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**Contact Details**: Dr Carol Lupton, RDD, Wellington House, Waterloo Road SE1 8UG. 020 7972 1451

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Valuing People and Research: The Learning Disability Research Initiative

Overview Report

Gordon Grant
Centre for Health and Social Care Research, Sheffield Hallam University, UK

and

Paul Ramcharan
Royal Melbourne Institute of Technology, Melbourne, Australia

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Acknowledgements

This overview report is based on the work of nearly 50 researchers involved in 13 studies constituting the Learning Disability Research Initiative (LDRI). The LDRI studies were commissioned by the Department of Health under the Policy Research Programme to inform the implementation and development of Valuing People. The studies were commissioned between 2001 and 2003, with the final study completing in 2007.

We thank the Department of Health for commissioning the LDRI studies and all the research teams for bringing their expertise and energy to the research programme. Though the teams have acknowledged the countless service users, personal supporters, families, staff, managers, commissioners and other stakeholders in their individual reports, we add our own thanks to them for making their experiences and insights available to the research studies. We hope that the findings from each of the studies and from this report provide insights about how to bring about better lives for people with learning disabilities and their families.

Dr Carolyn Davies and subsequently Dr Carol Lupton managed the LDRI at the Department of Health and we thank them both for the constancy of their support and direction. In this task they were ably supported by managers who provided guidance and help to us at different times, so we express additional thanks to Ruth Chadwick, Annette Boaz and Sharmila Kaduskar.

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Finally, as academic co-ordinators of the LDRI, we would like to thank Joanne Clarkson, who provided us with administrative support when we were both based at the University of Sheffield, and Margaret Flynn and Alex McClimens, who offered advice on this document. Finally, we acknowledge the support that Sheffield Hallam University and Royal Melbourne Institute of Technology, our employers when we completed this report, have given us.

Gordon Grant
Paul Ramcharan
Foreword

When Valuing People was published in 2001 it was the first major government policy statement about learning disabilities for thirty years it set out a cross-government approach to jobs, housing, and education as well as health and social care. It articulated a vision for people with learning disabilities as, first and foremost, citizens active within society and with rights to have choice and control over their lives.

Government policy in the years since Valuing People was published has taken further the agenda of independent living and personalisation for people who have need of some support in their daily living. “Independence, Well-being and Choice” and the White Paper “Our Health, Our Care, Our Say”, and the cross-government “Improving the Life Chances of Disabled People” together set out a comprehensive strategy which aims to put people using services, their families and carers firmly at the centre of their care, assessing their own needs, having real choice as to how these needs are met, and having access to the full range of universal public services.

This report of the Learning Disability Research Initiative pulls together a very substantial body of research which shows changes in practice and outcomes following on from Valuing People, and also highlights gaps and challenges to delivering the strategy. In so doing, this research programme makes a tremendously important contribution to policy and practice development and will be particularly valuable to work to refresh the Valuing People strategy and take forward the next steps needed to deliver the vision.

As this report demonstrates, Valuing People has already had a substantial impact on the lives of people with learning disabilities. But it also shows that there is still much to be done, especially in reaching those people less able to speak for themselves. Our task now is to continue this transformation of people’s lives so that people with learning disabilities can play a full part as citizens, gaining more choice and control over their lives.

David Behan
Director General for Social Care, Local Government and Care Partnerships
Executive summary

Introduction

The report aims to synthesise and weigh the outcomes of the LDRI by evaluating the evidence for its contributions to policy and also, importantly, to emergent practice related to the inclusive research agenda. In linking the findings of the LDRI studies to wider literature, the report can also be seen as bringing together contributions to academic and practice knowledge.

Part 1 of the report (Chapters 1 and 2) outlines Valuing People’s ambitions and how the LDRI studies map on to the central principles of rights, choice, independence and inclusion. The genesis of the LDRI as an inclusive research programme is described, and the aims, scope and methods of the LDRI studies are briefly outlined.

The main contributions of the LDRI studies to the implementation and development of Valuing People are described in Part 2 in relation to the White Paper’s four principles (Chapters 3–6). Part 3 of the report is devoted to assessing the wider contributions of the research: to Our Health, Our Care, Our Say (Department of Health 2006) in Chapter 7; to the inclusive research agenda in Chapter 8; and to future directions for research and development in Chapter 9.

Main findings, policy and practice messages

Rights and risk (Chapter 3)

The LDRI studies provide evidence about the growth of advocacy, particularly self-advocacy, and the increased opportunities for people with learning disabilities to participate in Local, Regional and National Forums where decisions are being made about them.

Away from participatory forums, however, there remain issues about the ‘visibility’ of many people with learning disabilities, especially those least able to speak for themselves. Front-line staff were aware of and concerned about many people with learning disabilities whom they considered to be unaware of their rights. Complaints procedures were considered to be a weak means of securing redress, and many of their operational features were unsatisfactory. There was not an ‘equality of arms’ between people with learning disabilities and non-disabled citizens in the establishment of equal outcomes from Articles of the Human Rights Act. Organisations were not fully compliant with the Human Rights Act.

At the interpersonal level some consultative styles were far from helpful in securing choice and informed consent for important treatments linked to the sexual health of women. In this respect GPs were found to adopt ‘conservative’ treatments that were atypical of what most women of a similar age would normally expect.
Health Action Planning and health facilitation were as yet insufficiently rolled out to make a significant difference to improved healthcare. Some people with learning disabilities were still not registered with GPs, while some GP practices were resistant to developing separate registers of people with learning disabilities. People with learning disabilities themselves were of the view that determinants of health, such as employment, housing and educational opportunities, were not always explored in their Health Action Plans.

As well as dealing with trying to establish rights, it is also necessary to deal with infringements of people’s fundamental human rights. In this respect it was shown that group cognitive behavioural therapy worked for a good proportion of men with learning disabilities at risk of sexual offending, helping them to be more knowledgeable about sexuality issues, more empathic and better able to discriminate between abusive and non-abusive sexual practices.

Research on symptoms of abuse showed how warning signs of abuse among people with high support needs included diagnostic criteria relating to post-traumatic stress and how, by observing changes in behaviour, it was possible to become aware that something was wrong in their lives. However, the research also found that therapy and counselling were not readily available and that evidence taking by the criminal justice system needs further development. Families of people who have suffered abuse are neglected, despite themselves experiencing trauma and self-blame. As a consequence many families in these circumstances remain mistrustful of services.

People with learning disabilities have not thus far had an opportunity to influence the design of integrated databases that can highlight inequalities in their lives.

A number of policy and practice messages follow:

*Promoting a culture of rights*

- issue further guidance on making organisations fully compliant with the Human Rights Act;
- invest in training and educational packages for the police, the criminal justice system and primary care teams to enhance redundant interviewing, evidence taking and consultation with people with learning disabilities;
- work on ways to maximise the visibility of infringements and to establish ‘equality of arms’ with the general population, so that people with learning disabilities secure levels of protection that guarantee outcomes enjoyed by other citizens with respect to freedom from abuse and neglect;
• continue to support the development of advocacy and ways of making complaints systems and rights more accessible in everyday services and life settings;

• seek to make the criminal justice system more accessible and supportive to people with learning disabilities when they appear as witnesses;

• in linking rights to outcomes, involve people with learning disabilities and their families in setting the outcome agenda for evaluating services in ways that help to address inequalities;

Protecting people from unwarranted risks and abuses

• make it easier for staff witnesses to come forward and report abuse;

• examine in more detail why it seems acceptable to some staff members to commit abuse against people with severe or profound learning disabilities;

• consider the role of unannounced inspection visits in services, with greater responsiveness to the concerns of loved ones, relatives and others who know a person well;

• give priority to staff training about abuse symptom recognition and post-incident reporting and management;

• consider the best ways to communicate information for families and carers about symptoms of abuse;

• improve the distribution and availability of counselling and support services for people with learning disabilities who have been abused, and for family carers who inevitably experience corresponding trauma;

• prioritise work with self-advocates and advocates around issues of abuse, and involve people who use services in evaluating them and making judgements about their quality;

• adopt cognitive behavioural therapy as one proven approach in working with men with learning disabilities at risk of sexual offending;

• extend knowledge around sexuality and relationships for all people with learning disabilities in line with expectations for the population as a whole;

• in organising to provide better support for sexual health, it is important to explore the scope for longer GP consultations, extensions to the role of family planning services, locally enhanced GP practices with specialist knowledge and the rolling out of Health Action Plans.
Comment

Promoting individual rights and protecting people from unwarranted risks and abuse requires a difficult balance between personal freedoms and scrutiny by functionaries of the State. Systems of ‘concerned vigilance’ are required to protect those citizens who are least visible and least able to speak for themselves. Systemic factors that infringe the everyday rights of people with learning disabilities, and indeed assaults upon them, are pervasive and need to be tackled. This is likely to be a priority task for the new Equality and Human Rights Commission.

Choice (Chapter 4)

Progress towards better choice making was evidenced through development of person-centred planning and health facilitation where implemented, involvement in the planning and governance of services, aided by development of advocacy and accessible information. However, there were ‘winners and losers’ in the present policy context.

Those less likely to gain access to person-centred planning included people with mental health or emotional or behavioural problems, people with autism, and those with other health problems or with restricted mobility. Organisational culture, values and commitment were important preconditions for the delivery of person-centred planning. However, outcomes were also shaped by investment in structures and resources, the evidence confirming that person-centred planning alone cannot universally deliver what people with learning disabilities need and want. Further, Direct Payments (not a subject of study in the LDRI) are least likely to touch those still not accessing person-centred planning, suggesting layers of inequality.

It was shown that person-centred planning, health facilitation, Health Action Planning and care management were insufficiently linked, leaving people with less than seamless support. Potential synergies deriving from such linkages were not sufficiently in evidence at this early implementation stage of Valuing People.

In terms of the experience of healthcare, people with learning disabilities and family carers were still struggling to understand what health facilitation and Health Action Planning were meant to accomplish. Lack of choices found in relation to the sexual health of women, perhaps one of the most personal of health needs, acted as a litmus test of the extent to which the freeing of the personal systems of control are required to help people understand that they have wider control over all their healthcare choices as implied in the Health Action Planning framework.

The production of guidance by one of the LDRI studies about easy-read or accessible information for people with learning disabilities
shows how different media can be put to good use in helping people to make choices and decisions. Easy-read information is likely to work best when those receiving such information are involved in its production, and where support workers, allies or family members are involved in supporting its delivery.

