

Shaping our future: a scoping and consultation exercise to establish research priorities in learning disabilities for the next ten years

Shaping our future: a scoping and consultation exercise to establish research priorities in learning disabilities for the next ten years

*Report for the National Co-ordinating Centre for
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Executive summary

People with learning disabilities are one of the most socially excluded groups in today's society. Very few have access to mainstream services for health, housing, education and employment, and over 50% live in the parental home, well into adulthood. It is important that research helps us to understand how to move towards equality for people with learning disabilities.

This scoping review and consultation found out what was important for different groups of stakeholders through regional workshops in the UK; following a systematic literature review in the key areas identified, research gaps were identified and discussed in a second round of workshops.

- The six most important areas of concern for people with learning disabilities were access to healthcare; getting good support; the right to relationships; housing; work and personal finance; inclusion in the community.
- There is a large volume of academic research in these areas, but people want more research about action, which helps us to understand how to make changes.
- We need clear evidence about the lives of people with learning disabilities and their families, so that government ensures there are resources to meet their needs.
- Research is needed about self-directed services, which affect every part of people's lives.
- There is an increasing number of people with profound and multiple learning disabilities, who are an important focus for future research.

Access to health care

- Research is needed about health outcomes, inequalities and access to health services for people with learning disabilities.
- We need more research about how to improve communication and access to health care for people with learning disabilities, both in primary care and in hospitals.
- Research should follow the Mental Capacity Act (2005) in looking at the provision of accessible information and support for medical decisions.
- We need to undertake research which will enable us to plan for people with profound and multiple needs, who may be technology dependent.
- We need to analyse the health risks to people with learning disabilities who live with 'supported living' arrangements, and find out how to change patterns of obesity and lack of exercise, as well as obtain information on use of alcohol and smoking.

Getting good support

- The big challenge for research in this area is to move with the policy changes, and to find out how support staff can successfully move out of the traditional 'Learning Disability' culture, towards a more person-centred way of working.
- We need more research from the point of view of people with learning disabilities and their families. Research should focus more on the role of families in leading individual budgets.
- The skills needed to work with people with people with profound and multiple learning disabilities are under-researched at present.
- Research should also focus on organisational change, and find out how we can effect the changes towards a new type of workforce.
- There is a need for research that engages with and empowers support workers, along with the people with learning disabilities they work for.

The right to relationships

- Although research has already given us plenty of evidence about social isolation of people with learning disabilities, we need research that can help us find out how people make and maintain friendships.
- There is a particular need to carry out research about these issues for people living on their own, or who no longer have day centre support.
- We need more research about sexuality, and sex education for people with learning disabilities, particularly from their own point of view.
- There is a gap in our knowledge about families where the parents have a learning disability. We need to know more about giving good support to those families. Research should also document the views and experiences of children in those families, as well as attitudinal and structural changes in the legal and social care systems.
- We need to know more about the issues for people with learning disabilities who take on caring roles.

Housing options

- We need evidence about the numbers and experiences of people with learning disabilities who live in different situations (renting, supported living, shared ownership, ownership, as well as residential care homes).
- Research needs to highlight good practice in giving people real housing options, good information, and choice about who to live with.
- We particularly need more research about the support offered to people with learning disabilities who live in their own tenancies, and about places where young people can learn independence skills.

- Some research could be led by families, and particularly could look at the

outcomes for people who live near the parental home, or who move away.

- There are research priorities about housing for particular groups, including those in the criminal justice system; people with complex needs who are moved out-of-area; people with profound and multiple needs or other physical impairments.

Jobs and personal finance

- Research needs to focus on poverty amongst people with learning disabilities and their families.
- With the advent of the Mental Capacity Act, we need research to look at how people can manage their personal finances, get good advice from mainstream financial providers, and receive appropriate information about financial decision- making.
- There are still many gaps in our knowledge about how to move local authority resources from day services into supported employment, and how to support job seeking and career progression. Employers' needs should also be a focus for research.
- Research is needed about the ways in which Further Education can help students with learning disabilities move into real jobs.
- We need more research about alternative forms of employment, including social firms, and the options for people with high support needs to have fulfilling lives.

Inclusion in the community

- Research about hate crime and bullying is a priority. This should be action research, that not only seeks to understand attitudes, but also to find measures for action against hate crime and bullying
- It is a priority for research to move outside the 'Learning Disability' box, and to look at the attitudes and needs of service providers and others who are outside the Learning Disability service world.
- Research should highlight the strategies which help people with learning disabilities go out and do the things they want to do. This will involve looking at support staff skills, as well as people and places in the community.
- We need research which will help us understand how people with learning disabilities can be equal citizens, and make contributions to society.

Recommendations

- 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 coordinated way than at present.
- Further reviews should be funded, to cover specific areas of research

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which this study was unable to cover (e.g. 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 action or demonstration sites are needed, which could enable us to learn from local good practice.
- 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.

The Report

1 Introduction and background

'People with learning disabilities are amongst the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes or have real choice over who cares for them. Many have few friends outside their families and those paid to care for them. Their voices are rarely heard in public. This needs to change.' (Valuing People, DH, 2001: 14)

1.1 People with learning disabilities and the current study

In the early twenty-first Century, people with learning disabilities in the UK are one of the most socially excluded groups, as was recognised in 2001 by the English Learning Disability strategy, 'Valuing People' (Department of Health, 2001). In 2008, the situation for many people with learning disabilities has not dramatically improved, as is acknowledged in 'Valuing People Now' (Department of Health, 2007).

'We have seen some good progress in some areas but unfortunately for far too many people with learning disabilities, much has remained unchanged... We are still faced with the same challenges, particularly in ensuring that people with learning disabilities can access mainstream services for health, housing, education and employment – the things that ensure equality of citizenship.' (Secretary of State for Health, foreword to DH 2007: 6)

It is vital that research is provided which underpins good policy and practice developments, to make a real difference to the lives of people with learning disabilities. The current report is about those research priorities.

In 2007, the Norah Fry Research Centre was commissioned by the National Institute for Health Research (Service, Delivery and Organisation) (NIHR:SDO) to carry out the current study, aiming to identify and reach some consensus among all stakeholders on research priorities in Learning Disability over the next ten years. During the course of this project, stakeholders at every level were consulted about research priorities, and this report is structured around the six main priority areas, which were identified by a series of regional stakeholder workshops. There were six priority areas for change in the lives of people with learning disabilities.

1. Access to health care
2. Getting good support

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3. The right to relationships
4. Housing options
5. Work and personal finance
6. Inclusion in the community

In all these areas, systematic literature searches were carried out, in order to review and evaluate research relating to Learning Disability since 2001. The gaps in knowledge were then identified, and taken back to key stakeholders in a further round of workshops, at which they were discussed, further gaps identified, and prioritised. They were then discussed with a group of invited researchers who are active in Learning Disability research, and sent out to leading development organisations in a validation exercise. Further details of methodology are given in Section Two.

1.2 Policy shifts in Learning Disability

This report coincides with the renewal of 'Valuing People', the Learning Disability strategy in England, and is therefore a timely contribution to the focus on Learning Disability at policy level. The main priorities in 'Valuing People Now' (Department of Health, 2007), which is out for consultation at the time of writing this report, are:

- personalisation – so that people have real choice and control over their lives and services
- what people do during the day (and evenings and weekends) – helping people to be properly included in their communities, with a particular focus on paid work
- better health – ensuring that the NHS provides full and equal access to good quality health care
- access to housing – housing that people want and need with a particular emphasis on home ownership and tenancies
- making sure that change happens and the policy is delivered – including making Partnership Boards more effective.

The considerable overlap between priority areas in Valuing People Now and in the current scoping exercise gives us confidence that these are indeed the areas of concern to people with learning disabilities and those who support them. Demographic changes also serve to underline the urgency of this focus. The population of people with learning disabilities is set to increase by an estimated one percent per annum (Department of Health, 2001) over the next 10 years, while currently this group forms some two percent of the general population (Foundation for People with Learning Disabilities, 2007).

The field of Learning Disability has not been short of changes in emphasis, and the publication of new policies. For instance, policy and strategy

documents at government level repeatedly emphasise the need for joined-up working and 'Progression through Partnership' (HM Government, 2007) sets out a vision of how the various government departments most closely involved in this area will work together, so that people with learning disabilities get a better deal in further education and training.

Additionally, Social Care and Health services are set to change, following the White Paper, 'Our Health, Our Care, Our Say' (Department of Health, 2006). The moves are towards a service system which is more open, transparent and user-led. One of the main mechanisms for promoting autonomy and social inclusion is increased provision of individual budgets for social services support (Prime Minister's Strategy Unit, 2005; Department of Health, 2006). The cross-departmental 'Independent Living Strategy' represents the practical implementation of those policies, and will affect the provision of social care support to all disabled people, including those with learning disabilities. The field of Learning Disability has in fact led the way (Duffy, 2003; Poll, Duffy, Hatton, Sanderson and Routledge, 2005) in demonstrating how disabled people generally can plan out their own support services, and be 'in control' of their own lives. Over the next ten years, we can expect changes in the concept of social and health care for people with learning disabilities, which will result in:

- better access to local, community health and social care services (Department of Health, 2006: 77-106)
- a more transparent way of ensuring that budgets for support are fairly allocated, and 'owned' by individuals (Prime Minister's Strategy Unit, 2005: 12-13)
- a stronger voice for people with learning disabilities, their allies, families and supporters (Prime Minister's Strategy Unit, 2005: 13).

1.3 The place of research in informing policy

In the context of these policy directions, and the demands on practice to be 'evidence-based', we need to consider the role to be played by research. As Bloor (1997) pointed out in the context of qualitative research, the policy community rarely seeks policies from researchers, but research is often commissioned simply to confirm a preferred policy option, or to back up a campaign. However, there are recent examples where accumulated research evidence has had a direct effect, often in combination with the demands of service users themselves. There can even be a direct influence on the passage of new laws. An example from the 1990s was the accumulation of research evidence led by disabled people (for instance Zarb and Nabash, 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 coincides with new Government announcements of support for carers.

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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 (SCIE, 2004) 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, McBride, Snelham, with Williams and Simons, 2002) which was followed by the production of accessible information about direct payments, as well as information campaigns including training and drama presentations. Representatives of leading development organisations in Learning Disability have recently formed a coalition, 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).

Since the first draft of this current report, the Coalition has published the findings from their own research, 'Tell it Like it Is', which are based on a survey that was specifically targeted to reveal evidence of cuts in funding. It continues to be important that research fulfils this function, and provides evidence about what is happening for people with learning disabilities, in their lives, housing, families, jobs and a range of other measures. Emerson, Malam, Davies and Spencer (2005) conducted a very useful survey of adults with learning disabilities in England, which was eagerly welcomed in the Learning Disability community, but those who seek to campaign for changes will want continued, targeted and re-analysed information. An example of how this can make a difference is the use of the Mencap's (2007) research on advocacy for parents with a learning disability. This has influenced the new Independent Living Strategy (Crown Copyright, 2008), which offers a commitment to develop advocacy, including advocacy for parents with a learning disability.

'Valuing People' (Department of Health, 2001) was linked from the start with a programme of research, commissioned by the Department of Health, and running alongside the development of the strategy itself. These projects are included in the current literature review. Perhaps more than any, the national survey (Emerson *et al*, 2005) has influenced the directions of change and the priorities flagged up in the renewal document, 'Valuing People Now' (Department of Health, 2007).

At the level of practice, there is perhaps a greater chance of research findings being used to prompt action. For instance, the body of research on 'active support' (Mansell, Beadle-Brown, Macdonald and Ashman, 2003; Felce, Lowe and Jones, 2002) has resulted in a climate where practice managers and commissioners now recognise the importance of the training

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and development of frontline staff, although the best ways to achieve changes in staff practice still need further work. Literature reviews for the current study revealed that most of the research carried out in Learning Disability since 2001 had direct implications for practice. However, research is often not communicated to practitioners in ways that make sense to them, and often remains in the annals of academia. When research can work in collaboration with practice partners (for instance, Mansell *et al*, 2003; Williams, St Quintin and Hoadley, 2006) then there are greater chances of the findings being implemented. Various models of action research may be best suited to ensure that stakeholders are involved centrally in the conduct of the research, and own its outcomes.

Research is related to policy and practice in many different ways. Not only does research potentially influence new policies or laws. Conversely, a new policy or law may be the trigger for social research. Is the policy being implemented? Does it make a difference? Policies can be changed by research evidence about what is happening in practice. For instance, the policy guidance for direct payments (Department of Health, 1996) was amended in the light of research about the experiences of people with learning disabilities who were restricted from getting a direct payment, because of the interpretation of the phrase 'people must be willing and able' in the original guidance (Ryan and Holman, 1998). The revised guidance emphasised that people could get support to consent and to manage their direct payment.

Research nearly always reveals gaps between policy and practice and any one of a number of research reports could be cited in this respect. An example would be Heslop, Mallett, Simons and Ward (2001) which revealed the wide discrepancy between policy on transition for young people with learning disabilities, and the actual experiences of families and young people themselves. To some extent, such gaps are inevitable and may be due to a time lag between policy and practice. Research has a role to play in maintaining a sense of alertness about the effects of policy and law. It is vital at present, as will be seen in this report, that there are continued efforts to monitor and report on the implementation of the Mental Capacity Act (2005) in the field of Learning Disability. There is also a sense in which we simply do not understand enough about how policy is translated into action, mis-translated, or ignored (Forbat, 2006). With all these considerations in mind, there is clearly a need for continued research which helps us to understand the mechanisms for change, as is recognised in the fifth 'main priority' in 'Valuing People Now': 'making sure that change happens' (Department of Health, 2007).

With the above considerations in mind, the current report seeks to recognise the value of a range of different types of research that might have an influence both on policy and practice. Research questions were thought of as falling into three categories:

I. RESEARCH ABOUT HARD EVIDENCE (such as the survey results in Emerson *et al*, 2005; Learning Disability Coalition, 2008). Surveys and

other largely quantitative research can yield a broad picture of what is happening for people with learning disabilities, and can give an understanding of how prevalent any particular problems are. Statistics are particularly useful in providing a rationale when policy-makers might be attempting to give a renewed focus to certain areas. An example of this would be the 'Valuing People' focus on transition, following research such as Heslop *et al* (2001) which revealed the widespread problems in implementation of guidance.

II. RESEARCH ABOUT CHANGE AND ABOUT HOW TO MAKE CHANGES HAPPEN (e.g. Cole and Williams, 2006; Social Care Institute for Excellence, 2004). It is not enough to describe what is happening; we also need research that helps both service providers and policy makers to understand *how* to make change happen. For instance, Cole and Williams (2006) included an analytic report that deliberately highlighted the principles of changing local authority day services towards community-based supports. It is likely that some of the current need for research about the processes of change will be met by looking outside the 'learning disability' sector. For instance, there is a large body of research about change in management and health structures, reported by the SDO. This could be very useful to review and apply to Learning Disability organisations.

Research about 'change' is not restricted to organisational and management issues. For instance, Chapter 5 highlights some of the recent research about workforce issues in Learning Disability, where several researchers have found that 'active support' methods are important in increasing activity and engagement amongst residents with learning disabilities (Felce *et al*, 2002). However, we still need to understand better how to make the changes towards active support, and indeed personalised support in general. Bradshaw, McGill, Stretton, Kelly-Pike, Moore, Macdonald *et al* (2004) found that the main factor in making training effective was the attitudes and involvement of the house managers. This type of research, then, helps us to understand what will be effective in producing real change at grassroots level, in the lives of people with learning disabilities who have the greatest level of needs.

III. BASIC RESEARCH WHICH IS ABOUT UNDERSTANDING UNDERLYING FACTORS, MECHANISMS OR CONCEPTS This type of research is much rarer in the field of social understanding, but essentially we were looking for elements of research studies that would help to advance basic knowledge. For instance, Jingree, Finlay and Antaki (2006) and other types of basic interactional research have a role to play in furthering basic knowledge of how communication works. This, in turn, will enable us to improve practice in ways that are based on research.

1.4 The social positioning of research about Learning Disability

Research in Learning Disability has grown over the past forty or fifty years,

to create a body of work which is relatively inward-looking. For instance, of the 37 research studies about community inclusion of people with learning disabilities that met the inclusion criteria of the literature searches in the current study, only three were found which collected data in contexts outside the Learning Disability service structure.

If policy is leading people to think 'outside the box' and to consider community inclusion, then research is urgently needed which has a wider focus than Learning Disability services and practice. Stakeholders in the current work frequently spoke of this theme, urging us to consider 'citizenship' as a theme, and to think about research about communities taking responsibility. We are also very short of research evidence which compares the situations of people with learning disabilities with measures from the general population. There is no doubt that there are very large holes in all these areas.

Additionally, Learning Disability researchers, including ourselves, could be urged to read more widely outside their speciality, since some of the answers to current questions could lie in other disciplines. All these themes are taken up again in Chapter 10.

Finally, the very important theme of user-participation has threaded through the entire study. Starting from the position that people with learning disabilities and their families are the primary stakeholders in research, as well as policy, we were led by the views and experiences which they discussed with us throughout the project. Instead of research being inaccessible, distant, and part of their oppression, many would argue that it is vital that people with learning disabilities are in control of the research agenda (Oliver, 1992; Walmsley and Johnson, 2003). Emancipatory and inclusive methodologies (Walmsley, 2001; Williams, Simons and Swindon People First Research team, 2005) enable people with learning disabilities to take an active role in constructing knowledge about their own situations and to lead, or take part in, research which concerns their lives. A research agenda that meets the challenges of the decade from 2008 will require that we find ways to continue to include people in the debates about research. We know from the current study that their insights and analysis of their situation matched and complemented those of academic researchers, and we hope that the dialogue begun in this study can continue.

1.5 Structure of this report

Section 2 will describe our methodology for this scoping exercise, both for the review of literature and the consultation. Following that, Section 3 presents a summary of the issues of concern for stakeholders in the consultation. Sections 4-9 deal in turn with each of the major topics of concern. These are the heart of this report, and each section contains:

- a) a summary of the literature, some information about the scope of the research and comments about methodologies

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b) a review and discussion of the outcomes of the research. These reviews both summarise our current state of knowledge, and start to identify some of the research gaps

c) a report of the discussions held with stakeholders, in order to identify priorities. Each of these sections concludes with a list of the main priority areas for research, together with some suggested research questions emerging from workshops and from researchers. The questions are not intended to be a definitive list, but are indicative of the main research concerns of all stakeholders.

Finally, Chapter 10 presents our conclusions and discussions about the shape of the future research agenda, in terms of research process as well as topic. The report concludes with some recommendations for funders and for future research.

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2 Methodology

2.1 Outline of methodology

This scoping exercise was carried out by the core research team (named as authors of this report), working with:

- a) the Foundation for People with Learning Disabilities, who had a monitoring and advisory role throughout the course of the study
- b) members of the Ideas Group¹ for Norah Fry Research Centre, who acted as co-researchers in the consultation.

2.1.1 Aims and objectives

This section presents an outline of the methodology used in the scoping exercise, and provides a reference point for other parts of the report. The overall aim of this study was to work with relevant stakeholders to reach a consensus on priorities for learning disabilities research in England over the next ten years. The original aim of the commission by the National Institute for Health Research (Service, Delivery and Organisation) (NIHR:SDO) was to 'undertake a broad review of Learning Disabilities research and the priorities' in the context of supporting the implementation of *Valuing People* (DH, 2001), and in the context of service modernisation. In the proposal for this work, we therefore specified four objectives.

- 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.

Since this research was commissioned in order to support social policy, and particularly to accompany the renewed policy initiative, 'Valuing People Now' (Department of Health, 2007), we felt it was particularly important to adopt the same social policy stance which focuses on the lives, supports and

¹ The Ideas Group consisted of five people with learning disabilities who were part of an advisory group for Norah Fry Research Centre. They represented two local self-advocacy organisations.

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services offered to people with learning disabilities, rather than on their medical conditions *per se*. We explicitly set out to find qualitative and quantitative research about any aspect of social life for people with learning disabilities, including access to Health services; our design was intended to prioritise the areas of greatest concern in the lives of people with learning disabilities.

The following outline gives a summary of the system we followed for establishing first, the research 'gaps', and then the research 'priorities' which are presented in this report.

- 1) Establish main concerns and issues of key stakeholders (First Round of workshops: see 2.1.2 and 2.1.3)
- 2) Use those areas of concern to determine key words for literature search (see 2.1.5)
- 3) Take summaries of literature searches and reviews back to a second round of workshops, to determine the clear gaps in the evidence and discuss priorities (see 2.1.7)
- 4) Take the same summaries of literature searches and reviews to a researchers' network meeting, to discuss the same issues (see 2.1.8)
- 5) Analyse data from steps 3 and 4 above, and make a list of research priorities identified by both the workshops and the researchers. Submit this list for validation to a range of development organisations (see 2.1.9)

2.1.2 Stakeholders

We have used the word 'stakeholder' throughout this report, to refer to the groups of people who took part in the consultation, and who are affected by the results of research about Learning Disability. Within this study, there were four groups of stakeholders.

- People with learning disabilities - people who identify themselves as a person with a learning disability. This included people who have been active as self-advocates and even as researchers. It also included people with high support needs, and some who did not use words to communicate.
- Family Members - people who have a family member with a learning disability. Some of the family members who took part in the consultation were people who had been active in shaping policy and leading change. Some of these family members had relatives with learning disabilities who had already moved out of the family home, while others were still caring for their relative.
- Professionals - this was chosen as an all-encompassing term for the full range of people working in the field of Learning Disability, who took part in the consultation. This included supporters of people with learning disabilities, practitioners, policy makers and service managers. It also

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included some representatives, as well as directors, of development organisations.

- Researchers - researchers were considered separately to other professionals within this scoping project. We attempted to reach as wide a range of researchers as possible within the field of Learning Disability.

2.1.3 Stage one – initial consultation

The first goal of the consultation was to identify the main areas of concern in the lives of people with learning disabilities. At this point we did not pursue a focus on research questions or outcomes, since this was a staged process where the outcomes of one phase led into the next. Rather, we asked people about what could be better in their lives, and to tell their stories and voice their concerns. This first stage in effect structured the ensuing parts of the scoping review.

This was the focus of a first round of four regional workshops, held in Bristol, Birmingham, Leeds and London. During both rounds of workshops, we worked closely with members of the Norah Fry Research Centre 'Ideas Group' (see footnote to 2.1). This is a small group of representatives of local self-advocacy organisations, and they helped to plan and present the workshop sessions.

People with learning disabilities, family members and professionals were invited to the workshops, by direct mailshots, advertisements on a Learning Disability email list, and using existing contacts and networking. For instance, a partnership board network attended one of the workshops, ensuring that we had good representation of all the key stakeholder groups. In total, the first round of workshops was attended by 127 participants in total. This consisted of 46 people with learning disabilities, 12 family members, and 69 professionals. We had wished to include more family members, and were successful in attracting a further four to the second round of workshops. In addition, some of the professionals who attended were also family members. The table below gives a breakdown of the composition of the first round of workshops. All participants were from organisations, groups or services where they had access to other views they could represent, and the people with learning disabilities in particular took this role seriously. On three occasions they came with information and ideas from their own groups, in one case written down.

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

The first round of workshops was designed in order to foreground the views and issues raised by people with learning disabilities themselves. It was also extremely important that we provided a space for other participants to have a say. To that end, we felt that certain measures would enable this to happen more freely, including a pre-session for people with learning disabilities, and the use of pictorial methods and written feedback forms.

There were three principles underpinning our design of workshops:

- 1) to ensure that a wide variety of potential stakeholders in Learning Disability issues attended and expressed not only their views, but the issues of concern to those they represented.
- 2) to give full support to people with learning disabilities, so that they could understand the purpose of each workshop, and so that their voices were in the foreground.
- 3) to include activities that would enable consensus to be reached over the most important issues, while not losing sight of the points made by everyone in the workshop.

Each first round workshop included:

- a) A pre-session for people with learning disabilities. Following warm-up activities, participants also shared their views on what 'research' was, to set the scene. They then divided into smaller groups and used a selection of pictures to identify issues that were of concern in their own lives. The pictures were taken from 'Photosymbols' (Worth 1000 Words Ltd, 2004) and were chosen to represent a range of life experiences, including family issues, health matters, education, work, living arrangements, and activities; this pre-session concluded with feedback from each group. Participants then decided in the larger group which were the main issues that were their priorities.
- b) There were also opportunities during the lunch-time and afternoon for

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anyone to note down concerns and issues they had, on post-it stickers that were attached to pictorial wall-charts.

c) The other participants (family members and professionals) joined the workshop at lunchtime. Following a brief presentation about the project, the afternoon session started with feedback from the people with learning disabilities, so that their views could provide the backdrop for the afternoon session. This was then followed by small group discussions for different groups of stakeholders. Professionals and family members worked in groups to identify Learning Disability issues that they felt were currently important. People with learning disabilities meanwhile had the opportunity to have their own group, and reflect on their dreams for the next ten years. They did this with pictorial facilitators, and fed back their dreams at the end of the afternoon.

e) A final feedback session was held in which each of the main discussion groups gave the main points they had discussed.

Data collected during main workshop sessions and all small-group sessions were scribed on to flip-charts. However, we also made audio-recordings of all discussions, and transcribed them in order to carry out a thematic analysis, which is the subject of Chapter 3.

The role of the Ideas Group (see footnote to 2.1) was also essential. It was extremely useful that we already had a working relationship with most of the individuals concerned, and that we trusted they would have plenty of ideas about the present project. An initial planning meeting, for instance, was held to try out some possible activities for the workshops. It was at that meeting that we worked out the 'What is research?' activity, as well as a warm-up activity which led into it. This was very successful in engaging workshop participants and focusing the workshop on the topic of 'research'.

2.1.4 Summary of procedure for reaching consensus on main topic areas

Following the first round of consultation, the evidence available about stakeholder concerns was as follows:

- a) audio recordings of all discussions at the workshops, which were transcribed and analysed qualitatively in order to identify the main themes
- b) comments about issues identified at the time in 'feedback' sessions, which were written up by facilitators, and attached to charts around the room
- c) flipchart sheets representing the end-of-session consensus on priorities – both for the people with learning disabilities (who presented their consensus priorities at the start of each afternoon session) and for other stakeholders (who gave feedback at the end of each day's workshop).

The analysis of these data resulted in both a 'long list' of all the themes and ideas mentioned, and also a short list that represented the priority themes

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– those that a) received the most mentions; b) were agreed on in feedback with all stakeholders. This process enabled us to identify the themes that were of most importance to the various stakeholder groups. Chapter 3 contains detail of the thematic analysis of the concerns raised in the first round of workshops. These issues were then used as the basis of the search terms (see *Appendix A* for details of each theme's search terms). These search terms were reviewed at a steering group meeting and circulated to researchers for comment.

2.1.5 Stage two – literature search and review

The second main goal of the study was to identify research gaps in the key areas for all stakeholders, by carrying out systematic literature reviews.

Inclusion criteria

This scoping exercise was to determine the research priorities for England and therefore the literature search was restricted to English language, U.K. based primary and secondary research published since the introduction of Valuing People in 2001. We explicitly set out to find qualitative and quantitative research about any aspect of social life for people with learning disabilities. The original brief for this work set the scoping review in the context of 'Valuing People' and the research that was commissioned to support it:

The White Paper, 'Valuing People' has been the framework for improving services for people with learning disabilities in England. To support the implementation of the White Paper the Department of Health's Policy Research Programme (PRP) commissioned a programme of research, under the auspices of the Learning Disabilities Research Initiative. It is now timely to undertake a broad review of Learning Disabilities research and the priorities. (SDO, 2006)

The reasons for carrying out the review were to describe the broad sweep of 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 more robust to limit the search both geographically and by time- span. A review of foreign literature would not have served to fill gaps in the knowledge base about English service provision. Similarly, we did include some research prior to 2001 in the final review; however, it was appropriate to focus on research since 'Valuing People' in 2001, since a review of older research would not necessarily reveal current research gaps and priorities.

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

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- 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 has also been included, at the specific request of NIHR SDO.

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

Although databases such as PsychInfo and Medline were originally listed in our proposal, they were subsequently excluded. An initial search for papers in those databases revealed a) an overlap with papers found through other sources; b) a preponderance of medical research about the aetiology and treatment of various conditions and impairments. This latter category was not the focus of the current review, since it focused more on the agenda put forward originally by 'Valuing People', a social agenda relating to the life chances of people with learning disabilities.

The titles and abstracts were reviewed to identify any studies that might be relevant and the reasons for exclusion were noted. Full copies of articles were ordered in cases where it was not possible to ascertain from the abstract if the study met the inclusion criteria. Additionally reference lists of studies identified were checked to identify other related research and hand-searching of key academic journals and practitioner magazines was undertaken. Experts in the field of Learning Disability were contacted in an attempt to identify further relevant published studies or any grey literature pertaining to the review, in order to minimise publication bias.

Search Terms

All search terms from the individual themes (see *Appendix A*) were combined with:

- learning dif*
- learning dis*
- intellectual disabilities

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- mental retardation
- mental handicap

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

Quality Appraisal

A reading tool was developed for data extraction and quality appraisal of all the research articles included in the review (see *Appendix B*). This covered the type of research, the main aims, methodology and findings of each paper, as well as details relating to sample size, analytical methodology, ethics and policy and practice relevance. We also carried out an appraisal of each paper, on a 1-5 scale, for methodology, ethics, sample size, references and usefulness. In order to check for consistency, the two main researchers (Marriott and Williams) met in order to compare a sample of scorings, and criteria for the scoring were revised. The scores enabled us to estimate the overall 'quality' of research studies, so that we could gauge their effectiveness in contributing to knowledge, and so inform the research review.

2.1.6 Quality appraisal of research reviewed

A pro-forma was devised in order to record the basic features of each item of research reviewed, as well as a measure of quality. The full form is given in Appendix B. The form recorded the type of research, main findings, methodology, sampling, ethical processes, policy and research implications. In addition, we scored each item for quality on a five-point scale according to:

- a) Methodology
- b) Ethics
- c) Sample type and size
- d) Referencing to the literature
- e) Usefulness

This was trialled with four members of the research team, and discussed with the consultant from the Foundation for People with Learning Disabilities. Following these trials, explicit criteria for the quality appraisal scores were developed, and these are given at the end of the proforma in Appendix B.

2.1.7 Stage three – follow-up consultation

The main goal of this stage of the consultation was to explore the research gaps with stakeholders, and to identify priorities. Following the literature review, a second round of consultation workshops was held in all four geographical areas again, to which the same participants were invited. 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 2: Participants at 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 of the nature of the task. 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.

This was the design of second round workshops:

Pre session in the morning for participants with learning disabilities. This started with a 'choice' exercise to act as a warm-up and introduction to the topics under discussion (choosing research priorities), produced as an easy-to-use game, with pictures from a library of accessible photo symbols (Worth 1000 Words Ltd., 2004).

Morning activity We asked people with learning disabilities to choose a 'priority theme' and to talk about their own, detailed stories and recent experience in that area. For instance, some participants talked about stories related to bullying; others talked about independent travelling and support, and others about experiences of the Health Service.

Stories were visually recorded, and fed back to open the full workshop session in the afternoon. They enabled people to refer back to the lived experiences, possible solutions, and the places where research could have a purpose in these real-life events.

Afternoon sessions As in the first round of workshops, other participants joined the workshops at lunchtime. These were both professionals and family members.

Small group discussions. Following presentations about the literature review, workshops split into mixed groups (of different stakeholders) to discuss two main theme areas per group. Each group received a summary

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of the literature review in those areas, and discussed a) the gaps in research that had been revealed; b) the ways in which they would prioritise those gaps. Summaries of the findings from the literature search were presented to participants and they worked within groups to reach agreement on research priorities.

Final priority discussion. A final feedback session put all the 'research gaps' up onto a wall chart, and asked participants (if possible) to reach a consensus on which ones they would fund first.

Data from these groups were recorded and thematic analysis was used to identify the main priority areas. The final consensus exercise in these workshops proved extremely difficult, as all the research questions that had been discussed seemed to be important, and so this report presents a range of questions generated during the consultation, under each of the main headings which were prioritised.

2.1.8 Stage four – consultation with researchers

Researchers in the field of Learning Disability were contacted to ask for their areas of expertise, preferred research methodologies and to express any interest in attending a focus group. The original identification was done via the Department of Health initiative to establish a researcher network. This was then supplemented to ensure that participants were representative of the various areas of Learning Disability research and of different research methodologies.

Nine researchers attended the group, and the discussions were recorded, the data were transcribed and thematically analysed to identify the research priorities highlighted and other relevant issues about research processes which were discussed.

2.1.9 Stage five – validation exercise

The findings from the analysis of stages three and four were collated in a questionnaire (see *Appendix C*). This was sent out to 15 National development and policy organisations, chosen to represent a spread of their focus about advocacy, self-advocacy, mental health and other health issues, and practical policy-related support. The questionnaire aimed to explore how the identified research gaps were viewed by them and how they fitted with each organisation's agenda. As we shall see below in the evaluation, this was not however successful.

2.2 Rationale for the methodology

The overall purpose of the scoping exercise, which is the subject of this report, was to 'achieve a consensus on research priorities in Learning Disability among all relevant stakeholders'. There were two principles underlying our choice of methods for data collection.

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a) We wanted to find reliable ways to listen to the views of all stakeholder groups, and to synthesize those views.

b) We wanted to provide systematic, research-based evidence of the gaps in research, so that stakeholders could consider them and help decide on research priorities.

It was essential to use methodologies which would bring research-based evidence back to the stakeholder groups, so that we could tie together the two elements of this study. The goals of the consultation, as well as the 'gap-finding' element of the literature review, were ambitious. Both required considerable creativity in finding methods that were both reliable, as well as flexible.

2.2.1 Rationale for consultation methodology

The consultation we undertook was designed to consult widely with all stakeholders. One possible way of doing this would be through a survey based on a questionnaire. Surveys (such as that carried out currently by DH, 2008) have the advantage of individual responses, which are not necessarily influenced by other respondents. However, it was felt that the goal of reaching 'consensus' would not be reached by such a method, and that it would be particularly hard to include people with learning disabilities themselves. The topic of 'research priorities' is a difficult one to conceptualise, and therefore a face-to-face method of consultation was more appropriate.

Ensuring that all views are listened to in a consultation exercise involves taking account of power relationships (Fairclough, 1995). Although this study did not use Critical Discourse Analysis (CDA), it took account of the fact that power relationships are embedded in all discourse. 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 stakeholders who attended the workshops, most of whom had direct, lived experience of learning disability. We wanted to find a way for them to actually set the agenda, based on issues in their own lives.

The methodology which we put into practice for the consultation was based on previous experience with similar projects (Cole and Williams, 2005), in which mixed groups of participants came together to discuss issues of relevance to a particular research goal. Essentially, this is somewhat like a focus group approach in which it has been shown that the role of the 'moderator' is of great importance. Focus groups offer a good vehicle for the development of ideas, and that is what we hoped for from the present workshops. There are certain advantages and disadvantages of this methodology.

- Participants all have an opportunity to offer their views.
- Participants interact during the discussion, and so their views will to

some extent be a reaction to what others have said.

- Group dynamics can mean that some participants are dominant, others are silenced.

In Cole and Williams (2006) we developed a workshop format which gave precedence to the views of people with learning disabilities. As their voices can easily be silenced in mixed groups, with family members and professionals, it is important to ensure that they have a chance to formulate opinions and gain confidence in their views. This was achieved, in the current study, by offering a pre-session to people with learning disabilities.

At the end of each of the pre-sessions, participants fed back to each other what their main points were (at the first round of workshops, these related to issues in their lives). They then chose how they would feed these back to the main workshop in the afternoon sessions. This workshop structure provided a clear way to ensure that the voices of people with learning disabilities themselves were strong.

The current study followed the model of previous studies carried out in the 'inclusive research' tradition (Walmsley and Johnson, 2003). Inclusive research is not a rigid model, but is better thought of as a flexible approach, with the overall goal of basing the research firmly in the lives and experiences of people with learning disabilities. Designing an inclusive project, as the Department of Health Learning Difficulties Research Team (2006) pointed out, means:

- *thinking outside the box*
- *being prepared to change*
- *planning to involve people from the start*
- *getting the right funding*
- *getting better at accessible information*
- *making sure that people with learning disabilities make a difference.*

(Learning Difficulties Research Team, 2006: 85-87)

Following a qualitative, thematic analysis of data from the first round of workshops, topics were established for the literature search and review. At the same time, however, views were sought from a variety of other stakeholders. A type of 'snowballing' methodology was used, in which the larger picture could be filled in with greater detail.

2.2.2 Rationale for literature review

The literature searches and reviews were designed to match the topics which emerged from the first part of our consultation. The methodology was based on standard methods for systematic reviews (CRD, 2001). We designed specific criteria, to include research since 2001, conducted in the UK, and about people with learning disabilities in our six main topic areas.

As mentioned in our methodology outline above, we strove to find a way to evaluate this research, and developed a critical appraisal tool, formulated originally from the model recommended by the Social Care Institute for Excellence (SCIE). However, as Arksey (2003) points out, the major point of the scoping exercise is to develop a map of the extent and nature of the literature in the field, rather than to address the issue of quality for individual research papers. Therefore, the critical appraisal tool was used simply to inform our own judgements, when writing our review, about findings which were based on effective and robust research.

The less standard goal of this literature review was to identify research 'gaps', and this was much harder to achieve. We needed a method which would take into account the views of all stakeholders. This was essentially an inductive and iterative process, based on:

- a) a consideration of research gaps mentioned in the literature itself
- b) a reconciliation of the concerns of workshop participants with the analysis of literature
- c) experience of the field of practice, policy and research.

The process of gap-identification was refined by conversations with key players in the world of policy, as well as discussions with researchers and development organisations. The input of Paul Swift from the Foundation for People with Learning Disabilities was invaluable in this regard, throughout the literature review and appraisal. However, essentially, the identification of research 'gaps' had to remain an open-ended process until the end of the project. The discussions about priorities in the second round of workshops certainly contributed to this identification, and very importantly, the focus group meeting with researchers held after the second workshops, was extremely helpful in both defining the gaps, and establishing a rationale for the priorities.

2.3 Evaluation of methodology

2.3.1 Reflections on the consultation workshops

This scoping exercise was a very substantial undertaking. There were certain limitations, most of which sprang from inherent difficulties in the task of reaching consensus on research priorities. It is intellectually challenging to review research knowledge and identify gaps in that knowledge, and it is also challenging to determine whether those gaps actually need to be filled. Therefore, the demands we made on all the 'relevant stakeholders' were very great. It was not simply about consulting with different stakeholders and coordinating their ideas. In order to ensure that the consultation made sense, it was necessary to develop ideas about what research could do, and what research could not do. In the workshops, these issues were hotly debated. The workshops were very creative and challenging places, where we learnt a tremendous amount from everyone.

Most of the stakeholders who came to the workshops were 'living the life' of Learning Disability. This was not a theoretical subject for them, but one which was of vital importance to their daily lives. The frustration with research which does not deliver change was a very keen one. These were the words of one workshop participant, and they echo many:

'What we need is action, not research. It is time to stop talking and to start doing.'

It is one thing to talk about what needs to be done; it is a further conceptual leap to think about whether research knowledge could help these things to be done. The methodology we adopted in workshops and other meetings, however did achieve success in focusing stakeholders on research as a topic. For instance, we started the first round of workshops with an exercise on 'what is research', and we included group exercises in the second round to design a research project around a particular research question. People with learning disabilities themselves talked about 'research which helps us to understand things', and wanted 'research to find things out, so we can change our lives'.

All participants had some sophisticated understandings of research, and many had been involved with research before. However, it was still sometimes difficult to link particular burning issues with the outcomes of research.

Another challenge facing the workshops was the mixture of different stakeholder groups. In particular, it has been found difficult in the past to enable people with learning disabilities and carers both to have a voice, and sometimes the inclusion of people with learning disabilities can lead to the silencing of other voices. However, we were very encouraged that these difficulties did not predominate. For instance, although we had planned afternoon sessions which would provide options for separate groups (people with learning disabilities in one group; other participants in another group), this was not always adhered to. People chose to mix their groupings, and on the whole this worked very well. It was also agreed by all that the inclusion of a pre-session for people with learning disabilities in the morning was very helpful.

2.3.2 Reflections on literature searches, appraisals and reviews

At the start of this study, we were confident that we would be able to search and appraise research since 2001, under search terms generated by all the matters mentioned at the first round of workshops. In fact, however, stakeholders at those workshops raised so many points about the lives of people with learning disabilities, that it would have been impossible to follow up everything that was mentioned. For that reason, we prioritised our searches around the topics which a) were represented as the 'main themes' in our analysis of data from the workshops; and b) were highlighted by people with learning disabilities at the workshops as the main themes. This

prioritisation was not a weakness of the study; the original aim was to 'identify the medium to long-term priorities for learning disabilities research and development' (NIHR, 2006), and the eventual outcomes from this study are more useful because they are grouped around the main issues on which consensus was reached.

Chapters 4-8 reveal how massive even that task was. There was a vast amount of literature to review, and the retrieval, reading and appraisal was the central part of this study. Since this literature represented many different research methodologies, we were careful to design our appraisal criteria to match these different methodologies. For instance, sample size is important for quantitative methodologies; however, the reverse criteria will operate for many qualitative methodologies, which can fail to deliver in-depth understanding by attempting to include too many participants. After a pilot period (20 appraisals), the two main researchers met to refine the criteria for appraisal. These criteria were also discussed with Paul Swift, from the Foundation for People with Learning Disabilities.

Perhaps the most contentious category was 'usefulness', which we decided to include. This was intended to go slightly further than a strict definition of 'validity', and to include the potential impact of the research findings, whether they were resonant with other findings, and whether they were timely. These judgements are necessarily, to some extent, subjective, and so we have decided not to include specific reference to them in the literature reviews.

Nevertheless, they enabled us to appreciate that a large volume of research could be 'used', and could have a positive impact on the lives of people with learning disabilities, if the findings were disseminated.

2.3.3 Reflections on establishing priorities

The identification of research 'gaps' is not an exact science. However, the audit trail for establishing, first the 'gaps' and then the priorities is presented in 2.1.1 above. Sometimes, a particular need arose very clearly from the literature. At other times, particular research gaps emerged from a consideration of the views and issues raised by people at the workshops, combined with creative thinking about existing research and methodologies. There are also new elements of policy and practice (such as individual budgets) as well as law (Mental Capacity Act, 2005) which determined the need for future research.

When it came to prioritisation, there could never be complete agreement about what research is going to be useful. As we have explained, the design of this study prioritised the views of workshop participants (people with learning disabilities, policy makers, managers of services, practitioners and family members). A few researchers did attend workshops, but primarily we heard their views through a researchers' meeting, by telephone or through email contact. As we have indicated, we were encouraged by many areas of overlap and agreement between all stakeholders, including researchers and

especially senior policy makers.

The research community, however, might have privileged access to understanding what research is vital to make a difference to our knowledge base. There were areas raised by researchers which we did not include in our literature searches. Some of these are very large areas, and so the volume of work involved would have been beyond the scope of this study. However, they could be taken up in future research scoping exercises, as specific topics for further analysis. We will list them here, for completeness, and take them up again in the final chapter.

- We will continue to need medical research related to particular syndromes, so that we can understand and provide appropriate interventions – e.g. for people with Prader-Willi syndrome.
- We need more basic research (for instance, neurological research) to help us understand the mechanisms underlying certain issues, such as epilepsy.
- Mental health issues for people with learning disabilities are an important focus for research. We still need to understand the mechanisms and to find appropriate interventions.

Finally, but most importantly, the arrangements for co-working with the Foundation for People with Learning Disabilities were very valuable indeed. At every stage, our meetings with Paul Swift from the Foundation helped us to develop the methodology and to keep our eye on the main goals of the exercise. In that way, we continually worked alongside the issues from a leading development organisation.

The validation exercise was planned originally as a more comprehensive exercise, that would engage with development organisations and validate the research priorities identified, by matching them with the agendas of these organisations. This proved to be an impossible task, partly due to difficulties with timing, but also due to the fact that research priorities cannot be easily listed and ranked. The very nature of the task was a disincentive to respondents, even though the project team had decided to limit the validation questionnaire to a few key organisations.

The returns gave us a view, albeit limited by the number of replies, of the degree of consensus between their agendas and the research priorities identified. However, it was not possible to determine a rank order of priorities from this exercise. On the whole, these responses draw us back to considerations of the type of research which can really make a difference. Many of these responses expressed frustration with traditional, academic research. Respondents were more in favour of development and action research models, which could help inform change. However, they have not yet had a chance to read the full report. In our view it will be important to continue the discussion with these organisations following its dissemination.

2.4 References Chapter 2

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3 Identification of important issues in the lives of people with learning disabilities

This section presents an analysis of the issues which were raised in our first round of four workshops, held in different parts of England. At this point we did not pursue a focus on research questions or outcomes, since this was a staged process where the outcomes of one phase led into the next. Rather, we asked people about what could be better in their lives, and to tell their stories and voice their concerns. This first stage in effect structured the ensuing parts of the scoping review. The themes that emerged from an analysis of what people said at the workshops determined our literature reviews, and subsequent identification of 'research gaps', and so this initial stage was very important for the whole study. The following thematic analysis is based on data from recordings of the discussions during the workshops, as well as written feedback scribed during the sessions.

3.1 Views of people with learning disabilities

3.1.1 Inclusion in the community: feeling at risk in the 'outside world'

People in all four workshops spoke about wanting to get out, and do things outside their own home. People wanted choices, and they wanted to move out of the 'specialist' arena of Learning Disability services. However, people 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 barriers.

Even if places are accessible though, people with learning disabilities said they often felt excluded as a consequence of other peoples' attitudes and how they were treated.

'Some people with learning difficulties get embarrassed when they are out, particularly if people are staring at them.'

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. There were many different stories concerning behaviour from others, ranging from name-calling by school children to criminal damage to property. One person said that name-calling made you feel that 'your brain is not working'. It felt very much as though these things had been happening for many years, but perhaps

people have only recently had the permission to talk about them and to be taken seriously.

3.1.2 Employment, achievement and contribution

The desire to achieve things and contribute to society was an important issue for people. Employment was an issue of great importance to people with learning disabilities in our consultation. By contrast with the traditional job menu of trolley-pushing and catering work, people in our workshops talked about the contributions that they had personally made to the Disability Rights Commission or to research projects where they had had paid jobs.

However, a range of barriers to employment was aired in the workshops, starting with the concerns people had about losing out on benefits. There was frustration at the limited amount of hours people can work while retaining their Incapacity Benefits. There was confusion around these limits and the variations across different areas, and some people thought they would not be able to give up their benefits. Other barriers to getting and keeping a job included employer attitudes and inappropriate college courses. If people with a learning disability are going to become active citizens then they need to join the workforce on an equal basis, with full respect from employers, as this person put it:

'Employers don't take people with learning disabilities seriously. They don't understand that we've got a disability.'

3.1.3 Getting respect from support staff

People spoke about support staff who patronised them or made them feel small. One person with learning disabilities mentioned a support worker who was sent by an agency to help with physical care tasks and wore a nurse's uniform. She said that she and her partner would not be seen going out with this person. The old 'medical' view of learning disability still underpins much of the support offered to people with learning disabilities and those at our workshops were very keen to describe their new vision of support. In addition to the perception of the support worker role, they had opinions on the attributes a good supporter should have:

- good knowledge of learning disabilities
- should help you to be as independent as possible and not take over
- not nosy!
- not abusive or bullying
- good attitude
- not lazy.

Choice and control were crucial aspects of what people wanted in terms of their support. With the right support, people realised that many of the

problems in their lives could be overcome. However, the relationship with the support worker was absolutely vital. People wanted to choose which staff supported them and they wanted to be given options about what to do.

Individualised support was important to people and it was noted that some people could benefit from supporters from the same culture or ethnic group. In one of the workshops, several people from minority ethnic groups attended, and they discussed particular culturally sensitive issues about arranged marriages. They felt that the issues about arranged marriages were extremely difficult for anyone, and that these things are made more difficult by immigration procedures, forms and systems which are inaccessible. One man said:

'It really helps to have my supporter, who can understand what I'm going through, and help me with all the paperwork. A lot of people would have no idea about all this'.

It was stated by many that qualifications do not always matter and that the right attitude from staff has a greater effect on the quality of care provided than training or qualifications do. People said they preferred it if there were not too many changes with staff-teams and many people spoke about staff leaving and the impact of this. Some of the more independent people with learning disabilities who came to our workshops were not in fact eligible for community care funding; they said that a minimum amount of support, delivered flexibly, could really prevent problems arising in their lives.

3.1.4 Where we live: the importance of choice and autonomy

Linked to the theme of respect was the issue of choice. All too often, people said, choices are limited for people with learning disabilities. This issue threaded through all the topics that were discussed in the workshops. For instance, in terms of housing, people felt they had been very restricted in their choices, even over who they lived with. Many people said this had a profound effect on their relationships and emotional life:

'People should live in the home that is right for them, so young adults shouldn't be made to live in a home where everyone else is a lot older'.

Some people living in supported housing didn't feel they had as much independence as they liked and that it can still be difficult to have a private life. Another person complained that staff shut the office door to have privacy within his home.

Choice was also an important issue when talking about other topics, such as jobs, relationships, education and leisure. It felt to many as if they were 'allowed' to choose the smaller things in life, such as what to eat, what to wear or where to go out. However, when it came to major decisions, they were considered incapable of taking the responsibility they wanted. This included, for instance, decisions about money, which seemed to have become more complicated for many. People felt they needed clearer

information and better help with budgeting.

Some people with learning disabilities in this study were aware of the Mental Capacity Act (2005):

'We have this group, where people have money – but they don't have access to their money when they need it, so because of that they can't go out when they want to. In that, you've got the Mental Capacity Act that's coming out, and there are rules. People with learning disabilities need to be aware of what the MCA means, and what it can do and what it can't do for them, and what their carers should be doing.'

3.1.5 Health services: access, information, communication

Decision-making, as people told us, was only possible with good information. People need to be able to understand their choices, and to see what the consequences of those choices will be, as one person said. Again, the theme of accessible information and communication ran through most of the topics discussed, but perhaps nowhere was it more evident than when people talked about access to the Health Service.

People with learning disabilities are the recipients of many strands of service provision; much of this is 'specialist' provision. However, when it comes to health issues, like any of us, people felt they had a right to access ordinary primary and secondary health care services. Access to these services came in for much criticism at our workshops. Firstly, general difficulties around access were mentioned. People with learning difficulties said they were often treated badly by the health service, as a woman at one of our first workshops told us:

'I went to the GP with my mum, but he only spoke to her. My mum told him not to do that, but I couldn't get my point across at all. I gave up really, because I couldn't understand what was going on.'

