mencap.

Oliver, M. (1992). Changing the Social Relations of Research Production? *Disability & Society* 7: 101-114.

Redley, M., & Weinberg, D.(2007) Learning disability and the limits of liberal citizenship: interactional impediments to political empowerment. *Sociology of Health and Illness*, 29 (5) 1-20.

Robertson, J., C. Hatton, *et al* (2005). "Staff stress and morale in community-based settings for people with intellectual disabilities and challenging behaviour: A brief report." *Journal of Applied Research in Intellectual Disabilities* 18(3): 271-277.

Rodgers, J. et al. (2004) *Information for All*. <http://www.easyinfo.org.uk>

Rose, J., A. K. Ahuja, *et al* (2006). "Attitudes of direct care staff towards external professionals, team climate and psychological wellbeing: a pilot study." *Journal of Intellectual Disabilities*, 10(2), June 2006, pp.105-120.

Carr (2003) *Has service user participation made a difference to social care services*. (London: SCIE <http://www.scie.org.uk/publications/positionpapers/pp03.asp>)

Stringer (1999) *Action Research*. London: Sage

Townsley, R., Rodgers, J. & Folkes, L. (2003) 'Getting informed: Researching the production of accessible information for people with learning disabilities', *Journal of Integrated Care*, 11(3), pp 39-43.

Walmsley, J. (2001). Normalisation, Emancipatory Research and Inclusive Research in Learning Disability. *Disability & Society* 16(2): 187 - 205.

Walmsley, J. and Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities*. London, Jessica Kingsley.

Williams, V. (1999) Researching Together. *British Journal of Learning Disabilities*, 27 (2): 48-51.

Williams, V., Simons, K. and Swindon People First Research Team (2005) More Researching Together. *British Journal of Learning Disabilities*, 32: 1-9

Williams, V., Marriott, A. and Townsley, R. (2008) *Shaping our Future: a scoping and consultation exercise to determine research priorities in Learning Disability for the next ten years*. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)

Zarb, G. (1992) On the road to Damascus: first steps towards changing the social relations of research production. *Disability, Handicap & Society* 7: 125-138.

Zarb, G. and Nadash, P. (1994). *Cashing in on Independence: Comparing the Costs and Benefits of Cash and Services*: London: BCODP

Appendix A Summary of issues raised in first round of consultation workshops

The issues raised by all stakeholders were important, but as can be seen above, the different groups emphasised different perspectives on the problems. People with learning disabilities themselves tended to talk about what they wanted in life, and about the barriers they experienced in living their lives. Family members could see issues about the iniquities of the 'system', and about their own vital role in providing support and advocacy. They also focused on solutions, such as person-centred planning, which could tailor support to the particular needs of each person with learning disabilities. Professionals, also, were solution focused. Naturally, they tended to look at the wider picture, and they were concerned about wider issues in society, about how to make change happen, and how to ensure we get the right balance between risks and safety.

An initial analysis of all data from the four workshops in this first round yielded a long list of matters that had been mentioned. This list of 29 topics is given below in alphabetical order:

1. Accessibility (including accessible information and access to community services)
2. Accessing the community (including leisure, transport, sport, holidays, and barriers – chiefly bullying and hate crime)
3. Black and minority ethnic issues (including racism and cultural differences)
4. Children (including bullying, friendship, support groups for children)
5. Citizenship and wider social issues (including politics, voting, bullying and hate crime, attitudes in society)
6. Communication (including the needs of those with complex communication difficulties; non-verbal communication; accessible information)
7. Daytime activities (including work, day services, community presence, social firms, drop-in centres, using direct payments for day activities)
8. Education (including special schooling; mainstream schools; college courses; qualifications; the work agenda; education for people with PMLD)
9. Employment (including paid jobs; the problems around benefits; discrimination in the job market; work experience; job seeking – including CVs and interviews)
10. Family issues (including bereavement; independence; cultural issues in families; family carers and direct payments; short-term breaks)
11. Friendships and relationships (including dating; making new friends; marriage; being a carer with learning disabilities)
12. Gender issues (including the position of women with learning disabilities in relation to any of the above issues)
13. General research issues (Community research; action research; implementation of research and good practice in research)
14. Health (including Health Action Plans; getting information and advice; diet and exercise; accessible information about health; communication of health

professionals; how to book an appointment and the difficulties in appointment systems; care for particular issues – e.g. dental care; pain management); access to treatment for cancer, dementia, dysphagia)

15. High support needs and multiple impairments (including prevalence; social exclusion; people with additional sensory impairments)