Policy and practice messages linked to the above are as follows:

- more work is required to develop systems that can support population-based data, linked to aspirations expressed in person-centred plans. Through this means, individual choice making has the potential to shape strategic thinking;

- mechanisms for more meaningfully involving people with learning disabilities in the Partnership Board processes are required, so that there is a more demonstrable connection between their involvement and outcomes;

- easy-read guidelines, produced in consultation with people with learning disabilities, have the potential to assist choice making. The guidelines now need to be tested in everyday practice;

- easy-read information is no substitute for valued interpersonal relationships as conduits for information sharing;

- direct Payments may offer a better option for developing services in ways that respond to consumer choice and demand. Partnership Boards and brokerage organisations will need to develop skills in responding to consumer demand, rather than merely managing the market.
Comment

Considerable progress has been made in setting the conditions that enable better choice-making by people with learning disabilities. These conditions were not as available to people from certain disadvantaged groups. A clearer distinction needs to be made between choice making per se and the things in life over which people wish to maintain control in order to sustain their sense of identity and personhood.

Independence (Chapter 5)

Progress in meeting some of the anticipated Valuing People milestones affected the implementation of person-centred planning and had knock-on effects in the realisation of goals for independence and inclusion.

Existing national and local datasets focus too much on service inputs and processes rather than on user-referenced outcomes that measure change in people’s life experiences. This militates against a culture where independence and inclusion are key ambitions to be monitored and evaluated in routine practice. In developing measures of outcome it is vital to involve people with learning disabilities and their families.

Structural factors were preventing more people from being engaged in paid work. These included rules relating to welfare benefits, the practical application of supported employment, employer attitudes, time-limited funding for employment initiatives and lack of knowledge of issues for people with learning disabilities and accessible qualifications for employment officers.

People with learning disabilities are not satisfied with many of the jobs they do, characterising them as task-based, routinised, unskilled and having low levels of autonomy and responsibility. They were looking for opportunities for careers and career advancement.

The emergence of Direct Payments and Individual Budgets were redefining the scope for people with learning disabilities to be commissioners and employers, and as such were creating new contexts in which independence could be expressed.

The role of Partnership Boards in relation to inclusion, whether in day services, employment, housing or other life areas, needs to be re-emphasised and a further strand linking their work to communities needs to be instigated if the co-ordination of service efforts are to lead to more independent lives. The link between person-centred planning, population needs analysis and service provision designed to produce independence are implicated in this respect.
Policy and practice messages arising from the above are as follows:

- policy implementation milestones are useful in holding people to account, but the consequences of failing to meet them can lead to disillusionment among service users and families at the very time when commitment all round is needed;
- confirming earlier guidance, person-centred planning alone does not enable people to achieve independence. Other structures and resources need to be in place;
- person-centred planning and care management were insufficiently linked. This needs to be addressed so as to provide people with seamless support;
- barriers to employment and mainstream housing need to be removed to improve the chances of people realising ambitions for independence;
- systemic factors like the structure of welfare benefits, the structure of the workplace and the disability label were observed to be holding people back from developing their career prospects and experiencing better job satisfaction. These factors need to be addressed. The joint report by the Department for Work and Pensions (DWP) and the Department of Health on work barriers published in 2006 seems to have these factors in sight, as does the work of the Office for Disability Issues;
- supported employment officers who practised according to best theory secured more working hours for their clients. This practice needs to be rolled out;
- the policy emphasis on self-directed care, Direct Payments and Individual Budgets seems likely to change the meaning of employment and productivity for people with learning disabilities. This will have implications for how independence is understood;
- recognition should be given to the fact that the effect on the families of people with learning disabilities who are abused is likely to undermine their ability to provide support that encourages independence: ‘once bitten, twice shy’;
- it is important to establish and publicise a baseline against which to measure achievements over time, and to place a stronger emphasis on outcomes related to the experiences of people with learning disabilities rather than on service inputs;
- national statistics should have the capacity to document potential areas of inequality – between people with learning disabilities and the general population, and within the population of people with learning disabilities;
• a more modern approach to databasing would help to focus on the monitoring of employment outcomes such as career progression, job satisfaction, pay and integration in the workplace.

Comment

Once again systemic factors were observed in a number of the LDRI studies as constraining progress towards independence in people’s lives. Markers of independence such as having a job do not capture what people want to achieve in terms of career progression, job satisfaction and integration in the workplace. Routine monitoring of services needs to be informed by shifts in people’s ambitions and also by new ideas about what independence means for people.

Inclusion (Chapter 6)

Person-centred planning was shown to have beneficial impacts on the ability of people to develop ties with family and friends and to engage some mainstream services. As such, important strides towards social inclusion have been made. This enhancement of what might be termed ‘opportunity structures’ provides a basis from which social capital goals can be consolidated, especially those relating to more enduring, trusting and reciprocal relationships.

Social inclusion achievements were not equally distributed across groups. People with mental health or behavioural problems did not fare well in social inclusion terms. The between-groups inequalities are of concern.

In relation to gaining access to community health services, problems with the supply of health facilitators, Health Action Plans and person-centred plans, and confusions about health facilitation roles were hampering progress. These can all be construed as structural problems. However, interactional issues played a hand in mediating experiences, especially the consultative styles of GPs.

Inclusion in governance has made considerable strides with the unparalleled growth of people with learning disabilities on Partnership Boards. However, the relationship between their presence and decision outcomes is not so clear and is worthy of further investigation.

Young people moving into adulthood are still experiencing losses of friendships during these critical changes in their lives. Many families lacked knowledge of transition plans or reported confusion about the procedures involved. Most were unhappy with transition outcomes. Bridging and bonding social capital opportunities both presented moral conflicts to some South Asian families.

For people in work, environmental and structural factors in the workplace limited prospects for people to be more fully included. The evidence suggests that people want to be able to achieve social capital goals for
themselves to be seen as successful in the workplace.

Policy and practice messages that arise from the above are as follows:

- there has been progress towards inclusion of people in personal networks and community activities, and to a degree in accessing mainstream health services, but there is less certainty about social capital gains. This needs further exploration;

- as with gains related to independence, inclusion was not equally distributed across all people with learning disabilities. The inequalities involved need to be addressed;

- in relation to accessing community health services, problems of supply, style of delivery and even confusion about new roles were hampering progress. Issues about resources, structures and professional education need to be addressed to correct these systemic problems;

- service-user involvement in governance would be helped by publishing stories about how user involvement leads to improved decision-making outcomes and demonstrating what features of ‘joint systems thinking’ facilitate this;

- better implementation of transition planning for young people is needed to improve the quality of placement options and the potential they hold for social inclusion and independence. A clearer focus on the five core outcomes of Every Child Matters (Department for Education and Skills 2003) would help in this regard;

- present strategies for bridging and bonding supportive communities, which might create trusting community relations, are perceived by some Asian families as unacceptable for their sons and daughters when contemplating social inclusion. The dilemmas involved would benefit from further debate with the communities of interest who face them directly;

- core competencies of staff valued by service users emphasise good interpersonal skills and relationships. This needs to be emphasised in recruitment and staff development strategies since it will also add value in relation to the personalisation and social inclusion agendas;

- strategies for promoting acceptance and integration of people with learning disabilities in the workforce need to be developed.

**Comment**

The LDRI studies contribute evidence illustrating factors that can assist steps to inclusion in personal networks, in community activities and in mainstream services. Again, as with independence, there seem to be winners and losers, and again there are systemic factors
holding back further progress. Bridging and bonding with communities based on predefined approaches can present problems for some people from ethnic communities, leading to less than successful strategies for building social capital. Enabling people not only to be part but to feel part of the community by playing active and valued roles will be a long-term commitment, primarily because it requires society to change.

**Wider contributions of the LDRI to policy (Chapter 7)**

The LDRI studies have a considerable amount to say about prevention and early intervention, more choice and voice for service users, tackling of inequalities and the targeting of more support for people with long-term conditions.

The proposals set out in the White Paper *Our Health, Our Care, Our Say* for preventive care will not work unless people with learning disabilities are registered with GPs. Proposals for integrated health and social care records will not succeed unless people with learning disabilities are an integral part of local databases. Current confusions operating in primary care teams about data protection legislation will have to be dealt with. Women with learning disabilities are being denied the range of choices around treatment options, with consequences not being fully explained. This means that self-management and self-care strategies are being undermined, as are choice and self-determination.

Proposals for more choice and a louder voice in the White Paper resonate with the aspirations of *Valuing People*. If choice making was to be equated with person-centred planning, then the LDRI studies suggest that there are likely to be winners and losers, with, on the whole, more vulnerable groups losing out. Proposals for the development of Direct Payments and Individual Budgets seem unlikely to touch those already least likely to benefit from person-centred planning, leading to the development of a fabric of inequity that disenfranchises those least able to speak for themselves.

At present neither advocacy, substitute nor supported decision-making systems are sufficiently well developed to protect those lacking in personal agency. That organisations are not fully compliant with the Human Rights Act further undermines the commitment to choice making. Finally, there was evidence that people with learning disabilities could make stronger contributions in Partnership Boards.

The White Paper seeks to tackle inequalities and improve access to community services. The relative disadvantage of people with learning disabilities compared with the general population was well illustrated by the findings of the first national sample survey of nearly 3,000 adults with learning disabilities (Emerson et al. 2005). The findings show on just about every criterion measure of health, inclusion, personal relationships, personal safety or control how much remains to be accomplished.
for people to enjoy equality of **outcomes** and not just **opportunities**. The LDRI studies also showed how, in particular, issues of personal safety and abuse can remain hidden, with individuals and families suffering in silence for lengthy periods without the supportive services available to meet their needs.

More support for people with long-term needs is another priority identified in the White Paper. The LDRI study findings reinforce the importance of this priority, especially in relation to the creation of an improved awareness of support and treatment options, the desire of people to take more control of their lives, backed by a more integrated system of health and social-care planning, and more support for family carers. This needs to be a life course commitment that embraces and deals with structural and relational impediments throughout people’s lives that allow people with learning disabilities and their families to make contributions to society and to fulfil their potential in a safe and supportive environment.

**User involvement in research (Chapter 8)**

The LDRI was a bold initiative in promoting an inclusive approach to research commissioning and research management. Researchers were invited to think about how they might embrace inclusive principles but were left to gauge how far these were ‘fit for purpose’. A team of people with learning disabilities was expressly commissioned to assess the experiences of the remaining 12 studies in involving people with learning disabilities in the research process. The LMI study describes the findings.

The LDRI has demonstrated that people with learning disabilities can play important roles in **commissioning** research. For the future, challenges are likely to include the following:

- developing standards by which to judge inclusive research proposals;
- customising the support needs of service user research commissioners;
- addressing the ethical issues faced by service user peer reviewers;
- ensuring that service users are involved in the pre-commissioning stages in helping to design research tenders.