There were complaints about the time it can take to be given an appointment, comments about how people can get very anxious when in a waiting room and then the inadequate length of appointments with doctors. There were also complaints about the complicated language or jargon often used by health professionals.

It was noted that such problems are often due to a lack of understanding about Learning Disability issues and some people in workshops had had experience of getting involved in training for health professionals. They said that some health care staff are unsure about how to interact with people with learning disabilities, especially those with profound and multiple learning disabilities (PMLD). Such ignorance or embarrassment can result in seemingly rude behaviour and contribute to the perception of not being listened to, or taken seriously.

Being excluded from information was felt to affect many areas of life, and was often identified as a barrier to becoming more independent. For instance, one person talked about the impossibility of understanding her

bills and other official letters. Another man had experienced a similar problem at work: *'On the form, they say that "accessible stuff is provided". So I phoned up, and they do not have accessible things.'*

Access to information was not just about large print, however. Many people talked about problems in communication, for example, with doctors and nurses who are unable to hold an ordinary conversation with their patients with learning disabilities.

3.1.6 Relationships and emotional life

People with learning disabilities in the workshops often told us about other people in their lives. These people included parents, family members and other relatives. However, they also included friends and closer relationships – including partners. People in the workshops often became very emotional as they told us about the problems they had had with relationships, as well as the joys, and the following comment was typical of many:

'A lot of things in life can be replaced but friends are irreplaceable.'

People said that it can be hard to make friends but even harder to keep these friendships due to practical difficulties and limitations, such as the time you can stay out in the evening. In one workshop, a man with learning disabilities talked about a friend of his who had died, and he was still in a state of grief some three years afterwards. This may be considered a natural consequence of bereavement, but this man complained that his friendship and his loss had not been recognised by others:

'I still want to send him letters and talk to him. But I don't get to see his family at all, and I think they've all forgotten about me.'

When it came to meeting new friends, people felt equally restricted. Sexual relationships were clearly a deeply held wish for most people, but one which they did not always feel they were going to achieve. Nevertheless, the 'dream activity' at the workshop encouraged one man to mention his fantasies, such as 'being a toy-boy to a rich, glamorous puss' and many talked about their wish to have children.

More than one person who came to different workshops had already been a parent, and had had their child removed into social services care. This was a desperately sad situation for them, and one in which they felt very helpless. Additionally, there were some people who were family carers for other members of their family, including partners. They spoke up about the lack of recognition given to them in that role:

'I've just recently become a carer, a carer with the label of 'learning disability' who cares for someone with multiple disabilities. And I've found there is no network for carers with learning disabilities.'

To summarise, people with learning disabilities told us that their goals were basically the same as anyone would have: they wanted good health; safe housing in a nice area; close and happy relationships with other people; a

paid job in which they could contribute to society. They also wanted to get out, and do ordinary things in the community, and to do all these things they felt they needed good support workers who would respect them and help them to take more choices and control over their lives.

3.2 Views of family members

3.2.1 A common cause

The parents and other family members who came to our workshops, like the people with learning disabilities, were all in different positions. What they had in common was their deep and continuing involvement with their relative with learning disability, whatever the situation. They were not talking about a 'separate cause', but very much a common cause. Parents said that they were the best advocates, but they also felt that they were the people who'd always be there for their relative. When things got tough, social services support would not always be adequate, and it was always the parents who carried the responsibility for ensuring things were alright. That happened particularly for those whose relative had high support needs – either profound and multiple learning disabilities (PMLD) or behavioural challenges.

Although these carers and parents were so committed, they also felt that the situation of carers was very unfair. They talked about the loss of their own life, the sacrifices they had made for their son or daughter and the consequent problems in carrying on caring. They were aware that family carers were an important and often unrecognised part of the social care system and they wanted to do something about this.

3.2.2 Concerns about the system

By contrast with the people with learning disabilities, the family members' concerns were more systemic. There were many issues that they had thought through and analysed, in what appeared to be a lifetime struggle against the system.

They found it hard to interact with local authorities; 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?'

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. For instance, they felt that the issue of direct payments and individual support was very important. In particular, they felt that families' roles would be increasingly vital. Several family members in one of the workshops were leading family-controlled trusts to support their relative to receive a direct payment. Employing support staff is hard work and family members were leading the way and learning from each other.

3.2.3 Families as experts

Although some of these people with learning disabilities were no longer living at home, the parents or relatives were still very closely involved, as advocates and organisers for the services supplied to their relative.

They felt strongly that support workers should learn directly from parents, and that tighter links between the family and the support workers would be beneficial to the person with learning disabilities. One family member felt that the ABC of support work should be 'attitudes, beliefs and commitment' and that parents were in the best position to ensure that this value base is transmitted to support staff. Another parent spoke about the value of having a good support worker, who related well to her daughter. This enabled her to get out and about, while still living at home. People felt that the relationship between support workers and family members is absolutely central.

3.2.4 Person-centred services

The main issue for family members was that person-centred approaches should be employed, so that support workers could know exactly the way in which they needed to work with each individual. They told us this was particularly important for people with learning disabilities who cannot speak for themselves:

'PCPs should be written from family perspective, as they are at the forefront of sorting out the plans.'

People with high support needs were a major area of concern for family members who attended these workshops. The question then arose about how to ensure that person-centred planning is taken on by support staff. Parents also complained that person-centred plans were sometimes ignored by social services care planning processes.

3.2.5 Access to mainstream services

Not only were specialist services generally construed as a 'problem', but also mainstream services had provided difficulties. Family members told us particularly about their experiences in health services with their son or daughter.

The main concerns of the carers attending our workshops were the lack of local health services that could accommodate the needs of people with PMLD and people who exhibit challenging behaviour. There was also concern that a person's learning disability is often used as a reason for poor health, even when there are clear indications of particular health problems such as epilepsy, and that health professionals made value judgements around what treatment is worthwhile:

'It is often thought that it is easier to take their teeth out than to look after them'

There were similar worries that people with learning disabilities were not prioritised for treatment for heart problems. There were concerns that people with learning disabilities were not getting basic health needs met and that meanwhile money was wasted by organisational changes in the NHS.

However, carers also acknowledged that there are some excellent specialist services out there; reference was made to an exceptional ophthalmology service. However they felt it was hard to find out about such services and that it was essential that information was shared more effectively.

3.2.6 Living in the local community

More widely, parents and family members were concerned that their relative should be included in their own local community. This concern related most directly to housing. One of the primary issues for family members was why it was still necessary for people to be sent away for residential services. It was felt that there is a tendency to ignore what individuals might want and need and simply to categorise people in terms of their support needs and put them all in together. However, it was also acknowledged that independence matters:

'Moving to your own place is important and not just living with your parents'

Some of the family members in our workshops had supported their relative with learning disabilities to move into a home of their own, either as a tenant or as a part-owner. In these cases, people were living in their own locality, and with support workers supplied by a direct payment. However, the moves had not been easy, and it had cost the families much time and effort in securing suitable accommodation.

When people with learning disabilities lived near to their families, they said that this helped with local connections and with opportunities for more activities, choices and social networking. This was not about 'independence' in a pure sense, but about independence with support.

For families, 'community' was very much the local community in which their son or daughter had grown up. It was here that people had friends, and were known in local shops and leisure centres. However, it was also clear that societal attitudes are problematic. This was not just with the general population; some family members felt that attitudes of professionals can also create barriers, and asked: 'Why do professionals think they know best?'

3.2.7 Choosing your own support staff

One of the main priorities for family members was good quality, local support. Family carers at the first round of workshops felt that we needed to know more about the impact of the loss of family connections when the

person is sent away from their own locality. Recruitment and retention of good support staff was mentioned as a big issue, and family members felt that it will continue to be so as we move further towards self-directed support.

Various problems around direct payments were addressed; one parent commented that she had found an appropriately skilled worker to support her daughter who had complex needs and yet she was obliged to match Local Authority pay rates and therefore could not afford someone with the necessary skills. Specific frustrations were addressed, such as the person with learning disabilities being forced to move into residential care once their direct payments had been used. This was regardless of the fact that the residential care was a far more expensive option than the direct payment costs required for the necessary support to keep them at home.

3.3 Views of professionals

3.3.1 Why is change not happening?

Practitioners and other professionals who came to our workshops were very aware of the changes that should have happened across the board, for all people with learning disabilities in the post-‘Valuing People’ era. They expressed frustration with the many things which they perceived not to have changed, and much of the discussion was about how to make those changes happen. For example, people pointed out that people with learning disabilities were still restricted in where they could live. They also talked about the fact that varying standards were applied in different local authorities, and that people with learning disabilities and their families still suffered a postcode lottery in accessing services.

The theme of ‘change’ was also linked to the issue of frontline support workers, as was summed up by this person:

‘Staff need support to make Valuing People happen in their organisation. You can tick boxes and have self-advocates involved and choose good staff but if the staff aren’t supported they will become demoralised and leave. Support workers often don’t have good conditions in their job and they can move on quickly. This is detrimental to the people being supported. We should tackle issues of poor pay, training and general working conditions’

There was also a realisation that, as a White Paper, ‘Valuing People’ (DH, 2001) was never enforceable, and that this very fact might reflect the lack of priority given to the needs and issues of people with learning disabilities at governmental level.

3.3.2 A meaningful life for all people with learning disabilities

People with learning disabilities’ are not a homogeneous group; practitioners and other professionals at the workshops 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 everyone has a good life. They also frequently mentioned the wider demographic picture, with 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 different. Some people are struggling to find a toilet they can use, while others are concerned about how they can travel around the world.

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. It was generally agreed that within the modernisation agenda 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.'

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

Like the other groups, they highlighted the benefit trap as a major obstacle to paid employment, and the need for targeted college provision to help people get jobs. Some of the people who came to our workshops defended day centres. Others, however, felt that day centres increase segregation, and were keen to find ways for people to find proper paid employment.

3.3.3 Safety, risks and supported living

As people with learning disabilities increasingly move into more open, supported living arrangements, professionals felt that there were issues about vulnerability. Again, it is hard to characterise their views as a whole, since in fact there were many different and conflicting views expressed. For instance, one practitioner talked about the need for warden-controlled housing schemes, where people felt safe and had adequate support on hand. This stance was questioned by others in the same group, however, and people felt that risks were in fact a necessary part of everyone's life.

As people with learning disabilities increasingly take up 'supported living' arrangements, it was felt that they would learn to manage risks for themselves. One person said that 'the risk aspect could hold people back' and felt that the risk assessment approach was mainly put in place to protect the staff involved.

'We need to be aware of risks for people with learning difficulties but health and safety assessment of risk can often interfere with daily life, like a person with epilepsy who isn't allowed out unless there are three members of staff available. What about human rights?'

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Risks related to many aspects of life, but in particular financial risk was discussed. There was a lot of discussion about the risks of independent living, and the vulnerability people have relating to money management and debt. However, it was also suggested that many non-disabled people struggle to manage their finances and that we should be wary of expecting higher standards from people with learning disabilities.

3.3.4 Outside the Learning Disability box

Attitudes were considered to be one of the major barriers to people feeling included in society. One participant felt that we make inadequate use of the media; we should look at the portrayal of people with learning disabilities, as the use of stereotypes can perpetuate outdated attitudes. She said that the media is a resource that could be used positively. It was also suggested that mainstream schools should be teaching children about people with learning disabilities:

'Is it possible to change attitudes by doing early work with children in schools?'

People said that we need to present the positive side of inclusion to the wider community, and that: *'We need to think outside the Learning Disability box.'* People said that some of the issues under discussion for people with learning disabilities could well be issues for other groups in a wider society, and that we have become too restricted in our thinking about Learning Disability:

'We need to look beyond learning disability and look at what is happening in the general world. Is bullying a part of the society and secondary school in general or is it targeted at people with learning difficulties? Maybe it should be addressed as a societal issue rather than just a learning disability issue.'

3.3.5 Access to mainstream health services

Simple solutions can be effective and save money even if they don't tick any boxes. An example was given of someone who used to have to have general anaesthetic twice a year for dental treatment as he didn't remember to brush his teeth. This required a trip to London and two supporters to help him. Instead a big picture of his toothbrush was put by his bed and when evening medication was given, staff checked if he had brushed his teeth.

Health Action Plans (HAPs) were frequently mentioned by professionals in our workshops. It was felt that these should be developed with health professionals and that if used properly they should lead to demonstrable improvements in health and also help to identify creative solutions to ongoing health problems. It was suggested that HAPs should be linked to financial targets of primary care trusts. It was reported that secondary and acute services often do not provide a good quality of care for people with

learning disabilities but that they are often think their practices are acceptable and are unaware of some of the problems. Therefore we need to highlight discrepancies between professionals' and patients' opinions of service quality and address these through training. In theory people with learning disabilities are included in National Service Frameworks but in reality we were told that many of the standards are not applied to them.

Some professionals were apprehensive that services are insufficiently prepared to cope with changing demographics in the Learning Disability population. Improvements in neonatal care over the last twenty years have led to an increasing number of children with very complex health care needs and adult services should be preparing to support this cohort. We were told that services need to be more forward-thinking in terms of planning delivery but also there should be more focus on preventive work with people with learning disabilities, such as better support to lead a healthy life in terms of diet and exercise.

3.3.6 Person-centred support

As with the other groups, professionals also identified frontline support staff as key players in changing the lives of people with learning disabilities. However, they also realised that there is still a lot of old-fashioned practice. Lack of, or poor, training for support workers was identified as one barrier and it was felt that people with learning disabilities themselves should be involved in providing training. However more importance was placed upon fundamental issues such as attitudes, which can be harder to change. People said that staff need to know how to interact with people with learning disabilities, and enthusiasm combined with a creative and innovative approach to problem solving are all attributes that good supporters should possess:

'Knowing what people want and what is good practice does not ensure that it happens. Some staff are able to make the impossible possible and some make the possible impossible – this is where it is about attitude.'

One group said that the medical model of learning disability is not always helpful. In order to change attitudes, it was agreed that we need to focus more on the social model of disability, and on person-centred solutions. There was also debate about the new types of support and concern that individualised support may make people more vulnerable and isolated.

There were some difficult cultural issues which were recounted at the workshops. One example given related to a teenage girl from Bangladesh who wished to be supported to go out socially and mix with people of her own age but her family did not approve of this. As the participant said, 'Whose values and choices are respected in this situation?'

Support given to the workforce was another issue discussed. If good supervision and support are not forthcoming, support workers can become demoralised and seek other employment. People with complex support needs require support workers with very good skills, yet care workers are

generally treated and paid as unskilled staff.

It was agreed that there is a massive variation in how person-centred planning is put into practice; ultimately PCPs are only as good as the people implementing them.

'When is PCP not PCP? Why doesn't it always involve the individual concerned?'

3.3.7 Relationships: sexuality, abuse, and learning

For practitioners, relationships and sexuality were linked with rights as well as with the possibility of abuse and risk. However, they also focused on education, which could help people with learning disabilities take more responsibility for their own sexual lives. We were told that education about sexuality is not offered to people with learning disabilities as a matter of course.

Parenting was also widely discussed by the professionals. There was consensus that support for parents with learning disabilities often comes too late and guidance and training are needed along with more accessible information. The topic of enforced abortion was also broached at one workshop with one professional stating that, while it may be illegal, she knew of undocumented cases. There was also a discussion about the fact that having children is a human rights issue and professionals should not be reluctant to use existing legislation such as the Human Rights Act to support people with learning disabilities who want a family.

3.4 Summary of the issues raised in the first round of 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)

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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)

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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)

For the purposes of a year-long review, it was necessary to rationalise and prioritise this long list. This was done, as explained above, 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 which were summarised are listed after each topic area below, 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 older people with learning disabilities. It will be noted that the issues that had been mentioned at least once in initial workshops, but subsequently had to be left out of the literature search were:

- Those issues relating to service processes (these had not been mentioned at all by people with learning disabilities), including person-centred planning and transition.
- Self-advocacy and advocacy (only mentioned in one workshop)
- Police, courts and the criminal justice system (only mentioned by one participant)

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- Gender issues
- Children and education (only mentioned once)
- Mental health and emotional support (mentioned twice, but excluded as it is a very large area of literature and could have taken over the whole review).

It is fully recognised that all of the above are important topics, and could be the subject of future reviews and prioritisation exercises. However, following the consensus and advice of workshop participants, the topics listed below are the ones which we used, in order to carry out the literature searches which will be described in the ensuing chapters of this report. Their relationship to the initial long list is given in the numbers after each theme, relating to the 29 issues mentioned above. For a summary of the procedure and evidence used in establishing priorities, the reader is referred also to Section 2.1.4.

3.4.1 Access to mainstream health services (Long list: 14)

- People with learning disabilities said they often have problems in accessing ordinary health care, including both primary services and hospitals.
- The issues raised included communication difficulties, lack of accessible information, and diagnostic overshadowing.
- Stakeholders felt that medical personnel often had inadequate training and understanding about Learning Disability issues.
- Health Action Planning (HAPs) did not appear to be used widely at present.
- The Health Service needs to be better prepared to meet increasing demands from people with PMLD and those with complex needs, including challenging behaviour.

3.4.2 Getting good support (Long list: 27 and 29)

- Flexibility of support, and meeting individual needs through person-centred approaches, was a common theme in our workshops.
- Family members and professionals were aware of the big changes underway in direct payments and individual budgets. They were concerned that workforce issues must remain high on the agenda because of these changes.
- Every group of stakeholders identified poor working conditions as a factor limiting the quality of support available.
- All stakeholders placed a stronger emphasis on the quality of the relationship between the support worker and the person with learning disabilities, than on formal qualifications.

3.4.3 The right to relationships (Long list: 10, 11 and 20)

- It is very hard to find new friends and to keep friends. People want a better social life.
- People very seldom choose who to live with.
- There are very few opportunities for people with learning disabilities to learn about sexual relationships.
- People want the right to be parents, to keep their children, and to have good support.
- People who care for other members of their family, or for partners, also need recognition as carers, and full support.

3.4.4 Somewhere to live (Long list: 16)

- People with learning disabilities wanted somewhere good to live, somewhere that was safe and near their friends.
- People wanted to choose the people they lived with; they said that this was seldom the case at the moment.
- People said they needed good support where they lived.
- It was important to stay in the local area, and particularly to stay near their families.

3.4.5 Employment and personal finance (Long list: 9 & 18)

- People with learning disabilities still have many problems about getting paid employment, choosing their own job, and pursuing a career.
- Benefits issues are still confusing, and are a real barrier for some.
- People said they needed more support with managing money.
- The financial system excludes people, by lack of accessible information, for instance about banks, bills and pin numbers.

3.4.6 Inclusion in the community (Long list: 1, 2, 5, 7 and 26)

- People with learning disabilities want to get outside the 'Learning Disability' box, and we must look to wider community and ordinary services in our thinking.
- Lack of accessible transport is one of the barriers faced by people who just want to 'go out'.
- Living in the local area is important, and family support continues to be important for people who want to have a life in their own community.
- People face bullying and hate crime all too often. It is important that this is treated as a crime.

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3.5 References Chapter 3

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

Mental Capacity Act 2005. London: The Stationery Office.

4 Access to Health care

Health is an issue of fundamental importance for the lives of people with learning disabilities. Historically, it was long considered that Learning Disability services should fall under Health, but we now understand that having a 'learning disability' in itself is not a health problem. However, there are many factors which create particular barriers and difficulties for people with learning disabilities, including:

- specific health problems associated with certain 'syndromes'
- factors associated with social exclusion, including poverty and lack of mobility
- lifestyle factors, including obesity and exercise
- lack of access to mainstream health services.

For all these reasons, stakeholders in our review were clear that research still needs to address the problems and barriers that they face in accessing health care. This review followed closely the issues raised by the stakeholders in our workshops. As explained in 2.1.1 of this report, the review also focused specifically on social research. Therefore any research papers which focused entirely on the following key topics were excluded:

- information about treatments
- aetiology of illness or impairment
- genetic research
- causes or treatment of dementia
- causes and treatment of mental health
- descriptions of specific syndromes.

This does not mean these are unimportant topics, and we know that research has to continue in all these areas, to improve the lives of people with learning disabilities and their families. However, this chapter deals in the main with research about lifestyle issues, access to generic health services and health inequalities. The specific search terms for the review are listed in Appendix A. They were all generated by the concerns expressed by participants in the stakeholder consultation, and so there is an emphasis on 'care' – e.g. 'cancer care' rather than 'cancer'. We will start with a review of the research since 2001 in those areas, before turning to the research gaps and priorities identified.

4.1 Research methodology: access to health care

4.1.1 Methodology

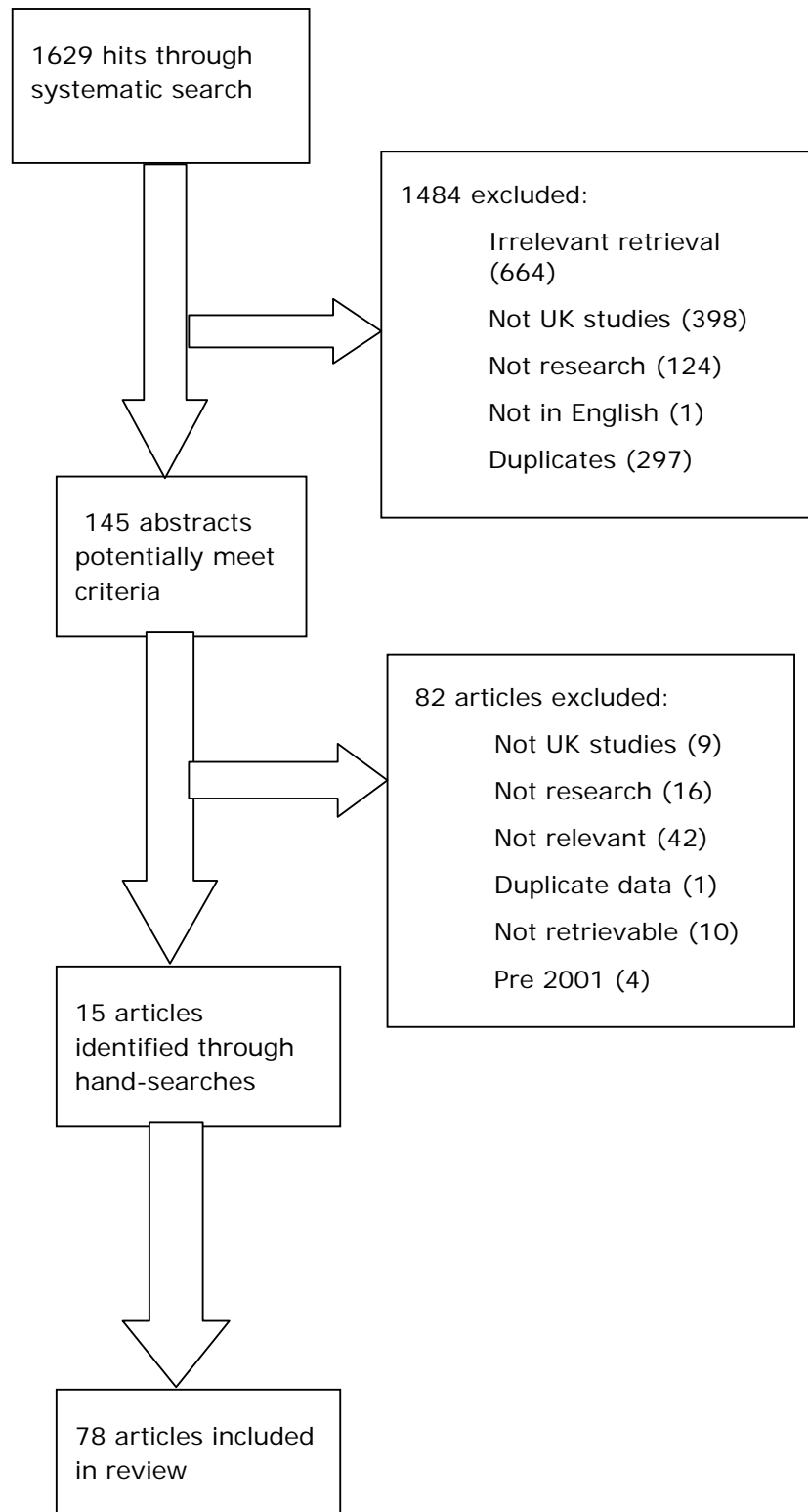
Using the search terms given in Appendix A, 'access to health care' yielded 1629 hits. These were sifted in two stages. 1484 were excluded at the initial retrieval stage; if there was any doubt about the relevance of the item, the abstract was retrieved and scanned. A further 82 articles were excluded at the abstract stage. The following rules for exclusion were applied systematically at both these stages:

- 1) Not about the topic (of health care and learning disability)
- 2) Not UK studies (where the research was based entirely outside the UK)
- 3) Not research or reviews of research (opinion papers without empirical basis; short practice descriptions were excluded)
- 4) Paper not written in English
- 5) Duplicates
- 6) Research published before 2001

A further 15 articles were identified through hand searches (including *British Journal of Learning Disabilities*; *Journal of International Disability Research*; *Journal of Learning Disabilities*; *The Learning Disability Review*) and so the total for the review in this area was 78. This process is represented in Figure 1 below.

Figure 1: Flow chart of the literature search for "Health"

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4.1.2 Evaluation of research reviewed

a) Quantitative research

A summary of the appraisal data for each topic in this report is given at the end of Appendix B. What follows here is an evaluative overview of the topic area. The research in this area was predominantly quantitative in its approach (34 papers, 44%). None of these studies explicitly used power calculations to inform the sample sizes and few of these were large-scale studies. Some of the larger studies collected data about people with learning disabilities via other health professionals (e.g. Bland, Hutchinson, Oakes and Yates, 2003; Taggart, McLaughlin, Quinn and Milligan, 2006). One large-scale study compared mortality rates for people with learning disabilities and the general population and this analysed data for 2436 adults (Tyrer, Smith and McGrother, 2007). Sixteen of the quantitative research studies (47%) did not directly involve people with learning disabilities, even as participants, although they were included on one research advisory group. The largest studies directly involving people with learning disabilities analysed data from 1542 participants in Emerson *et al's* survey (2004). One of the quantitative studies statistically analysed data from only nine participants (Bradley, 2005) and many of these small studies recommended the topic should be further explored with larger samples.

b) Qualitative research

Just over a quarter of the studies reviewed (23 papers, 29%) used a qualitative methodology. The primary methods for data collection were semi-structured interviews and focus groups. Methods for analysis of the data included content analysis, grounded theory, phenomenological analysis and a framework approach. None of the qualitative studies in this review employed other data collection methods such as direct observation.

Thirteen of these (57%) studies collected data from professionals or family members as opposed to directly including people with learning disabilities. However three of the projects had people with learning disabilities working as researchers and another included them in an advisory group. Overall there is a paucity of research which directly explores the experiences of people with learning disabilities in relation to their health.

Two of the qualitative studies (Kirk and Glendinning, 2004; Chadwick, Jolliffe, Goldbart and Burton, 2006) related to people with high support needs but focused on the perspective of professional carers and family members. Therefore there are no studies identified in this review which provide the narrative of people with high support needs. For the research findings to be more representative, researchers must find a way to include the voice of people with more severe learning disabilities.

4.1.3 Scope of research

Table 3: Research studies about health for people with learning disabilities since 2001

Inequalities in access to health services	16
Lifestyle factors	13
Health checks and screening	10
Communication	11
Staff roles and training	18
Dysphagia	4
Pain management	4
Children	4
Palliative care	7
Dental health(not retrieved)	5
Total in critical review	78

A total of 78 relevant papers were identified in the literature review of health care. These were classified into 10 separate themes, although many papers contributed evidence to more than one theme.

- Sixteen papers (21%) explored inequalities in access to health services. Such research has demonstrated increased mortality rates for people with learning disabilities and identified barriers to both primary and secondary care.
- There was also a body of work around staff roles and training, exploring various health professionals' roles and training needs. Only a small proportion (3 papers, 4%) of these evaluated the impact of a training programme.
- Ten studies (13%) contributed evidence around communication. These addressed systems of communication between professionals as well as communication between professionals and patients. Some of this research looked at the utility of accessible information.
- The relationship between lifestyle factors and health was explored in 13 studies (16%), with over half of these relating to diet. However there was also research about exercise, substance use and socio-economic status.
- Only a small proportion of the papers specifically focused on older people

(4%), or children (5%), and any particular health problems they may have.

- A larger proportion of the studies specifically related to people with high support needs (9%) and some of the other studies may have included people with high support needs.
- None of the studies specifically discussed culture or ethnicity as issues nor did they explore any particular health needs in relation to different ethnic groups.

In general, the research studies included in this review did not tend to overlap with other themes, despite the fact that many aspects of peoples' lives, such as relationships and housing, will affect their health. There were several studies, however, which dealt both with health care and support.

4.2 Findings and outcomes from the research: what we know and what we need to know

4.2.1 Inequalities in access to health services

Reviews

There have been two major reviews of research in this area since 2001, conducted by Alborz, Glendinning and McNally (2005) and Elliott, Hatton and Emerson (2003). Alborz *et al* (2005) reviewed evidence which showed that many people with learning disabilities have basic unmet health needs and may access GPs and dental surgeries less often than others. The particular factors were to do with physical access, communication problems between health professionals and patients, and provision shortage. The research reviewed by Elliott *et al* (2003) particularly highlighted the significantly poorer health of people with learning disabilities than the general population in a number of priority areas such as mental health and dementia. Research had also revealed lower incidence of health checks for people with learning disabilities, and poor collaboration between primary and secondary health services.

Empirical papers

The extent of health inequalities for people with learning disabilities is most dramatically illustrated by increased mortality rates in comparison to the general population (Tyrer *et al*, 2007). These authors analysed data for people with moderate to profound learning disability showing that both all-cause and disease specific mortality rates were over three times higher than those for the general population. These rates varied considerably with age and there was also a clear gender effect, with increased rates for females. People with Down's syndrome and women living in cities were at a particular high risk of dying young. Statistical analysis of the data available for people with learning disabilities discharged from long-stay hospital into the community has also revealed unexpectedly high morbidity rates for those moved into community care, but not for those who stayed in health

care (Read, 2004). The author suggests that selection bias could account for the high mortality rate but these studies do indicate there may be specific groups of people with learning disabilities at an increased risk and it may be appropriate to target interventions at these groups and to explore why these groups are particularly vulnerable. For example, Duff, Scheepers, Cooper, Hoghton and Baddely (2001) analysed data from people living in institutional hospitals and found an unusually high proportion of deaths caused by stomach cancer. They proposed this was due to high levels of *H. pylori* infection and that closure of institutions without evaluation of these levels may spread the infection into the community. Mencap used a series of case studies to highlight serious failures in health care services for people with learning disabilities (Mencap, 2007). The six case studies presented in 'Death By Indifference' related to people with profound learning disabilities who died in hospital. Mencap argued that these deaths were all preventable and called for an independent inquiry. There is clearly a need for more research to find out why the inequalities in health persist. For instance, are people with learning disabilities being denied certain health procedures or operations?

The research clearly demonstrates that major improvements are needed for health care services, and there is a body of work which has looked in more detail at what changes are required for both primary and secondary care. Thirty nine per cent of people with learning disabilities receive less eye care than the general population, yet a very high rate of satisfaction was reported when eye examinations were offered to a sample of adults with learning disabilities (Starling, Willis, Dracup, Burton and Pratt, 2006). People with learning disabilities are often reliant on others to initiate their contact with health services, but even when this does happen there are many other obstacles which limit the quality of care provided for them in both primary and secondary care, including:

- physical access, transport to appointments and parking (Lennox, Nadkarni, Moffat and Robertson, 2003; Cumella and Martin, 2004)
- lack of reliable and valid measures and assessments (Bollands and Jones, 2002; Ruddick and Oliver, 2005; Brown and MacArthur, 2006)
- less regular health checks and preventive health care
- lack of knowledge of Learning Disability in mainstream health care professionals and appropriate staff training (Bollands and Jones, 2002; Wharton, Hames and Milner, 2005; Brown and MacArthur, 2006)
- communication problems between patient and clinicians (Ruddick, 2005; Wharton *et al*, 2005;)
- poor collaboration between GPs, primary health care teams and specialist services (Bollands and Jones, 2002; Wharton *et al*, 2005; Brown and MacArthur, 2006)
- clinicians speaking to carers and not the patients (Lennox *et al*, 2003)
- appointment waiting times (Lennox *et al*, 2003; Wharton *et al*, 2005)

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- diagnostic overshadowing (Mencap, 2004)
- discrimination (Mencap, 2004).

The studies cited above used a variety of methodologies. Most were from the perspective of people with learning disabilities and their families, but some included the opinions of professionals as well. Other research has identified further problems from the clinician's perspective:

- consent issues, particularly around invasive treatment (Cumella and Martin, 2004; Sowney and Barr, 2006)
- inadequate information provided from carers, community learning disability teams and GPs (Cumella and Martin, 2004)
- challenging behaviour (Cumella and Martin, 2004)
- dependence on carers (Sowney and Barr, 2006)
- lack of knowledge and training (Sowney and Barr, 2006).

Moreover there are additional problems involved in a hospital admission. These include:

- anxiety about the stay, exacerbated by lack of information and emotional support (Bollands and Jones, 2002; Cumella and Martin, 2004)
- carers expected to be there constantly to provide practical support (Cumella and Martin, 2004; Wharton *et al*, 2005)
- inadequate facilities for those with complex needs (Cumella and Martin, 2004; Wharton *et al*, 2005).

As the above summary shows, there is plenty of evidence about barriers to health care faced by people with learning disabilities. However, there appears to be a gap in research which explores solutions.

One study (Hannon, 2004) reviewed explored if a pre-admission assessment improved the experience of a hospital stay for people with learning disabilities. This was a qualitative study with a small sample. However all the participants' experiences of their admission were better than expected. The participants described being treated the same as other patients and being satisfied with the standards of cleanliness and food. Carers reported good support from the hospital staff and the hospital staff were very positive about the input from the community nurses. There were some negative issues such as doctors not speaking directly to the patients, but overall it appears that the pre-admission liaison work was effective in making the stay a more positive experience.

Key points for the research agenda

- People with learning disabilities are facing premature, preventable deaths because of failures in health care.
- There is evidence that people with learning disabilities may be directly and indirectly discriminated against in terms of their health care,

particularly those with complex needs and behavioural challenges.

- Liaison and preadmission work can improve hospital stays from all perspectives, including that of carers.
- There are gaps in research which would help us understand the reasons for health inequalities, more precise issues around access to treatments, and research that could analyse and spread good practice.

4.2.2 Lifestyle factors

Reviews

Two literature reviews of obesity and Learning Disability were retrieved (Ells, Lang, Shield, Wilkinson, Lidstone, Coulton *et al*, 2006; Melville, Hamilton, Hankey, Miller and Boyle, 2007), showing that prevalence of obesity in adults with learning disabilities appears to have increased over the past 20 years, reflecting changes in the rest of the population. However the majority of studies reviewed in these papers suggest that there are higher rates of obesity than for the general population, and that obesity is a significant factor contributing to reduced life expectancy. Moreover it should not be assumed that a healthy BMI reflects a good nutritional diet as less than 10% of people with learning disabilities have a healthy diet, and there is clearly a general need for nutritional advice for many adults with learning disabilities (Ells *et al*, 2006). Furthermore obesity tends to occur at a younger age, leading to earlier obesity related problems such as diabetes (Melville *et al*, 2007).

Empirical research

Our search found seven papers exploring diet and nutrition in relation to Learning Disability (Marshall, McConkey and Moore, 2003; Kennedy, Pannell and Summers, 2004; Bradley, 2005; Chapman, Craven and Chadwick, 2005; Emerson, 2005; Ells *et al*, 2006; Melville *et al*, 2007). Emerson (2005) reported findings from a large scale survey of over 1500 adults with LD living in supported accommodation. The data from this and from two literature reviews of obesity and LD (Ells *et al*, 2006; Melville *et al*, 2007) show there are a number of risk factors for obesity:

Taken together, these show there are a number of risk factors for obesity, including:

- gender – women are at higher risk
- severity of disability – people with mild learning disabilities are more likely to be obese
- living environment – higher risk for those living in less restrictive accommodation
- staffing levels – higher obesity rates where senior staff are missing
- specific syndromes – e.g. Prader-Willi syndrome, Down's syndrome

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- medication – psychotropic medications commonly prescribed can cause significant weight gain.

As obesity increases the risk of diabetes, cardiovascular disease, hypertension, various cancers, gallstones and osteoarthritis, it is clearly a major concern that its prevalence is so high and still growing. To address this, a number of researchers have explored the potential benefit of dietary advice/health promotion classes for weight loss (Marshall *et al*, 2003; Bradley, 2005; Chapman *et al*, 2005). There was evidence that these led to weight loss for most participants and Bradley (2005) noted improved diets for all the participants, in particular an increased consumption of fruit and vegetables. Chapman *et al* (2005) employed a more rigorous methodology as they used a control group, whose body mass index (BMI) increased over the time-scale of the study. In comparison those receiving health promotion information, dietary advice and activity programmes showed a statistically significant weight reduction. These findings suggest interventions can be effective, but perhaps the difficulty lies in initiating action in the first place; in phase one of their study Marshall *et al*, (2003) found 122 people had been identified for weight reduction but action had only been taken for 34 per cent of them. Therefore these authors suggest that health professionals and support staff have an important role to play and that there is also a need for training and advice for support staff around nutrition and exercise. Case studies have shown that staff can be very receptive to such initiatives (Kennedy *et al*, 2004). However, these authors discuss the fact that guidance for people with learning disabilities about good nutrition must be balanced with their right to make 'unhealthy' choices about their lives, but it should be ensured that these are informed choices. There have also been cases where people with learning disabilities are restricted by factors that staff deem to be important, such as prioritising cheap food over healthy options (Kennedy *et al*, 2004).

In comparison to the research on obesity, there is a paucity of research looking at the health risk of being underweight. Marshall *et al* (2003) identified a small proportion of adults with learning disabilities who were underweight and argued that this necessitates further research.

Exercise is another crucial factor related to obesity and people with learning disabilities, particularly those in supported accommodation, tend to have sedentary lifestyles (Emerson, 2005). Hawkins and Look (2006) identified levels of physical activity for people with learning disabilities and while their rates were higher than those suggested by previous research, they were still lower than for the general population. They identified five main barriers to activity, namely:

- lack of understanding of the benefits of exercise
- mood
- lack of awareness of available options
- risk assessment issues

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- financial constraints.

Funding for physical activities could prove to be cost-effective in terms of the benefits in physical and mental health so the authors argue this should be prioritised. However, little is known about what would really work in terms of motivating people with learning disabilities to take more exercise. A 16 week exercise programme for people with severe and profound learning disabilities was evaluated using Goal Attainment Scaling (Jones, Walley, Leech, Paterson, Common and Metcalf, 2006). Although participants exhibited little weight loss, there were significant gains in aggregated goal attainment in terms of behaviour, access to community-based activities, health and physical competence.

Smoking and alcohol intake are other important lifestyle factors, but little research focuses on people with learning disabilities and the evidence is mixed. Two studies have highlighted a need to address these issues, as there are increased rates of smoking by adolescents with learning disabilities (Taylor, Standen, Cutajar, Fox and Wilson, 2004; Emerson and Turnbull, 2005). Those with mild learning disabilities are more likely to smoke more heavily and, even controlling for the level of learning disabilities, it was found that smokers were more aware of the health risks than non-smokers. This dissociation between knowledge and health-related behaviour, as is argued in these papers, has implications for more support and health education for this group, using accessible materials. In general, there appears to be a need for more research about the health risks of independent living for people with learning disabilities.

More recent work has revealed continuing unmet needs of people with learning disabilities who misuse substances (Taggart *et al*, 2006; McLaughlin, Taggart, Quinn and Milligan, 2007). Taggart *et al*'s survey showed that alcohol was the substance most likely to be abused and that the risk factors related to this were:

- being young and male
- having a borderline learning disability
- having a mental health problem
- living independently.

Professionals described a lack of training for staff working with people with learning disabilities and substance abuse issues. Semi-structured interviews with staff working with this population showed that services rarely met their needs and these authors argue that it is imperative that clear protocols and frameworks are established to allow Learning Disability and Alcohol and Drug Services to collaborate more effectively (McLaughlin *et al*, 2007).

The final lifestyle issue addressed in the research studies retrieved in this review is socio-economic status. Emerson and Hatton (2007) concluded that socio-economic disadvantage may account for a significant proportion of the health inequalities for people with learning disabilities, in terms of both physical and mental health. This suggests that health promotion for people

with learning disabilities may need to be aimed at more deprived families and moreover that social policies must address socio-economic inequalities and their contribution to health status.

Key points for the research agenda

- There is evidence that many lifestyle factors, including diet and exercise, contribute to the health inequalities experienced by people with learning disabilities and that these must be addressed.
- Interventions such as dietary advice courses or exercise programmes may have significant and varied benefits for people with learning disabilities.
- Much of the research clarifies the particular risk factors, indicating groups that should be targeted by health promotion work.
- Professionals need education about how to support people with learning disabilities to lead a healthy lifestyle and how to work with those with specific problems such as substance misuse.
- There are gaps in research about the health risks of independent living, and about what works in terms of encouraging people with learning disabilities to take more exercise.

4.2.3 Health checks and screening

Empirical research

Several studies have investigated the benefits of providing structured health checks to people with learning disabilities (Cassidy, Martin, Martin and Roy, 2002; Martin, 2003; Baxter, Lowe, Houston, Jones, Felce and Kerr, 2006). These have all demonstrated positive effects, including the fact that these checks highlighted treatable conditions that may not have received attention (Martin, 2003; Baxter *et al*, 2006). Cassidy *et al* (2002) found that 94% of those attending their first check had a physical health problem warranting intervention; such problems were reduced at subsequent checks and both carers and patients were happy with the checks and felt them to be a good idea.

From the literature reviewed, the health gains from health screening programmes appeared to be both significant and sustained. In one study the incidence of health need detection was twice as great for people who had been through the screening programme and they also had much higher level of met new health needs in comparison with a control group (Cooper, Morrison, Melville, Finlayson, Allan, Martin *et al*, 2006). The authors concluded they had identified an effective intervention requiring minimal staff time, training and additional costs, which should be implemented in both rural and urban areas. There is some debate about who should be responsible for undertaking health checks. GPs may be reluctant to be responsible for this; three-quarters of those surveyed by McConkey, Moore and Marshall (2002) in Northern Ireland felt this would be better provided within the context of special services

In addition to annual health checks, research has also looked at the inclusion of people with learning disabilities in routine health services such as specific screening programmes. However evidence suggests that cervical, breast and testicular examinations for people with learning disabilities were rare (Bland *et al*, 2003). For the women who do receive invitations to breast screening programmes, their attendance rate is much higher than that of the general population (Davies and Duff, 2001), and so these authors argue that all eligible women with learning disabilities should be included in mammography databases

The uptake of services such as eye-examinations and dental checks is much lower for people with learning disabilities than for the general population. When Starling *et al* (2006) offered eye tests to a cohort of adults with learning disabilities they found it was possible to undertake this with all those who accepted. Some people with profound learning disabilities needed to be assessed at home and some could not use conventional tests, but an adequate examination was successful for everybody. Assessment in a familiar and safe environment will improve success and should be offered when necessary.

Valuing People (DH, 2001) stated that all people with learning disabilities should have a Health Action Plan (HAP) by June 2005. This was an area identified as requiring further research at our workshops by all stakeholder groups. Some of the people with learning disabilities stated their desire to have a HAP but they had not been able to identify who should assist them with implementing this. A large-scale project which involved 12 primary care trusts (PCTs) across the UK concluded that there needs to be effective collaboration between PCTs and specialist services to introduce HAPs (Giraud-Saunders, Gregory, Poxton, Smith and Towell, 2003). There was a great deal of consensus from all the stakeholder groups that there is a need to know how many people want a HAP, how many people have one and whether they are leading to better health outcomes. Only one piece of literature retrieved in this systematic search related directly to this issue (Mir, Allgar, Cottrell, Heywood, Evans and Marshall, 2007) and it demonstrated that HAPs were by no means fully implemented yet, and that many people with learning disabilities and their carers do not fully understand HAPs. The authors of this study recommend that local funding should be identified in order to permit the introduction of annual health checks linked to HAPs.

Key points for the research agenda

- Annual health checks can help to identify treatable health problems and demonstrate sustained health gains for individuals.
- When people with learning disabilities are included in screening programmes for the general population, their take-up rate is higher than for others.
- A research gap exists about health action plans (HAPs), in terms of the extent of their use and their link with health outcomes.

4.2.4 Communication

Reviews

Another priority raised in our workshops was the need for accessible information in regard to health and this covers a whole range of services. However, a review of Northern Ireland research by McConkey (2006) showed that the provision of accessible health care information is not straightforward as many of the issues and ideas are complex. This review found little evidence that health promotion was an integral part of service delivery to this client group in either specialist or primary health care.

McConkey (2006) also argued that, in order for people with learning disabilities to give informed consent to clinical treatment, they may need easy to understand information about the types of services available to them.

Empirical research

All the research reviewed in this area was in agreement that communication is vital to receiving good health care and it is also crucial for services to be well run and effective. Watson, McDonnell and Bhaumik (2005) evaluated a multidisciplinary single point of referral (SPR) system for adult LD health services. They argued that many people with learning disabilities are reliant upon Community Learning Disability Teams, or their GP, to refer them on to appropriate specialists. Therefore systems need to manage the sharing of patient information in order to ensure each patient receives appropriate input and is able to access health services they need. In many areas, separate referral systems have led to inefficient working and communication. A single point of referral system can significantly reduce waiting times from referral to assessment, and also help to ensure that referrals are appropriate (Watson *et al*, 2005). As well as improving multidisciplinary working, there was an increase in professional satisfaction.

Various systems and tools have been used to improve communication within multidisciplinary teams and it has been hypothesised that Client Held Hand Records (CHHR) can help to share information between professionals and encourage the patient to take an active role in their own health (Kennedy, 2003). Concerns about their utility include the fact they are not always available, as they are the responsibility of the patient. Alternatives to the CHHR include the health monitoring tool aimed to improve communication and liaison with health care providers on behalf of people with learning disabilities with complex communication needs. Curtice and Long's (2002) evaluation supported its continuing use, as it facilitated appointments and there was also evidence of it being used proactively, for example to support referrals. There are many difficulties in obtaining reliable self-reports, but this is crucial in order to genuinely include people with learning disabilities in discussions and actions relating to their personal health, as is envisaged by the health action planning (HAPs) system described and evaluated earlier (Mir *et al*, 2007). The Health Status Measure represents an attempt to develop a reliable self-report tool to be used by people with learning

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disabilities (Ruddick and Oliver, 2005). Reasonable internal reliability was found for most of the scales but it is not suitable for people with non-verbal communication.

By contrast, the Disability Distress Assessment Tool (DisDAT) was specifically developed for use with people with profound communication difficulties (Regnard, Reynolds, Watson, Matthews, Gibson and Clarke, 2007). This uses behavioural cues to assist with identification of distress; carers report it is easy to use and it could be of use for clinical teams.

These studies have reviewed the use of tools to improve patients' communication of pain to professionals. However in our workshops one of the most commonly raised issues was that of professionals' ability to communicate directly with people with learning disabilities. Both people with learning disabilities and their family related situations where the patient has been ignored and all questions directed at the carer. Similarly many professionals highlighted the lack of training about Learning Disability issues for general health care staff. Despite the prominence of this as an area of concern for all stakeholder groups, there was only one study identified for the review that explored communication, and so this would appear to be a research priority area. Murphy (2006) used focus groups to explore communication between people with learning disabilities and GP staff. They identified specific problems such as waiting rooms environments, continuity and lack of training for GPs. They were able to identify some solutions such as double appointments, but GPs felt they did not have the time for training, despite their need for it. While patients wanted a reduction in reliance on carers, they were not always able to understand the GP's advice, nor did they know how to communicate it to others; Murphy argues that pictorial or written information to take home could assist with this. This study also noted people with severe communication problems are often excluded from research studies and so an effort was made to recruit people who use communication aids such as picture symbols or Talking Mats®. Other research studies have also demonstrated that people with learning disabilities are able to be included in this type of research and have the ability to identify their own, personal needs, as in a study exploring what older adults want from their doctor (Fender, Marsden and Starr, 2005).

Accessible information about health issues was examined in two studies. Dunn, Stenfort Kroese, Thomas, McGarry and Drew (2006) examined the utility of a video for explaining the role of psychology and found that this did significantly improve participants' knowledge of psychology services. This information was better retained when they were shown the video in three sittings, rather than at one time-point. Further research is needed to explore the long-term maintenance of such knowledge. Tuffrey-Wijne, Bernal, Jones, Butler and Hollins (2006) conducted some research about accessible information for people with learning disabilities who were affected by cancer and discussed the desperate need for information (see *Palliative care* for further details).

Two other studies used different methodologies to investigate knowledge

about psychotropic medication (Strydom and Hall, 2001; Heslop, Folkes and Rodgers, 2005). Semi-structured interviews were used with people with learning disabilities, their carers and their doctors and these revealed that few people with learning disabilities were fully informed about their treatment, but they did assume their carers know all about the medication. Conversely the study showed that while carers knew how to administer psychotropic drugs, many were not aware of the reasons for prescription nor the potential implications (Heslop *et al*, 2005). Especially with medications with common side effects, these authors argued that carers and patients should be given more information and this should be tailored to the individual's needs. It may be there is a need for further research into how to best provide such accessible information. This will be particularly important under the new Mental Capacity Act (2005). One of the few randomised controlled studies identified in our review investigated the benefit of accessible medication leaflets. Participants with mild learning disabilities were randomised to receive either verbal information, or a specifically designed leaflet in addition. Paradoxically, those who received the leaflet had significantly reduced medication knowledge and understanding (Strydom and Hall, 2001). These authors speculated that this finding could possibly be accounted for by the tendency of health professionals to spend less time explaining medication if they have written information to give. Therefore in the short-term at least, patient information leaflets may confuse people with mild learning disabilities. Nevertheless the authors recommend the continued use of their specially designed leaflets. If recommendations by researchers contradict the evidence from a research study it perhaps suggests there was little point in undertaking the research, or that it could highlight methodological shortcomings.

Key points for the research agenda

- There is an evidence base to suggest single point referral systems are effective and improve health care delivery.
- There are many different issues affecting the quality of communication between people with learning disabilities and health professionals.
- However, we still do not know enough about good communication strategies, and how to help medical staff improve their practices.
- Accessible information about services, illnesses and treatments are all essential, but assumptions about the utility of these cannot be made and further research is needed to explore the most effective/appropriate formats.
- The Mental Capacity Act (2005) requires medical professionals to give patients accessible information, so that they can make health choices. This will be a priority area for further research.