16. Housing (including choice, choosing who you live with; supported living, residential care, independent living, and ownership)

17. Mental health and emotional support (including medication; talking therapies; bereavement)

18. Money management (including benefits and savings; banks; capacity issues and financial abuse)

19. Older people with learning disabilities (including dementia)

20. Parents with learning disabilities (including how to get information about parenting; pregnancy; human rights of parents; getting good support as parents)

21. Person-centred planning (including best practice in PCP; impact of PCP; the involvement of family members and health action planning)

22. Police, courts and the criminal justice system (including offenders with learning disabilities; being a witness to a crime; hate crime; relationships with the police)

23. Policy and national guidance (Valuing People; Equality 2025; NSFs)

24. Self-advocacy (including self-advocacy, peer advocacy and the development of the confidence to speak up)

25. Services (including participation via partnership boards; evaluating service outcomes; access to services; multi-agency work)

26. Society and the media (including attitudes, social isolation; police attitudes to hate crime; the impact of legislation; representation in the media)

27. Support (including individual budgets; person-centred planning; qualifications of supporters; the needs of people from BME groups; regulation of supporters; employing your own support staff)

28. Transition (including the role of families and carers)

29. Workforce (including supporters' attitudes; training for support staff, relationships with support staff, conditions of work and pay; and abuse by support staff)

Appendix B

Databases

The following databases were searched for relevant research papers:

- IBSS (BIDS)
- ASSIA
- British Education Index
- SCIE
- CINAHL
- SSCI – Web of Science
- Sociological Abstracts
- Cochrane Library
- Dissertation Abstracts

Appendix C

Search Terms

All search terms from the individual themes were combined with:

- learning dif*
- learning dis*
- intellectual disabilities
- mental retardation
- mental handicap

If any stage of a search identified over 200 articles, then the search term was refined.

Search Terms for “Health”

Health action plan*

Health + information/advice

Diet

Exercise

Health + accessible information

Health professionals + communication

Health professionals + continuity

Health + appointment*

Healthcare access

Health + special*

Dent*

Health + inequalit*

Mental health

Health + medication

Cancer care

Palliative care

Dementia care

Postural care

Pain management

Dysphagia

Health + therap*

Health + management

Hospitals/acute care

Health + targets

Health + research

Search terms for “Support”

Staff/support workers + working conditions

Staff/support* and choice

Staff/support* + relationship

Staff/support* + flexibility

Staff/support + person-centred planning

Staff/support + independence

Staff/support + communication
Staff/support + qualifications
Staff + quality of support
Staff/support + direct payments
Staff/support + problems/difficulties
Staff/support + ethnic*
Staff/support + quality
Staff/support + eligibility
Staff/support + regulation
Individualised support
Support + safety/risk
Staff/support + employ*
Staff/support + options
Staff/support + in-control
Staff/support + individualised budgets
Workforce/staff/professionals/supporters
Workforce/staff/professionals/supporters + attitudes
Workforce/staff/professionals/supporters + training
Workforce/staff/professionals/supporters + job satisfaction
Workforce/staff/professionals/supporters + relationship*
Workforce/staff/professionals/supporters + communication
Workforce/staff/professionals/supporters + pay
Workforce/staff/professionals/supporters + recruitment
Workforce/staff/professionals/supporters + impact of
Workforce/staff/professionals/supporters + qualification
Workforce/staff/professionals/supporters + abuse

Search terms for “Friendships, relationships and parenting”

Friends*
Relations*
Dating
Marriage
Friends* + loss
Relations* + sex*
Parents with learning di*
Famili* + gate-keepers
Parents + information
Parents + pregnancy
Parents + support
Parents + attitude

Search terms for “Housing”

Housing
Supported living
Independent living
Residential care

Search terms for “Work and money”

Employ*/job* + pay

Employ*/job* + benefits
Employ*/job* + minimum wage
Employ*/job* + hours
Employ*/job* + discrimination
Employ*/job* + disability discrimination act
Employ*/job* + risk ass*
Employ*/job* + work experience
Employ*/job* + choice
Employ*/job* + CVs
Employ*/job* + interview*
Employ*/job* + training
Employ*/job* + gender
Employ*/job* + high support needs
Employ*/job* + exploitation
Supported employment
Employ*/job* + support
Money + support
Money + bank*
Money + capacity
Benefits + savings
Money management
Financial abuse

Search terms for “Inclusion in the community”

Leisure activities
Transport
Sport
Holidays
Community + access + barriers
Community + safety
Community + independence
Community + choice
Community + inclusion
Community + support
Accessibility
Access* + community
Access* + services
Accessible information
Hate crime