In relation to service user involvement in **managing the research programme**, attention should focus on:

- publishing better guidance for research contractors about the requirements and standards for easy-read research proposals and final reports;
- the intellectual, logistical and economic factors involved in producing easy-read research outputs, tied to an appreciation of the rationale and goals of knowledge dissemination and utilisation;
• further exploration and evaluation of the potential for more creative methods of research dissemination through performance arts, and their effects in transforming people’s views and behaviours;

• service user involvement in research governance, which is useful in continuous testing of how emergent evidence is going to benefit the service user community and policy.

The LMI study contributed evidence about the opportunities and challenges of engaging people with learning disabilities in the remaining 12 LDRI studies. It showed that there is a need to think about:

• who funds pre-protocol work undertaken by service users;

• the economic and non-economic costs to service users of becoming involved in research in different roles;

• ethical challenges that can and do arise in inclusive research, so that their effects can be mitigated or their chances of occurring can be avoided altogether;

• the added value of inclusive research, requiring some assessment of different types of knowledge and of standards or frameworks for assessing these different types of knowledge. This is a very challenging agenda, and one upon which much rests;

• a code of good practice for inclusive research, based on a recognition of the different contributions people with learning disabilities are making to research.

Comment

Inclusive research can be looked upon as having reached the end of a first phase in which it has established its credentials in process terms. By this is meant that we now know a considerable amount about how to put it into practice. The second phase is more likely to be concerned with outcomes – what kinds of knowledge are attributable to inclusive research, how knowledge claims of inclusive research can be assessed and authenticated, what the benefits of the experience are to individual service user researchers (individual capital) and to project teams, what forms of partnership make inclusive research effective, and whether good science and good inclusive research practice can be brought together.

Building on the knowledge base (Chapter 9)

In the final chapter some reflections are offered about the LDRI as a research programme, the types and quality of knowledge generated, and how the evidence can be built upon.

It is argued that, as a research programme linked to Valuing People, the LDRI has an internal coherence. Like any programme of research it also has its natural limits – the studies are products of their time; they reflect
varying emphases on processes and outcomes; they demonstrate a mix of cross-sectional and follow-up designs but over restricted timescales; they illustrate some difficulties but also lessons in locating ‘hard-to-reach’ groups; and they show that while coverage of Valuing People’s main objectives was probably good enough, it was less than comprehensive.

Two systems for gauging the quality of knowledge in health and social care research are briefly discussed. When applied to the LDRI studies it was shown that, with the established healthcare research model built on a hierarchy of methods and knowledge, the LDRI studies straddle the ‘mid-range’ of the hierarchy. In the contrasting social care linked taxonomy, the LDRI studies were shown to illustrate a very considerable variety of types and sources of knowledge which remain, for all social care research, difficult to evaluate.

In terms of building on the evidence base, a focus is suggested on research that:

- links the panoply of structural barriers in people’s everyday lives to strategies and policies that can remove them or mitigate their effects on people’s achievement of their personal ambitions;
- continues to evaluate the quality of interactional experiences people face in their everyday lives, since these are central to their experience of social inclusion, control and quality of life;
- builds on baseline measures available from the LDRI studies and the linked national sample survey of people with learning disabilities in order to demonstrate gains in relation to rights and risk, choice making and control, independence and inclusion;
- is capable of demonstrating how the roots of inequalities in relation to access to and outcomes of interventions and support can be tackled;
- can demonstrate social capital as well as social inclusion gains in people’s lives and what makes the difference;
- is informed by a better appreciation of interdependencies between people with learning disabilities, their families and other supportive communities of interest in a shift towards ‘relationship-centred’ support;
- examines the effectiveness of different types of accessible or easy-read information in everyday use, for different people, in different contexts;
- evaluates initiatives required to deal with iatrogenic community health services;
- continues to evaluate ‘joined-up’ services at the individual level across the life course, and also at the local strategic (Partnership Board) level as these experiences are likely to shed light on moves towards the operationalisation of whole-systems thinking;
• continues to evaluate inclusive research strategies, but by moving towards an emphasis on **outcomes**, the types and standards of knowledge generated, the fitness of that knowledge for different audiences and uses, the individual and social capital gains that ensue, and the partnerships that make this work.

*Valuing People* is now six years old. Many of the sweeping changes introduced have been captured by the work of the LDRI study researchers. There has been considerable progress, yet there is still a long way to go to realise the core ambitions for rights, choice, independence and inclusion. It is important to see the present findings as setting the scene for a refreshed *Valuing People* with an agenda of questions to inform continuing development work, monitoring and research.
Introduction

Purpose and status of this report

When *Valuing People* (Department of Health 2001a) was launched in 2001 it was the first White Paper dedicated to people with learning disabilities and their families in England for 30 years. As such it was quickly recognised as a landmark document that was welcomed for the impetus it gave to new ways of working designed to improve the lives of people with learning disabilities and their families. Like other important national policy initiatives it created opportunities to learn lessons from the changes it was seeking to bring about, as well as in relation to the challenging task of putting the policy into practice. In seeking to do this, *Valuing People* committed government funding of £2 million from the Department of Health Policy Research Programme for an associated programme of evaluation research. This programme became known as the Learning Disability Research Initiative (LDRI).

Thirteen LDRI studies were commissioned between 2001 and 2004, the last one of which was completed in 2007.

The names of each of the 13 studies, and the abbreviations that will subsequently be used in this report, are shown below.

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<th>The LDRI studies (and their abbreviated titles)</th>
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Up until the time when the LDRI studies were commissioned, the Department of Health had adopted four broad criteria to judge the suitability and standards of research proposals: scientific rigour, fit with research brief, policy relevance and value for money. To this, therefore, a fifth was added: user involvement. As things turned out the studies were commissioned in three waves. Following the first wave when 10 studies were commissioned, some funding was deliberately held back because it was felt that there were insufficient good-quality proposals in some themed areas. This led to a second call for proposals for projects about setting baselines and performance measures for evaluating Valuing People and also about health facilitation. Two studies were eventually funded dedicated to these themes. Given the commitment to learning lessons about inclusive research, the Department of Health subsequently commissioned a 13th study from a group of people with learning disabilities to assess the experience of service user involvement in the other 12 LDRI studies. This was one of the first truly user-led research studies commissioned by the Department’s Policy Research Programme.

As will be seen, the funded studies represent a very broad portfolio of work. In this, to a large extent they reflect the principal philosophical strands of Valuing People that underlined the central importance of rights, choice making,
independence and inclusion, but even so they do not encapsulate every part of the White Paper.

As with any group of projects linked to a policy initiative, they are also ‘caught in time’. Since the publication of Valuing People in 2001, other significant policy initiatives have emerged dedicated to advancing the modernisation agenda across health and social care, the most notable being the Green Paper Independence, Well-being and Choice (Department of Health 2005) and subsequently Our Health, Our Care, Our Say (Department of Health 2006), which seeks to achieve better preventive strategies through earlier intervention, giving people more choice and control, tackling inequalities and improving access to community services, and finally by providing more support for people with long-term needs. These share some of the central ideas and principles from Valuing People and have further refined or consolidated them. The LDRI projects, therefore, have relevance not only to Valuing People, but also to national policy reforms that have since emerged.

Like any other overview, this report cannot and does not set out to capture every last detailed finding from all of the commissioned studies. For that the interested reader is directed to the main reports of the individual studies, references for which can be found in Appendix 1.

As academic co-ordinators and authors of this report, we take responsibility for any flaws or weaknesses it may contain. The views expressed are ours, not those of the Department of Health or of the research teams. However, we have tried to remain faithful to all of the studies and have aimed to reproduce in these pages what we believe to be the strengths of all the work that has been completed.

**Scope of the report**

Part 1 of the report concerns important contextual details necessary for making sense of this programme of research. In Chapter 1 we describe the policy context and how the LDRI was linked to this. The values, objectives and provisions of Valuing People are outlined, as are links with other policy developments. An account is then given of the genesis of the LDRI, the commissioning process and the arrangements that were subsequently made to establish programme management and co-ordination arrangements. Chapter 2 introduces the LDRI studies and details their aims, scope and methods, and links them with the Valuing People principles of rights, choice, independence and inclusion.

Part 2 of the report seeks to synthesise the findings and main lessons from the LDRI. It weighs evidence from the studies against Valuing People principles and objectives in an attempt to establish where the main
contributions are to the White Paper’s ambitions, to illuminate what has been achieved and to identify where different kinds of challenges remain.

Part 3 of the report examines the wider contributions of the LDRI studies. In Chapter 7 we assess the contributions of the LDRI to Our Health, Our Care, Our Say (Department of Health 2006). Lessons about inclusive research are reviewed in Chapter 8, together with an account of the findings from the LMI study commissioned to assess experiences of user inclusion in the remaining 12 LDRI studies. Finally, building on this programme of research, suggestions are made in Chapter 9 about directions for future learning disability research.

Throughout the report we refer to other bodies of evidence in order to locate where the LDRI studies are making contributions to knowledge. We also draw from findings of the separately commissioned first national sample survey of adults with learning disabilities (Emerson et al. 2005), promised by Valuing People, since this provides a baseline mapping of experiences about what life is like for people with learning disabilities, what support they receive and what they want and need.

For the sake of brevity in the present report, we have kept methodological detail to a minimum and presented boxed summaries of key learning points. We have also elected to produce a companion volume summarising the findings and policy messages from each of the studies (Grant and Ramcharan 2007). These summaries were the result of a collaborative process between the research teams and the academic co-ordinators, and can therefore be read as validated co-constructions.
1 Making sense of the LDRI
Chapter 1: Policy and the LDRI in context

Policy and the emergence of a national strategy

The politics of the new millennium contrast substantially with that of the post-war period. Barely 50 years ago institutional living was at its height. Since then, a succession of pioneer thinkers, seminal research and substantial change in policy frameworks and patterns of service delivery have revolutionised the ways in which we construe ‘best practice’ for people with learning disabilities.

Valuing People was published at an important juncture where a number of ideas were brought together for the first time: the value of diversity had superseded what were innovative models based upon ideas of normal and socially valued lives in the community; recognition of the need to build up services in the community as part of community care policy (Department of Health and Social Security, 1971) had given way to models of individual planning (Blunden 1980) and, subsequently, to person-centred approaches; the centrality of linking the provision of services to a strategic local and national planning framework had been recognised from the earlier Welsh Strategy (Felce et al. 1998); the emergence of advocacy alongside a rights-based agenda had built in a system of accountability to people with learning disabilities unprecedented in the past and supported by legislation; and the importance not only of services but of inclusion in all areas of life, including the community, education, leisure and employment, had become central to testing the potential of community care to deliver a quality life for people with learning disabilities and for their family carers.

Valuing People sought to bring these ideas into reality. It was the first English national strategy for people with learning disabilities for over 30 years and, potentially, opened an important new era in developing better lives for them. How then did Valuing People envisage bringing about such change?

What did Valuing People set out to do?