4.2.5 Staff roles and training

Empirical research

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A group of papers was identified for this review relating to staff roles in health care. Findings from such research may not be very generalisable, as for example one study has noted inconsistencies across areas in terms of how the skills of Community Learning Disability Nurses (CLDNs) were employed (Boarder, 2002). There was evidence of a growing number of referrals and complex cases for CLDNs with increasing levels of pregnancy also adding to their workload. Messent (2003) explored factors contributing to job dissatisfaction and these included:

- lack of local CLDNs
- weak administrative support
- 'duty of care' preventing a waiting list which leads to less frequent client visits
- no uniform guidelines for discharging clients
- lack of resources.

It was felt that there was a lack of clarity about the role and responsibilities of CLDNs; over the last decade the role has evolved and this has been explored recently by Barr (2006). Currently there is a stronger focus on health, although nurses often have a monitoring rather than clinical role. This author argued that a consequence of these changes is that nurses require appropriate training so they can have a more active public health role. This paper also drew attention to joint working, recommending that nurses must be aware when people with learning disabilities cease to require specialist nursing services, and discharge such patients to be supported by primary care services.

The need for closer links between Learning Disability and Primary Health Care Teams has been identified in several studies (Boarder, 2002; McCray and Carter, 2002). It appears that these teams are unsure if they are meeting the health needs of people with learning disabilities but may not make use of all the resources available to them. Responses to a postal questionnaire from over 100 practice nurses revealed that none were working with advocacy services (Powrie, 2003). Similarly a survey of health professionals (including GPs, health visitors, physiotherapists and dieticians) showed that only 36% had any contact with their local Learning Disability team (Hames and Carlson, 2006). Worryingly, none of the respondents identified that the team could be involved in facilitating the general health care of people with learning disabilities. All these papers suggest that better links must be forged between Learning Disability professionals and primary care providers in order to improve the quality of health care received by people with learning disabilities. Better collaboration between Learning Disability teams and mainstream health professionals is needed to ensure that mainstream practitioners understand they are not expected to "treat" the learning disability but should just be using their clinical experience as they would with other patients (Giraud-Saunders *et al*, 2003).

Specific issues about the consent process and screening programmes have

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been identified; Powrie (2003) claimed that these could be addressed through joint funding by health and social services of initiatives and staff training.

Training was a topic on which there was a great deal of consensus from all the stakeholder groups represented in our project. Overwhelmingly people identified a strong need for better training about Learning Disability issues for mainstream health professionals. The perspective and training of practice nurses was explored via a postal questionnaire and this showed that despite the growing workload with people with learning disabilities, only 8% had ever received any training on communicating with people with learning disabilities (Melville, Finlayson, Cooper, Allan, Robinson, Burns *et al*, 2005).

Having clearly demonstrated the training needs for primary health professionals, these authors subsequently developed and evaluated an intervention (Melville, Cooper, Morrison, Finlayson, Allan, Robinson *et al*, 2006). They compared the benefits for a group of practice nurses of receiving:

- a training pack in conjunction with a training programme
- only a training pack
- nothing.

The training intervention had a positive impact in terms of knowledge, skills and clinical practice, with a significantly greater change in knowledge and self-efficacy for those receiving the programme as well. Such education programmes should be theory based and outcomes should be systematically assessed.

Previous research exploring the barriers to accessing mainstream secondary health services has noted that lack of education for the staff is one of the primary problems (Bollands and Jones, 2002; Wharton *et al*, 2005; Brown and MacArthur, 2006; Sowney and Barr, 2006). Given that over a quarter of people with learning disabilities attend hospital annually, it is surprising that only one of the studies reviewed here evaluated Learning Disability training given to staff in a general hospital (McMurray and Beebee, 2007). All attendees found this training useful and identified how this could also improve their work with other groups of patients, such as those with communication problems through strokes or limited English. Both knowledge and confidence improved following attendance at a one-day course and the authors argued this should be mandatory for all hospital staff. Furthermore they felt that service user involvement in the training is crucial. Following the evidence of this study, it would seem that there is a need for action research, to find out more about how service users could be further involved in such training.

A few studies have explored the effect of training on attitudes and expertise of professionals in more specific roles, such as optometrists (Adler, Cregg, Duignan, Ilett and Woodhouse, 2005). They compared the effects on

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attitudes, expertise, knowledge and confidence of an educational programme comprising both lectures and supervised patient contacts, with lectures only. Both groups showed significant improvement in terms of knowledge and confidence, but only those who had experience of patient contact showed significantly better results on the attitude outcome. Therefore this research suggests that training will be more effective if it incorporates clinical experience with real patients.

Tuffrey-Wijne, Hollans and Curfs (2005) explored the specific training needs of palliative care staff in relation to work with people with learning disabilities. The training needs they identified were in relation to:

- communication
- assessment and symptom control
- patient comprehension
- empowerment
- ethical/consent issues.

They discuss the need for the development and evaluation of a training programme that encompasses these topics.

The role of CLDTs has been explored from the perspective of Occupational Therapists (OTs) using semi-structured interviews (Lillywhite and Atwal, 2003). The OTs regarded the other professionals as having unique roles within the team, but felt that the majority of people in the team did not have a comprehensive concept of the OT role. These authors also found little evidence of joint working with other professionals and noted that overlap between professional roles is not well managed. In order to ensure appropriate referrals, and therefore ultimately improve the service to people with learning disabilities, it was concluded that professionals should have a good understanding of the roles within a multidisciplinary team and there should be strategies in place to encourage partnership working.

A large study exploring the Valuing People health targets was one of the few health related research articles to discuss the issue of ethnicity. Mir *et al* (2007) recommended that members of CLDTs would benefit from specific training on "double discrimination" to help them effectively support people with learning disabilities from minority ethnic communities.

Key points for the research agenda

- Training for mainstream health professionals is crucial and there is some evidence that it is likely to be improved by the active involvement of people with learning disabilities, and by clinical experience with real patients.
- Integrated working between health and social care trusts needs to be improved in order to maximise skills and resources and ultimately deliver a better service for people with learning disabilities.
- It would be useful to have more action research in this area, particularly about people with learning disabilities training medical staff.

4.2.6 Dysphagia (difficulty in swallowing)

Empirical research

Few studies have investigated dysphagia management for adults with learning disabilities, which is surprising given that it is common and has potentially life-threatening implications. Research with carers shows that they had better knowledge of some aspects of management guidelines than others. For example, information about equipment and food consistency appeared to be better retained than advice on support and prompting (Chadwick, Jolliffe and Goldbart, 2002). This study also identified some discrepancy between compliance and knowledge, suggesting that Speech and Language Therapists (SLTs) may need to plan refresher sessions for support staff. The evidence shows that adherence to guidelines developed by SLTs is generally good, particularly where they are more concrete (Chadwick, Jolliffe and Goldbart, 2003).

A subsequent study (Chadwick *et al*, 2006) further explored the barriers that make some of the guidance harder to follow, and identified:

- achieving correct consistency for food and drink
- achieving the correct positioning
- using support and prompting strategies
- time pressures
- staff turnover
- insufficient reviewing of SLT strategies by carers
- objections from more cognitively able people about the modifications to food and drink.

The authors acknowledged the conflict between individual choice, which is promoted by policy, and SLT recommendations that are primarily designed for health reasons. They suggested that more accessible explanations for the guidance are provided, staff ratios are increased at mealtimes and that inter-disciplinary working between SLTs and physiotherapists is increased. They stated the need for further research to determine the most effective method of training carers. The final study included in this review that relates to dysphagia identified predictors for asphyxiation, which is a significant cause of mortality for people with learning disabilities (Samuels and Chadwick, 2006). These were:

- speed of eating
- cramming food
- premature loss of the bolus into the pharynx.

These risk factors highlight the importance of the work by health professionals to develop appropriate eating strategies and suggest aspects of the process to target. Dysphagia management is a research priority.

4.2.7 Pain management

Empirical research

Pain is a subjective experience and consequently it is usually defined by the patient directly. However when the patient has learning disabilities, there may be problems with cognition and communication that lead to a failure to recognise and thus manage pain. Previous research has demonstrated that general nurses find it difficult to perceive their patients' pain accurately, but this review only identified one study exploring the issue for Learning Disability nurses (Donovan, 2002). This study emphasised the need for nurses to recognise changes in verbal and non-verbal behaviour and to be aware that such changes might be due to untreated pain. It was also highlighted that nurses should not make assumptions about the causes of pain and that they should be aware that some patients may have the ability to speak, but still have problems in articulating a concept such as pain.

The largest study in this area focused specifically on people with learning disabilities and dementia (Kerr, Cunningham and Wilkinson, 2006). This project interviewed:

- people with learning disabilities and dementia
- support staff working with these people
- CLDT staff
- GPs.

Thematic analysis showed that issues such as staff training about pain recognition and management is urgently required and also the need for a formal assessment tool. Subsequently the authors made a list of recommendations for frontline staff, other health professionals and service commissioners. There have been some steps towards developing a formal tool to identify distress in people with profound communication difficulties (Regnard *et al*, 2007). Further work is needed but a tool such as the DisDAT may help to make identification of distress a more objective process. Kerr *et al* (2006) identified themes about pain management as well and discussed medications and non-pharmacological interventions, but little has been done in this area. A case-study of a woman with learning disabilities living with chronic pain described reduction in pain and also improvements in depression, anxiety and activity level following an intervention process that included education, activity scheduling, relaxation and cognitive therapy (Lewis, Bell and Gillanders, 2007).

Key point for the research agenda

- There is a need for further work about pain recognition and management, especially for people with profound and multiple learning disabilities.

4.2.8 Children

Empirical research

The literature searches only retrieved four papers focusing specifically on children. Given the rise in neonatal survival rates, we have a growing population of children who are technology dependent, and their needs are an important topic for future research. Two of the studies related to the health care input in schools for children with learning disabilities (Marshall and Foster, 2002; Moore, McConkey and Duffy, 2003). Both of these showed that the majority of the school nurse's time was spent on routine tasks such as tube feeding, suctioning and dealing with asthma/epilepsy needs. They were also involved in staff training and health promotion classes and liaison was identified as an important aspect of the role. Other staff felt that they should not be expected to meet the health care needs of the pupils and valued the presence of the nurses. Marshall and Foster's (2002) quantitative data suggested that the key skills required for the role were relatively narrow and that the role provides limited opportunities for personal development for trained nurses. They propose that an NVQ-trained health care worker would be a suitable person to undertake this job.

Wharton *et al* (2005) explored the accessibility of general NHS services for children with disabilities and they identified a number of barriers. These included some practical issues such as lack of disabled parking spaces, noisy waiting areas and narrow corridors. They also felt that better preparation stating specific requirements, increased flexibility and more continuity would improve accessibility. Finally they identified issues about staff training, especially around communication and the need for better support during a hospital stay so carers are not required constantly.

Finally, one study used in-depth interviews to research the experiences of families caring at home for a technology dependent child (Kirk and Glendinning, 2004). This identified major problems in terms of support, equipment and general service provision. It was clear that families felt professionals massively underestimated the impact on the family unit as a consequence of the need to fit family life around the technology and its routines. Furthermore they reported that professionals specifically failed to acknowledge the emotional costs and the distress of causing pain to your child while trying to care for them. Recommendations included the need for a designated key-worker to co-ordinate service delivery and the importance of professionals valuing family involvement.

Key point for the research agenda

- An important research priority is the area of health support for children who are technology dependent. This will be even more important as they grow into adulthood.

4.2.9 Palliative care

Reviews

Two literature reviews conducted by Tuffrey-Wijne (2003) and by Tuffrey-Wijne, Hogg and Curfs (2007a) revealed a paucity of empirical data relating to the palliative care needs of people with learning disabilities. However, these reviews have highlighted many pertinent issues including:

- late presentation of illness – diagnostic overshadowing
- ethical issues around consent to treatment and decision making
- pain and symptom assessment
- conflict between the wishes of family/professional carers/patient
- difficulties relating to the patient's understanding
- communication problems
- service planning and staff training needs.

As previously demonstrated by the literature relating to health checks and screening, people with learning disabilities are often not accessing cancer screening programmes, which could partially account for the disproportionately high level of certain cancers in people with learning disabilities (Tuffrey-Wijne, 2003). Despite this, there has been little focus on resources for people with learning disabilities affected by cancer. Furthermore, it was concluded by Tuffrey-Wijne that future research should explore the psychological and social impact of a terminal illness and look at how peoples' spiritual needs are addressed at this time (Tuffrey-Wijne *et al*, 2007a).

Empirical research

Tuffrey-Wijne (2002) presented a case study about palliative care needs, and highlighted issues about consent to treatment. Additionally, the initial symptoms of pain were misunderstood, as behavioural in origin. Additionally, there were problems about staff understanding and training needs, a point that has been explored in more detail in semi-structured interviews with palliative care staff (Tuffrey-Wijne *et al*, 2005). Communication was the major concern (for more details see 4.2.4) and it was felt that educational developments should address this issue. A small scale survey explored this issue and recommended that the care and management of people with a learning disability who are terminally ill, should be a core component in the nursing curriculum (Ng and Li, 2003).

One study was retrieved which used the Nominal Group Technique to seek the views of people with learning disabilities on end-of-life care needs (Tuffrey-Wijne, Bernal, Butler, Hollins and Curfs, 2007b). Traditionally, palliative care provision has been based on the views of professionals and this was one of few studies to attempt to provide the voice of people with learning disabilities on such a sensitive topic. The participants were able to identify what they considered to be the most important issues, namely:

- involvement in one's own care
- presence of family/friends

- activities
- physical comfort measures.

This research demonstrated that this is an appropriate methodology to use with people with learning disabilities and more specifically, that people with mild/moderate learning disabilities are able to express views on the issue of palliative care.

Tuffrey-Wijne *et al* (2006) explored the information needs of people with learning disabilities relating to cancer. Initially they had wanted to include people with learning disabilities who had cancer themselves but this proved problematic as potential participants identified by Learning Disability nurses could not be recruited, as either family or care staff raised objections to disclosure of the diagnosis to the patient.

This finding raises a plethora of ethical issues in itself and justifies further research, particularly in view of the introduction of the Mental Capacity Act. The researchers conducted the research with a small number of people with learning disabilities who had a friend/relative affected by cancer and their supporters. Data analysis revealed that participants were clear that at the time of illness they had not been given adequate information and yet they did appear capable of comprehending it. The book used in Tuffrey-Wijne *et al's* (2006) study did not address all their information needs, but using it provided an opportunity for further questions to be voiced. They also used the book as a prompt for telling their own personal story suggesting it may potentially have a therapeutic use. The researchers concluded that people with learning disabilities have a need for a wide range of accessible information and staff should be able to use such resources to provide sensitive support.

Key point for the research agenda

- Palliative care for people with learning disabilities is under-researched. It is often the case that the topic is avoided with people with learning disabilities themselves.

4.2.10 Dental health

Previous research has identified an unmet need for dental care for people with learning disabilities (Cumella, Ransford, Lyons and Burnham, 2000). There were five articles relating to dental health identified through the systematic review but it proved impossible to retrieve them. Therefore there is no formal critical review relating to this sub-theme. However, the issues raised by people with learning disabilities in the workshops possibly relate more to action than research, since they identified that many people with learning disabilities do not have a dentist and that they are expensive. Family members also raised dental services as a priority but this was in relation to the ability of dental staff to deal with people with learning disabilities, particularly those with profound needs. From the information that was available from the identified papers it seems that, as with other

health professionals, there is a need for dental students to receive specialist information and training about Learning Disability (Barr, Kane, Keenan and Cullen, 2003; Coyle, Saunderson and Freeman, 2004). Other research identified that adults with learning disabilities living in the community may have more unmet oral health needs than those in residential care (Tiller, Wilson and Gallagher, 2001). Giraud-Saunders *et al* (2003) recommended that PCTs should be responsible for ensuring that people with a learning disability are registered with dentists.

4.3 Discussion of gaps identified in research on access to health care for people with learning disabilities

As indicated in 2.1.1 of this report, the priorities discussed with participants in the final round of workshops arose from the preliminary summaries of the research review. These issues were also discussed with a researchers' network meeting, and the discussion there was tape-recorded, transcribed and analysed. The following represents the main points in those discussions. A list of the priorities and questions identified appears at the end of the chapter.

4.3.1 Access to general health services

Despite the large volume of research into health issues of people with learning disabilities, 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]

People with learning disabilities, their families and supporters wanted more evidence about what was happening in the health service. They wanted to know whether people with learning disabilities are better served in one area or another, and particularly whether certain NHS services are being denied to people with learning disabilities. Although our literature review revealed some recent research about preventable mortality and lack of adequate health care among people with learning disabilities, this was felt to be an important enough topic to warrant further investigation. There is a long list of health questions suggested by people at the workshops. Although there is a large body of good quality research in this area, the focus of our participants was entirely on finding out more about how to implement positive strategies. For instance, we know that people with learning disabilities are often left out of routine health screening tests. However, workshop participants wanted to know how we can improve take-up rates.

Some people in the workshops had had recent experience of GP services, or

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hospital admission. In some cases, their experience was good, but they were aware of the basic problems (which are also highlighted in the research), such as:

- medical staff who cannot communicate with people with learning disabilities
- information which is inaccessible
- GP surgeries which are unfriendly, or difficult to use.

One of the workshop groups spent some time thinking about the kind of research that would really make a difference. They felt that practical interventions should be piloted and evaluated, so that others could learn from them. For instance, can we work with practice managers and receptionists to improve the experience of people with learning disabilities at surgeries? Small interventions could be piloted and evaluated, for example, giving first or last appointments if people find it hard to wait in a crowded place.

In another workshop, similar topics for research were discussed:

What are the critical components needed to ensure that people can get a local service? - availability of expertise, outreach services, support?

There was considerable consensus on the importance of providing evidence about take-up of health services, in such a way that local PCTs really had to take notice and change their practices.

4.3.2 Communication

We still need more research which really helps us to understand what communication skills medical practitioners need. If hospital staff, dentists and others feel they do not know anything about Learning Disability, then we need to define the knowledge and skills that would fill that knowledge gap.

Some stakeholders felt that we could look at what makes 'good' and 'bad' health care workers, from the point of view of people with learning disabilities themselves. They wanted to know how doctors could best explain what is happening to people with learning disabilities who are receiving treatment:

'Attitudes need to change in general – some people can be very helpful but in general this is an area which could be improved.' [person with learning disabilities]

Research that underpins training initiatives was therefore prioritised. In one workshop, it was felt that we could also learn by looking at training for medical practitioners which has been run, or has involved, people with learning disabilities. A team of people with learning disabilities in that area are being trained as health care trainers, and will be working with local medical practitioners. It was felt that the emphasis should be very much on

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practical research, which helps us to know how to improve health services for people with learning disabilities.

4.3.3 Information

Accessibility of information was also a major topic, both for workshop participants and for the researchers' meeting. It was also suggested that if we knew how to make health services more accessible, then this would help all patients:

'If it works for people with learning disabilities, it will pretty much work for everybody. For instance, accessible information – signage around hospitals' [Researcher]

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.'

At every level, workshop participants talked of their problems in getting good information – about what services existed; about the precise way of getting appointments; ways of remembering appointments; knowing how to understand the effects of treatment. In acute services, emergency admissions were felt to be a particular problem for people with learning disabilities. We know from the research that a pre-admission appointment can be very helpful; this will not be possible in emergency situations, and so some type of emergency information pack and strategy needs to be in place. Action research, again, could clarify how best this type of system could work.

4.3.4 'Special' health care needs

Instead of being included in ordinary health services, those with the greatest levels of need are often 'cared for' by the Health Service, and are offered specialist treatment. In some cases, we know that this means being sent away to out-of-area placements which may continue for many years.

'How many people (including children) are in health services (NHS & Independent) who are not getting any "treatment" but are really a "delayed discharge" or "stuck" in the NHS?' [Researcher]

Participants also felt that it would be useful to have more evidence about the extent of these practices, especially in the light of arguments about generic health access.

As health interventions for premature babies progress, an increasing number of children with profound and multiple learning disabilities (PMLD)

are surviving into adulthood. These are people who may be dependent on technology, such as tube-feeding, and research prior to 2001 (Townsend and Robinson, 2000) explored the social barriers posed by these issues. Sometimes these children were having problems in accessing ordinary schooling or social clubs, as their health and feeding needs could not be met. Some of the research we reviewed included children and adults with PMLD, and some was of particular relevance (such as the work on recognising indicators of pain by non-verbal signals).

However, very little of the existing research focuses exclusively on the particular issues raised by people with PMLD and technology dependency. This is a clear priority for future research:

'What are the gaps in the health care system for people with complex needs?' [Workshop participant]

Those who are dependent on medical interventions, such as suction, medication or tube-feeding, cannot separate out their health care from other parts of their lives. However, it is their parents who have to learn to become experts in their care during the early part of their lives. As they grow into adulthood, there is an urgent need to ensure that their future needs are understood and prepared for. Adult social services, as well as health services, need to make provision, and research can help us understand how these services will work best.

4.3.5 Inequalities in health outcomes for people with learning disabilities

We know from recent research that health outcomes for people with learning disabilities may be compromised by a number of factors. Barriers in accessing health services have been mentioned in our literature review, and these are well documented. However, some people with learning disabilities face additional health risks which are associated with particular conditions (for instance, epilepsy) or syndromes (for instance, dementia in people with Downs Syndrome). Despite having greater health needs than the non-disabled population, people with learning disabilities may face inaccessible health services, which discriminate against them in the offer of routine treatments.

In order to understand and take action on health inequalities, it was felt by researchers that we need to have better evidence about the mortality rates of people with learning disabilities, compared with non-disabled people, and the underlying reasons for health inequalities:

'The starting point is that we recognise there are very considerable health inequalities, and then there is the research question about how we understand that. What are the mechanisms which explain that?'
[researcher]

We need large-scale studies, which provide evidence of the extent to which national strategies and targets are being met in the Learning Disability

population.

In the workshops, health inequalities were also considered an important priority for research. As we have seen, workshop participants tended to focus on positive strategies for improving access to health services. However, they were also keen to point out that particular groups of people may face additional health risks. This included carers (family members of people with learning disabilities) who we know are at far greater risk of suffering from mental as well as physical health problems (Williams and Robinson, 2000), parents who themselves have learning disabilities, older adults with learning disabilities, and those in the criminal justice system. It was felt in two of our workshops that people with learning disabilities from BME groups may face particular issues in accessing health care:

'There is a need for training around reciprocity of cultural values, health provision and how to communicate.' [professional]

For all these groups, it is important that we understand the particular risks they face, how to take preventive measures, and how to ensure prompt, effective treatment.

An important initiative introduced at the time of Valuing People was HAPS. We have seen that the one study funded by the Department of Health in the wake of Valuing People (Mir *et al*, 2007) found that HAPs were not properly implemented at that point. People in our workshops felt strongly that they still wanted to know more about health action planning, and to find out how many people with learning disabilities have a HAP, and whether they are leading to better health outcomes.

Some of the issues identified here about health inequalities may well be addressed by a good health action planning process, whereby the needs of people with learning disabilities are accurately recorded, monitored and communicated to health professionals. However, if this system really has not improved outcomes for those who have a HAP, then we need to know, so that we can pursue alternative ways of working for a more equal health service for this group.

4.3.6 Public health

As we have seen in the literature review, research into public health and lifestyle issues for people with learning disabilities has shown us clearly that there are greater risks of obesity, and a tendency to low exercise levels in this group. One study has also shown that the barriers may include lack of easy information, which will enable people to understand the risks they face. In the workshops, participants discussed how useful 'accessible' information actually is. They felt it would be useful to find out what are the best formats for communicating information about health and lifestyle issues:

'We need more research into this as the evidence is mixed we need to establish how to improve it and what is the best format, e.g. internet,

leaflets, videos' [Workshop participants]

One study showed that accessible information about psychotropic medication actually confused people with learning disabilities. However, it is not clear how this type of information is actually used. In order to encourage more people to take exercise, for instance, we need to know what factors will work in getting over both information and motivation.

As Emerson and Hatton (2007) showed, socio-economic differences may account for a large part of the health inequalities observed. This may also be true for public health issues, such as diet and exercise, and it would be useful to have more information about the interplay between these factors, in order to target better health interventions.

Researchers in this consultation also pointed out the need to follow up the 'health risks' of independent living, since we know that people with learning disabilities may be vulnerable to a higher level of health risk when living in 'supported living' arrangements, rather than in staffed homes. We also know from the literature review that there are gaps in our knowledge about the rate of smoking and alcohol use among people with learning disabilities.

'There's a whole public health information dimension, which I think is really crucial. So that we ask, what are the risks and how are those risks changing over time?' [researcher]

Issues such as obesity, of course, may not simply be due to sedentary lifestyles. Although our literature search was not able to cover syndrome-specific issues, we know that some groups of people with learning disabilities face particular risks of obesity (for those with Down's or Prader-Willi syndrome, for instance).

Research must continue to explore the underlying mechanisms, so that we can provide better, targeted health services and advice to these groups of people.

4.3.7 Summary of research priorities about access to health care discussed with all stakeholders

The consensus about the main priorities in health care research related to inequalities in health outcomes. In turn, these were linked very closely with ideas for practical, action-based research which would help people with learning disabilities to have fairer access to generic health services. All the particular questions, topics or areas for research listed below are those that were suggested by workshop participants or by research network participants.

Inequalities in access to health care services

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

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- 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.)?
- How do we improve take –up rates of routine examinations (like smear tests) by people with learning disabilities, and do they help?
- How do specific initiatives by GP practices to include people with learning disabilities work? Do funded initiatives have better outcomes?
- How can we work with practice managers and receptionists to improve the experience of people with learning disabilities at GP surgeries?
- To what extent have people with learning disabilities benefited from national plans, such as the NSF's?

Training needs of medical professionals

- What are the communication strategies needed by medical professionals working with people with learning disabilities?
- How much training for medical professionals has been (and can be) run by people with learning disabilities?
- What knowledge do consultants and staff in acute services need about Learning Disability?
- What is the role of specialist Learning Disability staff in working with medical professionals?

Information strategies

- What are the best information strategies, to ensure good services? (appointment reminders, using pictures and audio)
- How can we improve both emergency and planned admissions?
- What is working well in Health Action Plans, and how can we make them more effective?

Health care of people with profound and complex needs

- What are the gaps in the health care system for people with profound and complex needs?
- What support is there for parents and carers of these people?
- How can adult services prepare for the increase in adults with complex and profound needs?
- How can health professionals help with the management of dysphagia?

'Special' health needs

- What is the extent of 'specialist' solutions to health problems? How many

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people with learning disabilities are in out-of-area placements in health settings?

- What are the health risks for people with learning disabilities in the criminal justice system?
- What are the health risks for carers?

Lifestyle issues

- What is the relationship between socio-economic differences and the health of people with learning disabilities?
- What are the health risks of independent living?
- What are the barriers preventing people with learning disabilities from getting more exercise?

4.4 References Chapter 4

4.4.1 References included in critical appraisal

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5 Getting good support

This chapter covers the topic of good support, which can be delivered by paid staff or one-one support workers; paid staff have many different job titles, but we will refer to them generically as 'support workers' here. Family members, as well as people with learning disabilities, were concerned to improve the quality of the support 'workforce', since the experiences of people with learning disabilities are so tightly bound up with the type of support they receive. The first section presents a review of research about the topics raised, and we will then turn to a discussion of the research priorities which were discussed at our second round of workshops, and with researchers.

5.1 Research scope and methodology

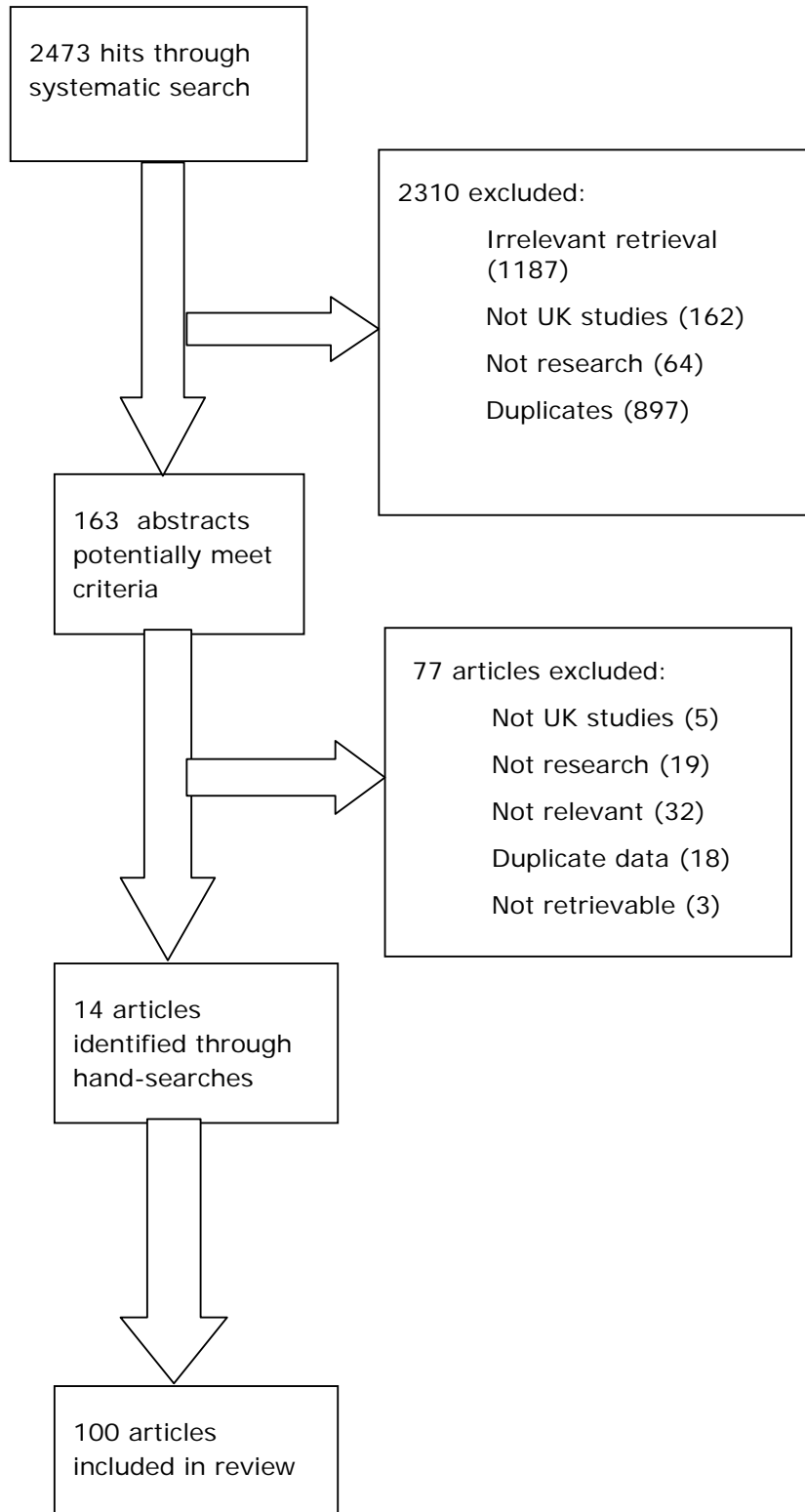
5.1.1 Methodology

Using the search terms given in Appendix A, 'getting good support' yielded 2473 hits. These were sifted in two stages. 2310 were excluded at the initial retrieval stage; if there was any doubt about the relevance of the item, the abstract was retrieved and scanned. A further 77 articles were excluded at the abstract stage. The following rules for exclusion were applied systematically at both these stages:

- 1) Not about the topic (of support staff and learning disability)
- 2) Not UK studies (where the research was based entirely outside the UK)
- 3) Not research or reviews of research (opinion papers without empirical basis; short practice descriptions were excluded)
- 4) Paper not written in English
- 5) Duplicates
- 6) Research published before 2001

A further 13 articles were identified through hand searches (including *British Journal of Learning Disabilities*; *Journal of International Disability Research*; *Journal of Learning Disabilities*; *The Learning Disability Review*) and so the total for the review in this area was 100. This process is represented in Figure 2 below.

Figure 2: Flow chart of the literature search for 'Getting Good Support'



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5.1.2 Evaluation of research reviewed

a) Quantitative research: large-scale surveys

A summary of the appraisal data for each topic in this report is given at the end of Appendix B. What follows here is an evaluative overview of the topic area. There is a strong body of robust, quantitative research about support staff. 39 of the studies retrieved by this search used essentially quantitative methodologies, with self-report rating scales, administered to direct care staff or to staff who had attended training courses. Two of these studies have large, stratified samples (Rose, David and Jones, 2003; Robertson, Emerson, Pinkney, Caesar, Felce, Meek *et al*, 2005a); others were restricted to populations who have completed a particular intervention or training course, although these were not necessarily small samples. Lowe, Jones, Allen, Davies, James, Doyle *et al* (2007) for instance had a sample of 275 staff.

These surveys are valuable in giving us a broad picture of the current situation, but necessarily give scant detail on why staff have responded in certain ways. For instance, Hatton, Emerson, Rivers, Mason, Swarbrick, Mason *et al* (2001) included data from a sample of 450 staff to report on factors associated with intended staff turnover. Work satisfaction is cited as a significant factor in staff retention, and it would be interesting to know more about what contributed to that satisfaction. This research has sought answers to questions about improvements in staff performance, and a long stream of research investigates staff attributions of challenging behaviour (e.g. Hill and Dagnan, 2002; Rose and Rose, 2005; Weigel, Langdon, Collins and O'Brien, 2006). However, studies can combine large-scale survey research with observations of staff behaviour. Felce, Lowe and Jones (2002) used observational methods to provide empirical evidence of the effect of learning, training or practice.

b) Evaluations of initiatives

Eleven studies were based on particular training initiatives, and were essentially evaluations. This body of research was mainly based on questionnaires to staff immediately after the training course, while some studies also looked at the outcomes Kaye and Allen (2002) for instance revealed that only 13 out of 40 physical interventions taught to staff in training were subsequently used in practice. These studies can offer information about particular training initiatives, but may be limited in their wider scope. A section of this literature also gets 'stuck': it is hard to tell if and why support staff do not benefit from training that they have had, for instance, in active support methods or in behavioural interventions (Bradshaw, McGill, Stretton, Kelly-Pike, Moore, Macdonald *et al*, 2004; Dagnan and Weston, 2006). As we shall consider later, this is still a priority for research.

c) Qualitative work and mixed methodologies

The quantitative work was complemented by some important qualitative studies (21) which reveal more about staff experience and views. For instance, Llewellyn and Northway (2007) used grounded theory to investigate the advocacy role of learning disability nurses. Qualitative methods which are well used afford insights which would be impossible via quantitative methods, as in Fish and Culshaw (2005), who used phenomenological analysis to reveal the conflict in the perception of physical intervention between staff and service users.

In addition to interview-based work, there was also a growing body of discourse work using conversation analysis to analyse what happens in interaction between staff and service users (Jingree, Finlay and Antaki, 2006; Antaki, Finlay and Walton, 2007; Williams, Ponting, Ford and Rudge, 2007). These methods focused in fine detail on very short extracts of recorded data, and helped to understand some of the ways in which policy gets translated (often mis-translated) into practice.

Williams *et al* (2007) and Hatton *et al* (2006) went directly to people with learning disabilities, to find out what they thought about the support they want. In the former case, two people with learning disabilities were employed as researchers. In the Hatton study, panels of people with learning disabilities, carers and professionals were formed, who determined criteria, helped to write 'scenarios' about staff skills, and then tested out the scenarios on their own staff.

It is possible that this area of research suffers from lack of communication between the various methodological strands. Questions which are posed, for instance, in primarily quantitative studies (concerning for instance the reasons for the lack of effectiveness of staff training) could perhaps better be answered by using qualitative methods. Conversely, specific in-depth studies could be more useful if they were framed in a quantitative evidence base.

5.1.3 Scope of the research

Table 4: Research studies about support and workforce for people with learning disabilities since 2001

Supporting people with challenging behaviour	31
Evaluations of specific forms of training	7
Active support, person-centred support	7
Support staff in relation to forms of supported housing	7
Preventing abuse (and sexuality issues)	8
Supporting health issues	6
Staff retention, stress and burnout	7
Careers: supervision and support for staff	5
Supporting people with profound and multiple learning disabilities	8
Staff roles and working with others	4
Communication and support for choice	3
Organisational issues	2
User defined competencies for support workers	2
Gap between policy and practice	2
Supporting people from BME groups	1
Total in critical review	100

The quality of life of people with learning disabilities is tightly bound up with the quality of their support workers, justifying the large body of work (103 articles) which has been carried out since 'Valuing People' in 2001 (DH, 2001). Following some comments about the balance of topics and the methodologies of these studies, this section will discuss the themes which cut across many of these topics, to outline what we already know from the research.

- Thirty-one percent of the published literature since 2001 on this topic is about staff supporting people with challenging behaviour. Since we know that some 10 to 20% of adults with learning disabilities have the label of 'challenging behaviour', and that their support is arguably the least well understood, this would seem to be an appropriate emphasis.
- Thirteen studies were about staff roles and training in relation to specific health issues (e.g. prevention of abuse, health issues) and evaluations of specific training initiatives. Training and support of staff are important, and

central to the concerns in the consultation workshops we have run.

- Many of the remaining studies were about staff roles, organisational issues and staff retention. They reflected a general concern with burnout and stress, which underlie the problem of lack of continuity in staff supporting people with learning disabilities.
- Only 8% (8 studies) were about the issues concerning participants at our workshops: being in control of their staff; having choice; having flexible staff to support them in the community. These consisted of three papers about person-centred planning and outcomes, three studies about communication and choice, as well as two which report user-defined competencies for support staff.

5.2 Findings and outcomes from the research: what we know and what we need to know

5.2.1 Supporting people with challenging behaviour

Reviews

There is a large body of research over the past decade, and beyond, about people with challenging behaviour, and how to manage that behaviour effectively. Ager and O'May (2001) in a systematic review of 103 intervention studies (up to 1997) found that there was evidence that behavioural interventions were effective, particularly when based on prior functional analysis of behaviour. However, they also concluded that staff training had little impact on staff performance without additional emphasis on organisational issues, and that it is more effective if it includes reappraisal of attitudes and expectations. More evidence was needed both for the value of social and psychodynamic approaches, and on the durability of change after intervention.

Empirical research

Given the body of research about supporting people with challenging behaviour or CB (32 articles retrieved), it would be hoped that some of the gaps identified by Ager and O'May. (2001) are now filled, and that we now understand more about the significance of CB and can help support staff to recognise the issues and the symptoms. We know from a survey of 281 participants carried out by Emerson, Robertson, Gregory, Hatton, Kessissoglou, Hallam *et al* (2001) that people with challenging behaviour were far more likely to be living in residential homes; it is therefore residential staff who will encounter most challenges. However, Mansell, Ashman, Macdonald and Beadle-Brown (2002) found that residential care home staff were not adequately prepared and were unlikely to have the high levels of skill required. Nevertheless, there is some research evidence that community settings for people with learning disabilities were associated with higher levels of engagement (Mansell, Beadle-Brown, Macdonald and Ashman, 2003a) and that the move from institution to community was

associated with a decrease in CB (Golding, Emerson and Thornton, 2005). Mansell, Beadle-Brown, Macdonald and Ashman, (2003b) carried out an interesting action study of people with CB in more person-centred housing which showed a reduction in the anti-social behaviours of the residents. These studies about housing are reported on in more detail in Chapter 7.

There were also a few papers which started to unpick what challenging behaviour might mean, and what the triggers might be – for instance, a symptom of post-traumatic stress disorder after abuse (O'Callaghan, Murphy and Clare, 2003), or a response to lack of stimulation in intensive behavioural units (Chaplin, McGeorge and Lelliott, 2006). However, in general the causal models of CB are taken as a given – that behavioural and environmental triggers are the key to understanding CB. We also have some evidence about the frequency of CB. McKenzie, Powell and McGregor (2004), with a sample that consisted of all of those enrolled on a Learning Disability nurse programme, found that 58% of them had been assaulted while working in LD services.

Robertson *et al* (2005a) found that behavioural methods are very seldom used by staff (less than 15% in various types of residential settings). By contrast, people were far more likely to have medication prescribed – up to 80% of those living in 'congregate' residential settings. Could staff be trained to use behavioural technologies, then, and would this be effective? McGill, Bradshaw and Hughes (2007) had mixed results in relation to students' learning about positive behaviour support (PBS); however, this may be different for practising staff. Lowe *et al* (2007) found that scores on staff confidence increased after PBS training. Although this study was outside the UK, in the Republic of Ireland, Grey and McClean (2007), in a non-randomised control group study found that person-focused training in PBS resulted in reductions of 30% in the challenging behaviour of residents, which was maintained 6 months after the intervention. All these studies claim that, if we knew how to train staff, positive behaviour support would be effective. That is why questions about the effectiveness of training are still of central importance.

A related strand of research has investigated questions about staff perceptions and attributions of CB. Why do staff respond as they do to people with challenges? Are there factors which are about the staff themselves, and how they understand CB? Tynan and Allen (2002) in a matched group design, showed that staff were more likely to use individual, medical explanations of CB in people with more severe learning disability. The hypothesis was that this would affect how that staff member reacts to the challenging behaviour. For instance, previous research showed that staff are more likely to intervene if they think people can control their behaviour, and can learn. The findings, however, are confusing. Dowey *et al* (2007) suggested that a one-day training workshop can help staff to understand behavioural causes of CB, but a relatively large study of 200 staff by Rose, Horne, Rose and Hastings (2004) revealed no associations between 'attributions' and how willing staff are to help.

The way in which staff feel about CB can of course affect them emotionally as well, and this can be a significant issue in staff stress, as Rose *et al's* (2004) study demonstrated. Qualitative research has sought to understand the causes of this stress. Jahoda and Wanless (2005) presented findings from a qualitative study of 36 staff members working with people with moderate learning disabilities, showing how staff members can often perceive aggression as an insult to their own identity. Staff often had dilemmas in dealing with CB, and could feel helpless (Whittington and Burns, 2005).

However, Jones and Hastings (2003) as well as Dagnan and Cairns (2005) and Bailey, Barr and Bunting (2006) concluded that there was little support for Weiner's model of attributions (that attributions of 'internality' determine the likelihood of anger and the offer of help). Weigel *et al* (2006) also found that attributions of internal causes of CB were associated with high levels of expressed emotion in clients, not just in staff. Rose and Rose (2005) provided a helpful summary, and concluded that staff tend to think about challenging behaviour in two stages. First of all, they explained it in terms of the unchanging attributes of the person; then they will think next about the social situation and what caused the incident. However, when staff are very stressed, they don't seem to progress to the second stage. Another interesting angle on this (Wilcox, Finlay and Edmonds, 2006) is that staff often feel 'blamed' for challenging behaviour. Thus, according to these authors, talk about the behaviour being internal to the person is a way of clearing themselves of blame. In general, staff were not sure about why challenging behaviour occurs (Whittington and Burns, 2005). All these studies focus on staff emotions, reactions, and reasoning. Most of them, also, are about negative emotions – only one study (Bell and Espie, 2002) included reports of satisfaction and positive rewards for staff.

Finally, in this section, there was a small group of seven studies about physical interventions. Most of these were about evaluating training programmes. For instance, Kaye and Allen (2002) found that only 13 out of 40 physical interventions taught in training were actually used by staff. People who had attended BILD training events evaluated new policies on control and restraint very positively (Murphy, Kelly-Pike and McGill, 2001), but even senior staff in services do not all have control-and-restraint training, and many were unaware of policies (Murphy, Kelly-Pike, McGill, Jones and Byatt, 2003). Three separate qualitative studies asked for the views of service users about physical restraint, and both Jones and Stenfert-Kroese (2007) and Fish and Culshaw (2005) found that clients all understood the reasons for physical interventions, although they described stress reactions and possibly abusive situations in their experience of physical interventions. Hawkins, Allen and Jenkins (2005) found that staff emotions were high when they were undertaking control and restraint, and all these studies found some conflict between the views of staff and service users about the use of physical interventions. Although there is such a large body of research in this area, therefore, we still do not know the answers to the basic questions about 'how to get it right' for people with CB. The move

towards more individualised services has got to be a strong focus for future research, but we will have to continue to investigate what type of interventions and training work best in terms of outcomes for people with CB.

Key points for the research agenda

- Most staff supporting people with CB work in residential services. More research is needed about the support needed by people with CB moving into supported living, or individual settings.
- Behavioural interventions are effective in reducing CB.
- Staff are confused about why CB occurs, they sometimes feel blamed, and they nearly always get quite stressed.
- Training does not always work well, and we need to understand better what will work. This is a still a focus for future research.
- Control and restraint training and policy are well received by staff.
- However, when physical interventions are actually used, they are often associated with staff anger. We still need research which goes beyond the techniques of intervention, and looks at the human relationships which underpin good support.

5.2.2 Staff stress, burnout and support for staff

Reviews

The literature about supporting people with CB was closely linked to studies about staff stress and burnout. However, a recent systematic review (Skirrow and Hatton, 2007) of 15 studies, including 6 that were UK based, revealed that levels of burnout among direct care staff were in fact lower than those in normative samples and that there appeared to be a trend for burnout levels to decrease over the last 20 years. They concluded that the changes towards community living have been of benefit to staff, as well as to clients, and also that those most directly in contact with people with learning disabilities have less likelihood of 'burnout' symptoms.

Empirical research

Nevertheless, working with people who show challenging behaviour and violence can be stressful (Raczka, 2005). About 1/3 of staff in learning disability services seemed to suffer from stress at the level of a mental health support need (Hastings and Horne, 2004). There was a link between personality, coping styles and stress (Rose and Rose, 2003), and some research has explored 'expressed emotion' in this respect (Dennis and Leach, 2007). Snow, Langdon and Reynolds (2007) found that staff burnout was associated with less stable and more 'internal' attributions of the causes of CB. Stress frequently means that staff consider leaving their job, and Robertson, Hatton, Felce, Meek, Carr, Knapp *et al*, (2005b) found that over a quarter of staff had emotional distress, and over one third were likely

to seek new employment in the following year. Apart from the challenging behaviour of clients, their stress was also due to low pay and being in places where they could not get support (such as 'non-congregate' settings).

Beyond the specific context of CB, however, the jobs carried out by support staff can be rewarding, if they are well supported by their organisations. Hatton *et al* (2001), for instance, explored the factors associated with staff turnover and burnout, as did Mascha (2007) for day services staff. Working conditions for staff were identified as a major source of stress, with no time away from service users and high noise levels. Conversely, support from other staff was shown to be very important, as well as a feeling of personal achievement in the job. Harris and Rose (2002) tested out a staff support and satisfaction questionnaire in services for people with learning disabilities, and Hodgkins, Rose and Rose (2005) described the successful effects of a stress-relief programme for staff. Some staff in Mascha (2007) also talked about the support they received from service users, although there is clearly a need for more research which focuses on how people with learning disabilities can and do support their own staff.

In general, positive attitudes among care staff were associated with a good team climate (Rose, Ahuja and Jones, 2006) and good organisational support, while frontline staff themselves most frequently requested the chance to talk to colleagues and to have good supervision (Holloway, 2004) in resolving the ethical dilemmas they faced in their job. However, the availability of good quality supervision (Davey, Desousa, Robinson and Murrells, 2006) and career guidance (Marsland, 2001) seems very limited, and has to be a priority in supporting the workforce. Under individual budgets (IB), people with learning disabilities will increasingly expect to supervise their own staff, and we need research to help us understand how to recognise and support this.

Key points for the research agenda

- Although stress can be a big problem among support staff, levels have decreased over the last 20 years. There is a research gap about the rewards perceived by support staff.
- Certain personalities and bad coping strategies can lead to burnout.
- Staff working with people with severe CB are more likely to become stressed.
- There is a problem in retaining staff, once they are stressed.
- Good organisational ethos, team work, supervision and the opportunity to talk with colleagues are all helpful to support staff.
- Future research should focus more on the relationship between the person with learning disabilities and their staff, especially under Individual Budgets (IB). We need to know more about how people with learning disabilities can support and supervise their own staff.

5.2.3 The effects of staff training

Reviews

Training for support staff, as noted above, was a theme which ran through nearly all the research since 2001 in this area. However, Campbell (2007) in a recent non-systematic review of training for staff supporting people with CB, showed that many staff members were working with no training or with short, quick-fix training. Campbell found that most of the research reviewed used subjective (staff self-report) outcome measures; despite the evidence that active support had positive effects, this review concluded that training seldom has been shown to make any long-term difference to practice. Campbell's conclusion was that we need to know more about staff who fail to benefit from training or do not take part, and we need to know about the mechanisms which ensure that training does have an effect.

Empirical research

Fourteen studies were about staff roles and training in relation to specific health issues (such as prevention of abuse, health issues) and evaluations of specific training initiatives. The general concern of these studies was to present and evaluate a particular type of training and its effect in practice, for example Harper, Hopkinson and McAfee (2002)'s exposition of the 'protective behaviour' approach, which helps staff understand how to help people with learning disabilities feel safe, and McKenzie and Paxton's (2004) work on a multi-agency core training programme for staff. 'Active support' training has been a particular focus in the literature, since active support as a model appears to be reliably associated with increased engagement among service users (Felce and Emerson, 2001; Mansell *et al* 2003a; Jones, Felce, Lowe, Bowley, Pagler, Gallagher *et al*, 2001; Smith, Felce, Jones and Lowe, 2002). Bradshaw *et al* (2004) considered whether or not active support training was effective in increasing the involvement of staff with clients. It was found that the main factor in making training effective was the attitudes and involvement of the house managers. However, when the training just relied on managers 'passing on' the messages, that also did not work well. The conclusion from all these authors was that the engagement and support of management is important. Jones, Felce, Lowe, Bowley, Pagler, Gallagher *et al* (2001) also found that active support training was more important for staff working with people with higher levels of need, than with more able groups, although Smith, Felce, Jones and Lowe (2002) found that active support training did not necessarily have an effect when working with people with challenging behaviour. There are clearly, therefore, differential effects of such training, and other factors that impinge on staff performance.

McKenzie, Sharp, Paxton and Murray (2002) also found that training had to be carefully tailored to the needs of individual service users, and the relationship between a person-centred plan such as an ELP (essential lifestyle plan) and staff training needed to be further explored. Maybe staff can also learn from stories about particular individuals, or even those that

are written by individuals. Barrett (2006) used autobiographical accounts of autism with teaching professionals very successfully.

Many studies (for instance, McKenzie *et al*, 2002) have evaluated short courses, which seem to improve staff knowledge, and Newman, Summerhill, Mosley and Tooth (2003) used a single-case study to show how an integrated approach to care planning, and staff communication training could improve outcomes for an individual with autism and severe CB. However, it is not easy to show that training actually improves outcomes in the long term, and as we have seen in Section 5.2.1, management support, rather than just training, appears to make most difference to staff practices. Interestingly, none of the existing research was about the involvement of people with learning disabilities in training their own staff, although it was flagged up as a recommendation in McKenzie and Paxton (2004), and this is a clear research gap for the future.