It is worth briefly summarising how Valuing People set out to deliver this ambitious agenda, as this will make it easier to see the relevance of the LDRI studies. Valuing People committed the Government to:

- an integrated approach by health, education and social care for disabled children and their families, with the Quality Protects programme targeting £60 million over three years on improving support for disabled children and their families;

- enabling disabled young people to have equal opportunities for moving into adult life, with new support from the Connexions Service;
• extending choice and control to people by developing advocacy, Direct Payments and a national framework for promoting person-centred planning;

• funding a national information centre and helpline in partnership with Mencap;

• enabling people to have access to a health facilitator and to have a Health Action Plan;

• completing long-stay hospital closure by April 2004;

• implementing a five-year modernisation programme for day services, with more individualised support, clear targets and bridging finance;

• setting targets for increasing employment opportunities for people, backed by local employment strategies;

• introducing the new Learning Disability Awards Framework (LDAF) to provide a new route to qualification for care workers;

• strengthening partnership working through the establishment of Learning Disability Partnership Boards.

Valuing People recognised that making these changes happen would require a long-term implementation programme over at least the next five years, and that this would oblige the Government to take some additional steps.

A Learning Disability Development Fund was therefore introduced in 2002 with capital (£20 million) and revenue (£30 million per annum) elements, the revenue element coming from old NHS long-stay funding released over time. A Learning Disability Task Force, bringing together wide expertise, including people with learning disabilities and carers, was established to advise the Government on ways forward. The Valuing People Support Team was established to provide leadership and steer implementation. Finally an Implementation Support Fund of £2.3 million was established to finance change over the first three years.

This was and remains a formidable agenda for change. It can be seen as requiring significant efforts by government towards seamless working across major departments and/or sections (the Department of Health (DH) and the Department for Children, Schools and Families (DCSF) in particular, and by implication the Department for Work and Pensions (DWP) in relation to proposals for employment). There is an emphasis on better developed information and advocacy systems to address what has been recognised as very patchy provision. The personalisation agenda is recognised by the emergent national framework for person-centred planning and by new health facilitation roles. Modernisation is further recognised through revitalisation of day services, LDAF, partnership working at local level, and the completion of long-stay hospital closure. Ring-fenced funding and infrastructure changes complete the picture.
The above agenda is guided by the four principles of rights, independence, choice and inclusion, and links between these principles and the LDRI projects are outlined below.

The LDRI in context

By the time of the launch of Valuing People, a substantial amount was already known about research capacity and research priorities, sufficient to develop and launch an initiative to support the key policy priorities represented in Valuing People. It was reported in Valuing People that there is already a considerable amount of research activity on learning disability in the NHS. Over 130 separate research projects, as listed in the National Research Register (NRR), have recently been completed. About £3m is being spent on 50 current studies. (Department of Health 2001a, paragraph 10.17, p.115)

The resultant research tender was launched in August 2000 ahead of the publication of Valuing People. The vision later outlined in Valuing People was that this £2 million research initiative funded under the Policy Research Programme at DH would inform the implementation of the new policy. The key foci for the research were envisaged as:

- service delivery in health and social care and its effectiveness to identify elements of good practice, implementation and sustainability;
- social inclusion, including access to good healthcare,¹ and the factors that create disability barriers in people’s lives;
- organisation development to show how staff performance in learning disability services can be supported to achieve better services. (Department of Health 2001a, paragraph 10.15, p.114).

In seeking to reflect the inherently inclusive approach set out in Valuing People, both the commissioning group and the commissioning process involved people with learning disabilities. For the research community the tender involved a two-stage commissioning process, with outline proposals invited prior to initial shortlisting and a subsequent invitation to submit a full proposal with an easy words and pictures summary.

The process of choosing which project proposals to fund was overseen by a commissioning group made up of: people with learning disabilities, their supporters, policy leads at DH, members of other government departments, academics and the research co-ordinators (see Appendix 2 for the full list of commissioners). Full consultancy rates

¹ An additional research tender in relation to access to healthcare for people with learning disabilities was later launched by the Service Delivery and Organisation (SDO) programme and a report published by Alborz et al. (2003).
were paid to people with learning disabilities involved with the commissioning group and to their support workers. Similar payments were also made for the work of people with learning disabilities and their supporters who reviewed research proposals.

Including people in these parts of the process was an innovative undertaking and all of us learned as we went along. A review of the effectiveness of arrangements for securing participation was undertaken by interviewing those people with learning disabilities involved as reviewers and commissioners, and these findings are further considered in Chapter 8.

In all, 144 research proposals were submitted in response to the first tender. Twenty fell outside the research brief, leaving 124 which were reviewed by academics and people with learning disabilities. From these, 30 proposals were shortlisted and researchers were invited to submit a more substantial proposal which was also then reviewed.

Out of these 10 projects were initially funded. However, the commissioning group felt the need to fund projects in two further key areas around the main dimensions of *Valuing People*. A new tender was undertaken as a result. This stated that ‘Ten studies have already been commissioned under the Initiative but the Department now wishes to fund two further pieces of work:

- the first will be on **access to mainstream healthcare**. Evidence suggests that mainstream NHS provision remains inaccessible to many people with learning disabilities and is often insensitive to their needs. Research is needed to investigate the factors currently inhibiting access to mainstream healthcare and to identify practical ways in which both access and sensitivity can be improved;

- the second will set out to establish an **evaluation baseline** against which the implementation and impact of *Valuing People* can be measured. It will identify and collate relevant secondary data describing the operation and impact of existing services, and develop, in consultation with key stakeholders, empirically grounded measures and targets for the assessment of subsequent service change.’

Finally, much has been said about the importance of involving people with learning disabilities in all areas of research (see Walmsley and Johnson 2003; Ramcharan, Grant and Flynn 2004; Grant and Ramcharan 2006), including the commissioning and management stages. But there remained questions about how this could be done and about what the experiences were of research projects in seeking to implement this inclusive agenda.
DH was keen to assess these issues for the 12 research projects funded under the LDRI. To this end DH entered a lengthy negotiation with the self-advocacy movement before funding a thirteenth project. This project involved a group of experienced self-advocates from around England, supported by Values Into Action, to undertake an evaluation of the involvement of service users in the LDRI research studies.

In all the LDRI consisted of 13 projects. Following the commissioning of the research projects, the commissioning group’s work came to an end, and in its place a reference group with an extended membership was set up to advise on the direction of the initiative (see Appendix 3 for full membership).

**From commissioning to co-ordinating a national research initiative**

A number of roles were allocated both to the reference group and to the co-ordinators. Of central importance to the LDRI was the communication strategy and the way that it operated. DH was eager to build innovation into the distribution of knowledge. In addition there were concerns that publication in academic journals represented too narrow an engagement to inform all potentially interested stakeholders. The reference group therefore prompted the co-ordinators to bring interim findings to stakeholders as the research proceeded rather than waiting until the end.

During the course of the initiative three newsletters were published and three annual seminars were held. Additionally, the co-ordinators contributed annually to the Government’s review of learning disability services and kept the Task Force up to date with developments.

In seeking to make closer links with the *Valuing People* Support Team, each of the completed LDRI research reports was sent to them so that they could distribute the findings to relevant parties on the ground. This essential mechanism became more important as the initiative proceeded and the final reports were read by members of the reference group and reviewed by external experts. The formal distribution of findings was therefore aided by the presence of a national co-ordinating body around policy implementation.

Strong and cohesive working arrangements around management of the initiative, a distinct communication strategy and an ethos of meaningful involvement therefore characterised the commissioning and ongoing phases of the LDRI. A system of half-yearly reports by projects via the co-ordinators informed the reference group about progress and fed directly into different parts of the *Valuing People* implementation framework. One might describe the role of co-ordination as managing an ongoing conversation around the emergent
work of the projects. Important in this was the way in which the research contributed to the agenda set by *Valuing People* around rights, choice, independence and inclusion. In the next chapter we look in more detail at how the projects related to these principles.
Chapter 2: The LDRI studies in light of the four principles of Valuing People

Research and the four principles of Valuing People

Valuing People was propelled by the four principles of rights, independence, choice and inclusion. Two of these principles, namely independence and inclusion, are arguably more concerned with desirable outcomes while the others, rights and choice, are more clearly tied to the means to achieve those outcomes, i.e. processes.

In addressing these principles in turn we provide justifications for linking particular LDRI studies to them. Since the studies had a significant array of aims, and differed in scope, sample sizes, data collection techniques and range of participants, we provide in this chapter boxed summaries of their aims and approaches, leaving more detailed descriptions to the companion volume (Grant and Ramcharan 2007).

Rights

Valuing People clearly asserts that the Government is committed to achieving rights for disabled people in order to eradicate discrimination, and states that ‘People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary’ (Department of Health 2001a, p.23). It then makes clear its intention that public services should treat people with learning disabilities as individuals, with respect for their dignity, and that discrimination on all grounds will be challenged. In the context of legislation such as the Disability Discrimination Act 1995, the Human Rights Act 1998 and the Mental Capacity Act 2005, Valuing People may be viewed as being tied to a wider and emergent policy framework, but in a way that specifically addresses the interests of people with learning disabilities.

This potentially powerful stance commands widespread support. It embraces rights that are easy to monitor (for example the right to grow up to vote, to marry and have a family), but also others in which measurement of outcome is more contestable (the right to a decent education and what this may imply about education standards and how to judge them) or subjective (the right to express their opinions and make choices, with help and support where necessary). Moreover, some of these rights (the right to vote, for example) depend for their achievement on other rights being respected (such as the right to express an opinion). We can already begin to see, then, that there is a difference between asserting rights and enabling them to be expressed, and that the securing of one right may help another to be expressed.
One of the main challenges for Valuing People was its commitment to reducing variation and promoting consistency and equity of services across the country. In seeking to prevent the differential impact of a particular standard, Valuing People aimed to make more widely available those forms of assistance that enable people’s rights to be expressed, especially information, advocacy and more personalised support. Although unable to encapsulate the full breadth of potential rights issues within policy specific to Valuing People, one LDRI project, the HRA study, specifically addressed the effect of implementation of the Human Rights Act 1998. In doing so it considered how the rights enshrined in the Act were being, and might best be, accomplished for and by people with learning disabilities.

The HRA study

The researchers assert that the Human Rights Act is ‘the most significant piece of legislation since the Magna Carta in 1215’. This study (the HRA study) aimed to assess the impact of the Act on people with learning disabilities. The researchers talked to 35 people with learning disabilities individually or in groups to understand the major issues in their lives and those which might be associated with the provisions of the Act. They examined case law under the European Convention around the rights of people with disabilities. An examination of Human Rights Act compliance was undertaken in a range of organisations: a NHS trust, a residential trust, a large charity providing services to people with learning disabilities, a further education college and a day service provider.

The complexity of rights implies not only positive outcomes but also the prevention of infringements. In this respect it would not be excessive to claim that in the absence of safeguards people’s lives may literally be at risk. Sadly, we know only too well that neglect and abuse still feature in the lives of some people with learning disabilities at home, in the community and in some of the still rather secluded service settings where people live (National Care Standards Commission 2003;
The central research question in this study was how, in the case of people unable to report abuse using words or signs, symptoms of abuse might be expressed and recognised by others.

A checklist of post-traumatic stress disorder symptoms in a manual used by clinicians to diagnose different psychological problems was examined. However, since the symptoms listed might differ from those exhibited by people with learning disabilities, 10 members of an established self-advocacy group also drew up a list of possible symptoms. These lists were discussed with families of two survivors of abuse and from the final list an interview schedule was developed for family carers. The contributions to the development of the research both of people with learning disabilities and of family carers as ‘experts by experience’ should be noted.

The new research checklist of symptoms was used to interview 17 families (relating to 18 victims, 9 men and 9 women), and data were collected in relation to each victim’s symptoms of abuse at three time points: before the abuse, immediately after the abuse and at the time of the interview, and the impact of these symptoms on carers.
The CBT study

The CBT study for men with learning disabilities at risk of sexual offending involved 13 cognitive behavioural treatment groups operating weekly over a year for 52 men with learning disabilities, 41 of whom were known to have engaged in sexually abusive behaviour.

Training was undertaken around human relations and sex education, along with a model for recognising sexually abusive behaviour. Further work was undertaken on a four-stage model of sexually abusive behaviour: thinking about sexually abusive behaviour; making excuses for why it is OK; planning to get access to a victim; and then overcoming the victim’s resistance and engaging in sexually abusive behaviour. The participants were supported to empathise with victims and given information about relapse prevention and post-treatment issues. Details of the treatment intervention are available elsewhere Sinclair et al. 2002. As well as collecting background information about each participant, change was measured using a number of well-known scales relating to sexual knowledge, distorted cognition, victim empathy and other variables.

The HRA, SA and CBT studies collectively addressed a number of the objectives of Valuing People concerning promoting rights, enabling advocacy, supporting carers and developing adult protection procedures.

Related to rights are the freedoms people have to exert control in their lives through expressing choices freely. Choice was the second of the Valuing People principles and it is considered below.

Choice

Valuing People asserts that people with learning disabilities want a real say in where they live, what work they do and who looks after them. It is acknowledged that for too many people with learning disabilities these have been unattainable goals. The intention now is to correct that so that everyone can make choices, including those people with high support needs. Many of the choices made by people with learning disabilities take place within their everyday relationships with families and with support workers. One of the LDRI studies examined issues around perceptions of job performance of support staff in residential settings.
The JP study

Developing measures of job performance for housing support staff was the main objective of this study. Core competencies were explored with four expert groups – service users, family carers, direct support staff and managers. Each group was asked to list the competencies they saw as important for support workers in residential services. The resultant long-list was narrowed down to around 20 items by a further process of rating.

The competencies were written up with examples of good, bad and indifferent practice for each question and placed on a rating scale. The scales were then tested over time to see if they were statistically sound.

The JP study provides knowledge to support the ongoing development of National Vocational Qualifications, the introduction of the Learning Disability Awards Framework (LDAF) and the skills, attitudes and knowledge of support staff. It also has the potential to inform partnerships with family carers.

However, choice making has been criticised as a rather weak concept that has also been subject to poor and inconsistent definitions (Flynn, Keywood and Fovargue 2003, Hatton et al. 2004a). Without some understanding of choice as a concept, it neither supports services to intervene appropriately, nor necessarily helps people make choices that are informed and based on a realistic appraisal of alternatives, with all possible consequences in view. However, the Mental Capacity Act 2005 has helped to address some of these issues for those individuals for whom mental capacity is deemed to be an issue in decision-making contexts (Gearty 2007).

Having a ‘real say’ in things is not the same as having a sense of control. This also raises the issue of rights once more. For example, for a vegetarian, the choice of food would be absolute – to be offered a non-vegetarian dish would not be a real choice. In this sense the vegetarian is starting from a position that is non-negotiable (Smull and Burke-Harrison 1992). It is something over which they have retained a sense of control, representing a position that is fundamental to their sense of identity and which implies far more than ‘having a real say’.

Choice making, then, is not the same thing as simply making a wish by expressing a choice. It contains layers of complexity that link the individual to authority figures and to environments that may shape their capacity to understand that there are choices to be made, to express those choices on the basis of good information, and to maintain a sense of control. Arguments about control being central to a sense of coherence have strong theoretical links in thinking about what helps individuals
to maintain a buoyant outlook in life (Antonovsky 1987). *Valuing People* saw at least some of the issues around choice as emerging out of the advocacy movement and from self-advocates themselves. In providing funding for such advocacy projects and linking them to the framework of change at local, regional and national level, it was possible to manufacture change based on the experiences of the self-advocacy movement itself.

Two further LDRI studies that linked individual choice and service response were the PCP and HF studies. Person-centred approaches place choice, control and self-determination for each person at the heart of planning for each person. ‘An evaluation of the impact of person-centred planning’ (the PCP study) examines the impact of this approach on people’s lives. In theory, issues relating to person-centred planning cover the vast majority of the *Valuing People* objectives since they provide the central link between the individual future of each person, the person-centred planning service and the community.

Health and, indeed, equal access to health services are central concerns of *Valuing People*. The Health Action Plan (HAP) as part of the PCP, together with a mechanism for facilitating health, were therefore seen as vital parts of person-centred planning. The Health Facilitation (HF) study examines the impact of choice and control over personal health.

### The PCP study

The PCP study aimed to evaluate the impact of person-centred planning on life experiences and on the costs of support provided to people with learning disabilities. It was also concerned with examining the personal, contextual and organisational factors that either facilitate or impede the introduction and effectiveness of the person-centred planning approach. The research involved linked stages: work to develop policies, procedures and practices to implement person-centred planning with organisations in four diverse localities with a particular commitment to it; evaluation of the impact on life experiences and circumstances over a two-year period for the first 25 people in each locality; and calculation of the comparative costs of support over time. Outcomes concerned adaptive behaviour; mental health; quality and volume of service and support received; social networks and affiliations; community activities; physical activities; risk; choice; and medication. Factors impeding or facilitating the introduction and effectiveness of person-centred planning were assessed by interviewing managers and practitioners in the study localities.
Another theme in the studies concerned the processes through which choice and control are experienced. The control of personal and sexual health is important given the long history of sterilisation and desexualisation of women with disabilities (Prillentensky 2004). Continuing negative attitudes towards sexuality and parenthood for women with learning disabilities (Cuskelley and Bryde 2004) indicate that such choice represent a litmus test of their personal control over their own lives. The CC study, like some of the other LDRI studies, resisted the professional and family carer view in favour of that of women with learning disabilities themselves. The study makes a contribution to knowledge about the exercising of choice and control, personalisation and decision making.

**The HF study**

This study aimed to establish how well health facilitation worked in improving access and delivery of health to people with learning disabilities and whether the outcomes of health facilitation met targets set out in Valuing People. A mixed methods approach was adopted. Face-to-face semi-structured interviews around health facilitation were carried out with 25 health and social care professionals. In-depth interviews were carried out with 15 people with learning disabilities and 17 family members or health facilitators to examine the experiences and effects of health facilitation. Focus group methods, shadowing and review of HAPs and analysis of case records for a sub-sample of individuals were also involved. Quantitative methods involved creating a register of all people in Leeds with a learning disability, designing and using a template to identify patients from practice lists for cross-referencing against the register, and then determining whether health facilitation changed the nature of contact with primary care teams.

**The CC study**

In the CC study the researchers worked with a group of women with learning disabilities to plan and design aspects of the research. The two semi-structured interviews were developed with their help and were conducted with 23 women with learning disabilities about their use and experiences of contraception, and with a further four women in relation to hormone replacement therapy. Questionnaires around similar areas were also developed for GPs.

A second study which is relevant to involving people fully in decisions affecting their lives examined one of the processes for maximising choice, ie providing easy-to-understand information for people with learning disabilities. Traditionally our understanding of communication has been based upon the
Independence

Valuing People states that the promotion of independence lies at the heart of the Government’s aim for the modernisation agenda (Department of Health 2001a). Recognising that people have different needs and capacities, the presumption is independence rather than dependence, with services providing support to maximise this. Independence or self-directed or self-managed care in this context is not meant to imply individuals doing everything unaided. This last assertion is important, as it suggests that we are not dealing with independence as a form of ‘aloneness’ in an unpopulated landscape, nor with individuals as free-standing, self-reliant and self-contained. There is perhaps a danger of downplaying the notion of interdependence and reciprocity in people’s everyday lives, where a sense of identity or personhood derives from the ‘give and take’ of everyday social relationships.

In this regard, community care policy is now moving to a second phase. Having established community living it is now necessary to manufacture the social fabric of trusting, supportive and lasting relationships in the community, ie to manufacture social capital (Winter 2000). As has been well captured in another context:

’recommunication difficulties’ of people with different impairments. The IFA study was, in contrast, based on evidence drawn from people themselves about their information needs and the formats which best suited them. The study also benefited from the involvement of people with learning disabilities as co-researchers, communicating with other groups and advising on the format of accessible project materials.

The IFA study

The IFA study aimed to produce and disseminate evidence-based guidance and evaluation tools for making information more accessible to people with learning disabilities. A literature review was undertaken around present best practice in making information accessible. This was supplemented by interviews with 30 individuals and groups who were ‘experts by experience’ about the best format and medium for easy-to-understand information for them. Twelve guidance documents were then produced and, once again, the advice of ‘experts by experience’ was tested with them.

Where the rights and choices of people with learning disabilities are defended and promoted it is still not necessarily the case that they achieve independence. Independence, the third principle of Valuing People, is considered below in light of the LDRI projects.
Personhood... requires a living relationship with at least one other, where there is a felt bond or tie. Without this as a minimum, the human psyche disintegrates... It is also necessary for an individual to have some place of significance within a human grouping, bound together on the basis of family, friendship, occupation, religion, neighbourhood. (Kitwood 1997, p.11)

What this suggests is that independence in this more rounded sense is dependent on the quality of relationships people enjoy in different domains of their lives, and on the opportunities that these provide for their skills, talents and capacities to be nurtured, tested, reinforced and recognised. Independence, then, is very much tied up with issues of inclusion, another of Valuing People’s key principles.

In among some of the key systemic changes introduced as policy by Valuing People were new models of both individual and service level planning. Partnership Boards for each local authority area were given the responsibility to develop plans and implement local services to meet Valuing People objectives for adults with learning disabilities. These Joint Investment Plans (JIPs), together with responsibility for implementation, were to be the product of inter-agency collaboration. The Partnership Boards were key to meeting Valuing People’s partnership working objectives.