The remaining research studies in this group were about particular issues in training, such as mental health needs (Costello and Hardy, 2005); how to employ touch with people with profound and complex needs (Dobson, Upadhyaya and Stanley, 2004) and the issue of personal and intimate care (Carnaby and Cambridge, 2002). In areas such as those, according to these studies, there is very little guidance for staff, and most staff seemed to be copying each other or simply guessing what to do.

Key points for the research agenda

- Materials produced by service users themselves are useful (for example, a study of the use of autobiographies by people with autism).
- Staff find it useful to talk and to share experience.
- Training for working with people with PMLD training has to be specific to the particular service users.
- We need to know more about how to link in staff training with individual, person-centred plans.
- Staff should be involved in identifying their own training.
- There is a major research gap about the involvement of people with learning disabilities in training their own staff.
- There are specific areas about staff support which may need more research attention, such as personal and intimate care.

5.2.4 Ethical dilemmas and the 'corruption of care'

Reviews

One of the central ethical dilemmas threading through the support offered to people with learning disabilities is the task of getting the balance right between protection and risk, as several authors pointed out (Holloway, 2004). However, some of the features of the support which we offer to people with learning disabilities appear to increase their vulnerability, and

abuse can often occur within residential facilities of various kinds. White, Holland, Marsland and Oakes (2003) in a non-systematic review of the literature identified systemic and cultural features of support which can lead to abuse of the most vulnerable people. Abuse like this was often 'naturalised' in services, and included joking, bullying, and power issues, according to White *et al* (2003). These authors argue that it is vital that we develop a new way of monitoring, but also of respecting and working alongside people with learning disabilities in less institutional ways, and working to prevent abuse, rather than just to respond to it.

Empirical research

Issues about abuse were taken up in eight of the studies reviewed. According to Davies, Northway, Jenkins and Mansell (2005), people with learning disabilities are not always believed by staff and staff have thresholds about whether or not they take action about abuse; they do not often take action about emotional or psychological abuse, and neglect is not seen as abuse. Some staff worryingly tended to take personal action in tackling suspected abuse, instead of following official reporting procedures, as was found in a survey of 150 staff (Taylor and Dodd, 2003), and there seemed to be a 'policy overload', with frontline staff not always aware of policies in this area (Northway, Davies, Mansell and Jenkins, 2007). Hogg, Campbell, Cullen and Hudson (2001) evaluated the effect of an open learning course on staff knowledge and attitudes towards the sexual abuse of adults. All these authors concluded that more training about abuse recognition and reporting were needed.

A related ethical dilemma for staff is about choice and control. While adhering in principle to the rights of service users to make their own decisions, staff also want to make sure they are safe, and that they look after their 'best interests' (Holloway, 2004). Jingree *et al* (2006) showed how these matters were played out in everyday talk, and how staff may produce affirmations of service philosophy, while exercising power over the choices people with learning disabilities actually have. In a large sample of 281 people who lived in settings which were explicit about the philosophy of empowerment, Robertson, Emerson, Hatton, Gregory, Kessissoglou, Hallam *et al* (2001) nevertheless found that people had very little support, even for mundane decisions, and no opportunity to make major life decisions.

There are many different 'specialisms' in Learning Disability, but for all of them communication with families and with other professionals is vital, according to Todd and Jones (2003) who found that parents often found professional contact difficult; parents in this study felt they were not listened to, and they felt they were being 'watched'. McCray and Carter (2002) and McCray (2003) carried out a survey of Learning Disability nurses, and concluded that it is important that future Learning Disability staff get better at listening to people with learning disabilities and their families.

In general, all this research seems to point out the gap between the

principles of 'Valuing People' (DH, 2001) and the way in which they can be put into practice. Forbat (2006) for instance found that senior policy executives do not focus on the key principles of policy, and there is very little guidance about what 'good practice' would look like. Conflicts for staff can also occur in the area of culturally specific support. Summers and Jones, (2004) found that support workers often had to achieve an uneasy balance between respect for family values and individual rights in areas such as bereavement and gender, when working with people from black and minority ethnic communities.

This body of research revealed major problems about institutionalised abuse, but also a surprising lack of connection with the support provided by family members, and support provided under the new types of self-directed systems. There is currently little research evidence about abuse in relation to IB users, and we will need further research to monitor the situation as IB progresses.

Key points for the research agenda

- Official procedures for reporting abuse are not always followed, and certain forms of abuse (emotional abuse or neglect) are naturalised and overlooked in services. Research will need to monitor the introduction of IB, to ensure that we know about incidences of abuse and neglect.
- Support staff face ethical dilemmas about getting the balance right between fostering decision-making, and attending to safety.
- People with learning disabilities have very few opportunities to make their own decisions.
- Parents and family members often feel disregarded by support staff. There is a need for more research which highlights the roles of families, particularly in supporting individual budgets.
- Research has given us plenty of information about the problems, but there is a gap in research which will help us understand good, facilitative support.
- There are large gaps in this area between policy and practice, and future research should look outside the Learning Disability arena, to learn how to bridge those gaps.
- Respect for different cultures can also conflict with respect for individual rights.

5.2.5 Supporting health

This section deals with research about support staff who have a role in health. To that extent, it overlaps with Chapter 4.2.5. For instance, research has emphasised the importance of frontline staff in supporting people with dementia (Wilkinson, Kerr and Cunningham, 2005), epilepsy (Pointu and Cole, 2005); with terminal illnesses (Ng and Li, 2003), and indeed with any form of pain. All these studies pointed out how important it

is for staff to learn the individual ways of communicating, which can help them observe and help their clients in very sensitive ways. This was also true about mental health issues (Bates, Priest *et al*, 2004). However, findings were mixed on the efficacy of these 'specialist' support staff. Jenkins and Davies (2006) for instance found that staff might be guilty of a failure to act on health problems that they knew about amongst their clients.

For instance, Ng and Li (2003) found a lack of consistent policy among 25 qualified Learning Disability practitioners in recording deaths in homes, and in some cases, the inability of care practitioners to actually recognise when someone was dying. By contrast, Donovan (2002) interviewed eight Learning Disability nurses, who could recognise changes in verbal and non verbal behaviour, and prioritised empathy in dealing with clients' feelings relating to pain. Only one study was found which examined the attitudes of non Learning Disability health staff. Tuffrey-Wijne, Hollins and Curfs (2005) showed that in fact 80% of palliative care staff did have experience of working with a person with learning disabilities, and were well aware of issues relating to communication, choice and consent. It would seem that professional links between Learning Disability staff and other health professionals would be very beneficial, but we need more research as well as action in this area.

McConkey and Ryan (2001) and Cambridge, Carnaby and McCarthy (2003) looked at staff roles in supporting sexuality. Over two thirds of staff seemed to have encountered 'incidents' in which people with learning disabilities may masturbate in public, or ask about sexual intercourse. Very few staff had training in how to support people in these areas, as Abbott and Howarth (2005) also found in relation to same sex relationships. It would seem from these studies that further research is needed about how to support many different kinds of close relationships amongst people with learning disabilities, including sexual relationships.

Key points for the research agenda

- Frontline learning disability staff often have a role to play in supporting their clients' health.
- It is important that these staff can recognise symptoms, including those of pain, but they are not always skilled enough to do this.
- Very few staff have training in supporting sexual relationships. We need more research about supporting close relationships, and how to get this right.
- There is a research gap about the relationship between 'specialist' Learning Disability staff and generic medical practitioners. This is discussed in the chapter on Health.

5.2.6 Choice and person-centredness

Reviews

One of the main goals of 'Valuing People' (DH, 2001) is that people with learning disabilities should have more choice and control, and person-centred planning has been promoted as a central tool in achieving that goal. However, Mansell and Beadle-Brown (2004) carried out a critical review of person-centred planning in the context of current policy, and found a limited evidence base for the efficacy of person-centred planning (PCP). Given the many problematic issues these authors highlight (including, for instance, the lack of social networks experienced by most people with learning disabilities) the assumption that person-centred services will be produced by this new type of individual planning is questioned. These authors concluded that changes in power relations, funding and staff training and support were more important than PCP in making the move towards personalised services.

Empirical research

The research reviewed for the current study also supported the argument that person-centredness implies changes in staff practices. People with learning disabilities in receipt of 'high quality' individual plans, as Adams, Mansell and Beadle-Brown (2006) demonstrated, do not always seem to have better quality of life. Person-centred planning by itself did not appear to lead to better outcomes, although person-centred practices (Parley, 2001) did make a difference.

Felce *et al* (2002) observed staff performance in 29 different housing schemes, and found that the 'engagement' of residents was associated reliably with only one factor, which was staff activity level. In other words, it was staff who were most actively involved who had the best effect.

Felce and Perry (2004) are among other studies which show that the trend towards smaller units of residential provision has not necessarily resulted in a better quality of life for people with learning disabilities, and that staff did not distribute their time and attention fairly – those with the most severe disabilities were often ignored. Choices, as Hatton, Emerson, Robertson, Gregory, Kessissoglou and Walsh (2004) also demonstrated, are more available to those people with learning disabilities who have higher ability levels. However, this study also noted that there are associations between greater community presence, fewer 'institutional' practices, and the choices available to people with learning disabilities.

What matters for those with the most severe impairments is perhaps that their own views and choices are respected. However, Llewellyn and Northway (2007) found that training and practice in advocacy differed widely. It is the day-to-day practices of support staff in ordinary communication which will give (or deny) choices, but we are seeing from some detailed work on interaction how disempowering conversations between support staff and residents in homes can be (Jingree, Finlay and Antaki, 2006; Antaki, Finlay and Walton, 2007). Despite their best intentions, staff tended to dominate conversations and to have power over what counted as 'good answers' to questions. It could be that new ways of

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supporting people individually, using a direct payment, will have better outcomes, and Williams *et al* (2007) showed how staff in these situations could use particular strategies to provide sensitive support, and to respect people and their choices. There are still major tasks for research in helping us to understand how good, facilitative support is actually done, and to translate these findings into practice.

Providing good support for people with profound and multiple learning disabilities (PMLD) is largely to do with communication, and Porter, Ouvry, Morgan and Downs (2001) found that staff's interpretation of communication must refer to the views and experience of those closest to the person with learning disabilities. Bradshaw (2001) also reported on the importance of staff matching their level of communication to that of the person they are working with, and Dobson, Upadhyaya and Stanley (2002) recommended using an interdisciplinary approach to training in this area. Additionally, it is important to be sensitive to the use of touch with people with PMLD. That is often their most effective way of communicating (Dobson *et al*, 2004), and these authors found that training in the use of touch has to be very specific to individual needs. It may also be that we need to look towards more creative ways of communicating, as evaluations such as Graham (2004) and Leaning (2006) have suggested. However, research has generally shown some disturbing signs of the breakdowns in communication with this group. For instance, Joyce and Shuttleworth (2001) found that staff were better at recognising individual signs of happiness than distress, and that consequently people with PMLD were sometimes engaged in activities that they showed dislike for.

An important recent study by Hatton, Wigham, Craig and Gudgeop (2006) for the Department of Health used well validated procedures to develop parallel sets of job performance measures, by people with learning disabilities, family members and managers. This work is beginning to show us what people themselves want from their support staff, namely friendly, trustworthy and reliable support which enables them to make their own choices in life.

A final comment must be reserved for the new ways of working, with direct payments and individual budgets (IB). With the exception of ongoing development work by BILD, and Williams *et al* (2007), surprisingly few studies since 2001 were revealed which examine workforce issues under the new IB systems. However, we know that many people with learning disabilities can take part in choosing their staff, and much depends on them learning the skills for staff selection. Townsley, Howarth, Graham and LeGrys (2002) offered guidelines for promoting change, so that service users could be more involved in staff selection.

Some of the work in Leece and Bornat (2006) about personal assistants for other disabled people is indicative, but it is clear from this literature review that many of the themes and issues about institutionalised abuse, community engagement, active support, skills training and the supports needed by staff themselves are going to be key questions to pursue in the

new contexts of IB.

Key points for the research agenda

- Person-centred planning does not necessarily lead to more person-centred support. However, staff can make a difference in adapting their interaction styles to encourage residents to take part in everyday activities.
- Residential staff often communicate with people in disempowering ways, and we need to understand how and why this happens.
- The beliefs of the staff can make a difference.
- It is possible to show how staff can provide 'empowering' support, and can respect people's choices. We need more research to understand these skills, and ensure they are translated into practice.
- The big research gap about support staff is to translate our knowledge and to discover what is relevant in the new context of individual budgets (IB). We need to know how staff can effect a culture change, and move into personalised ways of working.

5.3 Discussion of gaps identified in research about good support for people with learning disabilities

As indicated in 2.1.1 of this report, the priorities discussed with participants in the final round of workshops arose from the preliminary summaries of the research review. These issues were also discussed with a researchers' network meeting, and the discussion there was tape-recorded, transcribed and analysed.

5.3.1 Individual budgets and support staff

The body of research about frontline support staff between 2001 and 2007 focused on staff in group homes, residential settings and occasionally day centres. The policy and practice shift towards Individual Budgets (DH, 2006) has given rise to a renewed, and distinct, interest in workforce issues. For instance, Skills for Care has a new programme of research planned under the New Types of Worker programme, and other major development organisations such as BILD are working on programmes to understand better the new workforce roles in order to translate these into training.

In the recognition that being in control of one's own support necessitates good quality support workers, people with learning disabilities, and particularly their family members in our workshops, were often concerned about the availability of good support staff who are employed by the person with learning disabilities. Participants in our workshops felt that we need research which will help us understand the factors which influence low and high turnover of staff, the availability of support staff for IB users, and motivation of staff. The research base since 2001 offers very little about the

qualities, role and actual practice of 1-1 support workers, particularly those who are employed by direct payments users. In one sense, the task will be about applying what is known to new contexts of support work. For instance, the bulk of work about supporting people with challenging behaviour is very relevant to the work of new types of support worker; similarly, the research on burnout and stress will be very relevant. However, it is not simply a matter of translating received wisdom into new contexts. There is much that is actually new, and will need to be underpinned by evidence. As more people with learning disabilities move to individualised support, there is a need for evidence about issues such as staff turnover, as well as the financial status of support staff under IB.

For instance, we know from research something about the factors which reduce staff stress, and give support and stability to a staff group. However, factors such as good supervision and sharing with colleagues are more likely to be missing from the experience of staff under IB.

'What kinds of support will help people to link up with colleagues & get training to reduce stress and staff turnover?' [Professional]

In the first instance, people with learning disabilities, as well as family members, wanted to know more about how to improve their own support staff. Parents in one of the workshops made a strong connection between person-centred approaches and the support people need:

'How can we provide the support people want, and not what the job description stipulates?' [Family member]

There is also a need to monitor the new system, as it emerges. For instance, one participant flagged up the question of frequency of abuse by 1-1 support workers. This was not just a plea for evidence; in order to understand better how to improve the supply of good support staff, there was a general concern with research to help us know how to effect change in the workshops.

Participants wanted research that would help us to know what monitoring systems work well, so that performance standards are maintained. People with learning disabilities also wanted to know how they could have a say in defining what they want from their own support staff. We heard about local initiatives by people with learning disabilities to supply training for their own support staff, and we know that some recent research has addressed this question directly (Hatton *et al*, 2006; Williams *et al*, 2007). However, there is clearly still a need to find out what works, so that all people with learning disabilities can have a say about their own support.

This topic was also discussed with researchers, and some more basic gaps in understanding were suggested. For instance, it appears that support staff have an overwhelming tendency to be sucked into the 'learning disability' culture, in which they are responsible for service users' actions. There has been recent research which examines how these things happen, in the context of residential homes (for instance, Jingree *et al*, 2006). However,

the question that we now need to address is how the 'new' type of support worker can move on from this way of working. A professional in one of the workshops also spoke about:

'Keeping fresh the 'ordinary' vision of a new support worker'
[Professional]

An important focus for research is to help us understand how we can stop staff from working 'defensively', as one researcher put it. For that to happen, we need to understand better what 'learning disability' culture is.

5.3.2 Support staff skills

The topic of IB was closely linked with two others – that of skills for frontline workers, and also the issue of organisational change. Taking first the research gaps about skills, a range of issues were identified, relating to particular roles performed by frontline staff. For instance, more people with learning disabilities want to find paid work, and contribute to society. However, there were no research studies since 2001 about the skills required by support workers to help them find employment. People with learning disabilities in one workshop spoke about how important it was for support workers to motivate them towards employment of some sort:

'When I said I want to get a new voluntary job, I said, I don't want to lie in bed all day, watch TV all day & look at four walls, because if you're doing that, there's no point in having [a support worker] to come and see you'. [person with learning disabilities]

Similarly, advocacy is an important part of the skills base for all support workers, but we do not have hard evidence about who gets advocacy, although there is some evidence about what people with learning disabilities actually want from advocates (Llewellyn and Northway, 2007). This will also be relevant to the new role of 'independent mental capacity advocate', as well as finding out more about the roles performed by new workers such as 'community facilitators', 'enablers' or 'brokers'.

The main focus on skills was, again, on process questions. The research reviewed showed some confusion on the question of how training can lead to skills improvement and better outcomes. However, the consensus is that support for organisations, management and on-the-job support makes a greater difference than one-off training sessions. Perhaps there is a need for more action research here, as this knowledge is not necessarily acted on in practice. As one researcher said:

'We need to find out what kind of training works better – do you take people out of their service into sessions? Or do you put the training in the setting, and train staff with the people they are supporting?'
[Researcher]

Workshop participants felt that they could supply new models to explore. For instance, parents wanted research which could explore how their own expertise could be better linked with the skills of support staff, while people

with learning disabilities wanted research which can underpin their own efforts to train and support their staff. They were particularly interested in research about how staff can be trained to help people 'make a choice'. The questions related to training and skills need to be re-thought in the context of one-to-one, user controlled support. If we are supporting people with learning disabilities to take more control of their lives, then they also need to be involved both in defining what they want from their support workers and helping to train them. These models have been touched on by Hatton *et al* (2006) and by Williams *et al* (2007). They now need to be put into action, and further developed to test their feasibility. Research is needed which links the issues for people with learning disabilities into the wider field of 'personal assistant' support, and takes up issues such as relationships, control and respect, so that we fully understand how people with learning disabilities can take their place in the new social care agenda.

We were told that research can also help with the understanding of some basic concepts which underlie the issue or staff skills. For instance, culturally sensitive support still needs to be properly defined. Recent research has explored some of the culturally specific issues for people with learning disabilities in the South Asian community, for instance, and also issues to do with bereavement in relation to different cultures. However, we still need to translate these issues into an understanding of how to provide good support, as one participant put it:

'What is culturally specific support? Is it just about understanding different cultures?' [person with learning disabilities]

Another fundamental issue for research which was discussed both in the workshops and in the researchers' network was that of 'safety' and 'risks'. Frontline support staff are rightly concerned to ensure safety, to take responsibility, and to carry out risk assessments. However, it is also important to get the balance right, and for people with learning disabilities to take a certain amount of responsibility for their own risks and to learn from their mistakes.

'Who's in control, and who is responsible? Trying to safeguard individuals can become another barrier to them living the life they want to. There may be an excessive concern with risk.' [professional]

A mixed group of participants in one workshop suggested that research could analyse specific incidents, to track back who took responsibility and how the balance between safety and risk-taking was maintained.

5.3.3 Organisational issues

Workshop participants grappled with the issue of how to move forwards in terms of providing good support. They knew that changes were needed, and they talked about what kind of research could actually help changes to happen. They particularly wanted research which shows us how to change organisations, so that they become more 'person centred'. They also discussed research which is action-based, and would help focus on

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particular examples where change has happened successfully, so that others could follow suit.

These concerns were matched by other respondents, particularly policy makers, who were interested in how research could help us understand organisational change. There is, of course, an argument (put by researchers in the network meeting) that people with learning disabilities will increasingly move outside 'organisations' and into a more individualised way of controlling their own services.

'Will there be an 'organisation' in 10 years time? If you go towards IB, there comes an issue about how you secure equality. We have to do that without putting in a whole set of structures in there that inhibit change, and actually doing things that people need.' [Researcher]

With these changes in mind, it was felt that research could provide evidence of how managerial practice is coping with IB. For instance, how many managers in social services departments are still exerting control over budgets for care, and how does this change when IB is introduced? For the foreseeable future, it is still the case that support staff are often employed by large or small provider organisations, or directly by social services. There was some consensus that we do need research about how organisational change can happen, and how for instance organisations shift from a 'process and target' culture to an outcomes focus.

Some of the research expertise needed may well lie outside the field of Learning Disability research, and so partnerships are needed between different disciplines here.

5.3.4 Supporting people with high and low support needs

People with learning disabilities are not a homogeneous group, and those with the highest support needs (by definition) are going to be the greatest consumers of support. There were worries in many quarters that the new focus on support staff under IB will leave out the particular needs of those with profound and multiple learning disabilities (PMLD) and those with challenging behaviour (McBrien and Power, 2002).

We know that a high proportion of research since 2001 has focused on how to provide good support for those with challenging behaviour, and this topic will continue to be important, especially if those people are to be included in the new moves towards 'community' and IB.

This consultation also highlighted the need to focus on more research to better understand the support needs of people with PMLD. For instance, researchers spoke about more detailed and basic research to focus on how staff can interact successfully with people who do not use words. We have a stream of research about particular models of interaction, such as intensive interaction, and we know that communication for people with PMLD has to be carefully interpreted by reference to close family members and

significant people for each individual. However, there is a need for a greater focus on the different contexts in which support is provided, and perhaps also for different research methodologies. We were told that there will be a big need to support the implementation of the Mental Capacity Act (2005) which came into force in October 2007. In this context, frontline support staff will be expected to undertake informal, functional assessments of capacity, and to record these appropriately. They will also be expected to follow the principles of the Act in relation to provision of good information, and supporting the individual's own decision wherever possible. These matters need urgent attention and will be an important focus for research.

By contrast with the issue of 'high support needs', some people with learning disabilities who came to the workshops felt that they missed out on getting support because of the low level of their needs. For instance, one person spoke of her increased need for support at a time of illness, and how inflexible the system had been in respect to meeting her needs.

'I needed an op back in May, which I had, but I found that the health care professionals that did it were very good & explained to me what would happen. I had more problems with the social care & they let me down. I tried to plan it but they didn't do their Independent Living Skills Assessment properly.' [Person with learning disabilities]

The issue will remain of how support services are going to be delivered to meet the relatively low-level needs of people who live more independently, alongside the needs of those in the high priority bands.

It would be useful to have evidence of how these matters are being addressed by social services departments, as well as other partners such as Health providers, financial services, and housing schemes.

5.3.5 Staff satisfaction, support and job status

Finally, a range of research gaps were identified under the general topic of staff support. An existing body of research does deal in depth with burnout and stress issues, particularly for staff who work with people who exhibit challenging behaviour. However, a recent systematic review (Skirrow and Hatton, 2007) suggested that levels of burnout among frontline LD support staff were less than for normative samples, and have shown a decrease in the last 20 years.

It would be interesting to take these international findings, and re-examine in detail the effect on staff stress associated with the new ways of working. All these findings need to be re-examined under new systems of IB, as we have seen above.

In one workshop, people spoke about research which gives us evidence on attitudes and social value of support work.

'How is the support worker job seen in terms of status and in financial terms?' [Family member]

These matters are important, since the motivation and stability of the new workforce will depend at least partly on the way in which society values their role. With that in mind, it was suggested in the researchers' meeting that the voice of frontline support workers needs to be included in the research and in the debates about their role:

'Could we empower frontline staff, by including them as partners in research and policy?' [Researcher]

The relationship between a support worker and a disabled person has to be one of respect. The support worker or personal assistant works for the disabled person. This basic relationship of employer/employee is much harder to establish for people with learning disabilities, and people in the workshops focused more on the fact that they 'liked' their supporter, or that they valued 'friendship'. It is clear that future research in this area must include the voices of all parties – frontline staff, people with learning disabilities, other disabled people, and parents. While being sensitive to their different perspectives, research also has a role in exploring how team work can be fostered among the different stakeholders, in such a way that the person with learning disabilities has 'person-centred' support.

5.3.6 Summary of research priorities and questions suggested by all stakeholders

There was considerable consensus on the priority for research in the area of frontline support. The most important research gaps are those relating to the culture change in support, which is we hope will be achieved with Individual Budgets (IB) and direct payments. We need to understand how to move over from the problems associated with institutional ways of working, and to support people with learning disabilities in person-centred ways.

All the particular questions, topics or areas for research listed below are those that were suggested by workshop participants or by research network participants.

Research about support staff and individual budgets

- How do we define what the 'new type of support' is? How do we stop staff from working 'defensively' and help them move on from the learning disability culture? Can we learn from research outside Learning Disability, about how to bridge the gap between policy and practice?
- What is the staff turnover in 1-1 support, and how does this compare with other provision?
- How do people with learning disabilities tell us what they want from their personal assistants or support staff?
- What is the experience of families, in leading individual budgets or direct payments for their relative with learning disabilities?

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- What support skills are needed to support people with challenging behaviour who have an IB, or live in individual settings? What are the outcomes?
- How widespread is abuse of people with learning disabilities by individual support workers? How do we monitor support staff under IB, and ensure that performance standards are high?
- What is the balance between creativity and keeping people with learning disabilities safe?

Research about support worker skills

- What are the skills needed for the 'new' type of support worker? How do we get this vision right, and translate it into practice?
- How many support workers are supporting people to find employment? What would it take to move support workers over into employment support?
- Who gets advocacy, and what skills do we need in advocates?
- How many family and friends are being paid to support people in the community?
- What training works best? How do we train staff to be 'person-centred' and to help people to make choices?
- How do we improve links between staff and family carers? How can support staff learn from carers?
- How can more people with learning disabilities support and train their own staff?
- What exactly is 'culturally specific' support? Understanding different cultures?
- How do we link staff training with person-centred plans, for individual people with learning disabilities?
- How are power imbalances played out, when support staff communicate with people with learning disabilities in different settings (their own home; residential homes; in the community)? How can communication change?
- Can we understand the processes by which people with learning disabilities are valued, and the relationship between support staff and the people they support?

Research about support organisations

- How do we change organisational culture? (Finding good examples and learning from them)
- How do commissioners and care managers adapt to new ways of managing? Are managers still controlling budgets for care?
- What are the differences between 'good' and 'bad' organisations?

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- What makes organisations change?

Research about supporting people with high support needs

- What is the role of community teams in supporting people with profound and multiple learning disabilities?
- What training models will work best? Do staff learn better on the job, or on training days?
- How do we support people with CB moving into supported living, or individual settings, and what are the outcomes?
- How can staff interact successfully with people who do not use words, and support them in the community?

Research about staff satisfaction, support and status

- How is the support worker job seen in terms of status and in financial terms?
- What support is needed by staff, in order to reduce stress? (including support from people with learning disabilities, and from families)
- What are the rewards for support staff, in terms of personal relationships and achievement?
- Could we empower frontline staff, by including them as partners in research and policy?

5.4 References Chapter 5

5.4.1 References included in critical appraisal

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6 The right to relationships

All human beings have rights and needs to pursue close relationships, and people with learning disabilities are no different in this respect. However, traditionally they have frequently been restricted, partly because of society's view that they are not responsible to manage a full relationship. Relationships are central for emotional stability, and the enjoyment of a fulfilling life. In this chapter, we cover not only friendships and social networks, but also sexual relationships and parenting – all of which are key issues for people with learning disabilities.

6.1 Research scope and methodology

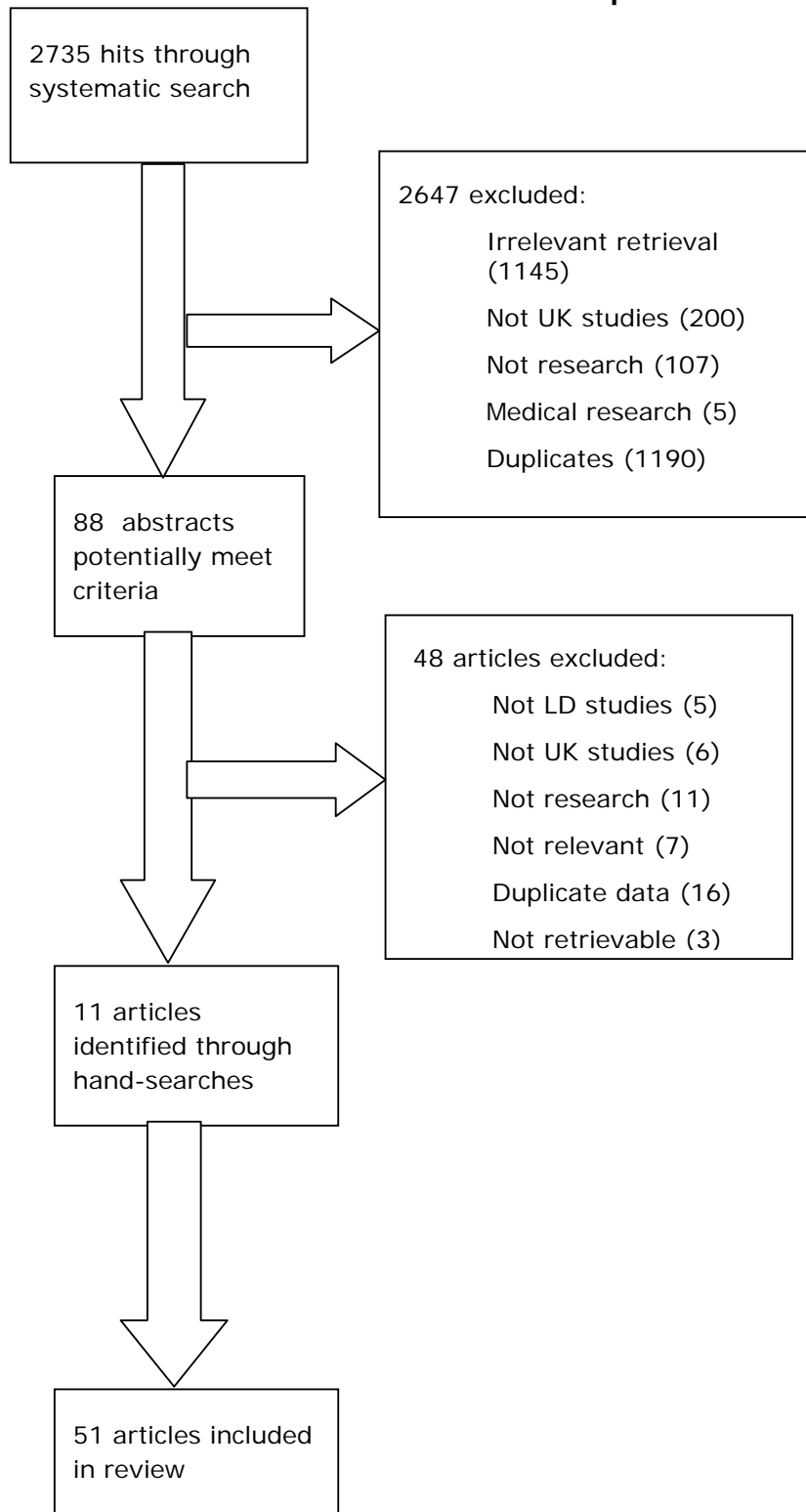
6.1.1 Methodology

Using the search terms given in Appendix A, 'relationships' yielded 2735 hits. These were sifted in two stages. 2647 were excluded at the initial retrieval stage; if there was any doubt about the relevance of the item, the abstract was retrieved and scanned. A further 48 articles were excluded at the abstract stage. The following rules for exclusion were applied systematically at both these stages:

- 1) Not about the topic (of support staff and learning disability)
- 2) Not UK studies (where the research was based entirely outside the UK)
- 3) Not research or reviews of research (opinion papers without empirical basis; short practice descriptions were excluded)
- 4) Paper not written in English
- 5) Duplicates
- 6) Research published before 2001

A further 11 articles were identified through hand searches (including *British Journal of Learning Disabilities*; *Journal of International Disability Research*; *Journal of Learning Disabilities*; *The Learning Disability Review*) and so the total for the review in this area was 51. This process is represented in Figure 3 below.

Figure 3: Flow chart of the literature search for “Relationships”



6.1.2 Evaluation of research reviewed

a) *Quantitative research: large-scale surveys*

A summary of the appraisal data for each topic in this report is given at the end of Appendix B. What follows here is an evaluative overview of the topic area. Twenty of the papers exploring relationships used quantitative methodologies, which is perhaps surprising as friendship could be viewed as a topic that is hard to quantify, while a qualitative approach could help to unpick certain aspects. The sample size within these studies varied greatly (4-4038) but only two studies discussed power levels at all (Robertson *et al*, 2001; 2006) of which just one was deemed to meet an acceptable level of power. Similarly only three studies used a sampling methodology that attempted to ensure the sample was representative of the population of interest (Srivastava, 2001; Robertson, Emerson, Gregory, Hatton, Kessisoglou, Hallam, *et al*, 2001; Robertson, Emerson, Hatton, Elliott, McIntosh, Swift, *et al*, 2006). Therefore, not all of the quantitative research was rigorous, and some of the statistical analyses employed may not have been appropriate for the smaller studies. One of the quantitative studies used people with learning disabilities as members of an advisory group (Emerson and McVilly, 2004).

The quantitative work gives us an overall picture of the extent of social networks, and social isolation, which is important since it underpins the issues for developing relationships. It also confirms and validates to some extent the concerns raised by people with learning disabilities in our workshops, who felt that it was extremely difficult to make new friends and to keep up old friendships.

b) *Evaluations of initiatives*

The evaluation studies invariably included people with learning disabilities as participants, but it was hard to tell from some of the papers how participants were approached and informed about the study. Only two mentioned the use of accessible information and were explicit about how they ensured consent could be deemed to be genuinely informed). Two of these studies included people with learning disabilities in a role beyond that of participants; one had people with learning disabilities as members of an advisory group for the project (Heslop, 2005) and in the other people with learning disabilities worked as co-researchers (Williams and Heslop, 2006). These evaluations are of potential importance in this field, as they help us to see what interventions might make a difference. This was the main concern of workshop participants, as we shall see later.

c) *Qualitative work*

Twenty one of the papers used qualitative methodologies to explore this area; the research into the experiences of parents with learning disabilities was largely qualitative in its approach. Qualitative studies were used to

explore peoples' perceptions about relationships and to provide their narratives. Such studies provided more in-depth information about these areas and the impact on peoples' lives. The quantitative evidence suggested that people with learning disabilities have lower numbers of friends and less dense social networks but it should not be assumed that this is negative. It is crucial to have some mixed or qualitative methodologies as otherwise researchers will be drawing conclusions from purely numerical data which may hide important nuances and detail.

The vast majority of the qualitative studies used interviews and focus groups to collect the data but one study employed an ethnographic methodology (Pockney, 2006) and in another, participants used photography to document their experiences (Booth & Booth, 2003a). In general, the qualitative studies were more likely to involve people with learning disabilities more actively with three studies having people with learning disabilities as members of a steering group or as co-researchers (Abbott and Howarth, 2005; Heslop, 2005; Williams and Heslop, 2006).

6.1.3 Scope of the research

Table 5:

Research studies about relationships for people with learning disabilities since 2001

	Total research papers since 2001
Friendships and relationships:	
Descriptive studies	16
Relationships/sexuality	5
Evaluations of interventions	13
Parents with LD:	
Child protections and the courts	8
Support	17
Total in critical review	51

Some observations about the papers included within this review are:

- A total of 51 relevant papers were identified in this literature review. These were classified into five separate themes, although some papers contributed evidence to more than one theme.
- Over half of the papers retrieved in this search related to friendships/relationships (31 papers, 61%). 21 papers (41%) dealt

specifically with parents with learning disabilities. There was one paper which related to both topics as it was a study of the social networks of parents with learning disabilities.

- The majority of the articles (30 studies, 59%) have been published since 2005, suggesting this is a topic that has received more attention in recent years.

Friendships and relationships

- Sixteen studies were primarily descriptive in their approach. These studies explored the number and types of friendships that people have along with factors that affect this, such as living arrangements, age and personality factors.
- Five of the studies more specifically dealt with relationships and sexuality. Three of these explored staff attitudes/experiences (one specifically around same-sex relationships), one looked at people's knowledge of the laws regarding sexuality among people with learning disabilities and one asked men with learning disabilities about their sexual identity.
- Thirteen studies evaluated a specific service or intervention, such as a befriending service, a course about emotional support (Williams and Heslop, 2006) an intervention for parents with learning disabilities, or a relationship service.
- We have included in this section of the review a paper by Robertson *et al* (2006), which set out to explore the impact of person centred planning (PCP) since one of their findings concerned the effect of this on social networks.

Parents and carers with learning disabilities

- There was a body of work relating to child protection and court proceedings (8 papers); these studies investigated the rates and risk factors for court cases for parents with learning disabilities as well as exploring the experiences of these parents.
- The majority of the research in this area provided evidence about the type of support needed (17 papers); this included practical and emotional support as advocacy.
- In the topic area of 'carers with learning disabilities', there appeared to be very little, if any, research carried out. This was compounded by the fact that the combination of the search terms 'caring' and 'learning disability' retrieved research about carers *of* people with learning disabilities. The concept of people with learning disabilities being carers is clearly an unusual and challenging one.

6.2 Findings and outcomes from the research: what we know and what we need to know

6.2.1 Friendships and social networks

Reviews

Encouraging social skills may be one way of helping to facilitate friendships, and one non-systematic review was retrieved which explored approaches to social skills development (Moore and Carey, 2005). This review found that peer mediated approaches appear to be a promising method for the development of social skills, which in turn facilitated friendships. However, they found little evidence of how generalisable the skills were, and how long they were maintained.

Empirical research

The research we reviewed revealed a picture of the major problems faced by people with learning disabilities in the area of friendship and social networks. The studies in this category focused on describing or quantifying peoples' social networks, feelings of social inclusion and exploring the factors affecting these. The evidence showed that in general people with learning disabilities tended to have much smaller social networks than the rest of the population (Emerson, Malam, Davies and Spencer, 2005; Pockney, 2006; Robertson *et al*, 2006). Furthermore these networks were less durable and diverse and mainly comprised staff, families and other people with learning disabilities (Forrester-Jones, Carpenter, Coolen, Cambridge, Tate, Beecham, *et al*, 2006). Pockney (2006) noted that participants with learning disabilities all chose to describe their staff as a 'friend' and this was in sharp contrast to the staff, who rarely used this term to describe the service users. It was clear that some of the staff felt uncomfortable about this disparity and it perhaps has implications for guidance for staff around day-to-day interactions.

Data from one of the larger surveys showed that the setting in which a person lives is a more significant determinant of the quality and content of friendship activities than personal characteristics (Emerson *et al*, 2005). Gregory, Robertson, Kessissoglou, Emerson and Hatton (2001) found that those living in village communities expressed greater satisfaction with relationships than those in community-based supports. Another study suggested that people living in smaller, community-based, less institutionalised settings will have larger and more inclusive networks (Robertson *et al*, 2001). However, one of the few longitudinal studies showed that 12 years of community care has not generally resulted in social inclusion, demonstrating that service providers still need to address the issue of social isolation (Forrester-Jones *et al*, 2006).

Other factors affecting friendships identified by researchers were:

- age - younger people tend to have larger social networks (Robertson *et al*, 2001; Abraham, Gregory, Wolf and Pemberton, 2002)
- autism – people with autism have smaller social networks (Robertson *et al*, 2001; Knott, Dunlop and Mackay, 2006)
- ability – those with higher abilities are more likely to have more diverse social networks (Robertson *et al*, 2001; Hall, Strydom, Richards, Hardy, Bernal and Wadsworth, 2005)
- challenging behaviour – this increases social exclusion (Robertson *et al*, 2001)
- support – active support can help to increase socialisation (Robertson *et al*, 2001)
- self-esteem – there is a relationship between self-esteem and community participation, which is moderated by age (Abraham *et al*, 2002).

Given that impairment of social interaction is a primary feature of autism it is unsurprising that this would be a factor which limits the number and quality of relationships. Knott *et al* (2006) found that children with autism can recognise that they have social difficulties but it appears that they still underestimate the extent of these. This study also highlighted parental concern about inappropriate social interaction, giving a clear focus for interventions relevant to families. We know that level of ability is related to friendship formation and most of the studies here did include people with a range of abilities, however none specifically focused on issues for people with profound and multiple disabilities. For example there was no research on how to facilitate friendships between people with non-verbal communication. Additionally it was clear that age is a factor and therefore we need to be aware that older adults with learning disabilities may be particularly vulnerable to social exclusion. All these are important research gaps.

Emerson and McVilly (2004) concluded that intervention at a systems level is what is critical for the facilitation of friendship rather than a focus on the development of social skills. Despite this, several other studies have argued that promotion of social behaviours can assist with social inclusion (Brackenbridge and McKenzie, 2005; Robertson *et al*, 2001). Brackenbridge and McKenzie (2005) explored what features make some adults with learning disabilities more popular than others. Their findings suggest that, as with the rest of the population, people with learning disabilities have specific preferences guiding what attracts them to form relationships with others. These included personality factors such as confidence and humour as well material factors, such as their possessions.

There is a general consensus from professional carers, family members and people with learning disabilities that there is little opportunity for people with learning disabilities to meet friends and even less to meet partners

(Jenner and Gale, 2006a). The need for support in forming and maintaining relationships has led to the development of a number of 'introduction services' across the U.K. Jenner and Gale (2006a) found that 98% of parents would support their children to use such a service to meet friends and 70% would be supportive of it being used to meet potential partners. While such a concept appears to have generalised support, the authors concluded that funding for such schemes can often be problematic. In order to promote the use of introduction services, we still need more research evidence about their effectiveness, and also potential problems of abuse.

Most of the research reviewed treated people with learning disabilities as a homogenous group but two studies explored the issue of relationships for specific groups. As part of ongoing research, Pawson, Raghavan and Small (2005) made specific reference to Asian people and tested the appropriateness of the Social Inclusion Interview Schedule, concluding that this will be a useful tool for the subsequent phases of their research. It has also been shown that sex offenders with learning disabilities have lower levels of social integration, which has implications for treatment. Paralleling the treatment of mainstream offenders and focusing on increased socialisation and attachment issues within relationships may be a useful approach (Steptoe, Lindsay, Forrest and Power, 2006). The studies reviewed here have highlighted a number of factors that can affect relationships and therefore identify potential interventions. For example it is clear that the type of support received can have a big effect. However, there is a gap in our knowledge about how to facilitate friendships. Practical research about support skills in helping people with learning disabilities maintain friendships could be effective.

Key points for the research agenda

- Friendships are important to everyone, including people with learning disabilities.
- People with learning disabilities tend to have much smaller social networks. These networks are mainly made up of staff, families and other people with learning disabilities.
- Factors affecting friendships include: age, autism, ability, challenging behaviour, accommodation.
- Developing and maintaining friendships is virtually impossible without good support.
- There are gaps in the research about how to facilitate friendships, particularly among people with profound and multiple learning disabilities.
- We need more research to evaluate interventions such as introduction services, so that we can understand better what works.

6.2.2 Relationships and sexuality

Only two of the five studies in this area were prior to 2006, indicating this is a topic that has received increasing attention more recently. However, the majority of the research has focused on staff attitudes and experiences. The main consensus from these studies is that there is very little formal guidance and policy for staff in dealing with issues around sexuality (Abbott and Howarth, 2005; McConkey and Ryan, 2001; Parkes, 2006). Consequently this research suggests that staff are generally unconfident about how to deal with situations that arise and there is a dire need for agreed protocols. Furthermore Abbott and Howarth (2005) and Parkes (2006) found that frontline staff need training around how to support people with learning disabilities in terms of their sexuality, particularly those in same-sex relationships. Further barriers to providing good relationship support identified by the studies were the views and concerns of parents/carers and staff, and in some instances, discriminatory attitudes towards people's sexuality.

O'Callaghan and Murphy (2007) used a questionnaire to explore people's knowledge of the laws regarding sexuality among people with learning disabilities and found they demonstrated very little understanding of these laws. This was both in terms of general laws and those specific to learning disability. This has clearly identified a need for better education concerning sexuality and legal issues.

There are large gaps in the research that asks people with learning disabilities directly about their experiences of sexual relationships, and explores their feelings and needs. A qualitative study by Abbott and Howarth (2005) explored in depth the views and experiences of people with learning disabilities who identified as lesbian or gay. They had frequently faced discrimination, and their relationships may not even have been recognised for the deep, personal experiences that they were. This meant that people in relationships were sometimes unnecessarily separated, and seldom had their feelings acknowledged. Further, it was hard for these people with learning disabilities to gain support from the gay community in general. Another study which explored individuals' experiences around sexuality and sexual identity concluded that the men viewed themselves as sexual beings but felt their opportunities to express their sexuality were often limited (Wheeler, 2007). Wheeler suggested that the Mental Capacity Act (2005) will have implications for policies relating to sexuality and will increase the need for advocacy services.

Key points for the research agenda

- Frontline support staff are often unconfident about situations that arise relating to sexuality and people with learning disabilities.
- There is a need for greater understanding of the law, as it relates to sexuality and people with learning disabilities.
- There are large gaps in the research about close relationships and

sexuality, from the point of view of people with learning disabilities themselves.

- However, we know that people with learning disabilities often face restrictions and discrimination when they try to develop a sexual relationship. We need further research to understand and change this situation.

6.2.3 Evaluation of interventions

Four papers were retrieved that explored the benefits of specific opportunities for the development of friendship. Only one study was identified which evaluated a relationship support service (Jenner and Gale, 2006b). The authors concluded that the service had been well-received by people with learning disabilities and their carers but that funding was problematic. Introductions had been made for over a quarter of the applicants and some case studies were presented. These highlighted issues such as the importance of the preliminary interviews and assessments being as comprehensive as possible. A larger scale study explored the views and experiences of the people involved in befriending schemes (Heslop, 2005). One of the strengths of this study was the inclusion of the perspective of all those involved (people with learning disabilities, their parents/carers, befrienders and staff). Purposive sampling ensured representation of schemes across both rural and urban areas and schemes for children and adults. This paper presented examples of good practice around the key issues identified, such as how to manage breaks, or the end of the service. Holiday breaks offer carers some respite and also opportunities for people with learning disabilities to meet new people. McConkey and McCulloch (2006) evaluated the benefits of one project and found the breaks were enjoyable and gave people the chance to try a range of leisure activities. The data suggested that holidays within mainstream settings were more enjoyable than those at specialist centres which had implications for service providers looking to provide respite breaks through holiday schemes. One limitation of such holiday programmes, according to these authors, was that people with higher support needs and more behavioural problems were less likely to take the opportunity of this type of break and therefore the carers most in need of respite were least likely to get this. A more recent method of initiating relationships is via the Internet (Personal Home Pages) and thematic analysis has shown that people with Down's syndrome can use their Home Page to portray a self-image as a person who is capable of having friendships. The guest book responses revealed that the majority of respondents were non-disabled (Seale and Pockney, 2002).

There are also other events in people's lives that can have an effect on their social networks and friendships such as housing, services and employment. However, benefits of these cannot be assumed. For example, Srivastava (2001) found that 18 months after a move from long-term institutional care into community care there were very few changes overall, although people were more likely to have someone they considered to be a special friend.

Evidence suggests that supported employment can help to increase social networks, which was linked to improvement in life experiences but there were no significant improvements in adaptive behaviour (Forrester-Jones, Jones, Heason and Di'Terlizzi, 2004). A larger study exploring the impact of person-centred planning demonstrated a positive influence on social networks, family contact and community-based activities but successful outcomes were related to having an effective facilitator (Robertson *et al*, 2006). Longer-term studies are needed to explore the ongoing impact.

It has been hypothesised that people with learning disabilities lack the necessary social skills to form friendships and various social skills training has been developed to overcome this. Elliott, Hatton and Emerson (2002) evaluated one such course for adolescents with learning disabilities and concluded that while the teacher observed improvements in conversation and assertiveness, there was a significant decline in the participants' self-ratings on these variables. These authors felt that it was possible that increased insight may lead to deterioration in confidence; groups may need to be smaller and more individually focused. One of the few studies to focus on people with severe learning disabilities demonstrated a significant increase in interactions between members of the group over 12 sessions (Whitehouse, Chamberlain and O'Brien, 2001). They also found that the group stopped meeting once the researchers withdrew and the members were reliant upon staff to facilitate it; the authors concluded that maintaining relationships is virtually impossible without good support. There are many potential benefits of courses and social groups, as peer friendships are a source of highly valued support and have been shown to be a key feature in emotional resilience (Williams and Heslop, 2006). These researchers developed a short peer-delivered course about emotional support, and the evaluation showed that it helped young people with learning disabilities to talk more freely about feelings, build confidence and mutual trust, which are all essential aspects of relationship formation.

Similar studies have targeted specific groups; Lynggaard and Alexander (2004) aimed to facilitate friendships within a home which was affected by the dementia of one of the residents. They found that a relatively short intervention with the group using visual aids, exercises and role plays did help to increase their understanding and empathy. Another group intervention was used with parents with learning disabilities (McGaw, Ball and Clark, 2002). Participants did make new friends and other positive social changes were found, however these outcomes did not improve the quality of the parent-child relationship.

The majority of these studies have focused on the relationship between people with learning disabilities but Laws and Kelly (2005) examined the attitudes of children towards disability, how these predicted their intentions to be friendly towards disabled children and the effect of knowledge on attitude. Children showed more negative attitudes towards behavioural problems than learning disabilities. They found that information about Down's syndrome led to more positive attitudes about learning disability but

information about cerebral palsy led to more negative attitudes towards physical disabilities. There were also evident gender differences; this study demonstrates some of the difficulties around introducing children with disabilities into mainstream schools and emphasises that it should not be assumed that providing extra information will aid the process of integration. Issues about social networking more generally will be taken up again in our section about community inclusion. However, there are clearly research gaps about close relationships and friendships between people with learning disabilities and non-disabled people generally. How do people meet new friends, how can they be accepted as friends, and how do such friendships develop over time?

Key points for the research agenda

- Schemes such as relationship services seem to be well received but funding can be difficult to obtain.
- Supported employment and person centred planning may help to increase social networks.
- Group training can be a useful method to encourage and facilitate friendship development but further research is needed, as some of the findings demonstrate mixed outcomes.
- There are gaps in our knowledge about how friendships and relationships are developed between people with learning disabilities and non-disabled people.