Moreover, Partnership Boards were to support the participation of people with learning disabilities and family carers and to build services leading to independent lives. The Strategies for Change project had relevance to the early work of Partnership Boards.

The SFC study

In the SFC study the aim was to explore the new planning arrangements and Partnership Board operations. A literature review of good practice in strategic level planning and the collection of data from invited experts at a series of seminars were supplemented by an analysis of the content of 104 of the first 127 JIPs. More in-depth data were collected about issues identified from the JIP review by lead commissioners and chairs of Partnerships Boards, including also an evaluation of the development programme for learning disability commissioners. Experiences of self-advocates on Partnership Boards were examined with the help of self-advocate researchers.

While each of the other LDRI projects in some way contributed to the independence agenda, those with a more specific relevance were the SE study, the PCP study and the BM study.
Inclusion

*Valuing People* makes the point that being part of the mainstream is something that most of us take for granted. Doing ordinary things such as going to work, looking after our families, and using transport and local services and amenities are what we all do. There is overwhelming evidence to show that far too many people with learning disabilities do not have the opportunity to do these things (Emerson et al. 2005). *Valuing People* hopes to make inclusion a reality for people by making it possible for these ordinary expectations to be commonly met, for mainstream services to be accessible to people, and for community inclusion to be typical.

There is compelling evidence that realising inclusion requires massive change on the part of the institutions of civil society, if not of society as a whole; and that through the actions of people, society creates major disabling barriers in people's lives (Barton and Oliver 1997), preventing many from living out their hopes and dreams in the community. Such barriers – stigma, discrimination, abuse, poor service co-ordination, limits to service funding, relative poverty, poor and inaccessible transport, worse health outcomes – have a long history, suggesting that quick fixes are unlikely and that *Valuing People* is addressing a substantial history of exclusion. This interpretation of the challenges to realising inclusion has the merit of making clear that

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**The SE study**

The SE study undertook a large survey of 600 employment officers across a range of agencies to examine their experiences with people with learning disabilities, their training and knowledge and the issues they faced in supporting people into the workplace. ‘Phone interviews with a representative sample of the agencies both tested and elaborated on these findings. The project team also interviewed 30 people with learning disabilities about their employment experiences, their experience of work support and, additionally, the outcomes for them across a number of life domains. Inclusion in their workplace was modelled using statistics, to understand better how to establish best practice in supported employment.

The SE study is important to an understanding of workforce issues and more specifically to raising the awareness of employers, employment agencies and workers concerning the skills, attitudes and knowledge needed to work with people with learning disabilities. The study also examined the experiences of people in making their own choices and decisions, in this way assessing the degree to which they had experienced inclusion in the workplace.
the expectations for change are centred on society and services, rather than on people with learning disabilities themselves.

The movement of young people with learning disabilities both into adult services and to adult lives has posed significant issues for quite some time. *Valuing People* proposed that for all young people at this transition period the aim should be for continuity in care and support to the young person and their family to ‘provide equality of opportunity in order to enable as many young disabled people as possible to participate in education, training and employment’ (Department of Health 2001a, p.41). It was recognised that people from black and minority ethnic populations ‘face substantial inequalities, discrimination and disadvantage. They are more likely to live in inner city areas, in substandard housing and to suffer discrimination in employment, education, health and social services’ (Mir et al. 2001, p.6).

### The SL study

The SL study aimed to examine the impact of ethnicity on transition experiences of young people and their families. It involved comparing service use, social networks, inclusion and choices of different communities. A purposive sample was recruited using a video and information sheets about the project in Urdu, Punjabi, Gujarati and Bengali, as well as English.

A sample, drawn from schools and services, of 43 young people with learning disabilities and their family carers was interviewed over two time points using the Social Inclusion Interview Schedule. Young people were further supported to talk about their lives using innovative methods for communicating relationships and ideas.

Further, the EO, HF and CC studies provide evidence about the inclusion of people in the mainstream and in generic services, while the PCP study offers an account of what contributions personalised support makes to the achievement of inclusion.

Finally, it is acknowledged that measurements of the success of new policy initiatives can be equivocal without a clear framework for assessing outcomes. In the study, questions were asked about the databasing requirements that would enable robust prospective monitoring and evaluation of *Valuing People’s* ambitions and achievements.
Valuing People and Research: The Learning Disability Research Initiative

The BM study

The project to evaluate the impact of Valuing People was based on three research phases. In the first phase, all existing national data sources were mapped and their usefulness for measuring the impact of Valuing People was assessed. As well as assessing each individually, the possibility of drawing data from the disparate sources was also assessed. By Phase 2 it was possible to identify key areas represented in the datasets against Valuing People objectives and wider service-related and quality-of-life outcomes. This phase involved a consultation with people with learning disabilities, family carers and those responsible for the collection of data about what information they saw as being important and suitable for collection to measure the impact of national policy. Phase 3 looked at practical ways of collecting, analysing and reporting information to government. It also considered some of the assumptions that should feature as underlying the collection of data and the outcomes sought.

Reflections on the LDRI studies

Above the LDRI projects have been mapped in relation to their association with each of the four principles of Valuing People. Not surprisingly in a single research initiative, coverage is not comprehensive. Despite this, the research represents a good balance of studies of key policy innovations, service-specific studies, studies tied up with user experience and those that looked at broad-scale outcomes. The relationship of the LDRI studies to Valuing People’s main objectives is shown in Table 2.1.

Like all research studies, the LDRI studies encountered their own challenges and problems in their implementation. We reflect on these experiences in Chapter 9.

Despite the vicissitudes of research, the projects nevertheless accessed a huge number of participants, and all successfully completed data collection. Samples varied from a national survey, ie a population sample (EO study), through purposive samples to convenience samples. The convenience samples were found in those studies involving difficult-to-reach groups. The breadth of sampling strategies overall indicates an absence of randomisation and of representativeness of samples, raising issues around what other criteria might be used to ensure the generalisability of the findings.
Table 2.1: The relationship between the LDRI studies and the Valuing People objectives

<table>
<thead>
<tr>
<th>Objective</th>
<th>SA</th>
<th>BM</th>
<th>JP</th>
<th>CBT</th>
<th>CC</th>
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<tbody>
<tr>
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<td>Objective 11 – Partnership working</td>
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A review of the participation of people with learning disabilities in different parts of the research process is outlined later. Chapter 8 is devoted to this issue, and it is there that an account is provided of the thirteenth LDRI study, the LMI study, that involved a team of people with learning disabilities researching the experiences of user involvement in the remaining 12 studies.

However, the LDRI also demonstrates a significant increase in people with learning disabilities involved in providing information as participants in the research process (most studies) and acting as expert groups. We have come to see their contribution in terms of the concept of ‘experts by experience’. Listening to these voices establishes the importance of making a constructive alignment (Biggs 2003) between the range of views expressed by ‘experts by experience’ and the policy and practice response. We comment further on this in the final chapter.

Diversity also characterises the dissemination approach of the LDRI projects. There has been a movement in this initiative away from the production of ‘academic papers for an academic audience’. All of the projects have presented their work at three annual conferences to aid wider stakeholder knowledge; they have reported in the LDRI newsletter in easy words and pictures; some have submitted easy words and pictures summaries of the study findings, and some of the final reports are posted on the Valuing People website. The products from the research have also included a guidance package on best practice (IFA study), a theatre production (SL study) and a substantial list of conference, seminar and local presentations alongside academic publications.

It is our view that the alignment between research and practice is being served well by the wider participation of people with learning disabilities in the research process and by dissemination to different audiences. While the moves in this direction are just beginning they seem important to pursue over time, alongside new ways of judging the merit and validity of research findings.

In light of these contentions we begin in Part 2 of this report to review the contributions of the LDRI projects to knowledge, policy and practice in improving the lives of people with learning disabilities.
2 The contributions of the LDRI to policy and practice
Chapter 3: Rights and risk

Some context

Legislative recognition by government of universal human rights and the rights of marginalised sections of society are now well established. Indeed, the proposal for the Equality and Human Rights Commission (EHRC), bringing together the Commission for Racial Equality, the Disability Rights Commission and the Equal Opportunities Commission, underlines government commitment in this area. Valuing People states that:

The Government is committed to enforceable civil rights for disabled people in order to eradicate discrimination in society. People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family and to express their opinions, with help and support to do so where necessary. (p.23)

It also states that public services must challenge discrimination on the grounds of disability and people with learning disabilities must have the full protection of the law. However, achieving rights and preventing abuse are never easy and require a substantial amount of work to accomplish. Figure 3.1 suggests a way of understanding rights and abuse. It indicates, for us all, that in the absence of a person’s ability to speak for themselves, some form of supported decision making, advocacy or substitute decision making will be required.

In this model it can be seen that where the voice of people is least heard they are least likely to be visible to others. Where the person is least visible and their voice least heard, the opportunities for the perpetration of abuse increases, whether that be active abuse or negligence. In many ways, self-determination through ownership of goals, as well as participation in decision making that accomplishes such goals, is vital – not least where others are acting in support roles on the basis of their perception of ‘best interest’. Such participation around everyday life choices helps establish personal rights while increasing visibility.

However, we know that articulate and able people are not spared the experience of abuse, and the model highlights the critical role of people and relationships in all our lives. People keep other people safe. In this view, the wider the network of relationships, the greater the potential for safety, increasing as it does the networks of people willing to challenge, such as other people with learning disabilities, relatives and neighbours, as well as support staff, advocates and guardians. They are vital both to protecting and to realising rights. And, indeed, for those who find decision making hard, the Mental Capacity Act has established mechanisms for ensuring that there are means by which people’s rights and needs can be met.
However, the vast majority of everyday life is lived without arbitration or decision making under the provisions of the Mental Capacity Act. Because of this, people’s values are important in day-to-day interactions and in terms of goals they wish to achieve. Defending rights therefore implies protection from risk, abuse and neglect, a system through which rights can be defended against infringement, and a system of values to guide everyday interaction.

Figure 3.1: Links between capacity, substitute decision making and visibility

- No capacity to know or recognise rights
- Knowing rights and entitlements
- Substitute decision making
- Advocacy required
- Articulating rights and infringements
- Having articulations heard
- Securing redress for infringements

- Not as visible
- Not as visible
- Not as visible
- Not as visible
- Voice heard
- Voice heard
- Voice heard
- Need for protection high
- Need for protection high
- Need for protection high
- Importance of risk taking high
- Guardianship
- Supported decision making
- Autonomous voice
- Autonomous voice
- Autonomous voice
All of the LDRI studies were in some way associated with issues of rights and choice. However, specific contributions were made by the HRA, SA, CBT, IFA, CC and LMI studies.