6.2.4 People with learning disabilities as parents and carers

The topic of relationships did not just cover the right to friendships and a sexual life. There were other relationship roles filled by people with learning disabilities, in which they felt unrecognised and unsupported. We retrieved 26 papers on the topic of parenting, which are reviewed below. However, the topic of carers with learning disabilities is also important. We know that people with learning disabilities living at home often take on reciprocal caring roles (Williams and Robinson, 2000), and Walmsley (1996) had also looked at family relationships from the point of view of people with learning disabilities. Both these papers discussed the tensions within the family, and the lack of recognition and support given to carers with learning disabilities. As is mentioned in Chapter 7, Bowey and McGlaughlin's (2005) study of people with learning disabilities living with older family carers highlighted that they sometimes did not want to make future plans for moving out, as they were aware of the fact that had caring roles for their elderly parents. However, as we have pointed out in 6.1.3, it was very hard to retrieve any research directly relating to caring roles of people with learning disabilities. The issue now warrants further research, particularly to map out the scope of this issue, and the different types of caring roles undertaken by people with learning disabilities, as well as the support they need.

Child protection and the courts

Reviews

James (2004) carried out a non-systematic review of the literature in order to identify the perceived risks for children of parents with learning disabilities, which were:

- lack of good antenatal care
- developmental delay – as a consequence of genetic/environmental factors
- behavioural problems/language delay
- abuse and neglect – more likely to be associated with partners/relatives.

By contrast, Tarleton, Ward and Howarth (2006) included a review of the literature relating to support of parents with learning disabilities themselves, and found that the perceived risks to the children may not be backed up by evidence. These authors found that, instead of receiving support, parents with learning disabilities frequently faced child protection proceedings. Once these have begun, they were disadvantaged by their learning disabilities in terms of understanding the rules of evidence and procedures.

Much of the research evidence reviewed in the following sections informed McGaw and Newman's 2005 report and Morris' (2007) Good Practice Guidance. Along with Tarleton *et al's* 2006 report, these publications summarised the existing evidence and identify strategies for providing good support. The data suggest parents with learning disabilities can be capable of coping with a parenting role, especially when provided with good, ongoing emotional and practical support.

Empirical research

Turning now to the growing literature on parenting research, studies have shown there are high rates (40 to 60%) of child removal from parents with learning disabilities (Booth, Booth and McConnell, 2005; Elvish, Hames, English and Wills, 2006). These authors admitted it was paramount to ensure the welfare and safety of the children of parents with learning disabilities, but there was some consensus that stricter criteria may be used when judging this group of parents, as compared with other groups.

Booth *et al* (2005) analysed court records to establish basic facts about the numbers of parents with learning disabilities coming before the Family Courts and the outcomes for these families. They found that parents with learning disabilities were disproportionately represented in care proceedings, with one in every six children at Family Court having at least one parent with a learning disability. Data showed that 47% of these cases were as a result of misguided parenting as opposed to actual abuse and that the vast majority of cases were brought due to neglect. It was found that many professionals focused on the parent's learning disability as a specific risk factor for neglect rather than objective evidence. Data from the

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files analysed suggested these parents had been offered little or no support, as it was assumed this would be ineffective. The authors concluded this contradicts findings from international research and is indicative of discriminatory treatment of parents with learning disabilities.

Other quantitative research which analysed Learning Disability Team and Social Services files explored the factors associated with children being removed from the family home (Elvish *et al*, 2006).

- Previous involvement in child protection proceedings – the removal rate sharply increased if the child had been involved in prior case conferences.
- Number of children – there was a very high removal rate for families with five or more children.
- Prior removal of a child – families who had already had one child removed were at an increased risk for losing another child.
- Parent's involvement with a Schedule One offender – even if this involvement was in the past, this was a factor related to a much higher removal rate of the child(ren).

Views and experiences of parents with learning disabilities going through care proceedings have been explored using a qualitative approach (Booth and Booth, 2004; 2005; Baum and Burns, 2007). In addition to providing personal narratives, these research studies identified common themes:

- Failure in support – many women spoke about inadequate support prior to the removal of their children, even when specifically requested.
- Inappropriate assessments – they are often difficult for the parents to understand and may emphasise deficits rather than abilities.
- Lack of advocacy – parents' voices were often not heard during proceedings
- Mixed messages and contradictory advice – feedback from some professionals involved can be in stark contrast to official reports submitted to court.
- There is a lack of support to help parents cope with the aftermath of having lost a child.

Qualitative interviews with professionals involved in care proceedings revealed that time issues were a key factor in shaping the experience of families in the court process (Booth, McConnell and Booth, 2006). These authors considered it to be in the best interests of the children for proceedings to move quickly but this can disadvantage parents with learning disabilities. For example, this does not take account of the fact that these parents may need a longer time period to exhibit changes in their parenting following professional input. Although there is accumulating evidence about these problems, there is still a gap in research which would help us to know how to change attitudes and processes in the criminal justice system, especially within child protection.

Support

It is clear from a review of the research discussed above that parents with learning disabilities are at a high risk of having their children removed against their wishes but equally it is apparent there are many potential areas for intervention which could impact positively on these families, and help to prevent child removal. Evidence supports the effectiveness of practical support for parents with learning disabilities but in order for this to be directed appropriately there is a need for mainstream services to be better at identifying these parents (Ward, 2007). One paper was retrieved which described a screening tool designed to assist professionals to determine if a referral to psychology services for a full assessment is necessary (McDonnell and Hames, 2005). However, Booth and Booth (2005) argued that the continuing emphasis on cognitive assessments was misguided as there was not evidence of a relationship between parenting ability and IQ. Furthermore if cut-off scores are used, it is possible there will be vulnerable parents who may not meet strict learning disability criteria, but who may still be in need of some extra support and should be included in service provision.

Various studies have demonstrated that in order for support to be effective, it needs to be both long-term and flexible (Guinea, 2001; O'Hara and Martin, 2003; Young and Hawkins, 2006). Furthermore O'Hara and Martin (2003) argued that it is crucial that there is good co-ordination between children's services and those supporting adults with a learning disability.

Other research has identified more specifically the type of support needed. For example, women with learning disabilities tend to receive very little antenatal support (Wates, 2003). Traditionally, antenatal classes are considered to provide an opportunity for parents to receive information and advice around labour and birth as well as to begin to prepare for life with a new-born baby. Therefore, this research argued that, if women with learning disabilities are excluded from such classes, they will be disadvantaged at later stages. It may be that parents with learning disabilities require support in order to enable them to attend mainstream antenatal classes (Tarleton *et al*, 2006). There are many everyday tasks which these parents may require support with after birth. Tarleton *et al* (2006) reported these as including:

- explaining things to their children
- managing their children's behaviour
- helping their children with homework
- ensuring the safety and welfare of their children
- understanding what professionals say
- helping with transport
- managing finances and paperwork

- practical tasks around the home
- coping with bullying or harassment.

This list highlights the need for the support to be ongoing, as Tarleton *et al* (2006) argued that issues such as managing the child's behaviour and ensuring their safety will clearly change as the child ages. On a wider level, parents with learning disabilities may need professional support to tackle problems such as poverty, debt and poor housing (Ward, 2007). There is a gap in our general knowledge about how support proceeds for parents with learning disabilities, as they and their children grow older.

Several studies were identified which evaluated various services and input for parents. The Supported Learning Project was established to provide personal support and development in self-advocacy for mothers with learning disabilities in order to help them address their children's needs (Booth and Booth, 2003b). One of the main aims of the project was to provide support and encouragement but interviews with the mothers revealed that over half had joined in order to improve their skills. They did not just want help with parenting skills but acknowledged that their own employability and literacy/numeracy skills were also crucial for providing a good quality of home life for their children. Wharton, English and Hames (2005) described a manual developed from a series of programmes designed for parents which was positively endorsed by both professionals and parents. The Child and Special Parenting Service was evaluated by Young and Hawkins (2006). It was considered to be important in preventing family breakdown and a particular strength was the bringing together of professionals who worked with the family as a unit rather than with the child or the parents. Again, the analysis revealed that this was a service valued by both recipients and professionals who referred people to it.

Although the research evidence demonstrates that parents with learning disabilities can benefit from appropriate support, fear of removal of their children can act as a deterrent to seeking support from social services (Wates, 2003). Furthermore, many parents have reported negative and stereotypical attitudes from professionals; Tarleton *et al* (2006) argued that it is essential that supporters should be non-judgemental, and feel that we need more knowledge about attitudes among a whole range of professionals and other family members, which will help to find ways to develop and change the discrimination faced by parents with learning disabilities.

Emotional support

In-depth interviews with parents with learning disabilities have revealed that these parents identified a need for more emotional support, rather than practical support (Guinea, 2001). It was concluded that although friends were identified as an important source of support by several participants, the parents did not have as wide a friendship network as parents in the general population. This was further verified by research employing a different methodology (Booth and Booth, 2003a). This study gave mothers cameras to enable them to document their personal experiences through

photography. They found the women included few photos of partners or extended family, suggesting a sense of isolation.

Two pieces of research included in this review specifically explored the relationships of mothers with learning disabilities with their male partners. Booth and Booth (2002) felt that their findings challenged existing preconceptions that male partners are exploitative and fail to contribute support. The majority of female participants were in long term relationships and these were important in their own lives and those of their children. Often the fathers did not make the traditional contribution in terms of fulfilling the breadwinning role but they did provide support in regard to child rearing. Similarly, Stenfert-Kroese, Hussein, Clifford and Ahmed (2002) found that, despite the fact that only half of the women reported partners who helped on a weekly basis, the majority of their participants perceived their partners as helpful. The authors suggested services should involve partners more, with an aim of improving the couples' ability to work together. The mothers' support networks were mainly comprised of family members, with just over half of the available support being viewed as 'very helpful'.

Evidence of the impact of extended family support upon the outcomes for the family was provided by an exploration of cultural differences in parenting by people with learning disabilities (O'Hara and Martin, 2003). This found that 85% of Bangladeshi children, who had a parent with learning disabilities, continued to live with their families and none were on the child protection register. In contrast, 40% of English children in the sample were taken into care, in line with previous statistics. The extended family support provided more stability for the child, although it was noted there could also be psychological difficulties for the parent. Tarleton *et al* (2006) also presented evidence of the benefits of extended family support.

However, they also highlighted that parents could feel disempowered by involvement of the wider family and produced strategies for professionals aiming to involve the extended family. These included:

- taking the necessary time to gain the trust of the extended family
- developing an understanding of the specific roles of individual family members
- keeping families involved with developments
- not getting involved in family feuds.

It should also be acknowledged that not all families would be deemed to provide appropriate support. There is evidence that many parents with learning disabilities have had poor models of parenting throughout their own childhood, and many report a high level of abuse (Elvish *et al*, 2006; Baum and Burns, 2007).

Alongside the evidence suggested that increased support can improve the chance of parents keeping their children living with them, it has also been

demonstrated there is a significant relationship between social networks and positive affect of mothers and also between recency of social contacts and self-esteem (Stenfert-Kroese *et al*, 2002). This suggests there are many potential benefits of providing appropriate social and emotional support. Of the mothers attending the Supported Learning Project, almost half acknowledged that their lack of self-confidence was a major barrier to their ability to learn new skills (Booth and Booth, 2003b). One of the ways in which the project aimed to increase self-confidence was through the development of supportive relationships with other mothers and with workers. One study included in this review evaluated an intervention, which was designed to increase social inclusion of parents (McGaw *et al*, 2002). While this was found to be effective in terms of increasing social contacts for the parents, there was no evidence that it resulted in improved relationships with their children. However, the authors suggested future research should include observational data which may reveal subsequent changes in the quality of the parent-child relationships. In line with other research, the emphasis was on long-term, ongoing support (Guinea, 2001; O'Hara and Martin, 2003).

Advocacy

In the 1990s, Booth and Booth researched advocacy support for parents with learning disabilities and found that parents felt better for having an advocate, even if there was minimal effect on their situation (Booth and Booth, 1998;1999). They found that effective advocacy provided both emotional and practical support for parents and therefore played a critical role. Advocates fulfilled many roles and at various times advocates had acted as:

- a witness – somebody to corroborate dealing with officials
- a voice – to help ensure the views of the parents are heard
- a go-between – liaising between families, professionals and services
- an interpreter – explaining jargon in a simplified way
- a scribe – helping with letters and forms
- a confidante – someone to share private information.

The current literature search only identified one study in advocacy, meeting the research criteria. Mencap (2007) evaluated two advocacy services which provided support for parents during child protection proceedings. Researchers interviewed parents, advocates and professionals involved with the case and examined the case files. They found a number of positive impacts of the advocacy services, namely:

- parents were treated with more respect during child protection procedures
- parents' voices were heard
- emotional support throughout the often stressful meetings

- advocates were able to challenge professionals' practice.

The report also identified key issues to be considered in terms of providing the necessary support for advocacy services to continue. These included the need for clear protocols, training and clinical supervision for the advocates and appropriate case-load limits.

Despite the growing body of work in this field, there is still a need for research to give a clearer picture of the experiences, feelings and outcomes for the whole family. For instance, the point of view of children who are brought up by parents with learning disabilities is under-researched, as well as the experience of those who are removed from their birth parents. In all this, the research needs to find ways to reconcile the tensions between child protection and support for the parents; there are strong leads for action research which will help to find practical ways of joint working between the different agencies involved with the family.

Key points for the research agenda

- Forty-sixty percent of parents with learning disabilities have their children removed from them; however, research has shown that it is possible for people with learning disabilities to be 'good enough' parents, with good support.
- There is a need for more research about the support needed by the whole family, as children grow up with their parents with learning disabilities.
- Parents with learning disabilities face particular discrimination and problems when they get involved with the criminal justice system. We need more research about how these problems can be overcome.
- We have research evidence about the kind of support which works, as well as the benefits of advocacy.
- It would be useful to have more knowledge about how different agencies involved with these families could work together, in order to provide good support to parents with learning disabilities.

6.3 Discussion of gaps identified in research on relationships for people with learning disabilities

As indicated in 2.1.1 of this report, the priorities discussed with participants in the final round of workshops arose from the preliminary summaries of the research review. These issues were also discussed with a researchers' network meeting, and the discussion there was tape-recorded, transcribed and analysed. The following represents a summary of those discussions.

6.3.1 Friendships and close relationships

As we have seen from the literature review, there is a broad range of descriptive studies about friendships and social networks of people with learning disabilities, revealing that their networks are much smaller than those of non-disabled people, and often limited to the situations in which they live and spend their days. Paid staff members are often counted as friends, while families naturally play a key role in providing a social circle for people with learning disabilities. People at the workshops said that the priority for research in this area was to move on and seek evidence-based solutions to underpin practice. Many people echoed the following statement by one professional at a workshop:

'Research has explored the numbers and types of friendships, and we probably don't need any more of that. We need to move on, and think about how people keep and maintain their friends.' [Professional]

A parent in one of the workshops pointed out that her daughter was more prone to losing friends than most of her counterparts:

'I think a lot of Mandy's opportunities have got smaller as she's got older, as the people she was at school with in our village have started moving away, and Mandy hasn't.' [Parent]

It was felt by all stakeholders that meaningful relationships were the most important and central part of anyone's life. For people with learning disabilities, this included romantic and sexual relationships.

Several interventions were discussed at the workshops, including dating agencies set up particularly for people with learning disabilities. It was felt that these should be evaluated, so that benefits and possible drawbacks could be determined, including the dangers of abuse. It was felt that, if the findings were disseminated more widely, more people with learning disabilities could potentially benefit.

What helps people with learning disabilities make new friends, and keep up with old friends? It is quite possible, of course, that the factors are the same as for other non-disabled people, and participants suggested that research needs to adopt a comparative approach here. As we will see later in the chapter on 'community', there is a raft of barriers which will hinder people from going out and meeting new friends. We know about the need for support; the lack of finances; the lack of skills and confidence. However, if research is going to help us change these situations, people said that we need to look at how support workers and family carers can best facilitate friendships. For instance, what could the support worker do, when accompanying a person to meet her boyfriend at a café? How could support workers seek out possible opportunities for relationships, and nurture those?

For many people outside the Learning Disability world, friendships and relationships are often formed through everyday activities, whether at school, college or in work. As was pointed out by the young people who

worked with Williams and Heslop (2005) in a study about mental health support needs of young people with learning disabilities, young people themselves can help each other, by offering friendship. Workshop participants said that we need more research to understand how to value these offers of friendship, to build people's confidence, and to ensure that voluntary and paid jobs for people with learning disabilities also offer them a range of opportunities for friendship.

Participants at the workshops, as well as the researchers' meeting, were very concerned about certain aspects of social isolation. People who are moving into 'supported living', and taking up individual tenancies, may be more isolated than those living in traditional group homes. At the same time, participants said that day services modernisation is resulting in the closure of centres which, arguably, provided people with learning disabilities with a social milieu, at least during the day.

'A lot of times, people say they will miss seeing their friends, when the day centre closes. The business of seeing friends during the day is important, as well as the night clubs. In a way, we could have research to see the various ways people can meet and make friends.'
[Professional]

Finally, we know that level of ability is related to friendship formation and most of the studies here did include people with a range of abilities; however none have specifically targeted issues for people with profound and multiple disabilities. For example there is virtually no research on how to facilitate friendships between people with non-verbal communication.

6.3.2 People with learning disabilities as parents and carers

When people do successfully establish relationships, this may include romantic and sexual attachments. A major issue for many workshop participants was the absence of information and appropriate education about sex, and they felt that research could help us better understand how to give good information about sex to people with learning disabilities.

Some of our workshop participants had become parents, and desperately wanted to care for their own children. Others simply wanted to have a family life of their own, or knew other people who had become parents. All of these people had had their children removed from them, and they were desperate to tell us about these situations. Although many of these individuals had been to support groups, they had also come up against a range of negative attitudes in society, from people who assumed that parenting was impossible for people with learning disabilities. They felt it would be important to do research about the attitudes and perceptions of different groups of people, including social workers, judges, and medical professionals such as midwives. It would also be extremely important to have more research about the attitudes and position of the parents of people with learning disabilities, who will then become grandparents in the event of a baby. It was felt that they often continue to play a key role in

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supporting the whole family, and their experiences should be documented and discussed, alongside the views of the parents with learning disabilities.

Although there is already a stream of research about parents with learning disabilities, and the support that they need, all stakeholders felt that it was important to continue to raise questions and viewpoints which could help us see parenting in a new light. One professional mentioned the time he had first met with parents with learning disabilities, and realised that his own preconceptions were challenged. It was felt that a gap in the existing research evidence is about the experience of children who are born to parents with learning disabilities.

'One of the ways you understand that there are parents with learning disabilities is if you hear from the children.' [Professional]

It was suggested that research should explore the family as a unit, from all points of view, including that of the children. For instance, do they get bullied at school? What are their feelings about the debates about their care? It was felt that it would be very informative to compare outcomes and feelings for those who are taken away from their birth parents, with those who are supported to stay with them. Although child welfare in these cases is paramount, it was suggested that it would be useful to have a cost analysis of parenting, to show whether it is more expensive to remove children from their birth families, or to provide support to keep the family together.

In terms of the actual support offered to parents with learning disabilities, some stakeholders suggested looking at specific types of support and evaluating interventions such as a new initiative to provide Keyring supported accommodation for parents with learning disabilities.

People said that it remains a priority to find out how children's and adult services can work together more effectively, so that families are supported, rather than split up.

Finally, an important question came up in one of our workshops, about caring for other family members. People with learning disabilities are often assumed to be in receipt of care, and not to be carers themselves. Nevertheless, we know that there are people who provide care for their ageing parents, and some who provide care for partners. In all these cases, people said we need more evidence about the extent of informal caring by people with learning disabilities, to promote greater recognition and support. Research about family carers has not included people with learning disabilities themselves, and this is an important gap:

'Research needs to look at us as carers. We don't get any recognition and support. But we don't even know how many people with learning disabilities are actually caring for other people.' [Person with learning disabilities]

6.3.3 Emotional life and identity

Relationships and friendships are not generally considered to be a 'fundable' support need, as pointed out in the researchers' meeting we held:

'To what extent do they see it as part of the public role, to help people have friends? One of the real problems we have is convincing people who hold the money, to take this seriously. They see their role in terms of bricks and mortar, risks, and physical health and so on'. (researcher)

Can we in fact have policies about 'happiness'? Although it was agreed that we cannot legislate for emotions, it is nevertheless the case that relationships are a Human Rights issue, and research is needed which takes a Human Rights perspective on these questions. Policy analysts need to look at how central the issue of relationships is, and how this is framed in Learning Disability policy in particular.

Instead of supporting relationships, services have all too often been a source of abuse (White, Holland, Marsland and Oakes, 2003). We know that local policies about the reporting of abuse, for instance, are not always implemented. We also know that there is something about the 'Learning Disability' culture which seems to lead to abusive relationships, particularly with those who have challenging behaviour or who cannot speak for themselves. When we discussed these findings with workshop participants, they felt that they have to remain top of the agenda for all research in this area, so that we can better understand and prevent abuse.

Comments from all stakeholder groups indicated that a person-centred support service is the key to good emotional support. However, this is not always what support staff deliver:

'Or do you want to try and change people's views on what they are there to support people with? If we are really providing a person-centred service, then we need to do it according to what is important to the person. Emotional support is important.' [professional]

It was felt that the challenge for both research and for practice was to get the correct balance between safety measures and risk-taking in this area. Relationships are vital, and always imply a degree of emotional risk. People with learning disabilities are often denied the opportunity to start a relationship, in case they are disappointed. It was felt that we need more research which will help us understand the emotional needs of people with learning disabilities, how best to support those needs, and how to get the correct balance between risks and safety in policy, and in practice.

A negative self-image can pose problems for any relationship, and it was felt to be important that identity issues are not forgotten, as some people commented in the researchers' meeting:

'Can people with learning disabilities get stronger by identifying as people with learning disabilities?' [Researcher]

People can build a sense of identity by working together with others who

have the label of 'learning disability', and this is arguably one of the reasons that the self-advocacy movement is so important. At present, however, self-advocacy groups are often struggling to survive financially, and this very valuable source of mutual support is becoming squeezed. Researchers in our network meeting pointed out that self-advocacy can give people with learning disabilities a stronger, more positive sense of their own identity. This is the basis for developing successful relationships at every level, and so they felt that research should focus on the changing situation in self-advocacy groups.

6.3.4 Summary of research priorities about relationships suggested by all groups of stakeholders

Out of all the topic areas in this consultation and review, the topic of 'relationships' was perhaps the most difficult to translate into research questions. Although workshop participants felt very strongly about relationships, they had some difficulty in thinking how the gaps in our knowledge could be met by research. The overall priority was to do with sexuality and parenting. There was also a small number of people who were interested to have more research about carers with learning disabilities. In all these cases, people are taking up roles which are unexpected for people with learning disabilities, and they were interested in research that would help them identify and challenge the barriers they perceived. All the particular questions, topics or areas for research listed below are those that were suggested by workshop participants or by research network participants.

Friendships

- What is the variation between different areas of the country, in the opportunities for socialising?
- To what extent are people with learning disabilities socially isolated (in their work; in independent living), especially after closure of day centres?
- Do people with learning disabilities have opportunities to go on holiday with friends?
- What practical help do people with learning disabilities need to keep in touch with old friends?
- What are the benefits, dangers (and possible safeguards) in friendship groups?

Parenting and caring roles

- What is the experience of children of parents with learning disabilities? (for instance, at school, or in later life)
- What is the experience of children who remain with their birth parents, compared with those who are removed from the family?
- What are the costs of providing good support to parents with learning

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disabilities, compared with the cost of separating families?

- How do we improve the relationship between children and adult services in terms of support for families?
- How do we provide better long-term support to parents with learning disabilities?
- Do parents with learning disabilities from different cultural backgrounds have the same problems? Is the rate of removal of children the same? If not, what is it that works for them?
- How do parent support groups work, and what constitutes good practice?
- How many people with learning disabilities are family carers? Do these people get recognition and support?
- Can we understand better society's attitudes towards people with learning disabilities forming relationships? (Social workers, parents, teachers, judges, managers, midwives)

Relationships and emotional life

- How can we reflect the importance of relationships in policy?
- What are the best ways of protecting people from abusive relationships?
- How can support staff realise the importance of emotional support and facilitating relationships?
- How do we best support people to learn about sex?
- What helps people with learning disabilities to be more confident?

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7 Housing Options

Housing is traditionally a topic which is bound up with support for people with learning disabilities. The majority of people with learning disabilities (at least 50%, according to Emerson, Malam, Davies and Spencer, 2005) have always lived at home with their parents, even during the period of the large institutions. With the closure of institutions, people have been re-settled in the 'community', but this raises a whole plethora of issues. The type of housing offered is crucial in enabling people to be part of their own communities, and also to get the support that they need. In 2008, we now have a growing range of housing options and models of support. However, over half of people with learning disabilities still live with their families, well into adulthood. Those who do move out have seldom chosen who they live with. We will explore some of these issues further in this chapter.

7.1 Scope and methodology: housing research

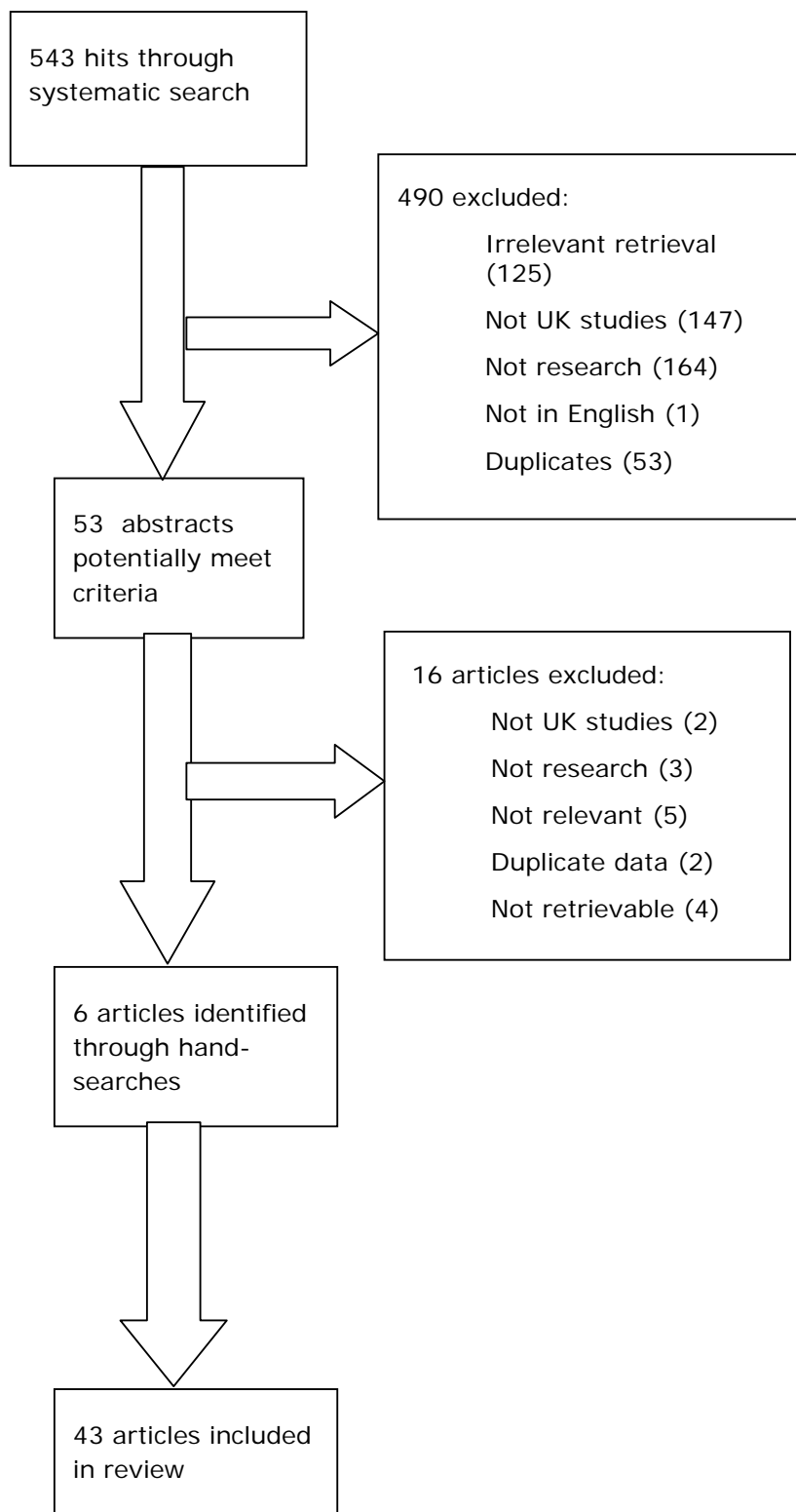
7.1.1 Methodology

Using the search terms given in Appendix A, 'housing options' yielded 543 hits. These were sifted in two stages. 490 were excluded at the initial retrieval stage; if there was any doubt about the relevance of the item, the abstract was retrieved and scanned. A further 16 articles were excluded at the abstract stage. The following rules for exclusion were applied systematically at both these stages:

- 1) Not about the topic (of housing and people with learning disabilities)
- 2) Not UK studies (where the research was based entirely outside the UK)
- 3) Not research or reviews of research (opinion papers without empirical basis; short practice descriptions were excluded)
- 4) Paper not written in English
- 5) Duplicates
- 6) Research published before 2001

A further six articles were identified through hand searches (including *British Journal of Learning Disabilities*; *Journal of International Disability Research*; *Journal of Learning Disabilities*; *The Learning Disability Review*) and so the total for the review in this area was 43. This process is represented in Figure 4 below.

Figure 4: Flow chart of the literature search for "Housing Options"



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7.1.2 Evaluation

a) *Quantitative research*

A summary of the appraisal data for each topic in this report is given at the end of Appendix B. What follows here is an evaluative overview of the topic area. In the area of housing, there was a split between quantitative and qualitative studies, with the former predominating (47% of the total number were quantitative; 35% qualitative). The main analytical tool for the quantitative research was multivariate factor analysis (Emerson, 2004a; Felce and Perry, 2004), generally based on data retrieved from rating scales or questionnaires administered to staff. Of this large-scale, robust survey work, two studies complemented data from questionnaires with interviews (Gregory, Robertson, Kessissoglou, Emerson and Hatton, 2001) and another with observations of staff and residents (Mansell, Elliott, Beadle-Brown, Ashman and Macdonald (2002a)

Because the focus of much of this work was on 'quality of life' (QOL), some of the debates in this literature revolved around what is meant by QOL, and how we evaluate it. Emerson's (2004a) comparison of QOL in clustered and dispersed housing, for instance, was criticised by Cummins and Lau (2004) for using objective, rather than subjective measures. However, Emerson (2004b) strongly defended his approach, and linked it both to methodological rigour, but also to the desire to create a more equitable society. Perry and Felce (2003; 2005) compared objective and subjective QOL appraisals, and found very little correlation, with the objective measures being far more useful in predicting and evaluating factors associated with housing.

Two of the major studies on which these papers drew had very large samples (1,542 in Emerson, 2004a) (495 in Mansell, Ashman, Macdonald and Beadle-Brown, 2002b) and so can be considered to be largely representative of particular populations in particular types of housing. Authors were generally careful not to claim results which cannot be proved to be valid, and many of the papers were reflective about methodology, and some were in fact about the methodology itself.

In quantitative research, however, associations between variables cannot always tell us about the causative links. For instance, when observing staff and resident activity levels, an overall relationship was claimed. However, this methodology does not tell us about the ways in which those activities are interrelated. It may also be said that relying on data from frontline staff questionnaires runs the risk of circularity, especially when the outcomes of the research are often that staff factors are key to understanding quality of life. However, this body of work has been important and has shaped our understanding of the relative outcomes of various forms of housing, and of moving the housing agenda forwards towards more individualised, dispersed housing.

b) *Qualitative research*

Qualitative research in this area, although rarer, relied both on focus groups and semi-structured interviews and associated analytical methods. Two studies in particular used large samples (Forrester-Jones, Carpenter, Cambridge, Tate, Hallam, Knapp *et al*, 2002; Fyson, Tarleton and Ward, 2007) large, and the findings were generally based on a thematic content analysis. This work resonates well with what we know about direct user views (e.g. liking for freedom and choice; preference for living with friends; dislike of conflict)

Qualitative research, although revealing, can often exclude those who cannot communicate verbally (Bowey and McGlaughlin, 2005). Forrester-Jones *et al* (2002) for instance, used carefully designed pictorial and other strategies for getting to know potential interviewees, but still found that 28% of participants could not answer any questions. This is a perennial problem with this type of qualitative method in Learning Disability research.

c) *Evaluations and single case-studies*

Two single-case evaluations (Sergeant and Brown, 2004; Whitehurst, 2006) were found that were not published in the academic literature. It is very likely that more such evaluations exist, which we were not able to retrieve. Although not based on objective, robust research methodologies, they may be very indicative for practice (about the design of buildings; the attitudes of landlords, and so on).

By contrast, in a more robust demonstration study, Mansell, McGill and Emerson (2001) investigated the outcomes for people with challenging behaviour (CB) who moved into non-congregate settings, and showed that this resulted in a reduction in the CB and increased community participation. This type of demonstration study is very important in leading the way to develop models and creative solutions for the future.

7.1.3 Scope of the research

Table 6:

Research studies about housing for people with learning disabilities since 2001

Outcomes of different models of housing	15
Support staff in different types of housing	5
Service users' views on where they live (or would want to live)	5
Out of area placements	5
Family members' views	2
Evidence about where people are living or future demand	4
Re-settlement from long stay hospitals	3
Research methodologies about housing	2
Renting, landlords and DDA	1
Building design for people with ASD	1
Total	43

In the years since 2001, there have been many changes in ideas and provision of housing for people with learning disabilities. Key to these are the understandings that housing and support are two conceptually separate issues, and do not have to be bound together (Simons, 2000). In most areas of the UK, hospital re-settlement is not still a major concern, but the outcomes for people who previously lived in institutions are still very much an issue. The interest in housing reflects an overall worry that moving to 'the community' may not have brought the benefits expected, and that we still need to weigh up the value and outcomes of the varied ways that people with learning disabilities live and get their support.

- About a third of the research in this area was about different models of housing and support. This included a small amount of emerging research about supported living, and In Control pilots.
- There was an overlap between this body of research and the work on support staff. Many of the studies about the outcomes of different housing models concluded that it is the support staff that matter. Five papers under specifically focused on that topic.
- The evidence base about where people live presently is not comprehensive. The studies that do exist tended to focus on particular sectors or geographical areas (Northern Ireland, residential accommodation,

and so on).

- There were very few research projects about actual housing availability, the types of housing which are needed, neighbourhoods and design of housing. The few studies in this area tended to be single-case studies or evaluations, and so there is clearly a big need for these to be replicated in larger-scale surveys.

7.2 Findings and outcomes from the research: what we know and what we need to know

7.2.1 Where are people with learning disabilities living?

Empirical research

In the UK, as elsewhere, the major option for people with learning disabilities has always, and continues to be, life in the parental home. Emerson *et al* (2005) found that 2/3 of people with learning disabilities in their survey lived in private accommodation, and, of those, some 75% lived with parents or family carers. A recent study by Buckner and Yeandle (2007) demonstrated that the support provided by family carers in all sectors saves the Government some £87 billion per annum. Research about housing, however, has naturally focused on forms of housing with paid support services, since those are the options over which policy-makers have some control.

Closure of institutions throughout the UK has resulted in various forms of 'community living'. Emerson *et al*, in their 2005 survey, found that just under 1/3 of adults with learning disabilities were living in some form of supported accommodation, and of these, two-thirds were in residential accommodation, and three percent were still in institutions. However, the situation is changing fast with the advent of supported living options and forms of self-directed support. There are still major gaps in our knowledge of exactly how many people with learning disabilities are living in their own tenancies, or living in properties that they own.

McConkey (2006a) provided some up-to-date information about people with learning disabilities in Northern Ireland, where there is a greater emphasis on purposeful, village communities. He concluded that people were usually placed in various residential accommodations according to availability of places, rather than according to factors relating to their needs. Mansell *et al* (2002b), however, found that nearly half of residents in homes provided by one national charity had severe behaviour problems, and a significant number had very substantial care or physical needs. Residential homes have clearly become the popular option for placement of people with the highest level of need.

We also know that there is still a tendency for local authorities in England to

place service users with challenging behaviour in 'specialist' housing away from their home area. Beadle-Brown, Mansell, Whelton, Hutchinson and Skidmore (2006) found that between 30 to 50% of placements in Kent, for instance, were out-of-area placements. There are financial incentives for providers to accept these placements, but Mansell, Beadle-Brown, Skidmore, Whelton and Hutchinson (2006) found that between 30 to 54% of these people had not been contacted by their own care manager in the previous year. The system clearly creates incentives for the people with the highest levels of need to be effectively ignored.

At the other end of the scale of ability, there is an unknown number of people with learning disabilities who become homeless, maybe because of the breakdown of social support (Hebblethwaite, Hames, Donkin, Colman and Forsyth, 2007). According to these authors, these people appear to be at particular risk, within the culture of homelessness, and are vulnerable to abuse from other homeless people. We also have some evidence about the situation for older people with learning disabilities who live in generic housing for older people. Thompson, Ryrie and Wright (2004) in a UK wide survey received responses from 530 homes for older people, and found that people with learning disabilities were significantly younger than other residents, were often placed in these homes in response to an emergency, and had very limited quality of life.

Key points for the research agenda

- Over half of people with learning disabilities still live at home with their parents.
- Of the others, 2/3 are in residential accommodation: these are mostly people with the highest levels of need.
- Many people with complex needs are sent away, to live in places far from their home area.
- People with learning disabilities who do not receive services are at risk of becoming homeless. We need more research to find out about their needs.
- There is a gap in our knowledge about the numbers of people with learning disabilities who are living in properties they own, or part-own, or where they are tenants.

7.2.2 Where would people with learning disabilities like to live?

Empirical research

Those researchers who have gone directly to people with learning disabilities find in general that they are well able to articulate their needs and wishes for future housing (Forrester-Jones *et al*, 2002; Barr, McConkey and McConaghie, 2003; Gorfin and McGlaughlin, 2003; Gorfin, McGlaughlin and Saul, 2004). People with learning disabilities generally are interested

not just in 'bricks and mortar'. Barr *et al* (2003), in a Northern Ireland context, found that people felt contact with their families was very important, and that they also wanted to live in places where they felt included in the local community. Gorfin and McGlaughlin (2003) reported that people with learning disabilities said the quality of where they lived was closely related to freedom and autonomy. Jahoda and Markova (2004) found that there was little difference between people moving from their parents' home and those moving out of long-stay hospitals. They all wanted to live in ways that avoided stigmatising attitudes from others in the community.

Although there was an emphasis in this literature that people with learning disabilities could in fact choose and voice an opinion on where they would like to live, McGlaughlin, Gorfin and Saul (2004) found that of 72 people with learning disabilities interviewed in one English city, 29 were living at home with elderly carers. They were often reluctant to express their views about moving, and showed concern for their family carers, although 39% expressed the view that they would like to move 'now or in the future'. We know from Williams and Robinson (2001) that some of these people living with elderly parents take on reciprocal caring roles. However, there is a gap in our understanding about how to support them, and to enable them to have a choice about their own housing needs.

Forrester-Jones *et al* (2002) followed up a sample of 196 people with learning disabilities who were living in the community, twelve years after resettlement from long-stay institutions. The things people liked about where they live were to do with independence, having their own possessions and doing what they wanted to do. By contrast with institutional life, people with learning disabilities preferred living in any form of housing in the community (McConkey, McConaghie, Mezza and Wilson, 2003). However, people also highlighted problems with fellow residents, and bullying, and Gorfin *et al* (2004) also found that the number of co-residents was associated with wanting to move. Conversely, this research by Gorfin *et al* (2004) found that some people suffered from boredom and loneliness, although it was not clear whether this was always associated with actually living alone. The very important issue of choosing who one lives with must loom large for all these participants, as it did for stakeholders who came to the workshops for the current review. People's quality of life has consistently been associated with good relationships. However, the issue of choice of fellow-residents is very seldom highlighted in the literature on housing.

The views of parents and carers are also very important in moving towards greater provision of choice in housing. As noted above, about half of all adults with learning disabilities still live in the parental home. Bowey and McGlaughlin (2005) in a focus group study, explored the views of families and professionals about housing choices, and found that a major concern of families was with risk. The most important factor for them was to ensure that their son or daughter was safe, and they were not willing to

compromise that need in planning for the future. Families still need more information about possible future choices for residential accommodation.

In the same study, reported in Bowey and McGlaughlin (2007) 55% of older carers were not ready or willing to make future plans for their relative. It is clearly important for planning to take place earlier on in the life-cycle of the family with a learning-disabled relative, as these authors found that the dynamic between carer and person with learning disabilities may change as the carer becomes older.

However, families whose relative had previously lived in an institution were also generally pleased with outcomes of moving, as McConkey *et al* (2003) found, although that study also revealed that 26% of families had previously been worried about this. Noonan-Walsh, Linehan, Hillery, Durkan, Emerson, Hatton *et al* (2001) investigated the views of relatives and their level of contact with relatives who had already moved on into supported housing, comparing campus settings with dispersed housing. These relatives tended to believe that current care was better than what had gone before. Their opinions were often based on the quality of staff support and standards of care, although they would also like improved staff ratios and better day activities for their relatives. There was a theme here, as with the service users, about local living arrangements. Where relatives were re-settled near their parental home, family members could and did keep in touch on a regular basis. It would be useful to find out more about the importance of living in the local community, and near the parental home, especially for those living in supported living or other more independent options.

Finally, does this body of research tell us what we need to know for future planning? We know that there is a growing shortage of places in residential care (Emerson and Hatton, 2004), but of course the demand for residential placements does not necessarily tell us about the quality of life for people with learning disabilities. We will turn shortly to research which seeks answers to that question.

Key points for the research agenda

- People with learning disabilities generally want to live in the local area they already know.
- There is a gap in our knowledge about the importance of local community, and living near the parental home, especially for people living in supported living arrangements.
- People want to live in non-institutional settings, where they can choose and have their own possessions and independence; they also want to choose who they live with.
- Families are concerned about risks, but generally need better information about housing options.
- Fifty-five percent of older carers are not ready to make future plans for

their relative with learning disabilities, many of whom will not be prepared to speak up about their own wish to move.

- Gaps exist in our knowledge about how to support people with learning disabilities living with older parents.

7.2.3 Costs and benefits of models of housing and support

Empirical research

Various models of supported housing have been promoted over the past 20 years. In the debates about various forms of housing, it is widely assumed that congregate settings (where people with learning disabilities, often with the same type of need, are grouped together) are more cost-effective than settings in which people live individually or in dispersed houses in the community. However, research has challenged this assumption. Hallam, Knapp, Jarbrink, Netten, Emerson, Robertson *et al* (2002) compared the costs of supporting people in several different settings, including village communities, NHS residential campuses and in community-based housing schemes. This research found that there were wide variations in cost, and these were not necessarily associated with particular types of provision. Those with higher support needs and challenging behaviour (CB) cost more, whatever the housing model, and smaller facilities were likely to be more expensive. Robertson, Emerson, Pickney, Caesar, Felce, Meek *et al* (2004) taking just that population of people with CB, examined the costs for two matched samples of 25 people, one group living in congregate, and the other in non-congregate settings. In fact, this study showed that non-congregate settings may actually be more cost effective than congregate.

The benefit of particular forms of housing, of course, is not just about the relative cheapness. It is primarily about quality of life, and as we indicated above, this is not always easy to measure. Hatton, Emerson, Robertson, Gregory, Kessissoglou and Walsh (2004) tested out a 'Residents' Choice Scale' and found it a reliable and useful tool. Objective measurements of quality of life, used in large-scale surveys, are probably the best measure we have of the overall outcomes from different forms of provision. For instance, Emerson (2004a) examined costs, inputs and outcomes for dispersed housing (rather than clustered), and found that people living in clustered housing tended to have more restrictions in their social opportunities, and to share their house with more people. They were more likely to live in places which were not really 'like home' in that they may also have been used for short-term care. McConkey (2007) confirmed this picture, for Northern Ireland, but added that another main predictor of social inclusion was the social competence of the person with learning disabilities. The major studies in this field have attempted to control for the compounding factors related to intrinsic differences in residents, but of course factors such as social competence and social opportunities are bound to be linked. Mansell *et al*'s (2001) study of people with CB in more person-centred housing showed a reduction in the anti-social behaviours of the residents. There is a need to continue with that strand of research, to

investigate the benefits for people with CB of living in person-centred ways.

Supported living, arguably, represents another step along the road to an independent lifestyle, and as we know, these options are currently being developed more widely in England. Emerson, Robertson, Gregory, Hatton, Kessissoglou, Hallam *et al* (2001) compared small group homes with supported living, in relation to both costs, inputs and outcomes. People in supported living were found to have more choice, and a greater number of community based activities. However, they were also more likely to have had their home vandalized, and were considered to be more 'at risk'. Since then, supported living has perhaps been more widely applied as a model; however, Fyson *et al* (2007) found that some supported living services were hardly distinguishable from residential care, and that residents still only had control over small everyday choices in many cases, not over major decisions. This was similar to the picture reported by Coates, Barna and Walz (2004), who found that contact with other people in the community remained non-existent or superficial for many people living in 'supported living' arrangements. We now need to have some better knowledge about how to change this situation, and to ensure that 'supported living' does match the standards and expectations set for it.

Key points for the research agenda

- Congregate settings are not necessarily any cheaper than non-congregate settings.
- People who live in dispersed houses in the community have a better quality of life, in terms of social inclusion and opportunities.
- We need more research about people with challenging behaviour who live in personalised accommodation.
- Supported living should give greater community opportunities, but it does not always deliver on this. We need to know why that is, and how to change the situation.

7.2.4 The importance of staff practices

Reviews

People with learning disabilities seem to be prone to living lives of under-occupation, with low levels of activity and engagement both inside and outside the home. This appears to be broadly true, no matter what type of housing arrangement is made for them, and it is particularly true for those with the highest levels of need, as shown by Felce and Emerson (2001) in a review of the literature. These authors also noted that ordinary housing stock and normative architecture were to be preferred; however, smaller size of accommodation was not necessarily better than larger units, in terms of outcomes for residents. In the literature reviewed, both over-staffing and under-staffing were shown to have negative effects, while the literature had shown a strong association between engagement in activity and some form of staff attention (especially instruction, prompting,

demonstration, guidance and praise). This review concluded that it is important to match staff training and performance more precisely to the level of needs of residents, as those with higher support needs have greater benefit from 'active support' methods, while those with moderate learning disabilities may not need such methods. Additionally, a non-systematic review by White, Holland, Marsland and Oakes (2003), referred to in Chapter 5, revealed the extent of institutionalised abusive staff practices in long-stay hospitals, but also in community-based residences.

Empirical research

Is staff performance related to the type of provision, or to the ratio of staff to residents? Felce, Lowe and Jones (2002a), in an observational study, found no significant differences between statutory, voluntary and private sector provision, and they noted that smaller residence size was actually associated with lower resident activity. Higher staff ratios resulted in residents taking part in less domestic activity, although more staff did mean that residents could get out more.

What is the key factor, then, in leading to an improved quality of life? As Mansell, Beadle-Brown, Macdonald and Ashman (2003a) report, the only reliable predictors of engagement in meaningful activity were:

- a) the overall level of adaptive behaviour of the person with learning disabilities
- b) the care practices of the staff.

Felce, Lowe and Jones (2002b) and Felce and Perry (2004) report a considerable variation in the attention that residents received from staff, and in general, those with the most severe disabilities received the least staff support. However, we know also from Mansell *et al's* (2002a) and other work in that group, that active support (active engagement of staff with individual residents) does make a positive difference to the activities of people with learning disabilities, especially those with the most severe level of needs. Gillett and Stenfert-Kroese (2003) also suggested that organisational culture amongst the staff could make a positive difference.

This focus on staff practices is borne out in recent and emerging literature about people with learning disabilities who receive forms of self-directed support. Valios and Ahmed (2006), for instance, in a single case study, mentioned the activities and attitude of staff as being a key to people with learning disabilities feeling more 'in control', as was mentioned in Chapter 5 in relation to 'support staff'. Despite our knowledge about these factors, we still know very little about what works in effecting changes in staff practices.

Key points for the research agenda

- The size of a house, and the number of support staff, do not always lead to a better quality of life for residents.
- People whose staff engage with them most are more likely to have meaningful, active lives.

7.2.5 Environment and safety

Empirical research

Does it matter at all, then, where people live? A concern for staff practices is important, but it must also be remembered that we also know how important it is for people with learning disabilities to be housed in local areas, near their family (McConkey, Walsh-Gallagher and Sinclair, 2005) and indeed to have accommodation that is safe, and is well-designed. An interesting unpublished evaluation, for instance, by Whitehurst (2006) demonstrated how important it can be to design environments which are appropriate for children with ASD. Features included a reduction of detail, good lighting, containment, and a sense of calm and order. These features are very likely to be equally important for adults with ASD.

The debates about 'safe' and secure accommodation are still ongoing, and Sergeant and Brown (2004) for instance, in a single-case study, defended and promoted the building of grouped, sheltered accommodation for those with challenging behaviour, claiming that these people thus gain greater autonomy and safety. Another study (Aston, Hill and Williams, 2007) was also found about the experiences of disabled people who rent, both from private and from social landlords. On the whole, social landlords were found to have a good understanding and reaction to their duties under the Disability Discrimination Act (HM Government, 2005), and to provide a measure of adjustments for their disabled tenants. However, this study was not differentiated for people with learning disabilities, and it would be useful to have more work to explore their experiences in the rental market.

In all these contexts, a major concern about people with learning disabilities must be to do with safety. Although people in more 'community based' supported living may be more at risk from vandals (Emerson *et al*, 2001), it must also be remembered that all staffed housing brings with it a risk of abuse. Therefore, staff are not just the 'answer' to quality living; they can also, frequently, be the problem. The reader is referred to section 5.2.4 of the current report. It has been shown that abuse is often due to systemic failures, and conversely, positive staff morale can be fostered through good management practices. Organisational culture, and good support for staff, has to remain a key focus in the research both on housing and on support.

This quick summary of the research on housing has moved increasingly towards the 'soft' variables of staffing, organisational culture and community engagement. It is noticeable that very little of the research revealed by our searches was actually about housing stock. We will see that stakeholders in our current study were very concerned about how to obtain housing, and this will remain a key issue as more people take up self-directed support. The issue of choice is absolutely vital to this debate, and it is salutary to remember that, in 2008, the vast majority of people with learning disabilities have not chosen the people they live with. These matters must remain high on the agenda for future research.

Key points for the research agenda

- It is important that people with learning disabilities can get safe, secure accommodation in their own local areas, as tenants or home owners.
- Some people, including those with ASD, may need specially designed housing.
- Staff can be abusive in residential homes; it is important to change this.
- There are major gaps in research about housing stock and how to obtain good housing, from the point of view of people with learning disabilities.
- We need to know how many people have chosen who they live with, and how we can create choices for people with learning disabilities about who they live with.

7.3 Discussion of gaps identified in research about housing for people with learning disabilities

As indicated in 2.1.1 of this report, the priorities discussed with participants in the final round of workshops arose from the preliminary summaries of the research review. These issues were also discussed with a researchers' network meeting, and the discussion there was tape-recorded, transcribed and analysed. The following represents the main points in those discussions. A list of the priorities and questions identified appears at the end of the chapter.