**LDRI contributions to knowledge, policy and practice in relation to rights**

Under the Human Rights Act 1998 public authorities now have to take action to protect fundamental human rights and to make their policies and procedures compliant. The HRA project summarises the provisions of the Act:

> [The right] to life; not to be treated or punished in a cruel way; not to be treated like a slave at work; to freedom and to be safe; to fair treatment in court and in meetings; to respect for private and family life; to have a religion and have your own ideas; to say what you think; not to be treated badly because of being a woman or a man, being black or white, having a disability or for any other reason; to keep and enjoy your own things; to education. (HRA main report)

The HRA study sees the legislation as being important not only in the prosecution of cases but in the development of a culture of human rights. However, in accomplishing the latter, public support will depend on there being clarity over rights, enforceability and diligence in enforcement, and the visibility of victims. This position is similar to Figure 3.1, and many of the HRA study findings question this visibility and the presence of a system of advocacy. On these grounds, the authors point out that there is not an ‘equality of arms’ between those whose issues and problems are unseen and unheard, such as many people with learning disabilities, and the general population. The inequality to which the researchers allude occurs both at the level of interaction and systemically.

At a systemic level, the authors point out that a disproportionate number of people with learning disabilities live in high crime areas and, in infringement of Article 3 of the Human Rights Act, are common targets for victimisation, bullying and harassment. Family carers and people with learning disabilities also find that the police are often sceptical and do not see them as ‘good witnesses’. Regional Forums (self-advocacy forums) have now had meetings with the Crown Prosecution Service and the Task Force has taken up disability hate crimes as an important issue for the future. It is worthwhile noting that the SA study into the abuse of people with severe learning disabilities might reconstrue such abuse as a particular category of ‘hate crime’ and as a potential way forward in building protective frameworks.
There are also pressing issues within public services. The HRA questionnaire to staff in different service support sectors found that 76% ‘strongly agreed’ that ‘very few service users use the formal complaints procedures’. Confirming the ideas in Figure 3.1, 82% of staff considered that clients did not understand the process, that 87% of clients could not communicate, that 65% lacked independent support and that 76% did not know their rights. Staff themselves found complaints procedures inadequate or illusory, bureaucratic, unresponsive and in conflict with professional interests. People with learning disabilities were often seen as storytellers, troublemakers, attention-seeking and, alongside staff pursuing complaints, whistleblowers. In these respects, the HRA study concludes that:

One of our key conclusions is that the role of the independent advocate is crucial in ensuring ‘equality of arms’ between the service user and the organisation being complained against.
(HRA main report, p.41)

In making an assessment of this gap, the authors point out that 93% of staff responding to the questionnaire strongly agreed that service users should have access to an independent advocate, but only 27% rated an effective independent advocate as being available in their organisation.

Box 3.1: The law, the Human Rights Act and infringements

- Issue further guidance on making organisations compliant with the Act.
- Invest in training and educational packages for the police and criminal justice system to enhance better interviewing and evidence taking from people with learning disabilities.
- Work on how to maximise the visibility of infringements and how to establish ‘equality of arms’.
- Continue to support the development of advocacy and to work on ways of making complaints systems and rights more accessible in everyday service and life settings.

At worst, it is entirely possible that abuse may occur in any environment in which there is insufficient ongoing scrutiny. A recent Task Force report (Commission for Social Care Inspection and Healthcare Commission 2006, Healthcare Commission 2007) points to widespread abuse within service settings, while an investigation into the palliative care experiences of adults with learning disabilities (Brown, Burns and Flynn 2005) and Mencap’s 2007 report Death by Indifference implicate hospitals in ‘allowing’ death more readily
for people with learning disabilities than for others. These reports remind us that even in the context of potentially hugely empowering legislation, the spectre of inadvertent neglect or abuse and systemic and institutionalised abuse can still exist.

The SA study reports that long-term care and respite services were the most common places where abuse was perpetrated outside the family home. In recent decades there has been much work done around such abuse. Brown et al. (1995) in their study of incidence found 1,400 cases per year in the UK, although they also suggest that this is an underestimate. Of these cases, two-thirds came to light when disclosed by the victim, but very few cases went to court. The number of cases of all forms of abuse is higher than Brown’s figure, and unreported cases are likely to be far higher among those with severe learning disabilities.

The SA research examined the experiences of 18 people with severe learning disabilities, 14 of whom had been the subject of sexual abuse, 9 of physical abuse, 8 of neglect, 18 of emotional abuse, 6 of financial abuse and 2 of medication abuse. These results confirm that abuses of different types often go together. Questions about the abuse were asked of family carers at three time points: questions about what had happened before the abuse took place, directly after the abuse and then at the point of the research interview. Family carers were often late to recognise that something was wrong, and then had major difficulties in coming to terms with managing what had happened. Seemingly inexplicable new challenging behaviours, loss of skills and accompanying symptoms similar to those of post-traumatic stress disorder were observed by family carers. Unusual or atypical behaviour was worst directly after the abuse.

Survivors experienced effects such as difficulties sleeping, self-harm, depression, anger and aggression, reliving the event and ‘startle’ responses. The researchers found that these symptoms were likely to meet the criteria of post-traumatic stress disorder. The effects were found to be long lasting. The availability of therapy was patchy and there were often major delays in accessing such specialist support. Few parents or other carers were offered help or therapy themselves, even though most felt traumatised, blamed themselves and described themselves as no longer able to trust people. In some cases parents had stopped using support services because of this breakdown in trust.

While the SA study was small, the findings build on an already well-established literature around issues of abuse and highlight a number of messages for policy and practice.
Box 3.2: Dealing with signs of abuse

(i) Recognising abuse

- Consider the wide distribution of a ‘symptoms of abuse’ checklist; give priority to staff training about abuse symptom recognition and post-incident reporting and management; consider the best ways to communicate information to families and carers about symptoms of abuse.

- Develop better understanding of the motivations of abusers and the factors that enable such abuse to remain hidden.

(ii) Protecting rights

- Prioritise work with self-advocates and advocates around issues of abuse and hate crime in ways that reflect the greater interests of people with learning disabilities.

- Seek to make the criminal justice system more accessible and supportive to people with learning disabilities when they appear as witnesses.

- Enhance reference and Criminal Records Bureau checking for new staff.

- Make it easier for staff witnesses to come forward and report abuse.

- Consider the role of unannounced inspection visits in services, with greater responsiveness to the concerns of loved ones, relatives and others who know a person well.

Box 3.2: Dealing with signs of abuse (continued)

- Involve service users more actively in evaluating services and in making judgements about their quality.

(iii) Services

- Improve the distribution and availability of, and investment in, counselling and other support services for people with learning disabilities who have been abused and for family carers.

The CBT study reports that over 90% of perpetrators of sexual abuse who have a learning disability are men. Estimates from other studies they report are that 42–53% of abuse – a significant proportion – is perpetrated by people with learning disabilities on other people with learning disabilities. The CBT study ran 13 cognitive behavioural treatment groups weekly over a year for 52 men with learning disabilities, 41 of whom were known to have engaged in previously sexually abusive behaviour. While cognitive behavioural treatment has been found to reduce recidivism among sex offenders in prison and those on probation, men with learning disabilities have not featured significantly in previous studies.

The treatment intervention published separately (Sinclair et al. 2002) set group rules, examined human relationships and provided sex
education, and introduced a cognitive model seeking to separate non-offending examples from offending examples and sexually offending. A four-step sexual offending model was then introduced: thinking about sexually abusive behaviour; making excuses about why it is OK; planning how to get access to a victim and overcoming the victim’s resistance; and being sexually abusive. The treatment also considered victim empathy, relapse prevention and post-treatment options.

Results of the CBT study indicate that, over the treatment period and, indeed, in the subsequent six months, participants increased in sexual knowledge, empathy and the ability to separate abusive from non-abusive examples of behaviour. The research identified those who had received other therapies prior to or concurrently with the programme and those considered to be on the autistic spectrum as the groups for whom the programme was less successful.

Where the most serious infringements to rights have been perpetrated, there remain many issues to resolve. The CBT and SA studies make a modest contribution to this knowledge and to improving practice. However, significantly more work is required to protect those who are most vulnerable in our society. The HRA research study found that questions of rights were accompanied by risks or contradictions. For example, in relation to the right to marry and have a family life, the study found negative attitudes among parents. While 76% of staff felt that consenting couples with learning disabilities should be enabled to have sexual lives, only 48% felt that contraception was readily available to their clients.

The issues around wider friendships are even more problematic. For example, in the first national sample survey of adults with learning disabilities (Emerson et al. 2005), it was found that 31% had no contact with friends. Even under a human rights approach it is virtually impossible to legislate in any way on friendships and choice. However, the fact that only 17% had a job and 18% had been in ordinary schools indicates that there is a long way to go to establish an opportunity structure for integration in the wider community. Once again, the HRA study found that 70% of staff felt that their clients could not go out when they wanted and only 40% of staff felt that they had enough opportunities to make new friends. At a more systemic level, the high rates

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**Box 3.3: Sexual offending**

- Adopt CBT as one proven approach in working with men with learning disabilities at risk of sexual offending.
- Extend knowledge around sexuality and relationships for all people with learning disabilities in line with expectations for the population as a whole.
of relative poverty among the population with learning disabilities is not something that allows self-determination to the extent necessary to make new friends or to make choices about where to live.

The HRA study points to several issues surrounding the healthcare of people with learning disabilities. Of relevance to this are Article 2 (the right to life), Article 3 (no torture, inhuman or degrading treatment or punishment), Article 14 (no discrimination) and Article 8 (respect for private and family life). At the systemic level, the HRA researchers suggest that:

*The HRA may have only limited impact on the issue of health care rationing because of the historic reluctance of courts to interfere with managers’ operational and funding decisions.* (HRA main report, p.127)

Health plays a central part in our lives and it is vitally important to produce equality of access to healthcare services and appropriate provision. *Valuing People* recognised the additional healthcare needs of people with learning disabilities and envisaged a Health Action Plan (HAP), which, as part of person-centred planning, would contain:

*Details of the need for health interventions, oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of medication taken, side effects and records of any screening tests.* (Department of Health 2001a, paragraph 6.15, p.64)

However, there may be further issues around providing equality of access to healthcare. For example, it was found in the HF study that GP practices did not regard as a priority the health of people with learning disabilities, despite the aspirations of *Valuing People* and related guidance (Department of Health 2002a), and were equivocal about maintaining a separate register and about using a purpose-built template for identifying people with learning disabilities on their registers.