Society's support for people with learning disabilities is largely delivered in two ways, through bricks and mortar, and through human resources. The research we have reviewed since 2001 has shown the tight connection between these two elements, and if anything, has shown the greater importance of staff support, over the 'bricks and mortar' of a house. Characteristics of the housing seem to be less important, and indeed, as people move more into an open market for their housing options, it might be considered irrelevant to engage in research which examines housing specifically allocated for people with learning disabilities. However, the move towards open housing options is far from complete, and stakeholders in the current review were most concerned to discuss how to get somewhere good to live. The choice is not a black-and-white one between open, independent housing and residential homes. Increasingly, there is a range of other alternatives, or half-way provision, and these need to be monitored, discussed and examined in terms of their effectiveness.

7.3.1 Housing options and distribution

As noted in our literature review, the research base is short of evidence about exactly where people with learning disabilities are living, how these patterns are distributed across the country, and what the outcomes are for different groups of people. Although we have the overall statistics for 2003/4 (Emerson *et al*, 2005), there were some specific questions posed by stakeholders who came to our workshops. For instance, we do not know

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how many people with learning disabilities rent their home, nor about home ownership:

'How much home ownership is there by people with learning disabilities?'
[Professional]

People in one workshop discussed the often false assumptions of safety within supported or residential care. Parents also felt that their own availability sometimes meant that social services pulled back from offering any residential options. It was easier just to leave someone at home with their unpaid carers:

'I don't think people get asked that question, whether they want to try something different. People assume that because they're in a house, that's where they stay. I don't think people are aware there are other options.' [Family member]

Better information about housing was a key theme, both for people with learning disabilities and for their carers. It was felt that we still need more evidence about where people live, what experiences they have in certain neighbourhoods (and whether that matters) and whether local housing departments are regularly taking into account the needs of people with learning disabilities. This type of evidence is important, not just for policy-makers and planners, but also for family members and for people with learning disabilities themselves. A clearer, evidence-based picture of housing will assist all parties in taking steps for themselves towards secure living arrangements.

A related, and equally important matter, was that of choice. People felt that choices were limited still, and were bound up with the important matter of safety:

'We know someone, she wants to move into independent living but the last offer she was given was on the other side of the city in an area she doesn't know, and it's not a very nice area either... she'd be vulnerable on her own...' [Person with learning disabilities]

Workshop participants prioritised research that would help us to know how best to support people to have a choice over where they live. They felt that people with learning disabilities could be involved in developing local housing strategies, and that research could highlight good practice in creating good housing options, so that social services and housing departments could follow suit. One person said, 'I'd like to look at the things that are working well', aware that there is great variation in what is on offer in different areas of the country. For instance, some people in Leeds were curious about the concept of 'housing brokers' and wanted to know more about how such practices were working in Oldham.

It was pointed out by researchers, however, in our discussions, that housing allocations should not be specially made for people with learning disabilities. Additionally, the availability of housing is bound to vary from one area to another, as it does for all of us. This is an issue for people with learning

disabilities who may not have control over which area they live in, and so these discussions highlight the need for some of our research strategies not just to focus on models of 'specialist' housing for people with learning disabilities, but to compare their experiences with those of non-disabled people.

7.3.2 Models of housing and support

We have seen that one third of the academic research since 2001 has been concerned with different 'models' of housing. Participants in our workshops wanted to know how we get away from models, and move towards person-centred planning.

'The person-centred notion has gone, we're still trying to fit people into boxes rather than saying 'Where do you want to live? How do you want to be supported?' [Family member]

However, as these models change and move on, it is inevitable that we will need to monitor them, and to continually update our knowledge of what works best, for whom, and in what circumstances. How does an individual budget affect your housing choices? A particular concern of some participants at workshops was the issue of supported living. There is still a very thin evidence base about what supported living consists of, and for some family members, for instance, it can be a frightening concept. They suggested that we need more research about the 'levels of support' offered in supported living.

However, a professional who attended one workshop was aware that supported living had not, as it were, lived up to its ideal. He suggested the topic of 'what went wrong with supported living?'. This idea links with some of the recent research, showing that supported living does not always differ substantially from forms of residential care (Fyson *et al*, 2007), but it was suggested by our stakeholders that it would be useful to understand in more detail how organisations have interpreted the principles of supported living, and to learn from those lessons:

'It's still happening, businesses are still being set up and put along a model which isn't doing what it said it was supposed to, so why are people still throwing money at it instead of looking at other options?' [Professional]

Families were aware of the particular levels of skill, independence and needs of their own particular son or daughter. A particular suggestion from one parent was for research about 'halfway' housing situations, where young people with learning disabilities could learn skills for independence.

Research which continues to monitor new developments in housing is going to be vital, as we move into an era of self-directed support, individual budgets and 'in control'. Very little research has so far directly addressed these issues. We know from the existing research on direct payments that people who receive a DP are generally very satisfied with the greater degree

of control they achieve over their own life, and over their staff. Likewise, the emerging evaluations of SDS (self directed support) and individual budgets (IB) show that those who use the new systems enjoy many benefits from them, in terms of greater control, an independent lifestyle and increased community opportunities. Some have found these options transformative. However, there will continue to be needs for research to reflect the realities of life as experienced by these new tenants, employers and home owners. Are they, for instance, lonely or vulnerable? What is the incidence of abuse, and how can we provide safeguards?

7.3.3 Families and Housing

As we noted in our section on frontline support workers, family members are the main source of support to people with learning disabilities, and we have noted in this section that some 75% of people outside the 'residential' sector are living with their parents into adulthood. Families will continue to be the experts on the support needs of their own son or daughter, and in securing good housing options, many of them wish to maintain those connections. However, parents sometimes find that their own role with their offspring is ignored, once they have left the family home, as a parent at one of the workshops said:

'Support has to work with families as well, and vice versa. Some support can be quite dismissive of families...and sometimes the two can end up putting themselves on opposite sides, and the person can get caught in the middle.' [Family member]

This echoes some of the research by McConkey in Northern Ireland, showing how important it is to work in partnership with family members (McConkey, McConaghie, Mezza and Wilson, 2003). We have seen that there is some existing research since 2001 about the views of families, and about their ongoing connections and contact with their son or daughter. However, stakeholders in two of our workshops spoke about the need for more detailed research to look at the experience of people with learning disabilities who live near their families. The hypothesis would be that they would enjoy more community engagement, and perhaps a better social circle. The ideas about 'local community' are part of the new policies towards independent living and inclusion. However, it would be interesting to compare the experiences of groups of people who live in different localities (near their family, or away).

Similarly, the decision about moving out of the family home has received some recent research attention. Particularly in the case of older carers, we have some information about their own perspectives, and a growing picture of the mutual dependence between older carers and their relatives with learning disabilities. A support worker in one of the workshops compared his own experience of growing up and moving out of his parents' home with that of the person with learning disabilities he supports. The group agreed that it would be useful to have research about how the decision about leaving home happens, and to compare people with learning disabilities with

non-disabled young people. There may be interesting similarities among parents' perceptions and roles, as well as key differences.

7.3.4 Housing and people with high support needs

Highest costs, as we have seen, are associated inevitably with people with the highest level of needs (although their outcomes are not always so neatly matched). Research still urgently needs to address many gaps in our knowledge about how to 'get it right' for people with high support needs – both those with challenging behaviour, and those with profound and multiple learning disabilities (PMLD). Both these groups were prioritised by stakeholders at our workshops, as well as by the researchers' network.

People with high support needs are often grouped together, in terms of their housing needs. However, one of the concerns of workshop participants was that we need to start offering the same choices about independent living, shared ownership and self-directed support to those with more complex needs:

'What would it take for people with high support needs to have supported living options?' [Professional]

At the same time, it was felt that we need more evidence still about what is happening at the moment for both these groups. In particular, if people with high support needs are being grouped together in residential provision, it would be useful to have more research evidence about the effects of this joint living. We know from existing research that people in congregate living complained about other residents, but we do not have any detailed or longitudinal research showing what the effects are.

A participant in one workshop said:

'I know of people who live in more supported housing, and you might get 3 people sharing a house. I know of one young man who was tagged as being aggressive. But then when you see there were people going into his room & taking his stuff, you see why. But he didn't have a choice and he was living somewhere where he didn't feel even his stuff in his room was his own, it wasn't safe.' [Supporter]

A common response to people with high support needs and CB, as we have seen, is to send them away to 'specialist' provision in out-of-area placements. We have some indicative studies on particular movements of people around the country, but we now need to know the 'bigger picture'. Researchers were aware that this practice needs to be described and understood more fully, in order to tackle the issue and make better local provision.

'(Out of area placements) are extraordinarily expensive, and it just takes the resource out of the local service, a last-minute panic. These are always Friday evening decisions.' [Researcher]

Some mapping of existing care planning decisions would be useful, together

with a cost analysis of out-of-area placements across the country. Researchers also felt that this issue was part of the Human Rights agenda, and should take priority. Certainly, if we need to release resources into local provision, we need to understand what is happening at present, and why it happens.

There has been some recent research interest in the population of prisons, and the proportion of offenders who turn out to have a learning disability. Those who are on the 'edge' of the service system may end up in a different service system, in high secure units or in prison, and we urgently need to have better information about how many people this applies to, and what their needs are.

Last but not least, workshop participants flagged up the needs of those with profound and multiple needs. As we noted in Chapter 1, this is a growing population, and a larger cohort of people who are technology dependent will soon be growing into adulthood. It is a matter of urgency to make sure that we know how to provide appropriate services at all levels, and housing has to be a central part of these services. If people need wheelchair accessible housing, for instance, how available is this in local areas?

7.3.5 Summary of research priorities and questions suggested by all stakeholders

The priority areas that emerged about housing research were to do with positive strategies for ensuring that more people with learning disabilities have real choices, including home ownership, shared ownership and renting. A first step in this would be research to provide clearer and up-to-date evidence about where people are now, and what their experiences are. There was also high priority given to research about family involvement, older carers and particularly the issue of living in the local community, close to family. Finally, people with high support needs were felt to be an important research focus, including those with challenging behaviour. It was felt that research could look further at personalised living arrangements for these people, and that could be backed up by evidence about current arrangements – in residential care and especially in out-of-area placements.

All the particular questions, topics or areas for research listed below are those that were suggested by workshop participants or by research network participants.

Research about housing options and distribution

- 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 have of living in certain neighbourhoods (comparing rough areas with better areas, for instance)?

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- What have local authority housing departments done, to include the needs of people with learning disabilities?
- How can people with learning disabilities be included in developing local housing strategies?
- How do we support people to have a real choice about where they live?
- What works well in housing options across different areas? What makes these things work well?

Research about models of housing and support

- What are the levels of support received by people in 'supported living'?
- How can we develop places for people to learn independence skills?
- What went wrong with supported living? (Understanding the processes of how organisations have interpreted supported living, and learning from those lessons)

Research about families and housing

- What is the experience of people with learning disabilities who live near the family home?
- What is the role of families in the decision about whether to move out of the family home (compared with non disabled people)?
- How can housing support services learn from families?

Research about housing for particular groups

- How many people with complex needs are moved out-of-area, what are the patterns, and how can we change this practice?
- What housing is there for people who need wheelchair access?
- Where are people with learning disabilities living within the criminal justice system?

7.4 References Chapter 7

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8 Work and personal finance

Paid employment has only recently been recognized as a possibility, and a priority, for people with learning disabilities. Day activities and day centres have predominated in services, and it is still not widely assumed that all people with learning disabilities will be able to work in open, paid employment. Alternatives to paid employment include voluntary work, placements, workshops and a variety of activities which combine learning, social activity and work. As will be seen, there are varied estimates of how many people with learning disabilities are in paid work; however, an optimistic figure would be about 10% of adults of working age. Disabled people are significantly more likely to have no formal qualifications, live in rented social housing, be unemployed and have lower earnings (Bajekal, Harries, Breman and Woodfield, 2004). There clearly exists a complex relationship between disability and social class effects of poverty, low skills and unemployment. Because so few people earn a proper working wage, the majority of people with learning disabilities rely on the benefit system. Living with impairment is expensive in terms of needs such as transport, home adaptations and personal support. This can deter those in receipt of a range of benefits who feel they may lose them by getting a paid job. The 'New Deal for Disabled People' (McClellan, Dench, Grey, Shanahan, Fitzsimons, Hendler *et al*, 2005) has seemingly been unable to overcome the barriers to work for people with learning disabilities (see Roulstone and Barnes, 2005). The themes of work and money were interrelated in many ways in discussions during this project, and this is why we present them as twin themes in one chapter.

8.1 Scope and methodology: research about work and personal finance

8.1.1 Methodology

Using the search terms given in Appendix A, 'work and personal finance' yielded 942 hits. These were sifted in two stages. 874 were excluded at the initial retrieval stage; if there was any doubt about the relevance of the item, the abstract was retrieved and scanned. A further 43 articles were excluded at the abstract stage. The following rules for exclusion were applied systematically at both these stages:

- 1) Not about the topic (of work, personal finance and learning disability)
- 2) Not UK studies (where the research was based entirely outside the UK)
- 3) Not research or reviews of research (opinion papers without empirical basis; short practice descriptions were excluded)

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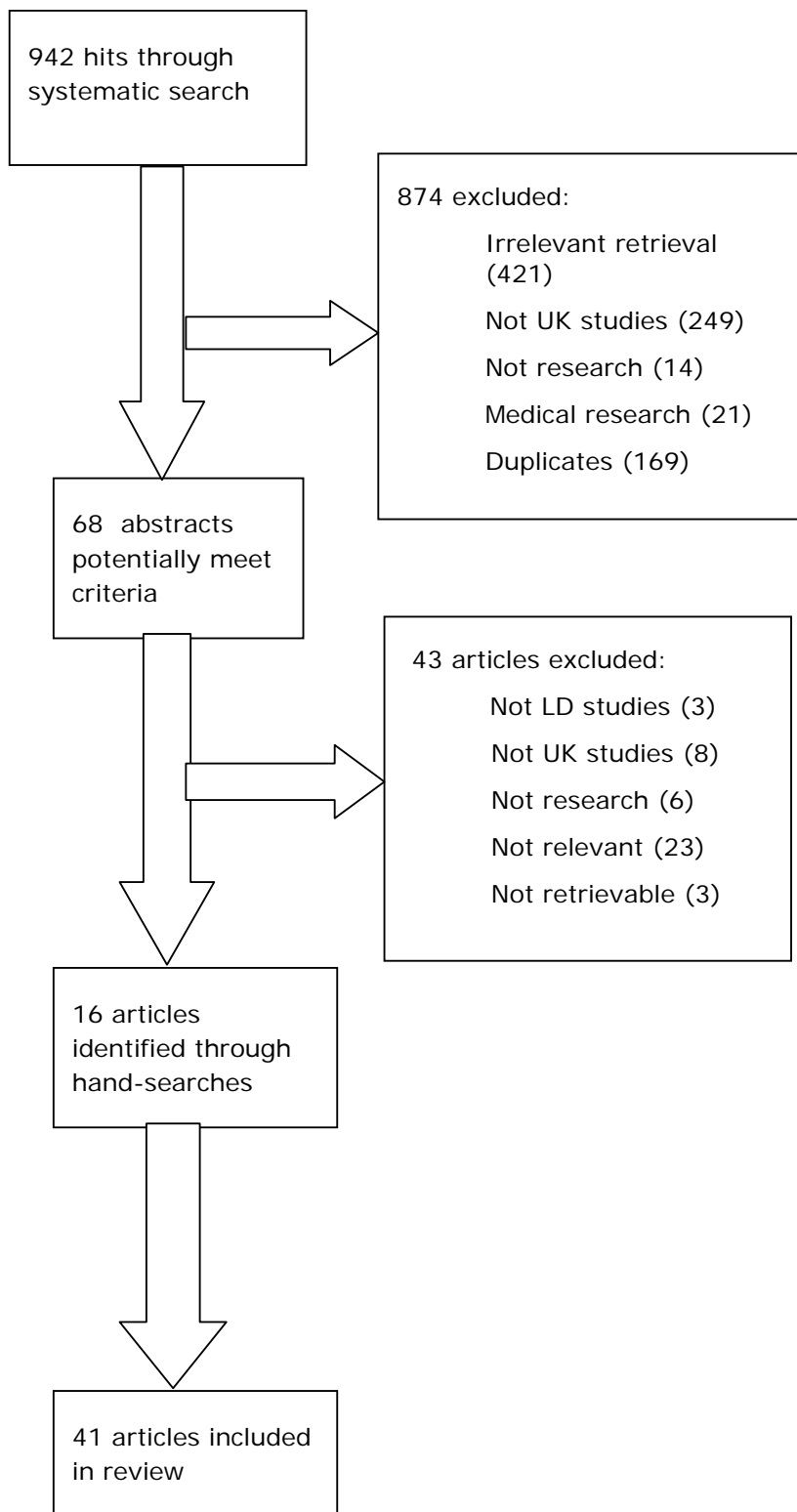
4) Paper not written in English

5) Duplicates

6) Research published before 2001

A further 16 articles were identified through hand searches (including *British Journal of Learning Disabilities*; *Journal of International Disability Research*; *Journal of Learning Disabilities*; *The Learning Disability Review*) and so the total for the review in this area was 41. This process is represented in Figure 5 below.

Figure 5: Flow chart of the literature search for “Work and personal finance”



Evaluation

a) Quantitative research

A summary of the appraisal data for each topic in this report is given at the end of Appendix B. What follows here is an evaluative overview of the topic area. Only 11 of the research studies (27%) about work and finance used a primarily quantitative approach. The majority of these conducted surveys of either people with learning disabilities or of employment agencies. There was a large range in sample sizes of people with learning disabilities (18-2898) and some studies had limited generalisability, as all participants were recruited from one employment agency. Similarly there was a wide spread of sample sizes in the surveys of services; one was a large survey of 2520 employment focused services (Arksey, Thornton and Williams, 2002), while another which sent the survey to 1111 agencies only received a six percent response rate and so data was only available for 63 agencies (Schneider and Dutton, 2001). There was also a wide range of data collection methods; two of the studies analysed assessment scores (Furniss, Lancioni, Rocha, Cunha, Seedhouse, Morato *et al*, 2001; Suto, Clare, Holland, and Watson, 2006) and Kilsby and Beyer (2002) statistically analysed data observational data. There was no evidence of sampling strategies to ensure the samples were representative for any of these studies.

b) Qualitative research

There were 18 studies (44%) which have been categorised as qualitative research in this area. Although the majority used case studies, interviews and focus groups, there were also different methodological approaches employed. These included an action research case-study, (Goodwin & Colgate, 2006) an ethnographic study (Riddell, Baron and Wilson, 2001), vignettes (Suto, Clare, Holland, and Watson, 2005a) and photography (Wilson, 2003). Many of these used fairly large sample sizes for this type of research; one reported on data from 232 interviews and nine focus groups (Beyer, Grove, Schneider, Simons, Williams, Hayman *et al*, 2004).

c) Evaluations of interventions

There were only 3 papers (7%) which evaluated interventions. Furniss *et al* (2001) evaluated a palmtop-based job aid for people with high support needs and made comparisons between this and alternative systems. Another two papers used different approaches to evaluate two interventions, designed to increase job-seeker determination. The first assessed the effectiveness using statistical analysis of quantitative data, (Kilsby and Beyer, 2002) while the second (Kilsby, Bennert and Beyer, 2002) used discourse analysis to provide further information and to validate the original findings.

8.1.2 Scope of the research

Table 7:

Research studies about work and personal finance for people with learning disabilities since 2001

Money:	
Financial situation	2
Access to financial services	3
Control and Capacity	5
Work:	
Employment rates and barriers to work	18
Wider benefits	6
Employment interventions and initiatives	24
Total	41

The vast majority of the papers retrieved in this search related to work (35 papers, 85%) while only a small proportion directly researched personal finance. A number of the studies about employment did make reference to the issue of benefits but unless this was a focus of the study, it was not deemed to be research relating to personal finance. A total of 41 relevant papers were identified in this literature review. These were classified into six separate themes, although some papers contributed evidence to more than one theme.

- Two papers (5%) researched the issue of poverty for people with learning disabilities; one explored levels of poverty and one investigated the reasons for people with learning disabilities being at an increased risk of poverty.
- Some of the research (3 papers, 7%) investigated issues about access to money. Banking services and systems have changed considerably over the last decade and this has had an impact on people with learning disabilities.
- The majority of the personal finance studies (5 papers, 12%) explored issues around control of money and capacity to handle financial decisions.
- Eighteen of the studies (44%) investigated the employment rates of people with learning disabilities and the barriers that limit the employment level for this group.
- Six studies explored the wider benefits of employment for people with learning disabilities, which can extend to self-confidence, social skills and quality of life in general.

- The largest proportion of the research (24 papers, 59%) focused on an exploration of how to overcome the barriers to work and included evaluations of various employment schemes.
- Three of the studies in this area focused on people with high support needs (Furniss *et al*, 2001; Weston, 2002; Smyth & McConkey, 2003) but none of the studies reviewed related to the specific needs of older adults or people from Black and Minority Ethnic groups.

8.2 Findings and outcomes: research about work and personal finance

8.2.1 Issues to do with personal finance: poverty, access and capacity

Empirical research

Poverty

Survey data from Emerson, Malam, Davies and Spencer, (2005) revealed that, according to their definition of poverty, 23% of people with learning disabilities were poor, and that people with learning disabilities were in general much less likely than the rest of the population to be able to afford things like holidays, hobbies or new clothes. People with lower support needs, with poor general health and living in private households were at the highest risk of living in poverty, whereas those with high support needs living in supported accommodation were more likely to be able to afford to buy things. In their scoping review, Williams, Abbott, Rodgers, Ward and Watson, (2007) explored some of the reasons why people with learning disabilities and their families were at an increased risk of living in relative poverty. They found that:

- The extra costs of living associated with a disability can reduce an already poor benefits-income.
- Family members who have a carer role find their incomes reduced, with insufficient help.
- The 'benefits trap' affects people who would want to work, but feel they could not match their incapacity benefits through earnings.

Family carers came under general scrutiny in recent generic work about carers (Buckner and Yeandle, 2007); this study calculated that carers of all disabled and older people save the UK Government in the region of £87 billion per annum. In other words, they are a major part of the financial equation for social care, and nowhere is this more true than in the field of Learning Disability, where over 50% of adults still live in the parental home. Williams *et al* (2007) reported that family carers often had to give up careers, to live on minimum income, and in some instances could barely afford to carry on caring. They reported that the benefits paid to carers are

a minimal reward for a lifetime's work. There are still major gaps in research that explores these issues.

Access to financial institutions

There is a growing need for people to have bank accounts due to the changes in systems for benefits payments. However research has revealed barriers to people with learning disabilities opening and maintaining bank accounts. Hurcombe (2004) found that most people with learning disabilities interviewed had experienced problems in accessing and using banking services. There was also frustration at being forced to change from a system they were able to manage and understand (collecting cash from the Post Office) to one that was problematic (opening a bank account).

A larger, more recent study undertaken in collaboration with researchers with learning disabilities has also explored the existing difficulties in using banks and building societies (Livingstone, 2006). She found that:

- Some of the buildings did not have easy access for people with disabilities.
- There was a paucity of accessible information on available services.
- Providing proof of identity was difficult.
- Providing credit references if necessary.
- Providing a signature was sometimes difficult.
- Some of the staff did not have a positive attitude towards people with learning disabilities as customers.
- Some people are refused an account as they are judged to lack capacity.

As part of their scoping study, Williams *et al* (2007) interviewed a range of financial support services, such as the Citizens' Advice Bureau and the Money Advice Trust. Data gathered revealed that such organizations do view their role as addressing the needs of the local community and that they do target specific groups of people. However none of the seven services interviewed said that they provided services to people with learning disabilities, despite the fact that the services provided would appear to be useful for this group, as they include teaching of budgeting skills for example. Therefore findings show that there remains a gap between what people with learning disabilities could benefit from and the services available. Further research should enable us to develop a greater, qualitative understanding of how these services support financially excluded clients, and how their services could be extended to include people with more severe learning disabilities.

Livingstone (2006) and Williams *et al* (2007) draw out the implications for banks and financial services, who should review their service provision to ensure they are not in breach of the Disability Discrimination Act. These

studies concluded that:

- Bank and financial service providers should provide disability awareness training for all their staff.
- There should be clear guidelines for signatories to a bank account for a person with a learning disability.
- Banks should liaise with Learning Disability organizations to provide accessible information leaflets.
- There should be clear policies and procedures to ensure that there are no inconsistencies between local branches of the same bank.

Capacity and control over money

During the course of the current project, the Mental Capacity Act (2005) has come into force, and should have an impact on the principles of capacity assessment for people with learning disabilities. For instance, people will have to be assessed separately for each decision, and there should not be blanket assumptions of incapacity. The goal of providing supported financial decision-making for people with learning disabilities is enshrined in the MCA, on which we have as yet no research data. However, financial capacity was dealt with in existing research we reviewed. For instance, many of the participants interviewed by Williams *et al* (2007) did not understand the concept of money or where it came from.

Unsurprisingly many also lacked control over their budgets and were often given small amounts of pocket money rather than having control over their whole budget. Data from Emerson *et al*'s survey revealed that over half the respondents (54%) said that someone else decided how much money they could spend weekly (Emerson *et al*, 2005). Even those adults who are living more independently can still find themselves under tight budgetary control (Williams *et al*, 2007). There appears to be a need for more support with finances as well as better education around money management. There is a gap in our knowledge about financial support strategies used in the family home, by comparison with strategies used by support workers and paid care staff.

In a series of studies, Suto *et al* (2005a; 2005b; 2006) used vignettes and semi-structured interviews to explore financial decision-making abilities in people with learning disabilities. Their evidence suggests that they may have poor decision-making skills, but that many individuals do have the capacity to be taking some personal financial decisions. Those with learning disabilities were found to make their decisions in the same way as non-disabled people, and both groups found that understanding the relevant information and reasoning with it were the most problematic aspects. The findings suggested that intellectual ability only had an indirect role in financial decision-making abilities and they concluded that basic education about money skills, combined with the opportunity to take everyday decisions will maximize an individual's capacity.

Individual lack of capacity means many people with learning disabilities are dependent upon others to assist them with their finances and indications from Williams *et al* (2007) were that this can result in financial abuse. Carers in this study were often concerned that individuals with learning disabilities could be vulnerable to offers of credit. However there is a lack of systematic evidence around the level of financial abuse suffered by people with learning disabilities.

Key points for the research agenda

- About 25% of people with learning disabilities are likely to be living in poverty.
- There is a lack of research evidence about the financial situation of families caring for a relative with learning disabilities.
- Access to financial services is difficult, because of lack of accessible information, and systems which discriminate against people with learning disabilities. We need to find out how they could extend their services to people with learning disabilities.
- Over 50% of people with learning disabilities do not have control over their own money, although research has shown that basic education and support could help them make financial decisions for themselves.
- There is a gap in our knowledge about how to give good financial support to people with learning disabilities.
- There are concerns about vulnerability and financial abuse, but little hard data.
- There will be a need to monitor assessments of capacity to make financial decisions, under the Mental Capacity Act (2005).

8.2.2 Issues to do with employment

Reviews

Paid employment is generally considered to be a positive and desirable option for people with learning disabilities; one non-systematic review and commentary (Jenkins, 2002), however, indicated that employment could be problematic if considered a desirable outcome for all people with learning disabilities. Although this review outlined the essential elements to achieve best outcomes for those in supported employment (including job placements; ongoing monitoring; worksite training and effective communication with supervisory staff), it also highlighted previous studies that pointed out the stress, financial problems and health problems that could be associated with paid work, and concluded that leisure could be equally fulfilling as work for people with learning disabilities.

By contrast, Goodley and Nourouzi (2005) in reviewing the field for a chapter in Roulstone and Barnes (2005), argued that the arguments about employment for people with learning disabilities have tended to focus on

'supply-side' measures, and reflect a model in which it is assumed that the individual with learning disabilities has to fit into an existing, inflexible labour market. According to these authors, there are gaps in our knowledge about how the labour market is changing and can change, and how work will be viewed for everyone in the twenty-first century. These issues will affect the lives of people with learning disabilities, as well as other socially excluded groups.

Finally, a review of research was carried out for the Department for Work and Pensions in 2006, and this review recognised fully the rights of people with learning disabilities in work. The barriers identified in the research reviewed were:

- low expectations of work among people with learning disabilities themselves, their carers and 'professionals';
- confidence and skill levels;
- transport problems;
- little focus in schools, further education and day centres on employment related activities and a lack of work-based support for people to access;
- lack of knowledge/understanding of what support is available to people with learning disabilities and their employers and how they can access it;
- lack of clarity around roles and responsibilities of different agencies;
- poor cooperation at national, regional and local level;
- inappropriateness of some current Jobcentre Plus provision;
- insufficient supported employment provision and funding associated with it;
- real and perceived benefit barriers to employment;
- need to improve training of Jobcentre Plus and other advisory staff.
- the need to explore and improve funding streams;
- the need to improve use of the European Social Fund (ESF).

The review made practical suggestions based on these research findings, including the need to prepare for work opportunities while still at school; to develop the role of person-centred planning; the role of FE colleges and Connexions; and the need for benefit reforms to make part-time working possible. A range of Governmental responses were set out, which required cross-departmental strategies, and these are currently being rolled out.

Empirical research

According to Emerson *et al* (2005), 17% of people with learning disabilities have a paid job and 6% have an unpaid job. More males than females are in employment and only 6% of people with high support needs have a job. However these figures have been disputed and other researchers in this area tend to refer to under 10% of people with learning disabilities being in paid employment (McConkey and Mezza, 2001; Hensel, Stenfert Kroese and Rose, 2007). Many workers with learning disabilities are employed for less than five hours a week, and only a minority work for more than 16 hours a

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week (Beyer *et al*, 2004; Emerson *et al*, 2005). There also appears to be a limited range of jobs taken up by people with learning disabilities, who are mainly employed in catering jobs, cleaning, retail and office work (Beyer *et al*, 2004). It would be useful to have more data on the breakdown of employment rates by gender and ethnicity. Emerson *et al* (2005) showed that people were more likely to have a paid job if they:

- had lower support needs
- did not have a long-term illness or disability
- were male
- were White
- lived with fewer people
- saw friends without learning disabilities more often
- lived in an area with higher employment
- were in general good health.

Other studies have also explored personal characteristics of people with learning disabilities who are employed and found that people who are more motivated and want change in their life are more likely to obtain a job (Rose, Saunders, Hensel and Stenfert Kroese, 2005; Hensel *et al*, 2007). In order to sustain a working role people had to be confident, assertive but not aggressive, informed about their rights and open (Roulstone, Gradwell, Price and Child, 2003).

Of the people in employment, Emerson *et al* (2005) found that nearly everybody (92%) liked their job and the vast majority of those who were unemployed would like a job. This is supported by Beyer *et al* (2004), who found that a significant proportion of those who were unemployed expressed an interest in obtaining a job. Semi-structured interviews were used to explore the future aspirations of school leavers with severe learning disabilities (Smyth and McConkey, 2003). Analysis of the data showed that almost all of the young people interviewed wanted to have a job but only half of the parents shared this aim. Therefore the evidence suggests that the majority of people with learning disabilities do have the desire to work and, in line with most of the population, they would prefer to have paid work.

It is clear from a review of these studies that there is a big discrepancy between the number of people with learning disabilities in paid employment and the number who would like to work. There is a body of work that has explored some of the barriers to employment that may at least partially explain this.

- Attitudes of schools, employers and some disabled people themselves can result in low expectations (Riddell *et al*, 2001; Watson, Williams, Wickham, Kyle and Dury, 2005).

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- There are still concerns about benefits. People who are in receipt of incapacity benefits are frightened to lose their entitlement, and many still find it hard to make work pay (Ridell *et al*, 2001; Schneider, Simons and Everatt, 2001; Schneider and Dutton, 2002; Wistow and Schneider, 2003; Watson *et al*, 2005; Wistow and Schneider, 2007).
- There is a lack of information for employers about the help that is available to employ disabled people (Watson *et al*, 2005).
- There is a lack of accessible information for people with learning disabilities (Watson *et al*, 2005).
- There is a lack of appropriate training and education (Riddell *et al*, 2001).
- There is often an absence of effective transition planning from education to employment (Jakobsen, 2002).
- Lack of co-ordination and co-operation between relevant agencies, departments and services results in fragmented provision (Schneider and Dutton, 2002).
- "Normalisation" attitudes can lead to unrealistic expectations of people with learning disabilities and therefore work situations can break down (Wilson, 2003).

Wider benefits

As shown in the survey results, the majority of people with learning disabilities in employment do enjoy their work (Emerson *et al*, 2005); other studies have specifically explored the wider benefits of employment. Forrester-Jones, Jones, Heason and Di'Terlizzi (2004) assessed how social life and skills were affected by work. They found that work can help to maintain social networks and also to give people with learning disabilities greater opportunities to socialize with people who do not use disability services. After working for a year, participants generally reported a better quality of life and were also happier with their home life. Other research has identified advantages including extra income, social contact, making a contribution, being occupied, greater control over their lives, increased self-esteem and health improvements (Jenkins, 2002; Beyer *et al*, 2004; Ridley and Hunter, 2006).

One study was retrieved which explored benefits to employers (Hemmings and Morris, 2004). This found that people with learning disabilities tended to stay in their job for longer than the general population, had a strong commitment to work, good punctuality and low absentee rates. Furthermore employing people with learning disabilities could enhance the public image of a company or business. Research has a role to play in exploring these factors and ensuring that good examples of employment are disseminated.

Key points for the research agenda

- Between 10 to 17% of adults with learning disabilities are in paid employment, but most of these have part-time, low paid jobs.

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- The majority of adults with learning disabilities would like to work, but are restricted by a range of barriers, including attitudes, concerns over benefits, lack of co-ordinated support, information and education.
- There are gaps in research about changes in the employment sector, and the place of work in society, which will affect people with learning disabilities.
- People with learning disabilities tend to stay in their jobs longer, and have a strong commitment to work.
- Work can help to maintain social networks and offer a better quality of life.
- We need more research to analyse and highlight successful work experiences of people with learning disabilities.

Employment interventions and initiatives

Reviews

The review commissioned for the Department for Work and Pensions (2006) which has been mentioned above, made some forty recommendations on how to support people with learning disabilities into work, and these are at the heart of the interventions and initiatives that are currently being developed. In particular, for instance, the DWP report suggested that more vocational courses may be of better use than accredited courses leading to recognised and specific qualifications.

Chadsey and Beyer (2001) in a non-systematic review of social relations in the workplace, highlighted four intervention strategies: social skills instruction, problem solving strategies, self-management techniques and co-worker assistance. Those who have problems forming social relationships at work were at a particular risk of losing their jobs. Chadsey and Beyer's review highlighted various intervention strategies and concluded that best practice is to teach more socially-appropriate behaviour to employees with learning disabilities, in combination with maximizing support services and resources that are typically available in work settings. This would include support from colleagues and also equipment and modified work schedules for example. It is likely that technological advancements may have a major role to play in the future in how people are supported within their jobs.

A further review article by Weston (2002), of literature that includes UK, American and Australasian experiences of supported employment, posits some problems with the job-coach model due to issues of dependency and inclusion, but concludes that natural supports do not need to be viewed as incompatible with job-coaching and that some people may benefit from both. Many of these factors need further research to improve the outcomes of supported employment for individuals. For example, good job matching is central to a successful placement but it can be affected by the well-documented tendency of acquiescence displayed by many people with learning disabilities.

Empirical research

If people with learning disabilities need better training for work, then it has often been felt that we first need to consider the role of day services in providing that training. There appears to be wide variation in terms of the emphasis placed upon securing employment by different day centres (Beyer *et al*, 2004). Interviews with attendees and staff showed that day centres should be encouraging work experience and also providing training in self-care/household skills as these are linked to the ability to sustain employment (McConkey and Mezza, 2001).

The Further Education system also has an important role to play in preparing students with learning disabilities for work (see the LSC strategy 'Learning for Living and Work', 2006). Jakobsen (2002) found only a few examples of effective transition from education to employment and made a number of recommendations for how this can be improved:

- Colleges should provide an informed choice of actual employment opportunities.
- Agencies need to work in partnership.
- Providers could obtain funding for sustainable transition to work provision.
- Providers and colleges should work with parents and carers.

Some people argue that it is more important for people with learning disabilities to take advantage of structured work-based training as this is likely to be a more effective route into employment than day-centre training (Swan and Newton, 2005). A two-year pilot scheme called Vocational Opportunities in Training for Employment (VOTE) was evaluated by Taylor and McGilloway (2004). This initiative was found to improve employment opportunities and prospects and the evaluation highlighted a number of factors that were critical to its success, namely:

- working closely with parents
- addressing the concerns of local employers
- sympathetic treatment of workplace issues
- effective partnership working.

Once people have obtained a job it is likely they will still need additional support to be able to continue. In Emerson *et al*'s (2005) survey 13% of respondents reported having being bullied at work and research shows this is more likely to be a problem if people lack supervision and support within their role (Wistow and Schneider, 2003).

One piece of research trialed the use of specialized laptops designed to help people with more severe learning disabilities perform complex tasks in their jobs (Furniss *et al*, 2001). They concluded it was effective in real work settings and has the potential to increase the efficiency and accessibility of

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supported employment services. Technology is outstripping research knowledge at present, and it would be useful to find out more about how technology is being used, and can be used, to support people with learning disabilities at work.

Employment schemes such as supported employment can provide a personal and tailor-made route into paid employment for some people (Watson *et al*, 2005). Although it is a somewhat disputed term, 'supported employment' is used here to refer to any scheme which provides support in obtaining and maintaining open, paid employment. A study to identify all the employment-focused services in England, Scotland and Wales found that people with learning disabilities were the group most commonly using supported employment services. Relatively few generic services were identified though, suggesting that "mainstreaming" service provision is not really happening (Arksey *et al*, 2002). For instance, a scheme in Northern Ireland, which was included in Cole and Williams' review (Cole and Williams, 2006), successfully offered a package of school-based work placements, followed by vocational training and job support as a 'specialist route' into work.

The body of work relating to supported employment included in this review used a variety of methodologies and considered a range of perspectives. The research reviewed identified the following factors as essential elements for successful supported employment:

- use of natural supports in workplace (Wistow and Schneider, 2003)
- better understanding of what support a person with complex needs may require (Jones, Morgan, Murphy and Shearn, 2002; Wistow and Schneider, 2003; Ridley and Hunter, 2006)
- social integration/training in social skills (Jones *et al*, 2002; Wistow and Schneider, 2003)
- good interagency working (Owen, Hewitt, Avis, Betts and Munir, 2005; Goodwin and Colgate, 2006)
- high quality, suitable job placements and greater choice of jobs (Jenkins, 2002; Wistow and Schneider, 2003; Wooff and Schneider, 2006)
- on-going training (Jenkins, 2002; Jones *et al*, 2002; Wistow and Schneider, 2003)
- strategies to increase motivation (Rose *et al*, 2005)
- vocational profiling (Kilsby and Beyer, 2002; Kilsby *et al*, 2002)
- creative use of job carving (Goodwin and Colgate, 2006)
- increased funding (Wistow and Schneider, 2007).

However there was some contention over the relative merits of all of these factors. Jones *et al* (2002) argued that job coaches feel natural supports are too unreliable. In a series of studies, interventions to reduce acquiescence

in vocational profiling were evaluated and demonstrated to be effective (Kilsby and Beyer, 2002; Kilsby *et al*, 2002). Cole and Williams (2006) in their practice survey of community-based activities, gave examples of day centre staff re-deployment, which appeared to be very successful. The key to making this happen appeared to be good training, a whole-authority approach, and ongoing support for staff. They concluded that moving funding over from day centres into supported employment has to be a priority task for local authorities. Research has an ongoing role in the development of strategies to maximize the success of supported employment.

Surprisingly, there has been very little research since 2001 which focuses on other forms of sheltered employment, including the development of social firms. One study was retrieved (Secker, Dass and Grove, 2003) which conducted a telephone survey of social firms in the UK and used their results to highlight indicators of best practice. These authors found that:

- It is important for workers to participate in the firm's development and operation.
- Workers and managers need expert advice about payment.
- Workers should be paid at minimum wage rates or higher.
- There should be opportunities for personal development.
- The workforce should comprise disabled and non-disabled workers.
- It is helpful to have involvement of carers and local socio-economic agencies in the development of the firm.

Cole and Williams (2006) also examined some examples of good practice in social firm development, and found creative use of shared budgets (local authority and LSC) in the development of work-based learning in small social firms, as well as social firms which were essentially formed by self-advocacy organizations. There is clearly a need for much more research to explore these new forms of work opportunity for people with learning disabilities.

Key points for the research agenda

- Day services should have a role in preparing people with learning disabilities for work, but there is wide variation in the way in which they fulfil that role.
- FE colleges have a key role in providing work preparation courses, and supporting students into paid work. It is still hard for them to achieve results, but this is a fast developing area.
- Supported employment schemes are widely used by people with learning disabilities who seek work.
- We know a lot about the factors in supported employment which are effective.

- There are still many gaps in our knowledge about how to move local authority resources from day services into supported employment.
- We need more research about alternative forms of employment, including social firms.
- There are gaps in knowledge about the potential use of new technologies in supporting people with learning disabilities at work.

8.3 Discussion of gaps identified in research on work and personal finance for people with learning disabilities

As indicated in 2.1.1 of this report, the priorities discussed with participants in the final round of workshops arose from the preliminary summaries of the research review. These issues were also discussed with a researchers' network meeting, and the discussion there was tape-recorded, transcribed and analysed. The following represents the main points in those discussions. A list of the priorities and questions identified appears at the end of the chapter.

8.3.1 Benefits and personal finance

'The disparities between rich and poor are just getting bigger year on year, and no-one seems to be dealing with that at any level of government. And as long as those forces are still in place, we will be left all the time with people in relative poverty.' [Researcher]

Research has indicated that poverty may well be an important issue for people with learning disabilities, and we saw in Chapter 2 how the socio-economic status of people with learning disabilities is linked to health outcomes. This was a topic of discussion in the researchers' network, and it was felt that we need more research which looks at the changing patterns of poverty and wealth in the UK, so that we can see exactly how people with learning disabilities and their family carers fit into these patterns. For instance, we know that the majority of people with learning disabilities live at home with their parents or family members; we also know about the negative impact on career prospects of carers, who take on a life-long, unpaid job for their relative with learning disabilities. Although we have recent cost-benefit analysis from Carers UK about the cost of caring, we need more evidence about the actual levels of poverty experienced by people with learning disabilities and their families.

If people with learning disabilities are to move on into situations of greater choice and control, then they will need to have greater access to their money. The impact of the Mental Capacity Act on financial control will be an important topic for future research. Williams *et al* (2007) and Emerson *et al* (2005) gave some indication that only a small proportion of people with learning disabilities do actually have control over their own finances. Those

that do have some control are often thought to be vulnerable to financial abuse, and stakeholders in the current study felt that we need better evidence about how widespread financial abuse actually is. The risks and benefits of 'supported living' were a major topic in the workshops.

We also know that financial institutions and sources of assistance are often inaccessible to this group. It would be very useful to have research which explored this situation further, and revealed how these financial advice services could also offer a service to people with learning disabilities. Participants in the workshops also felt that family finance was still an important topic to explore. They felt it was important to find out more detail about what happens within families, and what it means for the whole family to be supporting an individual with learning disabilities:

'How many people with learning disabilities have access to their own money? For how many people does it go into the "family pot"?' [Professional]

Clearly, this research would need to be sensitive to the different needs within the family, and to the many different ways in which families approach questions of finance. The sacrifices made by family carers, in terms of financial security and career, are substantial, and their own contribution should be recognized financially in much more substantial ways. The current carer's pension is a first step in that direction, but family members need to be active in leading research to highlight their own financial situation.

Many people with learning disabilities, as we have seen, depend on state benefits for their livelihood. However, at the same time, most adults with learning disabilities would like to have paid work. Research has shown us continuously that benefits are still posed as a 'barrier' to paid employment. As one person at a workshop said:

'I like voluntary jobs because they don't upset my benefits' [person with learning disabilities]

This person told a detailed story about her moves into voluntary work, and argued that we need more research about the advantages of voluntary work. Others in the same workshop agreed with her. It was also felt that forms of work which were initiated by voluntary organizations, such as People First, could be the focus of 'best practice' research. However, some of the practitioners in the same workshop felt that this focus on voluntary work is a symptom of lack of information about benefits.

'(We need) more information on benefits situation... it's posed as a great barrier, but half the time people's cases haven't actually been properly assessed. We need a tangible tool that's accessible' [Professional]

As in other topic areas, workshop participants tended to prioritise research which related to positive strategies for change. For instance, participants in one workshop asked about the alternatives to benefits – the systems of tax credits, for instance. It would be useful to have research which highlighted good examples of people with learning disabilities who have actually moved

on into work, and which would analyse the ways in which they made this move financially viable. Are these options cost-effective and do they lead to better outcomes? Of course, all this research needs to be set against the context of continuing efforts by the Department for Work and Pensions to tackle the benefits system, and provide a system which would give greater incentives to paid work. In some ways, as researchers commented to us, we know that benefits problems exist, and what is needed now is action to improve the situation. However, other stakeholders felt that research must continue to highlight the situation of people with learning disabilities, so that their needs are taken into account in DWP reforms.

8.3.2 Job seeking and job retention

We have seen from the research that only a small proportion of people with learning disabilities (between 10 to 17%) have any form of paid work. We also know that the majority of these people do need some support in obtaining and keeping a job. Supported employment services, which we know to be effective, are thin on the ground, and so stakeholders in the current study felt that we need to look at the expertise and skills of other staff in Learning Disability services. For instance, what knowledge of employment issues do social services or day services staff have?

We know that there are a few practical case studies, showing how day services staff can move over into employment support. This type of re-deployment merits far greater research attention, so that we can fully understand how to reconfigure resources at local authority level.

At the same time, employment research needs to maintain a broad perspective, and to look at Learning Disability issues in the context of other groups in society. One workshop group suggested that it would be interesting, for instance, to have research which compared the experience of people with learning disabilities with non-disabled people in obtaining a job. What services do job centres give to people with learning disabilities, and how could those services be improved?

Once in the workplace, people with learning disabilities are often unsupported by specialist services to any great extent. We know that research has focused on 'natural supports' in the workplace, but workshop participants felt that people with learning disabilities are often uninformed about their rights as employees. There is clearly a need for more research about these issues, which impact on people who have already obtained a job. People with learning disabilities, like other disabled employees, have a right to 'Access to Work' monies, and one workshop participant told us about her experience:

'I needed more support, like a personal assistant. And also my taxi to get to work. So they helped me to get Access to Work. But it was really difficult, and I'd never have managed it on my own with all the forms'.
[Person with learning disabilities]

This person suggested that it would be useful to find out how many people

with learning disabilities are taking advantage of Access to Work, and how the scheme could be made more accessible and easier to manage.

Finally, the employers' perspective was also felt to be under-researched. In our review, we did find one study which looked at employers' perspectives of their workers with learning disabilities, but workshop participants pointed out that there were very few incentives for employers to take on someone with a learning disability:

'For employers, there's no incentive to choose people with learning disabilities to do a job [less productive], in fact in a tighter market there are clear disincentives. We need more research which is employer-centred.' [Professional]

8.3.3 Vocational learning and progression

Although education was not highlighted in this study as a major topic of concern, this was partly no doubt attributable to the range of interests represented in the workshops. However, the school education system was mentioned in relation to attitudes (community attitudes towards people with learning disabilities) and in relation to the work aspirations of young people with learning disabilities. Moving on from school, it was felt that FE colleges are very varied in their approach to finding jobs and working with employers. Stakeholders in the workshops felt that it would be useful to find more examples of good practice in FE, and to share them. It was particularly felt that college staff could probably learn from the practices of good 'supported employment' services, and work with employers more effectively:

'Are the LSC researching what the skills of people with learning disabilities are and how to communicate them?' [Professional]

Career structure and progression was another topic, suggested both in the workshops and by our group of researchers:

'People with learning disabilities have been supported through supported employment or other initiatives, are now saying quite rightly that they want career progression. But they are not getting the support to enable that to happen.' [Researcher]

One person with learning disabilities told us a story about his experience of work, and about learning for work. He had been to a college where he had studied independence skills for many years. All changed when he was offered the chance to do a work preparation course, which gave him the chance to learn 'on the job':

'I just got on with it, and no problem. It was great getting to work, and having something to get up for in the morning. It was difficult to learn, but much easier than in college doing all those tests and paperwork.' [Person with learning disabilities]

Despite the research in supported employment which exists, we know that

there are still big gaps in our knowledge about effective routes into work from Further Education colleges. With the new LSC initiatives about 'Learning for Living and Work' (2006), more research is needed to monitor and develop the role of FE colleges as partners in employment support.

8.3.4 Meaningful lives for all people with learning disabilities

Having a meaningful life is not just about paid employment. As we have seen from existing research, improved social networks and personal fulfilment can also be important effects of employment. Clearly, much depends on the employer and the workplace, and those who seek open employment will sometimes run the risk of social isolation. Researchers were aware that the closure of day centres, combined with a move towards individual services, may lead to greater social isolation for people with learning disabilities, who already have few friends outside the family circle, as we saw in Chapter 4. They therefore felt it was important to continue to research the experience of those who are in work, as well as those who are receiving individual support for their 'day activities'.

'They are not fully integrated into the workplace in many situations, so they are doing work, but often in rather isolated places of work. And a contributing factor to that is that they're also working part-time.'
[Researcher]

This discussion also relates to the new roles of community enabler or employment support worker, which we discussed in Section 5. As the Learning Disability workforce takes on new roles, it is very important that research can monitor these, and also highlight good practice and help practitioners to understand what these roles entail.

In terms of social work opportunities, as we have seen in the literature review, there is surprisingly little recent research on developments in social firms, although we know that these options are often preferred by people with learning disabilities in practice. It would be useful to have some clear evidence about the range of models of 'social firm' and how effective they are in providing community-based, fulfilling work opportunities for people with learning disabilities.

People with learning disabilities in our workshops were very clear that they had much to offer society. They talked about their caring roles, and about paid work they had done, as well as other ways in which they carried out important and meaningful jobs. One person spoke about her job in a research project:

'What I did on the project will help all people with learning disabilities. We made a pack, and it was one of the best things I did.' [Person with learning disabilities]

Other people with learning disabilities had carried out training for health professionals, and talked about the importance of doing this work:

'They listen to us when we go and do training. We tell them our stories.'
[Person with learning disabilities]

Workshop participants questioned what 'real work' actually is, and whether it is for everyone. Particularly for those with high support needs, they felt it may be important to find opportunities for work beyond 'open employment'. There will be a need for future research which investigates how many people are taking up opportunities for voluntary work; micro-enterprises; social firms and advocacy work. All these new types of work activity could be the basis for action research, which will help us to understand the strategies for change, to include people with learning disabilities with the highest support needs.

8.3.5 Summary of research priorities and questions suggested by stakeholders

It was widely recognized by all stakeholders that the goal of employment is still very difficult to obtain for all people with learning disabilities. The priority identified by workshop participants was very much about the practicalities, and about how we can find ways of overcoming the well-known barriers, including the benefits trap.

However, there were also priorities identified about wider issues, such as working with mainstream services, and especially with employers – to ensure that they have incentives to employ people with learning disabilities. In general, issues to do with poverty, financial situations of families, financial abuse and financial advice were all considered to be under-researched, and of great importance. All the particular questions, topics or areas for research listed below are those that were suggested by workshop participants or by research network participants.

Benefits and personal finance

- What are the changing patterns of poverty and wealth in the UK, and how are people with learning disabilities and their families doing?
- How can people with learning disabilities be supported to get better information about benefits, and to manage their benefits while working?
- What are the alternatives to benefits? Could we explore new models – e.g. disability pensions?
- How could mainstream financial and advice services be made more accessible to people with learning disabilities?
- What are the best ways of giving people with learning disabilities good financial advice – from families, support workers and services?
- What is the extent of financial abuse?
- How is capacity assessed for financial decision making, under the Mental

Capacity Act (2005)?

Job seeking and job retention

- How do we move local authority resources from day services into supported employment?
- How does the experience of people with learning disabilities compare with that of non-disabled people in getting a job?
- What is the knowledge of employment issues among social services staff, support workers, day services staff?
- Wages and rights: do workers with learning disabilities get a fair wage? What is the spread of earnings? Do they know their rights in the workplace?
- How could job centres serve people with learning disabilities better?
- How effective is 'job carving', and how can it be sold to employers?
- How do we get more information out about Access to Work?
- How do we understand what would give incentives to employers to employ people with learning disabilities?
- What are the new 'gadgets' people can use at work, and how could these help employees with learning disabilities?

Vocational learning and progression

- What are FE colleges doing to find jobs and to work with employers? (Research to find good examples and share them)
- How many people go on to get real paid jobs, after voluntary work placements?
- How do we develop career progression for people with learning disabilities?
- What kind of learning really helps people get jobs?

Meaningful lives for all people with learning disabilities

- How socially isolated are people with learning disabilities in their day activities or at work?
- What roles do community enablers have, and are they effective in finding meaningful activities for people with high support needs?
- What is 'real' work? Is work for everyone?
- How is the employment sector changing, and how does this affect people with learning disabilities?

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9 Inclusion in the community

Finally, we turn to one of the most important overall perspectives in this scoping review, the idea of 'community'. This term can mean many different things, but for the people with learning disabilities in the consultation it was primarily about being included in ordinary activities, meeting people from outside 'learning disability' services in which many people live and spend their days. We know that there are strong policy leads for strategies to 'mainstream' services, and to look towards community responsibility. This also came up as a key topic in the workshops.

9.1 Scope and methodology: research about inclusion in the community

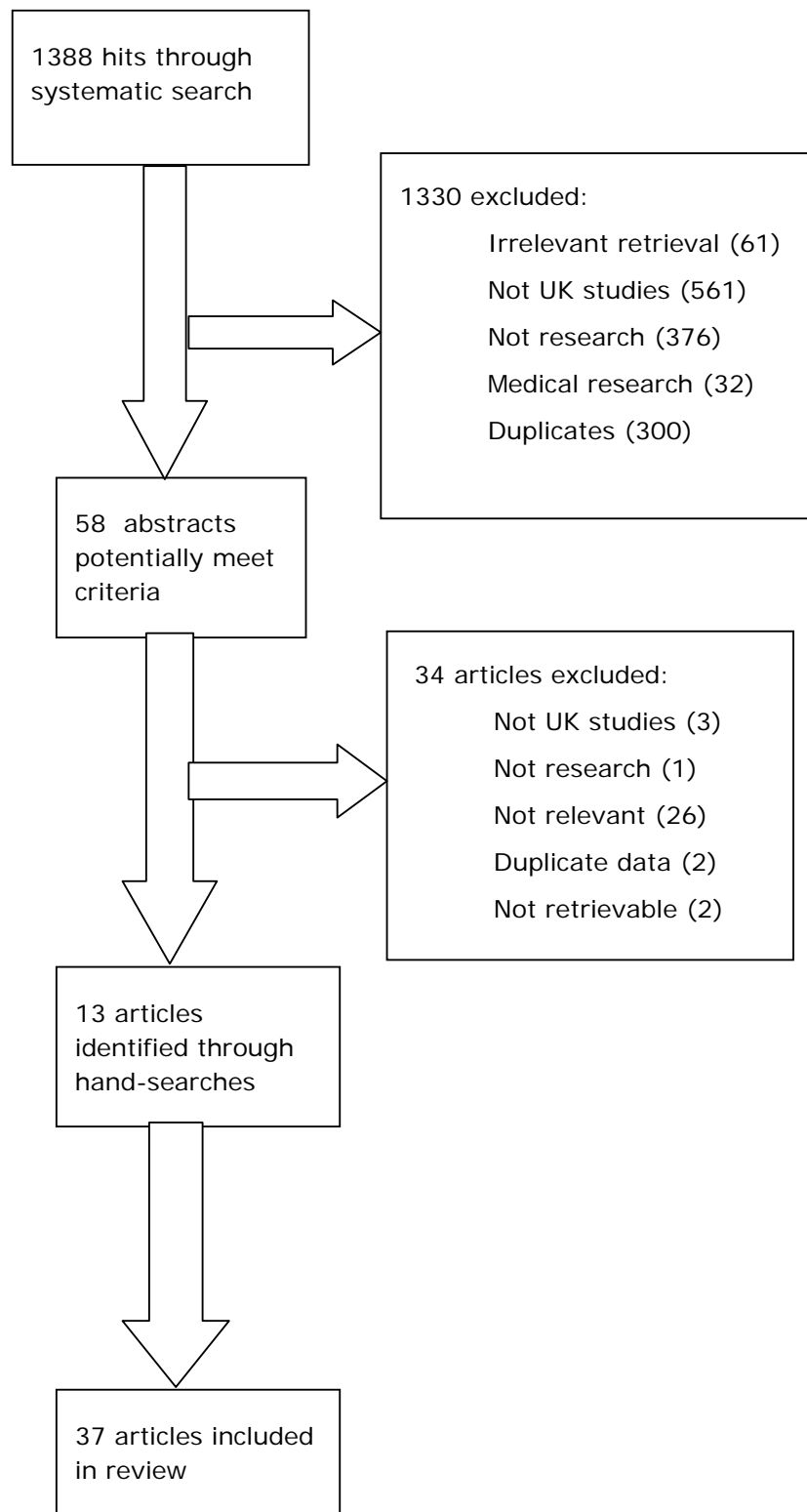
9.1.1 Methodology

Using the search terms given in Appendix A, 'work and personal finance' yielded 1388 hits. These were sifted in two stages. 1330 were excluded at the initial retrieval stage; if there was any doubt about the relevance of the item, the abstract was retrieved and scanned. A further 34 articles were excluded at the abstract stage. The following rules for exclusion were applied systematically at both these stages:

- 1) Not about the topic (of work, personal finance and learning disability)
- 2) Not UK studies (where the research was based entirely outside the UK)
- 3) Not research or reviews of research (opinion papers without empirical basis; short practice descriptions were excluded)
- 4) Paper not written in English
- 5) Duplicates
- 6) Research published before 2001

A further 13 articles were identified through hand searches (including *British Journal of Learning Disabilities*; *Journal of International Disability Research*; *Journal of Learning Disabilities*; *The Learning Disability Review*), and so the total for the review in this area was 37. This process is represented in Figure 6 below.

Figure 6: Flow chart of the literature search for “Inclusion in the Community”



Evaluation

A summary of the appraisal data for each topic in this report is given at the end of Appendix B. What follows here is an evaluative overview of the topic area. Methodologies to examine community inclusion first have to engage with the question of what this term actually means. Community inclusion is a slippery item to measure, and hard to define. In fact different research studies identify a range of indicators, including social networks; activities inside and outside the home; networks of people outside the Learning Disability settings. It is perhaps not surprising that a small group of papers retrieved were about conceptual matters, where the main focus was exploration of these meanings.

Similarly, research methodologies in this topic area showed a very varied and patchy picture. They ranged from large-scale quantitative studies, with samples of 620 (McConkey, 2007); 343 (Mansell, Beadle-Brown, Macdonald and Ashman, 2003) to single case studies (McConkey and McCullough, 2006). There were also two inclusive studies, one of which was led by self-advocate researchers (Hart, Shane, Spencer and Still, 2007).

a) *Quantitative methodologies*

The search revealed two large-scale longitudinal cohort studies. Hall, Strydom, Richards, Hardy, Bernal and Wadsworth (2005) reported on a follow-up study of a UK birth cohort from 1946, identifying all those with mild or severe learning disabilities in that cohort (N= 5362) at the age of 43. The outcome measures used were quite gross ones (e.g. rating of satisfaction with social life); however, the study offered a comparison between outcomes for people with learning disabilities and their non-disabled peers, showing how the former group's friendship circles were more limited. Another study (Forrester-Jones, Carpenter, Coolen, Cambridge, Tate, Beecham *et al*, 2006) followed up 213 people from an original cohort of 272, who had been resettled twelve years earlier from long-stay hospitals. This study used far more sensitive tools to measure community inclusion, such as a 'social network guide', administered at an individual level.

Some of these studies used smaller samples (Reynolds, 2002), but had a greater focus on investigation of the causative factors surrounding community involvement. Small, focused samples can also be very useful in providing direct comparisons; Hall and Hewson (2006) reported on a comparison of community use between 1995 and 2002, by the same group of people with learning disabilities in eleven community-based houses.

Predictive factors for community involvement were explored through multi-variate factor analysis by Baker (2007), Mansell *et al* (2003), McConkey (2007). Mansell *et al* (2003) measured active support practices by questionnaires to staff, but also by observational techniques, which gave a picture of the outcomes for people with learning disabilities. However, these observations were all carried out within group homes, and did not particularly focus on community engagement outside the home.

Robertson, Emerson, Pinkney, Caesar, Felce, Meek *et al's* (2005) survey of neighbours' views used a 'matched groups' design to compare the situations of those in congregate and non-congregate settings. Although there was a relatively small return (64 questionnaires), this was a new and interesting way to measure community engagement, by looking at the issue from the point of view of others in the community.

b) Qualitative methodologies

Given that there is still much to understand about the nature of community involvement, there is a surprisingly small amount of good quality qualitative work in this area (9 studies). Those studies which we did find generally used semi-structured interviews or focus group methods to collect data about the experiences and views of people with learning disabilities themselves (Abbott and McConkey, 2006; Hart *et al*, 2007) and access workers (Devas, 2003). Some of these studies used interesting methods for data collection. For example, Abbott and McConkey (2006) used photographs to promote discussion in focus groups, followed by smaller groups to discuss what worked best for them in pursuing community activities. Llewellyn and Northway (2007) used an interesting method to define the 'advocacy' role from the point of view of people with learning disabilities; these definitions then formed the basis for questions put to focus groups of Learning Disability nurses. These novel methods of data collection were not always matched by sophisticated analytical methodologies, and most authors claimed no more than 'thematic' or 'content' analysis. Llewellyn and Northway (2007) were the only authors to have developed a more grounded analysis, very firmly based in the meanings of participants.

Hart *et al* (2007) deserve a special mention, as this was a study led by a group of researchers who have direct experience of the label of 'learning disability'. Not only did these researchers take part in the research, but they were directly in control of the analysis, as discussed in their report. Hart *et al* decided to use a thematic analysis which related the answers and findings back to the framework developed by the group. Finally, inclusive qualitative methods were also used by Cole and Williams (2006) in their practice survey and analysis of 'best examples' of community activities for people with learning disabilities. Following a survey, site visits were carried out by mixed teams, including a researcher, a person with learning disabilities, a commissioner and a parent.

There was a notable absence of ethnographic studies, and this again deserves a mention, since it could be argued that community inclusion consists of social activities which could be directly observed, recorded and analysed. Most of the work retrieved was essentially within a positivist framework, in which the participants' views were taken as direct indications of experience.

c) Case studies and individual evaluations

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Finally, 25% of these studies were actually individual case studies, and small-scale evaluations of initiatives. These were generally not carried out in a robust way, but were more concerned to highlight particular practices. These studies can of course be very valuable in offering creative ideas and directions for future practice and research. For instance, Devas (2003) looked at the different roles of access and support workers in enabling people with learning disabilities to use a sports centre, and Bates (2001) investigated inclusive volunteering opportunities by means of six case studies.

9.1.2 Scope of the research

Table 8:

Research studies about people with learning disabilities being included in the community since 2001

Basic ideas about inclusion		4
The general picture: evidence about community inclusion		7
Learning Disability day services		3
Factors associated with opportunities for community engagement		8
Choice and self determination		2
Hate Crime		1
How to facilitate community inclusion	Leisure activities	3
	Use of IT	1
	Supporters' roles	1
	Person-centred planning	1
	Accessible information	2
	Information to parents	1
Holidays		1
Outside the Learning Disability service focus	Police	1
	Neighbours	1
Total		37

Policy strategy and guidance since 2001 has strongly emphasised inclusion in the community for all disabled people, and puts forward a vision of inclusion for people with learning disabilities in the wider community, outside the realm of Learning Disability services. It will be evident from this

literature review that this emphasis is not matched by a body of research evidence to underpin practice.

- Five studies were about factors associated with opportunities for community engagement, and set out to identify predictive factors in living arrangements (Baker, 2007; Hart *et al*, 2007; McConkey, 2007) and staff practices (Taggart and McConkey, 2001; Mansell *et al*, 2003). This group of studies also suggested barriers to social inclusion faced by the research participants.
- A further seven essentially gave information about the amount of community inclusion (Reynolds, 2002; Forrester-Jones *et al*, 2006; Hall and Hewson, 2006) and activities (Beart, Hawkins, Stenfert Kroese, Smithson and Tolosa, 2001; Drew and Rugg, 2001) of various cohorts of people with learning disabilities. Again, these studies generally included reference to the barriers faced by participants. A national practice review of community-based day activities (Cole and Williams, 2006) is included in this section.
- Nine studies (24%) were about the practical value of various initiatives and practices in promoting community inclusion. Some of these were evaluations of small-scale initiatives or single-case reports. Others, such as Robertson, Hatton, Emerson, Elliott, McIntosh, Swift *et al* (2007) were major research studies investigating the impact of initiatives such as person-centred planning.
- The one study about hate crime (Perry, 2004) has been listed separately, since this was an important issue raised in the present consultation.
- Three studies emerged which were essentially about Learning Disability services, rather than about community inclusion. These included one which was about the uptake of services by families from Black and minority ethnic communities.
- By contrast, there were only two studies which addressed issues and participants outside the Learning Disability world. These included a small-scale evaluation of awareness training for the police, and one more robust study of the attitudes of neighbours to people with learning disabilities (Robertson *et al*, 2005). One of the studies listed under leisure (Andrews, 2007) could possibly be added to this list, but it still represents a very small proportion of the research effort in this field since 2001.

9.2 Findings and outcomes of the research: what do we know and what do we need to know

9.2.1 How 'included' are people with learning disabilities?

Empirical research

Some thirty years after the start of institutional closures, and seven years after 'Valuing People' (DH, 2001), community inclusion is still an elusive goal. The most robust research in this area still shows that people with

learning disabilities may live 'in the community' but are not necessarily part of it (Forrester-Jones *et al*, 2006). These authors followed up a large sample of people (213) who had been re-settled from hospitals twelve years previously, and found that other people with learning disabilities and staff still made up the majority of their social networks. Hall and Hewson (2006) carried out a follow-up study, with the same group of 60 people who had been part of a study in 1995. They all lived in eleven community-based houses which were staffed and run by a local NHS Trust. These authors found that there was no improvement on any measure between 1995 and 2002, that 88% of the residents went out less than once a day, and that 55% had no 'personal visitors' at all during the four weeks of the study. These results were unequivocal and bleak. Many people with learning disabilities are living lives which are isolated and uneventful. De-institutionalisation is associated with greater community contact, but the 'community use' and activities of people in group homes is still low by comparison with others in the general population (Baker, 2007).

Much of the research underlines the finding that people with learning disabilities predominantly use 'special' services, and day activities which are arranged specially for them. Reynolds (2002), for instance, asked managers of 34 residential homes in two urban settings about the activities of the residents with learning disabilities, and found that creative activities were greatly valued. Most of these activities took place at home, and the residents generally only had access to 'specialist' settings such as day centres.

However, this situation might be changing for younger people with learning disabilities. Beart *et al* (2001) discussed leisure opportunities with young people with mild and moderate learning disabilities, in five focus groups, and found that these participants undertook a wide variety of community-based leisure pursuits. A small quantitative study (Drew and Rugg, 2001) with occupational therapy students gathered data about client activities, which the students had seen during placements. 'Supporting leisure activities' was the category most frequently mentioned among all groups of OT students.

Positive community presence might also be linked with higher ability levels. A study which followed through a birth cohort (Hall *et al*, 2005) found that people with the most severe learning disabilities were the least likely to attain the 'markers' of social inclusion, such as home ownership, marriage and having a job. Other research (for instance, McConkey, Walsh-Gallagher and Sinclair, 2005) has also concluded that those with higher levels of dependency are less likely to be included in their local communities.

None of this means that community inclusion is impossible, and Cole and Williams (2006) carried out a 'best practice' review of community-based day opportunities across the UK. They noted a gap between research and practice in the area of day opportunities for adults with learning disabilities, with practice often outstripping research-based evidence. People with higher support needs were sometimes left out of new thinking about community

inclusion, but there were some positive practice examples, where people had one-one support and individualised services. This report shows what can be done, and analyses the factors that enable local authorities to look beyond the 'specialist day centre' approach. Much of this is about creating a new vision about person-centred practices, valued and fulfilling work lives, and individual budgets for social care. We urgently need more research which analyses good practice, and helps us to move forward in this area.

Key points for the research agenda

- People with learning disabilities are still often separated from their own communities, and from ordinary activities.
- Many people with learning disabilities still predominantly take part in activities provided by Learning Disability services.
- Those who have less 'dependency' and higher levels of ability have a greater chance of community presence.
- It is possible that practice is outstripping research in the area of community inclusion, and that there is good practice in certain pockets of the UK. This is an important research gap.

9.2.2 Barriers to social inclusion

Empirical research

What prevents people from taking on full and active roles in their local communities? Participants in this consultation emphasised negative attitudes and bullying, but there was little research to draw on in this area. One study by Perry (2004) about bullying led to a pack about rights, personal safety and recommendations for the police. Most of the studies mentioned below also mentioned 'community attitudes', and negative experiences of people with learning disabilities themselves. Given the prominence of hate crime and bullying for people with learning disabilities in our workshops, there are clearly still research gaps here about how to recognise and tackle hate crime.

The same list of barriers was repeated in different studies.

- People with learning disabilities themselves do not have knowledge and social skills; support staff are lacking; location of housing can have a negative effect; there may be a lack of community amenities and unhelpful community attitudes (Abbott and McConkey, 2006).
- Transport can be a barrier, as well as the lack of a friend or supporter (Beart *et al*, 2001).
- There may be insufficient staff in group homes to support people on a 1-1 basis (Reynolds, 2002).

Some research has indicated that certain forms of housing provision might pose greater constraints on people's community presence. This is certainly

true of institutional, congregate settings (Baker, 2007). Compared with a 'community group' of people with learning disabilities who had always lived with families, those moving out of hospitals did show increases in their levels of community participation. The most reliable predictors found in this study for community participation were:

- a) not living in an institution
- b) having relatively higher levels of adaptive behaviour
- c) having individually written community access goals.

However, McConkey *et al*, (2005) found that, once people are living outside congregate, institutional settings, the form of housing does not appear to make much difference. In general, the best predictor of community engagement was the individual's level of dependency.

Managers of community homes in Reynold's (2002) study perceived the major barrier to creative leisure to be expense (including the expense of support staff). However, a body of work which appears also in the 'Housing' chapter in this report, focused on staff practices as the one reliable factor in predicting the activity levels of people with the most profound and complex learning disabilities. Mansell, Elliott, Beadle-Brown, Ashman and Macdonald's (2002a) focus on staff 'active support' practices was the most robust and convincing analysis of what actually does make a difference in activities and engagement for people with the most severe learning disabilities. In Northern Ireland, Taggart and McConkey (2001) also found a distinct shortage of good practice in terms of active support, and argued that resettlement does not necessarily result in decreases in challenging behaviour.

The link between challenging behaviour, high dependency and lack of community presence was a major theme which threaded through this research. It appears that we know plenty about the barriers to full community involvement, and the characteristics of those who do become more included in their communities. The gap in research is clearly about strategies for changing these things, for providing good support, and for changing communities.

One study was carried out in an unusual way, by people with learning disabilities themselves (Hart *et al*, 2007); they found that people who had more choices also did more things in the community. They also found that the level of support mattered, and that parents did not always allow people to make their own decisions. They pointed out that most people with learning disabilities did not have full control of their money, and this was also a major theme in Williams, Abbott, Rodgers, Ward and Watson (2007) in a scoping review about financial issues for people with learning disabilities (see Chapter 8).

Finally, any list of 'barriers' must include reference to lack of friendships. In some ways, this is a circular argument, since arguably, community inclusion is very much about doing things together with your friends. Thus the

barriers to making and keeping friends are also going to feature as barriers to community inclusion. Forrester-Jones *et al* (2006) offered a differentiated picture of the social networks of people with learning disabilities, and the extent to which they are still often restricted to other people with learning disabilities, and the staff who are paid to support them.

Key points for the research agenda

- There are many factors which seem to stop people having active lives in their own communities.
- Negative attitudes, discrimination and hate crime are major problems, but we need more research about how to tackle these problems.
- There is more research about barriers than about solutions to community inclusion. Barriers include:
 - lack of support staff, and specific skills among support staff
 - financial difficulties, which include lack of control over one's own money
 - transport difficulties.
- Difficulties in making and keeping friends are linked with difficulties in going out and doing things in the community.

9.2.3 Person-centred planning and choice

In general, those who are more able seem to have greater opportunities for choice (Hatton, Emerson, Robertson, Gregory, Kessissoglou and Walsh, 2004), and this is also associated with greater community presence. However, Robertson, Emerson, Hatton, Gregory, Kessissoglou, Hallam *et al* (2001) in a sample of 300 people with learning disabilities in residential accommodation, found that very few had opportunities for self-determination, including over mundane decisions. According to current policy (DH, 2001), the first step towards community presence and an 'ordinary' life is a person-centred plan (PCP). However, the research since 2001 tends to show that not everyone has equally good outcomes from PCP (Robertson *et al*, 2007). The same study also revealed that 'modest positive changes' were found for those who had PCP, in community-based activities and choice.

Nevertheless, research continues to find examples of good practice in developing person-centred provision, which responds to the goals of individual people with learning disabilities, as expressed in their PCPs (Cole and Williams, 2006). These developments nearly always depend on good corporate planning around individual goals, and a change in service culture towards responsive, accountable services. The moves towards individual budgets (IB) will make a big difference to person-centred approaches and the ability to access mainstream activities. However, there is as yet no research which really documents these changes.

Key points for the research agenda

- There is a strong link between making choices and being more active in the community.
- Community-based activities can be increased by individual, person-centred planning.
- There is a gap in research which documents the moves towards community inclusion for people who have individual budgets.

9.2.4 How do we facilitate community inclusion?

Empirical research

Underlying the discussions about community activities for people with learning disabilities was an assumption that 'special' Learning Disability services and community are two opposed realms. However, 'special' services can help with inclusion, rather than be a hindrance. Henley (2001) took that view; basing his arguments on a single case study of the history of a day centre, he showed how the personalisation agenda had led to closures which left many people with learning disabilities without any day activities. Mencap (2002) supported that view, and argued that more funding is needed to make 'modernisation of day services' a reality for all. Families from BME groups (Hubert, 2006) seldom got any good services at all, and so a step towards community inclusion for those groups might be to have good specialist services, which are more culturally sensitive and which include all those with more profound and complex needs. In a more direct way, support workers will increasingly have roles as community facilitators or enablers, and Llewellyn and Northway (2007) examined the advocacy role of Learning Disability nurses, noting that people with learning disabilities wanted their supporters to help them with ordinary leisure and work activities. One-one support workers or personal assistants will also have increasing roles in enabling people with learning disabilities to use ordinary community facilities, and there is a large gap in research about the skills they need to carry out this task effectively.

We now move to evidence about positive social inclusion. Cole and Williams (2006) carried out a survey of the literature and practice on use of community based day opportunities. They found some examples of good practice, where people used local services; found creative solutions to barriers such as transport; and had real, paid jobs. These were analysed to see what can help people make that leap from special services into ordinary life. They reported that commissioners and service providers need to think beyond 'services'. Guidance on practical strategies to achieve community connections was needed. Planners and managers have to engage with the community, and with activities, services and organisations outside the 'learning disability' world. This report also suggested ways for social services departments to think more holistically about each individual, and to consider ways of merging their day services and residential budgets, so that people with learning disabilities could have individual support workers.

More generic solutions, available to all, are explored by other studies.

People with learning disabilities could make use of computers to get better information about leisure, or indeed to communicate with others over the Internet (Hegarty and Aspinall, 2006). There have also been advances in communication aids (Germain, 2004) which can potentially help young people to talk about their leisure activities. We now have guidance on accessible information (Levy, 2005; Ward and Townsley, 2005) which should help people to know more about their communities, and McConkey (2003) showed that families also wanted information about community opportunities.

The barriers to community inclusion mentioned above can all be turned around, in order to establish facilitative factors. For instance, Chapter 5 showed that active support methods used by residential staff (Jones, Felce, Lowe, Bowley, Pagler, Gallagher *et al*, 2001; Mansell *et al*, 2002; Smith, Felce, Lowe and Jones, 2002) were important, and there was also much solid evidence that it does matter where you live, and in what type of housing. Supported living seemed to help social inclusion (McConkey, 2007). Other positive factors for supporting community inclusion that were explored in the literature are paid employment, which can lead to better social networks and better leisure opportunities (Forrester-Jones, Jones, Heason and Di'Terlizzi, 2004); development of friendships (Srivastava, 2001); short breaks and holidays (Preece and Jordan, 2007).

Key points for the research agenda

- The right type of staff support can help people use community facilities. However, we need to understand better what skills support workers need in order to be successful in this task.
- It does matter where people live, and in what kind of housing. However, we do not understand precisely the outcomes (in terms of community engagement) for people who are living near their parents, or in their own local communities.
- Paid employment in the daytime leads to better leisure in 'leisure time'.
- People need good information, and research has shown us what information really works well for people with learning disabilities. They also benefit from using computers to find out information and communicate.
- Friendships and holidays help people get out and do more activities.

9.2.5 Perspectives of community providers and neighbours

Empirical research

As we have seen, there are surprisingly few studies which are actually based in the 'community' and which look at how ordinary services can adapt to people with learning disabilities. Given that participants in our workshops urged us to look 'beyond the Learning Disability box', this represents a very clear research priority. Of the few studies retrieved in this category, Bailey, Barr and Bunting (2001) analysed police attitudes, and pointed out the

value of training in shifting those attitudes towards more positive ones. A study by 'Active Nottingham' highlighted the sports activities of disabled children, and the links between a sports college and a special school, as well as a similar project in Kent, and a study by Devas (2003) interviewed sports personnel as well as people with learning disabilities and social workers. She concluded that both effective support as well as comprehensive access must be in place before people can make a meaningful choice about involvement in sports.

The problems involved in doing ordinary community activities may not be specific to people with learning disability. People with aphasia (Bunning and Horton, 2007) may face similar issues. Another theoretical paper (Clarke, Lhussier, Minto, Gibb and Perini, 2005) developed a model of 'location' for people with learning disabilities. Services needed to get to know the individual and their family, and there may be 'safe' places between the inside world of Learning Disability and the outside world of open, mainstream services. Interestingly, when attitudes of those outside the Learning Disability world were actually sought, these were not necessarily negative. Robertson *et al* (2005) found that contact between neighbours and people with learning disabilities living in the community was very limited. Two-thirds of neighbours, for instance, did not know any of the service users by name. However, where there was personal contact, positive attitudes were much more prevalent. Contact with neighbours was greatest when homes were small-scale and when people with learning disabilities did not go out together as a group. It was also true that the majority of neighbours were positive about community care, and problems with neighbours were predominantly minor. If people with learning disabilities are going to access the community around them, it is really important that research in this area explores attitudes, needs and issues of the other people who are part of that community.

Key points for the research agenda

- Access to ordinary community facilities and services can be facilitated by training and by effective support.
- Attitudes of neighbours to people with learning disabilities are often positive, and are aided by increased contact with individuals.
- It is important to move research outside the box of Learning Disability services. There is a large research gap about attitudes, needs for information and perspectives of mainstream service providers, those who use ordinary leisure facilities and friends and neighbours.

9.3 Discussion of gaps identified in research on community inclusion for people with learning disabilities

9.3.1 Tackling negative attitudes, bullying and hate crime

When asked to identify research priorities, the most common theme from people with learning disabilities was that of hate crime and the fear of negativity. When people spoke about the places they wanted to go to, and the activities they preferred, their stories were regularly marred by their experiences of name-calling, bullying and sometimes downright abuse. One woman spoke of being stalked by young people in her local area, and another man had regularly been targeted by gangs of people, who shouted out names at him. People have often been told to ignore this type of thing, but increasingly, they are coming to recognise it as 'hate crime'. As one person with learning disabilities said:

'We need to educate more people, who haven't got disabilities. The rest of the community.' [Person with learning disabilities]

Although there has been one study about hate crime (Perry, 2004), and there are now several initiatives to increase reporting of hate crime, it was felt that we still lack evidence that would raise the profile of this issue. It would also be important to examine the effect of hate crime on people with learning disabilities themselves, and the possible links with mental health problems. Researchers in the network meeting we held also raised the issue of 'community hostility', and the measures that could be taken to tackle these problems.

The research evidence that we do have about community attitudes is thin, but that which does exist often reflects relatively positive attitudes, as in Robertson *et al's* (2005) study of neighbours. It could well be that negative attitudes towards disability are held mainly by certain groups, such as young people or those who themselves feel vulnerable. Research about this issue therefore needs to be sensitive to the possible factors in influencing people's attitudes. This is a particularly important issue currently, as a greater number of people with learning disabilities are living semi-independently or with minimal support.

Social isolation and vulnerability were issues which concerned the researchers' network:

'If people haven't fitted into the wider community, there is some issue about how that will happen. If you look at direct payments and all the atomising influences, the questions that you are raising are much bigger than they were 10 years ago.' [Researcher]

People with learning disabilities themselves may turn for support towards the criminal justice system, and there were stories in our workshops of how people had been assisted by the police. However, they also felt frequently

that they were not believed or taken seriously.

'There's some work (training) going on here, through advocacy, on how the police interview people with learning disabilities...it would be good to find examples where people are getting training.' [Professional]

9.3.2 Communities taking responsibility

The question of communities taking responsibility was raised both by the researchers' network and by some of the professionals who came to the workshops. In particular, people talked about getting outside the 'learning disabilities box', and ensuring that research has a wider focus.

'It's important to be talking with people who aren't in Learning Disability - e.g. bereavement counsellors, leisure services, transport workers, doctors & nurses, mainstream schools, young people (channelling it into education) - not just focus on those who work with people with learning disabilities. This can contribute to building community - inclusiveness... what makes communities include everybody?' [Professional]

Since our literature search revealed very few studies that included contexts and participants from ordinary community services, we felt this was probably an important gap. We currently simply do not know what it would take for people with learning disabilities to make greater use of non-specialist services, such as Citizens Advice Bureaus (CABs), sexual health services, or leisure facilities. A group at one of the workshops spent time in designing very creative research proposals, which would look at: a) what 'generic' service providers need to know about Learning Disability; b) what people with learning disabilities need to know about generic services. Action research such as that could help to bridge the gap between people with learning disabilities and ordinary community services.

Some of the people who came to workshops were in self-advocacy groups which had tried to improve community relationships, and to carry out training for services such as the police. They were well aware that one-one relationships and direct contact helped to make things more accessible for people with learning disabilities generally, and they wanted practical research which would help us to break down the barriers:

'How can we build more one-to-one relationships to make these services more accessible - 'Opening the Door'. How can we look at training (police, but also bar-staff, etc.) on how they deal with people with learning disabilities?' [Person with learning disabilities]

Another interesting suggestion at one of the workshops was that specialist services create a mystique around issues which are quite commonplace:

'What are the effects of the words we use? Like "access the community", "leisure", "fair access to care"?' [Professional]

Getting in touch with those outside the Learning Disabilities box might well be simpler than we think.

9.3.3 People with learning disabilities contributing as active citizens

Community is a two-way process, and people with learning disabilities said they did not simply want to 'take' from society, but also to contribute. They wanted fulfilling lives, and part of this was to feel they have something to offer. People with learning disabilities at one workshop felt that their status as carers was an important issue, and that it often was not recognised that people with learning disabilities could take on responsibility for others. In self-advocacy groups, people regularly support and help each other, but many of these groups are facing financial constraints and often closure. The researchers' network recognised the importance of this issue:

'The people who went there had reciprocity, contact with each other, value. And involvement with the outside world as well through being involved in evaluations and so on. We might understand the value of contribution by looking at the negative impact, when you remove structures that are self-created, rather than being service-created. So that's like redundancy.' [Researcher]

Many of the self-advocates who came to workshops were involved in activities which contributed directly to solving the problems they saw in society. These included training and research projects:

'All we do is training, [at the moment] training staff to support people through bereavement... all the people in Roots told their own stories... one person whose wife had died was told that he wasn't allowed to go to the funeral because it would upset him...' [Self-advocacy supporter]

These issues relate also to opportunities to take on work, both paid and voluntary, and to have jobs which confer status. A social model approach to research will look broadly at the systemic barriers which face people with learning disabilities, and will pose questions about the changes that could be made to society as a whole, to make it more inclusive. For people with learning disabilities to be recognised as equal citizens, we need some fundamental shifts in attitude, and these too can be a focus for research.

9.3.4 Going out

The most straightforward question about community inclusion, from the point of view of people with learning disabilities, is how do they 'go out'? Many people who came to workshops would still like to have more active and fuller lives, and they find themselves restricted by many of the barriers which have been listed in existing research – lack of support; transport problems; lack of money; and concerns for safety.

One woman who came to a workshop presented her story about going out.

'I decided I wanted to go by bus to a nearby city, but my support

workers discouraged me, saying they could not help me to learn the route. But my parents helped and supported me to do this. I was very proud when I made it on my own, and phoned my mum on my mobile. I now want to travel to Cardiff by train on my own, but my parents are not sure this is safe, as I would not be able to manage a large, confusing station when I got there.' [Person with learning disabilities].

This story raised several issues for people in the workshops, including the role of parents and the difficulty of getting the balance right between safety and risk-taking. The aspirations of people with learning disabilities to 'go out' are not extraordinary, and research needs to concern itself with how to tackle the very ordinary barriers which people face, such as the confusing nature of railway stations, maps and timetables and use of mobile phone technology.

Finally, the issues for people with high support needs were particularly highlighted by one man who came to a workshop. He himself had a one-one support worker, and they were able to go out together and do whatever the person with learning disabilities decided he wanted to do. However, they were aware this was rare, and people who cannot communicate with words, or who have challenging behaviour, still do not get the same opportunities for 'community-based support' as other people with learning disabilities. Our literature review did reveal some examples of initiatives to provide community-based supports for people with high support needs (e.g. Cole and Williams, 2006). However, there is clearly far more work to be done in this area. Researchers suggested that we could look at how people got good support, perhaps from their own family members, to do ordinary activities. Supporters are the interface between people with learning disabilities and the outside community, and research and development relating to their role is vital.

9.3.5 Summary of research priorities and questions suggested by all stakeholders

The top priorities in the area of 'community inclusion' were generally about research that looks at community attitudes, the tackling of hate crime, and how we improve the confidence of mainstream services to provide for people with learning disabilities. The overwhelming issue for research was about how we get communities to take responsibility. All the particular questions, topics or areas for research listed below are those that were suggested by workshop participants or by research network participants.

Hate crime

- How widespread is hate crime against people with learning disabilities?
- What effect does bullying or hate crime have on people with learning disabilities?
- How could the criminal justice system be adapted to help people with learning disabilities get a fair deal?

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- How can we improve support for people going to court?

Communities taking responsibility

- What do we mean by 'community'?
- How can we improve awareness of learning disability in mainstream education?
- What do people with learning disabilities want from a sexual health service (or other non-specialist services)?
- What do mainstream service providers need to know about Learning Disability, and what do people with learning disabilities need to know about mainstream services?
- What is the relationship between specialist and non-specialist services?
- How does the law apply to the barriers people with learning disabilities face?

Citizenship

- How many self-advocacy groups have struggled or closed down, and what is the effect on the members?
- How can we ensure people have good support groups and self-advocacy groups?
- What do people with learning disabilities contribute to each other?
- What might it take to enable more people with learning disabilities to make contributions to society, and to have these recognised? And what counts as a contribution?

Opportunities for people with learning disabilities to go out

- How many people with high support needs do 'ordinary' things?
- How can we make leisure services more accessible?
- What is the role of families and support workers in helping people to go out? What skills are needed by all parties, so that people with high support needs can go out and do what they want to do?

9.4 References Chapter 9

9.4.1 References included in critical appraisal

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10 Summary and discussion

10.1 *Summary*

The aim of this scoping exercise was to achieve a consensus about the priorities in Learning Disability research for the next ten years, by involving as many different groups of stakeholders as possible. Although there were some tensions and differences between the perspectives of these various groups, it was remarkable how well all the stakeholder groups agreed on the fundamental priorities. People with learning disabilities, family members, practitioners and policy makers, as well as researchers all agreed on the following:

- a) Research needs to be better linked with changes in practice, and to achieve that we need a better understanding of the factors that lead to change.
- b) The important areas for progress were access to health care; getting good support; the right to relationships; housing options; work and personal finance and inclusion in the community.
- c) Research in all these areas needs to look to future changes in social care (such as individual budgets and self-directed support) as well as changes in the population of people with learning disabilities.

People with learning disabilities identified, by and large, issues in their lives which were about their aspirations (for instance, about relationships or a job) and about their health and support needs. They tended not to talk about mechanisms to secure these things, which are high on the policy agenda at present. However, some of the other stakeholders pointed out the importance of mechanisms such as person centred planning (PCP) and individual budgets, and we have included these as key aspects for future research priorities. Following our research review, we discussed with all key stakeholders what the most important research priorities were, and the following section presents a summary of those priorities.

10.1.1 **Access to health care**

- Research is needed about health inequalities and access to generic health services; research needs to give us robust and differentiated evidence about health outcomes for people with learning disabilities.
- We need more research about how to improve communication and access for this group, both in primary care and in hospitals. There is a particularly important need to explore the most effective forms of accessible information which can be used within a medical context following the Mental

Capacity Act (2005).

- We need to establish the current use and effectiveness of Health Action Plans.
- Increasingly, we need to undertake research which will enable us to plan for people with profound and multiple learning disabilities, who may be technology dependent.
- We need to analyse the health risks to people with learning disabilities in particular situations, such as supported living, and find out how to change patterns of obesity and lack of exercise, as well as obtain information on use of alcohol and smoking.

10.1.2 Getting good support

- The big challenge for research in this area is to move with the policy changes, and to find out how support staff can successfully move out of the traditional 'Learning Disability' culture, towards a more person-centred way of working.
- We need more research about staff practices under individual budgets and direct payments, partly to monitor workforce issues, but also to ensure safety of people with learning disabilities from possible abuse.
- We need more research from the point of view of people with learning disabilities and their families, so that they can say what they want from support staff. In particular, it is a priority to examine the role of families in leading the changes towards individual budgets.
- Research should also focus on organisational change, and find out how we can effect the changes towards a new type of workforce.
- The skills needed to work with people with people with profound and multiple learning disabilities are under-researched at present.
- Alongside all these priorities, the rights, status and satisfaction of support workers and others working with people with learning disabilities are also an important focus for research; there is a need for research that engages with and empowers support workers, along with the people with learning disabilities they work for.

10.1.3 The right to relationships

Although research has already given us plenty of evidence about social isolation of people with learning disabilities, we need to find out how to ensure that this situation changes. Research can help us find out how people make and maintain friendships.

- There is a particular need to carry out research about these issues for people living on their own, or who no longer have day centre support.

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- We need more research about sexuality, and sex education for people with learning disabilities, particularly from their own point of view.
- There is a gap in our knowledge about families where the parents have a learning disability. Research needs to focus on the day-to-day lives and support needs of those families as well as attitudinal and structural changes in the legal and social care systems; research should also document the views and experiences of children in those families, as well as children who have been removed from their birth families.
- We need research about people with learning disabilities who are taking on caring roles for others.

10.1.4 Housing options

- We need robust, clear evidence about the numbers and experiences of people with learning disabilities who live in different situations (renting, supported living, shared ownership, ownership, as well as residential care homes).
- Research needs to highlight good practice in giving people real housing options, good information, and choice about who to live with.
- We particularly need more research about the support offered to people with learning disabilities who live in their own tenancies, and about places where young people can learn independence skills.
- Some research could be led by families, and particularly could look at the outcomes for people who live near the parental home, or who move away.
- There are research priorities about housing for particular groups, including those in the criminal justice system; people with complex needs who are moved out-of-area; people with profound and multiple learning disabilities or other physical impairments.

10.1.5 Jobs and personal finance

- Research needs to focus on poverty among people with learning disabilities and their families.
- With the advent of the Mental Capacity Act, we need research to look at how people can manage their personal finances, get good advice from mainstream financial providers, and receive appropriate information about financial decision-making.
- There are still many gaps in our knowledge about how to move local authority resources from day services into supported employment, and how to support job seeking and career progression. Employers' needs should also be a focus for research.
- Research is needed about the ways in which Further Education can help students with learning disabilities move into real jobs.

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- We need more research about alternative forms of employment, including social firms, and more options for people with high support needs to have fulfilling lives.

10.1.6 Inclusion in the community

- Research about hate crime and bullying is a priority. This should be action research that not only seeks to understand attitudes, but also to find measures for action against hate crime and bullying.
- It is a priority for research to move outside the 'Learning Disability' box, and to look at the attitudes and needs of service providers and others who are outside the Learning Disability service world.
- Research should highlight the strategies which help people with learning disabilities go out and do the things they want to do. This will involve looking at support staff skills, as well as people and places in the community.
- We need research which will help us understand how people with learning disabilities can be equal citizens, and make contributions to society.

10.2 *Validation of the priorities*

At the completion of this scoping exercise, we wanted to know how the identified areas for research fitted with the agendas of national development and policy organisations. For this purpose, as described in the methodology, we sent out a questionnaire with all our main research priorities to 12 leading development organisations, and three other individual providers. As mentioned in Chapter 2, this exercise was not successful, partly because of time constraints for the organisations concerned, and partly because specific research questions were sometimes perceived as irrelevant. We only received five responses (33% response rate) and only three of those filled the numerical ranking. However, one response was from an umbrella organisation, representing ten major Learning Disability organisations. Further, four development organisations had taken part in the regional workshops.

First, we asked respondents to rate each priority area, and the examples of research questions, on a five point scale (with 5= "yes, definitely should be funded": 1 = "definitely not"), in order to indicate how important each research question was, in relation to the agenda of their organisation. The results which emerged from that exercise ranked the six priority areas in the following order:

Work and money	5
Health	4.5
Community	4.5
Relationships	4

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Support staff	4
Housing	3

Within each section, different respondents made particular comments on each item, and the full results are given in Appendix C. However, the research questions which scored highest over all the respondents were:

- 1) The issue of bullying and hate crime, and especially how the criminal justice system can be adapted to give people a fair deal. How can we improve support for people going to court?
- 2) Individual budgets, and how we can ensure that performance standards among staff are monitored under IB.
- 3) Research about parents and carers with learning disabilities – in particular, how many people with learning disabilities are themselves family carers? Do they get recognition and support?

It will be recalled that the research questions were divided into three categories – evidence, action and understanding. Although these categories are never in fact mutually exclusive, this seemed a principled way to ensure that we had a spread of different types of research. Of the three types of research, people in development organisations showed a preference for ‘action’ research. Some of the issues relating to increased understanding were noted as irrelevant, and it was also often considered irrelevant to have more evidence (for instance, one respondent felt that research about support staff training was not relevant, and another felt that evidence about citizenship is not needed). However, the number of responses to the validation questionnaire was low, and overall, it is probably sufficient to note that all of the research priorities and individual research gaps we listed had a score of 3 or more from at least one organisation. The mean response scores from the three organisations which filled in the form are given in Appendix C. The research agenda which stakeholders identified appears to have at least some resonance for development organisations. Given that these organisations are at the forefront of change, this vote did provide some validation of the agenda for the research priorities emerging from this scoping study.

Research on workforce issues was felt to be important, particularly if it related to the changes due under individual budgets (IB). However, the particular research questions listed from workshop participants were refined by some of these respondents. For instance, it was felt that research needs to take a focused look at the ‘new roles’ which are being developed under IB, and some felt that we already have a fair idea of the skills needed by support workers. What we need to know is how to ‘make it happen’. One comment was about families and people with learning disabilities leading the way, and another about looking at the skills/networking for supporting into local communities, or community connecting. The focus on people with profound and multiple learning disabilities (PMLD) was broadly welcomed, and also the ideas about organisational change:

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'It is important to look both at support workers, and also the wider workforce issue e.g. the role and influence of leadership and management, organisational culture.' [Development organisation]

Again, these respondents were most interested in research which would help us know how to move things forward towards goals of person-centred support.

Research about hate crime, as we have seen, was high on everyone's agenda. It was felt that perhaps the tightening of eligibility criteria for community care might lead to greater vulnerability, and that research could give us a better understanding of these issues. Initiatives that already exist to tackle hate crime could be better drawn together, so that we can learn the lessons from them. Ideas about citizenship and social inclusion were also commented on:

'We need to look at other research areas and then overlap with these ideas, in relation to all excluded groups. What makes an inclusive community?' [Development organisation]

There were positive comments about the focus on 'going out', as some of the service user groups who work with these organisations had indicated that this was important to them.

Within the housing agenda, there was general agreement that these research issues were important. However, some respondents also pointed out that we may need to know more about new ways for people with learning disabilities to develop their independence skills, by the use of assistive technologies. Again, there was a positive focus on learning how to find new housing options for people with learning disabilities, and how to link housing with individual budgets.

Paid employment, it was felt, is an important priority – and has been flagged up also under Valuing People Now (Department of Health, 2007). One respondent said that we:

'Need to know more about how to change assumptions about work from early childhood, so that people grow up expecting to work.' [Development organisation]

They felt that employment was part of the 'life journey' of people with learning disabilities, and needs to be put into the context of their whole life. As was discussed in our workshops, one of the main barriers still appears to be the benefits trap, and respondents to the questionnaire also felt that we need to know more about how people can take up paid work, and really make it pay. Although this might be considered a development issue, rather than a research issue, nevertheless participants at one workshop had flagged up the possibility of disability 'pensions', and other ways of making employment possible, as a topic for 'best practice' research.

Comments about health research echoed the need to make things happen. Respondents said that we do know what is going wrong in Health, and some

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cited the Mencap report, 'Death by Indifference' (Mencap, 2007). We also know quite a lot about the barriers that stop people getting good access to health care. What we need to understand is how to make the changes, and how to move things forward. Some types of action research may help us do this, but in many ways, this is also a development issue.

Finally, research on relationships was felt to be a key area for people with learning disabilities themselves:

'We know this is very important topic for people with learning disabilities. This is a key issue for our advisory group, Build for the Future.'

[Development organisation]

The emotional life of people with learning disabilities was felt to be a very important topic, and it was felt that research may be able to help us know best how to support people's relationships.

Some of the development organisations listed other topics for us, and also raised general issues about research which should be mentioned here. Of the other topics, some were related to areas we had highlighted. For instance, being included in the community could lead to research about transport, accident prevention and also consumer rights of people with learning disabilities. Lifelong learning was also mentioned, and specifically, learning about new technologies. It was also said that parents and family carers needed to be leading research and development, and those who are innovators (for instance, in developing new types of support with direct payments for their relative with learning disabilities) could lead the way for others. Research, of course, is not the answer to everything. This fact was frequently mentioned by respondents to the questionnaire, and echoed some of the discussions in workshops about actions arising out of research.

'As ever, we need to overcome the barrier between research and getting something done in practice.' [Development organisation]

This person pointed out that, whatever happens in research, the directions of social policy have been determined. One of the overarching concerns is that there are diminishing resources to support an expanding population of people with learning disabilities. This has led to rationing, and a focus on those in the 'highest priority' bands; it also leads to a continued reliance on parents and families, who are not supported as they should be in their task of caring for their relative with learning disabilities. Therefore, perhaps the most important message of all is that research should provide evidence about the current position for people with learning disabilities, so that we can campaign for change. The 'Learning Disability Coalition', which comprises a group of leading Learning Disability organisations in England, put it like this:

'It is difficult to prioritise and, having studied the proposals very carefully I am struck by the overwhelming need for research into whether existing policies, structures and resources are capable of delivering the aspirations which your research has identified.'

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The feedback we receive from people with learning disabilities, carers, families, directors of social care, workers in the field and interested organisations is that widespread cuts to services are taking place and that the “support” system is under pressure.

This means that the enabling, prevention and inclusion agendas with which the issues you raise are identified are currently jeopardised and lives are impoverished.

Currently much of this information is anecdotal and uncoordinated even though it is reported in the local press.'

10.3 Cross-cutting themes

The division of research priorities and concerns into six areas was, to some extent, an artificial measure. People's lives are holistic, and the concerns they raised in the workshops were about their whole lives. Many of the studies we read, which had been accessed under one search term, were also applicable to other areas. Additionally, some of the themes raised in workshops and with other stakeholders could be traced through all six of the priority areas, and are essentially cross-cutting themes. The first three cross-cutting themes are about specific groups of people with learning disabilities. As was said at one of our first workshops:

'A lot of the research with people with learning disabilities is too wide and generic and ignores the age differences etc. We need to stop talking about people with learning disabilities as though they are a single group of people.' [Professional]

Although we did not do specific searches on these terms, we have been able to identify some of the issues within each of the main topic areas.

10.3.1 People with profound and multiple learning disabilities (PMLD)

People with PMLD are often excluded from research studies, in two different ways. When recruiting participants, it is often hard to include those who have extreme differences in their communication. Many qualitative studies, in particular, rely on verbal interviews, and it has long been known how difficult it is to realistically include people with PMLD in interviews. In survey work, which collects data from staff or other informants, people with PMLD will be more likely to be included by default. However, it is also notoriously difficult to ensure that fully informed consent is obtained from this group (Dye, Hendy, Hare and Burton, 2004), and they are often excluded from research on the grounds that they lack capacity. This situation is set to change, with new codes of guidance from the Mental Capacity Act (2005), aimed at ensuring that people with learning disabilities are not unnecessarily excluded from research, and that those who cannot consent for themselves may be included via a consultee.

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The issues of consent apply to any methodology, quantitative or qualitative. However, there are clearly some data collection methods which lend themselves more neatly to the inclusion of people with PMLD. In particular, observational methods are a good choice, since they enable the researcher to have a direct interface with the real, lived experiences of the person being observed. Ethnography, interaction analysis, the use of video, and time-sampled observations are all underused in Learning Disability research, and could be ways of developing more knowledge about the communication needs, and the skills for supporting, those with PMLD in many different situations (for instance, within the Health service; when going out; inside the home).

A second way in which people with PMLD are excluded from research is that their specific needs are overlooked. As observed, people with learning disabilities do not constitute a homogenous group. Where research recruits large samples of people from a range of situations, these samples often do include a range of people with different needs. It is easy for the analysis to then overlook the different and specific issues that might arise for people with PMLD, as opposed to other groups. For instance, in studies about support workers, the topics of sensory methods and practical care skills will only be applicable to some sub-groups of people with learning disabilities, not to all. In studies about health, it is vital to distinguish those who really will not be able to report their symptoms, from those who simply need more time in order to do so.

Despite these problems with inclusion of people with PMLD, the research we reviewed did deliver some knowledge about this group. Twenty papers overall focused specifically on this group, which we will briefly summarise here:

- People with PMLD are particularly badly served by generic health services, and many medical practitioners will not be able to understand forms of communication which are non-verbal. This is extremely important if people are in pain (Regnard, Reynolds, Watson, Matthews, Gibson and Clarke, 2007).
- Creative ways of communicating, including the use of music therapy (Graham, 2004) and sensory stimulation (Leaning, 2006), are important, but probably under-used.
- Support staff may over-interpret the communication of people with PMLD. They need to work with all those who know the person, in order to make accurate assessments of individual communication (Porter, Ouvry, Morgan and Downs, 2001).
- People with PMLD are often considered as a 'special group' in terms of the moves towards community involvement. It is frequently thought that they still need day centres, for instance. However, there are some innovative examples of including people with PMLD in community activities (Cole and Williams, 2006).

- Families with a relative with PMLD have a particularly important role to play in supporting their relative (Kirk and Glendinning, 2004). Parents are also expected to be constantly available during periods in hospital, to provide practical support (Cumella and Martin, 2004; Wharton, Hames and Milner, 2005).

10.3.2 Older adults with learning disabilities

There is no particular reason to expect that older adults with learning disabilities are systematically excluded from research. However, similar arguments could apply to this group in some respects, as applied to people with PMLD. Research may well be needed which focuses on the particular issues for older adults, otherwise, their needs will be subsumed and possibly lost in a wide range of other concerns. Their particular needs are likely to be:

- social - this is a group for whom family living may no longer be a possibility, and so people may be seeking accommodation which particularly meets their needs
- health-related - dementia and the physical issues associated with ageing
- occupational - this is a group of people approaching or at the age of retirement, often without every having had a paid job

Studies about the specific needs of adults with learning disabilities and dementia were not included in this review. Of the research retrieved in the main topic areas, much of the research reviewed did not take a specific focus on older adults, and so it was hard often to tell whether they were included at all. From the six studies that did focus on their needs, we found out that:

- Health screening is a problem for older people with learning disabilities (Bland, Hutchinson, Oakes and Yates, 2003); however another study (Fender, Marsden and Starr, 2005) found that older adults with Downs Syndrome were able to say what they wanted from their doctor, particularly when working together in small groups.
- In terms of housing, there is often a dearth of good choices. We know that life within generic homes for older people is not always a good option, as the adults with learning disabilities tend to be younger than other residents (Thompson, Rylie and Wright, 2004). The staff are often unaware of their particular needs; boredom and lack of stimulation are major problems.

10.3.3 People from black and minority ethnic groups (BME)

The literature searches in all six priority areas only revealed two papers which specifically focused on people from BME communities. As with the other groups outlined above, we know that it is often difficult to recruit people from BME communities to research projects, since they tend to have

less contact with services overall. Our workshop participants spoke frequently about 'cultural issues' and culturally specific support. However, there was very little research evidence backing up any sound knowledge of what these cultural issues actually are. From existing research:

- We know that people from BME groups may live in families where they have different social roles from those which we aspire to. For instance, choices and self-determination may not always be valued in different cultures, and attitudes to death were one particular issue over which differences were found (Summers and Jones, 2004). These differences can cause particular tensions for support workers.
- People with learning disabilities from BME groups may also have particular difficulties in accessing the health service, and in obtaining health support specific to their needs, although we need more work in this area.
- From previous research, we also know that many people in these groups face 'double discrimination', through their race and disability (Baxter, Poonia, Ward and Nadarshaw, 1990). Therefore it is likely that issues of bullying and hate crime will apply particularly to people with learning disabilities from BME groups.

It might not always be the case that specific research is needed, to focus on these particular groups. In many cases, generic research outside the Learning Disability field could inform our views. Participants from the BME research community thought that was true about people from BME groups; it is also probably true about older people with learning disabilities, and particularly those with dementia. However, findings from other research will need to be specifically applied to the situations in which people with learning disabilities live and work. For instance, there is a specific issue about people growing older, without ever having had a job. There may also be particular issues about people with learning disabilities who are not allowed to occupy 'adult' roles, who may be at risk of abuse, and who have difficulties in forming relationships with other adults.

10.4 *What types of research are needed?*

The current review and consultation were carried out with the express intention that research should be an activity which can make a 'positive difference' to the lives of people with learning disabilities. When we set out to consult with various stakeholders, we always began with that proposition.

From the start of our first round of workshops, stakeholders who attended had some very sophisticated and thoughtful views about research. We started each of the morning sessions with people with learning disabilities, by asking them for their views on what 'research' meant. Far from this being a learning exercise for the participants, we found that we learnt a lot from their views. People said that research should be about knowledge, but also about action and certainly about changing things.

As a part of our second round of workshops, we included an activity for all participants, which was essentially about designing the kind of research they would want. We took examples of actual research studies, and gave those research questions to groups of participants, who were asked to look at how they would go about designing a research study. This activity led to some very thought provoking responses, and they underpin the following discussion.

10.4.1 Dissemination and use of existing research

One of the most striking findings in the current project is the sheer volume of research about Learning Disability that has been funded, carried out and written up during the period 2001-2007. Given that we excluded topics which had not figured on the 'top six' priority areas, and that within the six priority areas we did not follow up large strands (such as mental health research), we know that what we reviewed only accounts for a proportion of the research published. The total number of studies we reviewed in all six areas is 326 (some of these contributed to more than one of our topic areas). This is the breakdown by gross methodology categories:

Quantitative research	133 (41%)
Qualitative research	107 (33%)
Other	86 (26%)

The vast majority of these research findings never reached the stakeholders who came to our workshops, and largely this is because they are published in academic journals, they take time and energy to read and synthesize, and quite often the world of 'practice' has moved on before the research findings are available. People with learning disabilities, professionals and family members often posed questions on which research had already been done.

- How should we give good support to people with challenging behaviour?
- What kind of housing is best for people to get out into their local communities?
- What sort of support do parents with learning disabilities want?

Of course, the existence of a body of research does not mean that any particular topic is a closed book. As the situation of people with learning disabilities changes, it is important that we refine and revise our knowledge on most areas. However, it is clear that 'evidence-based practice' is often a myth.

In order to make research more effective for change, it clearly needs to be better targeted at those who are working in the field. However, it is possibly also the case that we need to look at the culture of Learning Disability management, and how far senior officers are prepared to engage with academia. One of the researchers we talked with told us about the culture he had known, as a senior officer in a social services department:

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'When reports came in, it was about – how can I get rid of this from my desk? If it was one page, then fine. I had one day a week when I went into the library and read articles, and I was considered to be very unusual. In local government, people who had a PhD were considered to be incapable of taking a decision. Your mind would be muddled, and perhaps this was true! There is a whole ideological relationship between the creation and the transfer of knowledge that we've still got to work hard at'. [Researcher]

Changes of policy and practice, of course, happen for many reasons which are entirely unconnected with the knowledge base provided by research. Political and economic pressures may cause changes in the provision of services, and even prompt moves towards new ways of working. By definition, new forms of social care, such as individual budgets (IB) cannot be based on solid research evidence, as they do not yet exist. Therefore, these new ventures tend to be piloted and evaluated as they are being introduced. The same could be said for 'supported living', and perhaps also for modernisation of day services.

When it comes to the majority of stakeholders who attended our workshops, including the people with learning disabilities and their family members, research can seem like a distant and inaccessible body of irrelevant knowledge. Family members, in particular, were often disenchanted by research. When people base their opinions on 'lived experience', they are unlikely to be shaken by evidence on the printed page. It is also true that a lot of research is about the actions and contributions of people who are unlikely to read it, for instance:

- research about frontline support staff
- research about the experiences of people with learning disabilities in employment
- research about GP receptionists.

This is a situation which causes considerable frustration. With limited resources, and people with learning disabilities whose needs still have not been adequately met, most of our stakeholders would echo the following words of one parent:

'Why is research not implemented? What helps this change? Why can't we do something out of the research – for instance, make sure that families can make a difference?' [family member]

10.4.2 Action and development

'It is time to stop talking and start doing' [Person with learning disabilities]

Many of the stakeholders who came to our workshops said openly that what they wanted was research linked to action.

'We said we wanted the research to be practical, like action research.'

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Could we just dream, and have these desired outcomes, and just do it? Rather than take time to ponder our next move? Of course we can do it!
[Practitioner]

Interestingly, their views were echoed by many other stakeholders, including directors of leading development organisations and policy makers. Instead of research, many stakeholders felt that what is needed is 'action' and development work. At the first workshops, stakeholders talked about action research which would lead to a programme of action:

'This methodology doesn't just watch what happens – it affects it.'
[Family member]

At one workshop, a group met in the afternoon session and came up with some interesting ideas for a new type of research agenda. They were aware of the limitations of some forms of action research:

'Action projects are often more practical, but they're only going to tell you about one bit.' [Feedback from group]

They suggested an agenda where action research would be led by groups of people with learning disabilities, who would generate their own research questions and use the findings directly in their work. For instance, a group in Leeds is developing their own work about personal assistants, and using their findings in developing an agency controlled by people with learning disabilities. In this way, research becomes part of a business venture, and is entirely controlled by disabled people, fulfilling the original idea of 'emancipatory research' (Oliver, 1992).

Action research does not have to be about small-scale, or local actions. Action research was originally conceived as a way for community stakeholders to take action for themselves, often with the assistance of a researcher. The idea is that people can learn to understand their own problems, and be part of the research endeavour. Action research is cyclical, and will alternate the 'finding out' phases with 'action' phases to try out the research findings. Essentially, this model was re-invented several times and in slightly different variations, at the various workshops. It is important that we continue to develop models of action research which really have an impact on policy and practice at the widest level.

One group, for instance, had a detailed discussion about the relationship that must exist between community stakeholders and researchers. They felt that people with learning disabilities needed researchers to work with them, but these people should be accountable and trustworthy:

'We wanted the power to remain with the people with learning disabilities, and that power included the money and the decision making being located with those guys. And we thought it was useful to have people who had research backgrounds, but we wanted accountability and trust in that relationship.' [Feedback from group]

From a different point of view, researchers themselves wanted their findings

to lead to action, and they felt that it is not enough just to 'disseminate', or to give a list of recommendations at the end of a report. They realised that forms of action research were the way forward, and they thought of stakeholders as including professional practitioners, managers and frontline staff, as well as people with learning disabilities and their families. If research is to make a difference, then it is essential to engage with those managers and practitioners who never read beyond the first page of a report:

'It's about research projects that have prolonged engagement, with people who are seeking to change things. That might generate more of the practical outcomes.' [Researcher]

10.4.3 Research based on the social model of disability

Most people who came to our workshops live with Learning Disability, as family members, as people with learning disabilities themselves, or as practitioners. As one family member put it:

'Tick boxes do not tell you what people's lives feel like.' [Family member]

All these participants have a direct personal interest in making progress for their own lives and for those like them. They do this within the constraints of wider pressures and systems, over which they do not necessarily have much power. For instance, those who fight for better support do not have the power to determine 'fair access to care' and who gets support at all. It is sometimes true that people can make a difference by the example they set in their own life. For instance, people with learning disabilities who go out to join their local leisure centre may challenge the attitudes of those they meet. In personal ways, social barriers can be addressed by individuals.

However, research in general should give people (including people with learning disabilities and family members) greater power to look more widely at the ways in which society treats disabled people. This is what Oliver (1992) intended with the new paradigm of social model research. One of the problems with practical, action-based research is that it sometimes tends to be small-scale and about particular interventions or actions. By contrast, some of the respondents to our research felt very strongly that research should have far greater power than it often lays claim to. The Learning Disability Coalition, for instance, responded to the questionnaire about research priorities with a call for overarching research, which is about the ability of the system to deliver support for all people with learning disabilities:

There is a serious need for overarching government research that assesses the ability of the system, within current resources, to deliver on Government policies as set out in:

- *Our Health, Our Care Our Say*
- *Strong and Prosperous Communities*

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- *Valuing People*
- *Putting People First*
- *Improving the Life Chances of Disabled People* [Response to questionnaire]

Researchers also talked about the more global issues which research should be addressing:

'There's a general theme running through all of this, about how the general values of Valuing People don't get played out on the ground, because of other concerns. The way money is allocated, or Health and Safety. And then there's a frustration that people in charge of these services do not produce what they're supposed to produce. And perhaps there should be explicitly research that looks globally at why these other priorities are always prioritised.' [Researcher]

A particular issue which they mentioned was the piecemeal nature of research funding, which can often result in individual research studies which do not build into a whole picture:

'The danger is that you get – the DH has ended up with a very bitty list of projects, which doesn't end up with a proper evaluation of Valuing People. The whole needs to be more than a sum of the parts. We need to do something more coherent. In terms of research in general.' [Researcher]

People in our workshops also mentioned this issue, noting that many groups are working on the same things in different parts of the country.

What types of research, then, will really make a difference, in terms of:

- a) Ensuring that policy rhetoric is translated into a properly funded system of support?
- b) Tackling and changing society's attitudes at large?

Empowerment of individual people is bound to be important, as the knowledge generated from such projects is not just 'technical'. However, many stakeholders felt that we also need a body of robust research which provides an evidence base about 'what is happening'. It is that type of evidence which will provide the arguments for changing government policy, and for campaigning for better resources.

'People have looked into identifying the problem, and sometimes you need some boring figures, to say 'Do you realise people with learning disabilities are dying 20 years earlier than others?' [Researcher]

10.4.4 Research that comes out of the Learning Disability box

Given that our 'research priorities' exercise was about the following ten year period, it is essential that we look forward to the new ideas and thinking that are changing the way services operate.

Ten years ago, people with learning disabilities were mostly going to day centres, and there were not many options beyond living in the family home or going into residential care. Gradually, things are changing. Policy, as we know, is changing even more rapidly than practice, and, if it is believed, we can envisage a future in which:

- Learning disability services are distributed in a more transparent, and user-centred way.
- People with learning disabilities take a full part in their local communities.
- Mainstream, generic services are better equipped to help all citizens, including those with learning disabilities.

In general, these are also the things which were wanted by the people who came to our workshops. At the first round of workshops, people with learning disabilities were asked to present their 'dreams' for ten years' time. These included scenarios in which they had freedom for their own successful relationships; paid work in exciting jobs which really matter; the ability to travel and go on holidays with good support workers.

Just as people with learning disabilities are emerging from the network of Learning Disability services, so too should research move out of the traditional mould of being just about 'learning disability'. Professionals at more than one workshop urged researchers to move 'out of the Learning Disability box'.

This can be done in many ways. For instance, it might mean that:

- Research is needed which looks more widely at society's attitudes and at people who have nothing to do directly with people with learning disability.
- Research is needed which focuses on mainstream services, such as health services, leisure centres or workplaces.
- Learning Disability research could learn from the findings of other disciplines. For instance, organisational and management research could help us make changes in service structures; economic research could help social services departments manage their budgetary changes.
- There are many themes in Learning Disability which may well apply to other disadvantaged groups, such as older people or other disabled groups. We need to take a less 'impairment specific' approach, while not losing the essential focus on the needs of those with learning disabilities. As one of the researchers said:

'If it works for people with learning disabilities, it will work for anyone.'

[Researcher]

In all these different ways, people told us that the focus of Learning Disability research has got to become wider. It is not sufficient to measure outcomes by the standards within the Learning Disability service world. We have to look towards research designs which will provide a comparative measure, and judge what happens for people with learning disabilities by the standards we would all want for our own lives.

10.4.5 Who are the researchers? People with learning disabilities and family members as active researchers

In the new types of research we are envisaging, many skills will be needed. Clearly, there are large and important bodies of research which will need the skills of specialists. Researchers in those fields will still be needed, and it is important that we do not overlook the necessity for a range of medical research, including:

- basic neurological research, which will help us understand the mechanisms underlying different impairments
- epidemiological research, which will give evidence about the numbers of people with learning disabilities in different categories
- research about treatments and their efficacy.

People told us that it is important that people at grassroots level are able to access the knowledge generated by research:

'I think it's about whose responsibility is it, to get that in the public domain, and how you can build the work on it. How can you help people who are using services, and family members, to use it? If knowledge is power, we need to work out a way for people to access information that is useful for them.' [Family member]

One of the strongest ways to take hold of knowledge is to be involved in generating it for yourself. As more people with learning disabilities are taking an interest in doing research, a body of work is slowly growing, which we will refer to here as 'inclusive research' (Walmsley, 2001). Sometimes this means self-advocates carrying out their own research (Abell, Ashmore, Beart, Brownley, Butcher, Clarke *et al*, 2007), and it may also mean people with learning disabilities being employed to take on full roles as researchers (Gramlich, McBride, Snelham, with, Williams and Simons, 2002), or people taking a role in controlling the research agenda, as in the current project. It is also possible for people with learning disabilities to be advisors on research projects, or consultants, so that they have some say in how the research is conducted. In the literature reviews carried out for this scoping review, only 30 studies (9% of the total of 326) were explicit about involving people with learning disabilities in more significant ways than as participants. This is not a large number, and it would be useful to find ways to increase the involvement within research of

all stakeholders.

As was observed in one of our workshop discussions, people with learning disabilities really care about the research they take part in. That is the real reason they do it:

'It's got to be something you really love, and you really think is important. That is so basic, they've got to want to come up with it and do it.' [Supporter]

When asked to design an 'ideal research project', all our workshop groups came up with designs in which people with learning disabilities and their families were centrally involved. The main issue was for them to hold power and control over the research process, in exactly the way described by Oliver (1992) in the 'emancipatory paradigm' of disability research. In two of these groups, people talked about team work, so that there would still be a place for specialist research knowledge. However, the positioning of the researcher should be very sensitive; as observed above, it was felt that researchers had to be accountable to people with learning disabilities and to their family members, and to be able to work directly with them.

10.5 *The biggest gap: how to make things change*

Valuing People Now (Department of Health, 2007) 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. This was an issue which threaded through the current scoping review, and represents the most fundamental of the priorities for future research.

Throughout this report, we have considered different ways in which research relates to both policy and practice:

1) Research can be triggered by policy or by law (for example the current research interest in the Mental Capacity Act 2005), 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 (Department of Health, 2007).

2) Research can also help to make or evaluate practical changes, and can impact directly on service provision or on 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.

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Research has an important role in helping to synthesise 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.

When asked to prioritise the ideas for research gaps that had been discussed at the workshops, most participants thought long and hard about where the funding should go. 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 may also be 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. If research is going to make a positive impact, we need to ensure that it fills this most important gap. In the years from 2008 to 2018, what we most need is knowledge which will help us to translate policy into practice for people with learning disabilities.

10.6 **Recommendations**

We suggested in our initial proposal for this work, that:

'We envisage that there will be continued evolution of ideas and thinking about research through the creation of a 'research interest network' created by the project itself.'

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It is important that the network created by this project is not lost. Although there have been other networks (for example, the network created by the Department of Health) of researchers during the course of this work, the current study included a wide range of stakeholders who were interested in research, including family members and people with learning disabilities themselves. Their contributions were vital to this study, and would also help to inform the continued direction of Learning Disability research.

The reason that we need research in Learning Disability at all is that people with learning disabilities are still largely socially excluded, they face many barriers in accessing ordinary services, and they suffer from many inequalities – in health, housing, economic status and employment. At the same time, society generally recognises that it has a duty to offer support to people who are vulnerable, and to ensure, for instance, that they are free from abuse. As we have discussed in this report, we are presently in a policy climate of change, where many fundamental issues are being discussed about the cultural values underpinning Learning Disability services, and the need to offer supports which enable people to be full citizens in our society. These changes also imply a major re-think of the way in which social supports are offered to people with learning disabilities, and how resources are managed at local and national level.

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.

It was also apparent from this study that at present, research is conducted in a fairly uncoordinated manner. We frequently found research studies that were conducted simultaneously, on virtually the same topic. Research in Learning Disability would benefit from far greater coordination, at the level of researchers and research centres. At the same time, funding of research would be more effective if it was also more co-ordinated. University research centres are dependent on funding to continue their research activities, and so planning for research expertise and development is almost impossible without some guarantee of funding. 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.

For all these reasons, we would like to conclude with a few general recommendations for funders.

- 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

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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.

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Appendix A

Systematic Literature Search Terms

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

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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

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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*

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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

Appendix B Critical Appraisal tools and results

Reading Tool for Data Extraction and Quality Appraisal

SDO Project - Reading Tool for Data Extraction & Quality Appraisal

First reviewer	
Date of first review	
Second reviewer	
Date of second review	

(1) Overview of research	
Author, year	
Type of research	
Topic area	
Aims of the research	
Is there a literature review? If so, any key issues to record?	

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Summary of main findings	
Who commissioned the research?	
(2) Research setting, sample and ethics	
Geographical area and scope	
Sample – size & who included?	
Sample – who excluded?	
How was the sample selected?	
Were ethical issues addressed properly? (e.g. evidence of ethical approval, consent, etc)	
(3) Data collection and analysis	
Methods used for data collection	
Methods used for data analysis	
Role of people with learning disabilities in the research	

(4) Implications and impact of the research	
Implications for policy	
Implications for frontline practice	
Implications for further research (including any gaps noted)	
Where is it published? Academic/Practitioner Journal?	

(5) Quality appraisal – in terms of robustness of methodology	
<p>Score up to 5 based on consideration of following factors.</p> <ul style="list-style-type: none"> • Clear explanation of and rationale for methodology? • Ethics? • Appropriate sample type and size? • Well-referenced? • Usefulness? 	Score and notes (score 1-5)

Classification for Types of research

- A Systematic reviews that only include RCTs
- B Systematic reviews
- C Non-systematic reviews that bring together references. This includes text-books.
- D RCTs
- E Non-randomised, experimental/intervention studies.
- F Other primarily quantitative research – state method used (e.g. survey, evaluation, etc)
- G Other primarily qualitative research – state method used (e.g. survey, evaluation, narrative research, case study research, ethnographic study, semi-structured interviews, etc)
- H Mixed methodology
- I Research based practice examples, checklists, guidelines.

Quality appraisal scoring guide

Following checks on inter-rater reliability, the following explicit criteria were agreed for the quality appraisal:

Methodology

- 1) Unclear – we don't know what was done exactly or why it was done
- 2) Clear explanation, but inappropriate method for research question
- 3) Reasonable method, but not very well-written, not clearly explained
- 4) Clear explanation and appropriate method
- 5) Clear explanation of method; method totally appropriate to research question; thorough discussion of methodological issues and shortcomings

Ethics:

- 1) Rights of people with learning difficulties contravened
- 2) Ethical approval discussed (or even mentioned)
- 3) Ethical approval and consent discussed
- 4) Ethical approval and consent discussed and accessible information was provided to facilitate consent process
- 5) Rights of people with learning difficulties are upheld and there is a good discussion of ethical issues, in addition to ethical approval and consent being discussed and accessible information provided
- 6)

Sample Size

Quantitative

- 1) Underpowered and making claims beyond what the data can show
- 2) Small sample, but doesn't make unnecessary claims
- 3) Reasonable sample but non-stratified
- 4) Stratified sample
- 5) Good sized stratified sample, acceptable power (explicit) and explicit about stratification

Qualitative

- 1) Sample is too large and affects the depth of the analysis
- 2) Clearly biased sample, e.g. excludes groups such as people with high support needs
- 3) Reasonable sized sample but could still be biased
- 4) Adequate sample, fit for purpose
- 5) There is enough data for saturation point to have been reached (i.e. saturation of themes)

References

- 1) Minimal/none
- 2) Evident gaps, although there are some references used
- 3) References ok but the issues not well discussed
- 4) Thorough background and good discussion of issues
- 5) Thorough background and good discussion of issues and the method for the literature review is explicit

Usefulness

- 1) Research conducted purely for own agenda, without convincing research evidence
- 2) Not very useful - some bias evident, some convincing analysis
- 3) Convincing analysis but contradicts common sense/ previous research
- 4) Convincing analysis and has resonance
- 5) Convincing analysis and has resonance and also is research that will have a high impact on the lives of people with learning difficulties

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	Critical Appraisal Scores									
	Methodology		Ethics		Sample size		References		Usefulness	
	Mean	Range	Mean	Range	Mean	Range	Mean	Range	Mean	Range
Health:										
Quantitative	3.71	1-5	2.34	1-4	2.88	1-4	3.44	1-4	4.00	2-5
Qualitative	3.73	1-5	2.95	1-5	3.60	2-5	3.32	1-4	4.05	2-5
Other	3.35	1-5	2.55	1-5	3.00	2-4	3.55	2-5	3.85	2-5
Support:										
Quantitative	3.27	1-5	1.33	1-4	3.71	1-5	3.19	2-5	3.51	2-5
Qualitative	4.21	1-5	2.46	1-5	4.17	2-5	3.13	1-5	4.33	2-5
Other	3.21	1-5	1.90	1-5	3.50	1-5	3.29	1-5	3.97	2-5
Relationships:										
Quantitative	3.94	2-5	2.88	1-5	2.94	1-4	3.67	2-5	4.33	2-5
Qualitative	3.50	1-5	2.71	1-4	3.44	2-5	3.44	1-5	3.94	1-5
Other	2.86	1-5	2.50	1-4	2.80	2-4	3.29	2-5	3.29	2-5
Housing:										
Quantitative	3.75	2-5	1.81	1-5	4.50	2-5	3.13	1-5	3.88	3-5
Qualitative	3.64	1-5	2.00	1-4	4.21	2-5	2.79	1-4	4.36	2-5

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Other	3.00	1-5	3.00	1-5	4.00	3-5	3.38	2-4	3.88	3-5
Work & Money:										
Quantitative	3.30	2-4	2.27	1-5	3.30	2-5	3.00	1-4	2.70	2-4
Qualitative	3.44	2-5	2.93	1-5	3.50	2-5	3.21	1-4	3.81	2-5
Other	3.40	2-5	2.57	1-3	3.80	3-5	3.70	2-5	3.40	2-5
Community:										
Quantitative	4.24	2-5	2.41	1-4	4.17	2-5	3.17	1-5	3.78	2-5
Qualitative	3.13	1-5	2.63	1-5	3.83	3-5	3.00	1-5	3.88	2-5
Other	2.60	1-4	4.00	3-5	3.20	1-5	3.17	1-5	4.25	3-5

Appendix C

Validation tool and results

Questionnaire about research priorities for Learning Disability in the next 10 years

For each question, please enter in the second column your assessment of how important it is that this research is done.

In thinking about your response, it would be helpful if you bear in mind the mission and agenda of your organisation. Would research in these areas fit your agenda?

5 = yes definitely

4 = yes probably

3 = could be, but not sure

2 = don't think so

1 = definitely not

There are 6 main topics which have been identified as priority areas. They are colour-coded below, and are (in no particular order):

Support workers, Community Inclusion, Housing, Work and Money, Health and Relationships.

These are split into different sub-themes. We would like your opinion on the main headings (in bold).

Under each heading, we have also included specific research questions that were suggested by stakeholders during our consultation. Please feel free to give us your opinion on those as well, and to mention any other areas you feel have been left out.

Please remember that we are trying to focus on what would be useful for *research*. Many other issues were discussed during our consultation, where we have found there is already a good body of research. There are also many issues on which progress is needed, but not necessarily research.

Thank you very much for taking the time to support this study. We hope it will be helpful to people with learning disabilities.

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Results of questionnaire, showing mean grade given to each research question and comments made by those who returned the questionnaire.

Support workers		
Is it a priority for us to have more research on frontline support workers for people with learning disabilities?	4	Important area overall but not these specific questions. What range of roles are people being asked to do?
1. Individual Budgets (IB). Do we need more research about support worker roles in the shift to IB?	4 .3	Need to be specific is this about people with IB.
a) Do we need more <i>hard evidence</i> about this topic?	4 .3	
What is the staff turnover in 1-1 support?	3.3	
How widespread is abuse of people with learning disabilities by individual support workers?	3.6	
b) Do we need to know <i>how to improve things</i> for people with learning disabilities using individual budgets?	4 .3	

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How do people with learning disabilities tell us what they want from their personal assistants or support staff?	3.6	<p>Including individuals who cannot communicate with words.</p> <p>How do we evaluate the performance standards</p>
How do we monitor support staff under IB, and ensure that performance standards are high?	4.6	
c) Do we need more <i>basic understanding</i> which will help develop good support using IB?	4.3	Fair idea of <i>what</i> skills needed – difficulty is making it happen. (This comment applies to whole of Q.2)
What is the balance between creativity and keeping people with learning disabilities safe?	4.3	We need people with learning disabilities and families to tell us what is good support, what attitudes, knowledge and skills people need to provide good support.
How do we stop staff from working ‘defensively’ and help them move on from the learning disability culture?	4.3	
2. Skills of support staff Do we need more research about the skills needed by frontline workers?	4	

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		A new approach and understanding of safeguarding, risk and protecting issues need to be developed to go with the growth of IB.
a) Do we need more evidence about this topic?	3.3	
How many support workers are supporting people to find employment?	3.6	
Who gets advocacy?	3	We need to look at the skills/networking for supporting into local communities i.e. community connecting
How many family and friends are being paid to support people in the community?	3	
b) Do we need to know how to improve the skills of frontline workers?	4	Suggested:
How do we train staff to be 'person-centred'?	3	How to help support workers to support people to find work?
How do we improve links between staff and family carers? How can support staff learn from carers?	3.3	How to change culture and behaviour?
Does support worker training teach supporters how to help people with learning disabilities make a choice?	4	Who trains, mentors and supports staff?
How can more people with learning disabilities teach their	4.5	It is important to look both a support worker, and also the wider workforce issue

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own staff?		e.g. the role and influence of leadership and management, organisational culture etc.
c) Do we need more basic understanding about staff support skills?	3.6	
What exactly is 'culturally specific' support? Understanding different cultures?	4.5	Including communication for those who do not use words. Little work done on this.
How are power imbalances played out, when support staff communicate with people with learning disabilities in different settings (their own home; residential homes; in the community)?	4	
Can we understand the processes by which people with learning disabilities are valued?	4	
3. Stress and support needs of staff Do we need more research that focuses on the motivation, stress or support needs of support staff?	3	
a) Do we need more evidence about this topic?	2.6	See comments against Q.2 above
How is the support worker job seen in terms of status and in financial terms?	4	
b) Do we need to know how to improve the motivation or support systems of frontline workers?	3.6	
		Again need to focus on supervision,

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		training, leadership, organisational culture etc.
What support is needed by staff, in order to reduce stress?	2.3	
c) Is there anything we need to understand better, in order to support frontline staff?	3.3	
Is it demeaning to people with learning disabilities to talk about staff stress and burnout?	4.5	Need to look at increasing stresses and accountabilities of working on own.
Could we empower frontline staff, by including them as partners in research and policy	4.5	Yes, very important.
4. People with high support needs Do we need more research about supporting people with profound and multiple learning disabilities (PMLD)?	4	Research into how people with profound multiple learning disabilities can be supported to keep themselves safe and develop positive personal strategies to do so.
a) Do we need more <i>evidence</i> about this topic?	4	
What is the role of community teams in supporting people with PMLD?	3.5	

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b) Do we need to find out how to improve support for people with PMLD?	4	
Do staff learn better on the job, or on training days?	3.5	
c) Do we need to understand better the support needed by people with high support needs?	3.6	Need to explore whole range of learning opportunities and their value to improving outcome for people e.g. peer support, coaching, mentoring, learning from families, training days, qualifications.
How can staff interact successfully with people who do not use words?	3.5	
Organisations Do we need more research about organising support for people with learning disabilities?	5	Need to look at existing and new emerging organisations.
a) Do we need more <i>evidence</i> about this topic?	4.3	
Are managers still controlling budgets for care?	4.5	This is very important in this period of change.
b) Do we need to find out how to improve organisations?	3.6	
How do we change organisational culture? (Finding good examples and learning from them)	4.5	

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c) Is there anything we need to understand better about organisations?	4	Needs to link to an understanding of what is “good” support and what is “poor” support.
What are the differences between ‘good’ and ‘bad’ organisations?	4.5	
What makes organisations change?	3.5	

Community Inclusion	Comments	
Is it a priority for us to have more research on people with learning disabilities being included in their local communities?	4.5	Need to look at examples of good community inclusion and when people feel safe and included as well. (BILD)
1. Hate crime	3.6	
Do we need more research about bullying and hate crime?		
a) Do we need more <i>evidence</i> about this topic?	3.5	
How widespread is hate crime against people with learning disabilities?	3.5	
What effect does bullying or hate crime have on people with learning disabilities?	4	There are a number of very positive local community initiatives about hate crime, often involving people with learning

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b) Do we need to find out how to combat bullying and hate crime?	4.6	disabilities, advocacy groups, and local police/authorities. These should be drawn together. (BILD)
How could the criminal justice system be adapted to help people with learning disabilities get a fair deal?	5	
How can we improve support for people going to court?	4.5	
c) Are there things we need to understand better about bullying and hate crime?	3.6	whether there is a link with the tightening of eligibility criteria for services/support, and the increasing vulnerability of people who are too "able" for support but are victims of "hate crime". (BILD) Need to understand why it happens. (FPLD)
2. People outside the Learning Disability world Do we need more research about communities taking responsibility?	3.5	Our Build for the Future Group have already provided some anecdotal evidence (BILD)
a) Do we need more <i>evidence</i> about this topic?	3.3	

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What puts people with learning disabilities off using ordinary services? (what are the barriers – accessibility, fear, etc.)	4.5	Needs to explore impact of people with learning disabilities training and telling their stories in schools. (BILD)
b) Do we need to find out how to improve community responsibility?	4.3	
How can we improve awareness of learning disability in mainstream education?	4	
What do people with learning disabilities want from a sexual health service (or other non-specialist services)?	3.5	
c) Are there things we need to understand better about communities and responsibility?	3.3	
What do we mean by ‘community’?	3.5	
What is the relationship between specialist and non-specialist services?	3	

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How does the law apply to the barriers people with learning disabilities face?	2.5	(BILD) Use of Disability Equality legislation.
3. Citizenship	3.5	
Do we need more research about the contributions of people with learning disabilities to society?		
a) Do we need more <i>evidence</i> about this topic?	3	
How many self-advocacy groups have struggled or closed down, and what is the effect on the members?	5	(BILD) Purpose of self advocacy Need to understand funding streams, role of local leadership etc.
b) Do we need to find out how to improve opportunities for people with learning disabilities to contribute to society?	4	Need to look at role of local commissioners in funding advocacy services.
How can we ensure people have good support groups and self-advocacy groups?	5	Clarity of purpose of self advocacy groups issue about "closed" groups and how young people are being supported.
c) Are there things we need to understand better about people with learning disabilities as citizens?	4	Need to know more about what it would take for people with learning disabilities to

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		be seen by others as equal citizens. (FPLD)
What do people with learning disabilities contribute to each other?	4	Not clear enough question (BILD).
What might it take to enable people to simply make contributions to society? And what counts as a contribution?	3.5	
4. Going out Do we need more research about opportunities for people with learning disabilities to go out?	3.5	Our work with TQN and BFTF group indicates this is a really important topic for people with learning disabilities. (BILD)
a) Do we need more <i>evidence</i> about this topic?	2.6	People face many barriers. (BILD)
How many people with high support needs do 'ordinary' things?	3	Very important to people. (BILD)
b) Do we need to find out how to improve the opportunities for people with learning disabilities to go out?	3.3	
How can we make leisure services more accessible?	3.5	Need to look at growth in training and learning in relation to community
What do staff in leisure centres, pubs, cafes, etc need to know about learning disability?	3.5	

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What do people with learning disabilities need to know about leisure centres, pubs, cafes, etc?	3.5	connections. Could follow up emerging evidence for IB pilots about increased community access by people with IB. (BILD)
c) Are there things we need to understand better about opportunities to go out in the community?	3	
What does it mean to think 'outside the Learning Disability box'? What are the differences in culture?	3.5	

Housing	Comments	
Is housing for people with learning disabilities a research priority?	3	Not a topic BILD has traditionally specialised in.
1. Housing options Do we need more research about options for actual houses and flats for people with learning disabilities?	2.5	
a) Do we need more <i>evidence</i> about this topic?	2.6	
How much home ownership is there by people with learning disabilities (compared with non learning disabled people)?	3	Much more about indentifying options and initiatives.

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How many people with learning disabilities move area? What are the patterns and the obstacles?	4	And sharing good practice.
What experiences do people have of living in certain neighbourhoods (comparing rough areas with better areas, for instance)?	3.5	
What have local authority housing departments done, to include the needs of people with learning disabilities?	4	
b) Do we need to find out how to get better housing options for people with learning disabilities?	3.6	
How do we support people to have a real choice about where they live?	3.5	
How can people with learning disabilities be included in developing local housing strategies?	3.5	Need to look at skills and knowledge of specialist housing brokers who can give accurate advice and support on housing options.
What works well in housing options across different areas? What makes these things work well?	3.5	
		Wider knowledge re

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c) Is there any basic understanding we still need to develop on housing options?	3.3	funding/benefits/ownership options.
2. Models of housing and support Do we need more research about models of housing and support?	3.5	Need to identify and disseminate good practice. (BILD)
a) Do we need more <i>evidence</i> about this topic?	3	
What are the levels of support received by people In 'supported living'?	1.6	
b) Do we need to find out how to make models of housing and support better?	3.6	
How can we develop places for people to learn independence skills?	1.6	
c) Are there things we need to understand better about models of housing and support?	2.6	Not just levels but quality of the support. (BILD)
		People learn best insitu where they need to use the skills. (BILD) Need better dissemination of good practice, e.g. assistive technology (FPLD)
		Yes, especially emerging models e.g. shared ownership.(BILD)

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What went wrong with supported living? (Understanding the processes of how organisations have interpreted supported living, and learning from those lessons)	3	But focus on good practice as well. BILD)
3. Families and housing Do we need more research about housing in relation to families of people with learning disabilities?	2.5	
a) Do we need more <i>evidence</i> about this topic?	2.3	Need better dissemination of information to families. (FPLD)
What is the experience of people with learning disabilities who live near their families?	2.5	
What is the role of families in the decision about whether to move out of the family home (compared with non disabled people)?	2.5	
Do we need to find out more about how to improve the links between families and housing?	2.6	
How can housing support services learn from families?	3	
c) Are there things we need to understand better about housing and families?	2.6	Need to look at options for people who have individual budgets.

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4. Housing and people with high support needs	3.6	<p>What is the link between cost and quality? How is the commissioning guidance influencing out of area placements? Specific work on individuals who have mental health needs.</p>
Do we need more research about people with high support needs and housing?		
a) Do we need more <i>evidence</i> about this topic?	3.6	
What housing choices do people who use wheelchairs have presently?	3	
What are the costs of out-of-area placements?	3.5	
How many people with learning disabilities are in prison or high secure units?	5	
What are the effects of living with other people who have high support needs? And what are the effects of living individually	3.5	
b) Do we need to find out more about how to provide good housing for people with high support needs?	4	
How do we provide more accessible housing?	3.5	
What would it take for people with high support needs to have supported living options?	3.5	

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		Mansell Report addresses this – the key issue is to gather evidence that focuses on people’s life experiences in different housing options.
c) Are there things we need to understand better about housing for people with PMLD?	3.6	
Why do people with high support needs have to live with others who have the same needs?	2.6	
Are out of area placements a contravention of human rights?	4	

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b) Do we need to find out how to get more paid jobs for people with learning disabilities?	4	Need to look at good practice examples people in employment of their choice. (BILD)
How could job centres serve people with learning disabilities better?	4	
How effective is 'job carving', and how can it be sold to employers?	4	
How do we get more information out about Access to work?	4.5	
c) Is there any basic understanding we need about paid jobs and people with learning disabilities?	3.5	Need to know more about how to change assumptions about work from early childhood, so that people grow up expecting to work. (FPLD)
How can we understand what would give incentives to employers to employ people with learning disabilities?	3.5	
2. Benefits and personal finance	4	Need to address the benefits "glass ceiling". (BILD)
Do we need more research about benefits and personal finance?		
Do we need more evidence about this topic?		
		Issues around capacity and financial planning/provision. (BILD)

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c) Is there any basic understanding we still need to develop about personal finances and benefits?	3.5	
How can we change the system to make part-time work possible for people on benefits?	4	
3. Vocational learning and progression Do we need more research about vocational learning?	4.5	<p>Find good examples via BILD networks.</p> <p>See comment on page 19 – need to think about this as ‘life journeys’. (FPLD)</p>
d) Do we need more <i>evidence</i> about this topic?	4	
What are FE colleges doing to find jobs and work with employers? Finding good examples and sharing them.	4	
How many people go on to get real paid jobs, after voluntary work placements?	4	
e) Do we need to find out how to get better at providing vocational learning and progression?	3	

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Does voluntary work open up real job opportunities?	3	
How do we develop career progression for people with learning disabilities?	3	
f) Is there any basic understanding we still need to develop about learning and progression?	3	
What kind of learning really helps people get jobs?	3.5	
4. Meaningful lives Do we need more research about meaningful lives for all people with learning disabilities?	4	Important issue but no need for more research. (FPLD)
a) Do we need more <i>evidence</i> about this topic?	3.3	
How socially isolated are people with learning disabilities in their day activities or at work?	3	
b) Do we need to find out how to make sure all people with learning disabilities have meaningful activities in their lives?	3.3	

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		Explore community asset building and what are the skills/attributes that support workers/community enablers require. (BILD)
What roles do support workers or community enablers have, and are they effective?	4	
c) Is there any basic understanding we still need to develop about meaningful lives?	3.3	
What is 'real' work? Is work for everyone?	4	

Health	Comments	
Is it a priority for us to have more research about health and people with learning disabilities?	4.5	In light of Death by Indifference, and Healthcare Commission audit, this remains a priority. (BILD)
1. Access to Health Services Do we need more research about the experience of general health services by people with learning disabilities?	3.5	
		Evidence needed to shift NHS

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a) Do we need more <i>evidence</i> about this topic?	4	<p>practice. (FPLD)</p> <p>Needs to build on information held by HCC and strategic health authorities.</p> <p>Needs to link to VPN policies and Mansell (BILD)</p> <p>Lots of evidence about 'how' – need to make it happen. (FPLD)</p>
What is the variation in the experience of people with learning disabilities of health services in different geographical areas?	3.5	
Are there NHS services which are being denied to people with learning disabilities (e.g. certain treatments, operations etc.)?	4	
What is the extent of 'specialist' solutions to health problems? (e.g. how many people with learning disabilities get 'stuck' in NHS services? How many people get sent away out-of-area?)	3.5	
b) Do we need to know <i>how to improve things</i> for people with learning disabilities in general health services?	4	
What are the critical components needed to ensure that people can get a local service (e.g. availability of expertise, outreach services, support etc)?	4	
		Provide information on routine

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How do we improve take –up rates of routine examinations (like smear tests) by people with learning disabilities, and do they help?	4.5	examinations. (BILD) Need to explore role of support workers and families in facilitating access to services.)BILD)
How do specific initiatives by GP practices to include people with learning disabilities work? Do funded initiatives have better outcomes?	4	
How can we work with practice managers and receptionists to improve the experience of people with learning disabilities at GP surgeries?	4	
How can we improve access to dental services for people with learning disabilities?	4	
How can we improve both emergency and planned admissions?	4	
What are the best information strategies, to ensure good services? (e.g. appointment reminders, using pictures and audio)	4	

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How can social care work better with health services, when someone with learning disabilities is ill?	4	
How much training for medical professionals has been (and can be) run by people with learning disabilities?	3	<p>Link to work of Mark Bradley at DoH, seconded to VPST, as joint project lead for promoting equality in mainstream NHS services for people with learning disabilities. They are looking at ways to increase the capacity of self advocacy groups to run training for NHS staff.</p> <p>Need to link to delivery of training for people with learning disabilities. (BILD)</p>
c) Do we need more <i>basic understanding</i> which will help access to general health services?	3.5	
What are the communication strategies needed by medical professionals working with people with learning disabilities?	4	
How can medical professionals empower people to make their own health decisions? Will the Mental Capacity Act help?	4	
What knowledge do consultants and staff in acute services need about Learning Disability?	4	
2. PMLD Do we need research about the health needs of people who have	4.5	

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profound learning disabilities and/or are dependent on technology?		
a) Do we need more <i>evidence</i> about this topic?	4.3	
What are the gaps in the health care system for people with profound and complex needs?	4.5	
What support is there for parents and carers of these people?	3.5	
b) Do we need to know <i>how to improve things</i> for people with profound learning disabilities?	4	
How can adult services get prepared for the increase in adults with complex and profound needs?	3.5	
c) Do we need more <i>basic understanding</i> about the needs of people with profound learning disabilities who may be dependent on technology?	4	
3. Health inequalities Do we need more research about inequalities in health outcomes for people with learning disabilities?	3.6	

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a) Do we need more <i>evidence</i> about this topic?	3	Need dissemination. (FPLD)
What are the mortality rates of people with LD, compared with the non-disabled population?	4	
To what extent have people with learning disabilities benefited from national plans, such as the NSF's?	4	
What are the health risks for people with learning disabilities in the criminal justice system?	4	
What are the health risks for carers?	4	
b) Do we need to know more about how to <i>improve</i> things in the health outcomes for people with learning disabilities?	3.6	How can they be developed uniformly across the country. (BILD)
What is working well in Health Action Plans, and how can we make them more effective?	3.5	
c) Do we need more <i>basic understanding</i> about health outcomes for people with learning disabilities?	3	
What are the mechanisms which explain unequal health outcomes?	3.5	

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4. Public Health	3	
Do we need more research about public health, as it relates to people with learning disabilities?		
a) Do we need more <i>evidence</i> about this topic?	3.3	
What is the relationship between socio-economic differences and the health of people with learning disabilities?	3	
What are the health risks of independent living?	3.5	
a) Do we need to know how to <i>improve</i> things for people with learning disabilities?	4	
What are the barriers faced by people with learning disabilities in getting more exercise?	3.5	
c) Do we need more <i>basic understanding</i> of public health in relation to people with learning disabilities?	3.3	
What causes people with particular syndromes (e.g. Prader-Willi Syndrome) to become obese?	3.5	

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Relationships	Comments	
<p>Is it a priority for us to have more research about relationships and people with learning disabilities?</p>	4	<p>Need to look at divergence in teen years. The change to being seen as 'other'. (FPLD)</p> <p>BILD work with TQN indicates this is very important topic for people with learning disabilities.</p> <p>This is a key issue for our advisory group, Build for the Future.</p>
<p>1. Friendships Do we need more research about friendships?</p>	2.6	
<p>a) Do we need more <i>evidence</i> about this topic?</p>	3	
<p>What is the variation in opportunities for socialising in different areas?</p>	2.5	
<p>To what extent are people with learning disabilities socially isolated (in their work; in independent living), especially after closure of day centres?</p>	3.5	

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Do people with learning disabilities have opportunities to go on holiday with friends?	3	
b) Do we need to find out how to improve opportunities for friendships?	4	
What practical help do people with learning disabilities need to keep in touch with old friends?	3	<p>Not just through meeting up but utilising online, for e.g. webcams.</p> <p>Issues about assertiveness in relationships especially for women.</p> <p>How do people develop and sustain friendships?</p>
What are the dangers (and possible safeguards) in friendship groups?	3	
How can people meet and make friends, when day centres have closed?	3.5	
c) Is there any basic understanding we still need to develop about friendships?	4	
2. Parenting and caring	5	
Do we need more research about parents and carers with learning		

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disabilities?		Not a topic BILD has worked on in any detail.
a) Do we need more <i>evidence</i> about this topic?	4.5	
What is the experience of children of parents with learning disabilities? (e.g. do they get bullied at school?)	4.5	About outcomes for children. (FPLD)
What is the experience of children who've been removed from their family (compared with children who remain in the family)?	4.5	
Is it cheaper to keep children with their own parents with learning disabilities, with support, or to separate them?	4.5	
Do parents with LD from different cultural backgrounds have the same problems? Is the rate of removal of children the same? If not, what is it that works for them?	4.5	
How many people with learning disabilities are family carers? Do these people get recognition and support?	5	
b) Do we need to find out how to get better at supporting parents with learning disabilities?	3.6	

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What do parents with learning disabilities actually do in parenting groups? Is it useful?	3.5	
How do we provide better long-term support to parents with learning disabilities?	4	
How good is the liaison between children's and adult services in terms of parenting?	3.5	
c) Is there any basic understanding we still need to develop on parents with learning disabilities?	4	
Can we understand better society's attitudes towards people with learning disabilities forming relationships? (Social workers, parents, teachers, judges, managers, midwives)	4	
3. Emotional life Do we need more research about people's emotional lives?	3.6	This is a major issue for people with learning disabilities.
a) Do we need more <i>evidence</i> about this topic?	3.6	
b) Do we need to find out how to help people get better emotional lives?	4	

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		And how expectations of people with learning disabilities in relation to the outcomes of their relationship. (BILD)
How can we reflect the importance of relationships in policy?	4.5	
How can we protect people from abusive relationships?	4.5	
How can support staff realise the importance of emotional support and facilitating relationships?	4	
Is there any basic understanding we still need to develop on the emotional life of people with learning disabilities?	4	
Can 'services' make people happier?	4	
Can people with learning disabilities get stronger by identifying as people with learning disabilities?	4	

Disclaimer

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Addendum

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