*Valuing People* recognised that ‘inequalities in health cannot be tackled without dealing with fundamental causes – including poverty, low educational attainment, unemployment, discrimination and social exclusion’ (Department of Health 2001a, paragraph 6.4, p.61). The HF study found that:

*People with learning disabilities themselves felt that determinants of health such as employment, housing and educational opportunities… were very relevant to their health but these issues were not explored in their Health Action Plans.* (HF study main report, p.3)
Indeed, the study also found that there was little understanding by them or by family carers about what health facilitation and HAPs were. Where HAPs did exist, family carers were often unaware of their role in health facilitation and confused by the level and detail of information. Better outcomes were found where an able and willing facilitator was appointed. However, in comparing the GP medical records of those who had adopted a health facilitation approach with those who had not, no significant difference was found in health outcomes. It is as yet very early on in the implementation of such facilitation, but the trend in the data shows more medication reviews and attention to health issues that have a bearing on lifestyle issues, indicating a potential to engage around positive health practices as well as medical intervention at times of illness.

Achieving equality of health outcomes as a right therefore involves engaging with systemic issues as well as those operating at the individual support and interactional level. The HF study provides a substantial number of recommendations about making resources available and about increasing awareness, stimulating action and organising around monitoring and review.

The HRA study identifies further issues in relation to healthcare that point to continued problems with issues of consent to treatment. Without such consent, health and medical interventions might constitute trespass (‘interference with bodily integrity’) or battery (‘touching without consent’). As the HRA researchers assert:

*In such a complex area we consider that a model of supported decision making needs to be adopted which would establish the person’s view and preferences and therefore the decisions they are communicating.*  (HRA study main report, p.103)

However, in the CC study it was found that, despite guidance issued by the British Medical Association and the Department of Health, there is still a lack of consistency and confusion among GPs. The study also found that GPs welcomed another person accompanying women with learning disabilities to private consultations for contraception and HRT. Of the 23 women attending consultations for contraception, 18 were accompanied, and all but one were happy about this. Additionally, there was a substantial lack of information held by the women: 14 did not know how their contraception worked; 11 lacked knowledge about reproduction; and of the four on HRT, none knew how it worked or how long they would take it, and none seemed to exercise choice or control over it. This endorses the findings of an investigation eight years ago of the healthcare decision making of adults with learning disabilities by Keywood, Fovargue and Flynn (1999), suggesting that little has changed in this area in the interim.
Given the disproportionate use of Depo-Provera and the view of half the GPs in a survey that this was their first-choice contraceptive for women with learning disabilities, it was concluded that:

The findings of this project demonstrate clearly that in some cases there is no clear link – either in the minds of women themselves or their carers and doctors – between actual sexual activity and the need for contraception. A ‘just-in-case’ mentality seems to be in operation…

(CC study main report, p.4)

Box 3.4: Suggestions for improving support for sexual health from the CC study

• Further knowledge from professionals around informed consent and choice and more readily accessible information.

The latter point regarding accessible information is vital, since choice without information on which to base comparative judgements between options might better be construed as prejudice. Issues of choice are central human rights. As the HRA researchers say:

Providing opportunities for learning to understand and express choices… should be fundamental to policy and planning… [and]… for enhancing communication. (p.103)

Issues of choice are further considered in Chapter 4.

Observations and conclusions

The principles of human rights can only be accomplished with a significant amount of work by people with learning disabilities themselves and by those who care about and for them. The LDRI studies have established some additional principles that might be used in thinking about recognising such rights and in framing appropriate responses.
The first principle is that of **making ‘hard-to-reach’ groups visible.** The extraordinarily difficult balance between personal freedoms and scrutiny by functionaries of the state is a fundamental issue in this respect. The systems of health facilitation and person-centred planning have the potential to join up information systems. However, they do not do the whole job. There remains a substantial number of people with learning disabilities who remain vulnerable and hidden, who require additional scrutiny and whose rights are most at risk of abuse and neglect. Systems of ‘concerned vigilance’ alongside already widely stated rights, principles and values should underlie additional strategies designed to protect the most vulnerable citizens.

The second principle, which is related to the first, is the idea of establishing **equality of arms** in the lives of people with learning disabilities with that in the general population. It is impossible to protect rights without systems of advocacy and checks and balances that empower staff and others to pursue actions in cases of infringement of rights. The systems that have been developed to support advocacy by maximising people’s ability to speak for themselves are to be applauded. More needs to be done to develop a level of scrutiny that does not stifle but that liberates through committed action against those who infringe not only stated rights but also everyday rights.

The third principle is **addressing the links between the individual and the system.** Systemic issues have been found in a number of the LDRI studies to prevent the accomplishment of rights at an individual level. For example, the SE study underlines the difficulties of training employment officers to be aware of the issues and best practices relating to finding work for people with learning disabilities; the HF project exemplifies the difference in values between GP practices and those espoused in *Valuing People* and its associated guidance; the level of service support and treatment provision for smaller groups – but nevertheless groups with a high level of need – was exemplified in the SA project both for people who had been abused and for family carers; and the SL study questioned the ability of service systems within education and adult day services to meet the specific needs of people from black and minority ethnic populations.

There are two levels of solution to these issues: better linkages across government, service and other settings and more effective bridging between personal experiences and systems responses. The flow of information between the two is an essential element in this equation.

There is a fourth principle, **measuring performance,** that relates to the flow of information. The BM study proposes that up-to-date ‘performance indicators concerning people with learning disabilities are almost
exclusively focused on inputs, processes and outputs rather than outcomes' (BM main report 2006, pp.6–7). In linking rights to outcomes, people with learning disabilities and family carers should contribute to shaping the outcome agenda, an agenda that should reflect the totality of lived experience and feed into government policies in ways that demonstrate inequalities.

The fifth principle is **manufacturing synergy**. The huge efforts of the self-advocacy movement and the structure provided by *Valuing People* to support the flow of information from local level to national decision making (outlined in Chapter 4) represents one such synergistic approach in which recognition of issues leads to cross-departmental action. Further work needs to be undertaken to manage this flow of information and to ensure it is sufficient and enables engagement. It may be that the new EHRC will play a key role in this respect. However, it is vital that this should accord with the choice and self-determination of each person with an intellectual disability, and it is to ideas around choice and self-determination that we now turn.
Chapter 4: **Choice**

**Background**

**Valuing People** aimed to give people with learning disabilities more choice and control over their lives by:

- developing and expanding advocacy services, particularly citizen advocacy and self-advocacy;
- fully involving them in decisions that affect their lives;
- increasing the number who receive Direct Payments;
- developing a person-centred approach to planning services;
- improving information and communication with people with learning disabilities.

(Department of Health 2001a, paragraph 4.2, p.45).

Four years after the publication of *Valuing People* and based on the views of 581 people with learning disabilities the *Valuing People* Support Team (2005) provides an optimistic assessment of its impact. In this report the participants thought that people were listened to more, that person-centred planning was making a difference, that people were being better supported to be independent and that the increase in Direct Payments was extending choice and control in their lives. The move towards Direct Payments has been further emphasised in *Our Health, Our Care, Our Say* (Department of Health 2006), which moves towards meeting sub-objective 3.3 of *Valuing People*:

*Making direct payments available to all those people with learning disabilities who request them and who meet the requirements of the scheme. Proposed Performance Indicator: percentage of people with learning disabilities receiving community based services who are receiving direct payments.* (Department of Health 2001a, p.124)

The *Valuing People* Support Team (2005) report pointed to a substantial growth of self-advocacy and citizen advocacy projects funded substantially via *Valuing People*. A strong mechanism for hearing the views of people with learning disabilities had been established, as shown in the useful figure provided on the *Valuing People* website www.valuingpeople.gov.uk. Over 1,000 people were reported to be on Regional Forums where self-advocates had made a real difference. Representatives from the Regional Forums take views to a National Forum and they take views to the Task Force which advises government directly. This indicates high performance in relation to aspects of Objective 3 of *Valuing People*:

- sub-objective 3.1 – promoting the rights of people with learning disabilities;
• sub-objective 3.2 – enabling advocacy to be available for people with learning disabilities who want or need it. (Department of Health 2001a, p.124).

More recently, the Learning Disability Task Force annual report for 2006/07 (Learning Disability Task Force 2007) points to the contributions to consultation around primary healthcare undertaken by the Disability Rights Commission, and contributions to Our Health, Our Care, Our Say (Department of Health 2006), the Office for Disability Issues’ (2006) Improving the Life Chances of Disabled People initiative, and prospectively to refreshing Valuing People.

The growth of advocacy and a structure for the flow of information that affects policy is a significant move in seeking to extend choice and control to people by giving them an independent voice. The philosophy of ‘nothing about us without us’ is significantly raising the profile of people with learning disabilities in decision making at the highest level. In terms of the sub-objectives around more choice and control, Valuing People therefore seems to have made a significant start in meeting sub-objectives or having these in train via additional policy:

• promoting the rights of people with learning disabilities;
• enabling advocacy to be available for people with learning disabilities who want and need it;
• making Direct Payments available to all those people with learning disabilities who request them and who meet the requirements of the scheme.

The minutes of the National Forum and Task Force also indicate the ways in which the views and interests of people with learning disabilities have moved into the policy arena around issues such as safety and prevention of hate crimes, health, services for those with autism, and transport, for example. The minutes show the extent to which government departments are being called upon to respond to the voice of people with learning disabilities and how self-advocates can act to bring together government departments around their interests.
LDRI contributions to knowledge, policy and practice in relation to choice

Despite the good news outlined above, the complexities of supporting choices for all people with learning disabilities have implications that are considered in several of the LDRI projects. There is a world of difference between offering people choices in terms of food and with whom they live, for example. The PCP study addresses sub-objective 3.4 about developing locally agreed protocols and procedures to ensure that services are based upon a person-centred approach. Sub-objective 3.5, which is about ‘ensuring that people with learning disabilities are fully and actively involved in all decisions affecting their lives’, is considered in relation to women and their reproductive healthcare needs in the CC study, while the IFA study examines best practice in the provision of easy to understand information. Three further projects have relevance in providing the value system for extending choices (the HRA study), putting in place the local planning mechanisms to make choice possible (the SFC study) and measuring the effectiveness of change (the BM study). When taken together, the studies indicate many complexities to extending choice and control in people’s lives.

The complexities of extending choice making are well exemplified in previous research showing that the move to community settings has increased levels of choice when set against choices in institutional settings. Indeed, Robertson et al. (2001) identify the ‘predictors of self-determination’ as settings with ‘home-like’ architectural features, living in a smaller setting with fewer people and in homes with organisational procedures for individual planning in place. Moreover, although participant ability has been found to be a predictor of choice and self-determination, some research has shown that even people with severe and complex disabilities can make tangible choices (eg Lancioni, O’Reilly and Emerson 1996).

Robertson et al. (2001) also found increases in choices relating to personal possessions and household routines but, in contrast, also found low levels of choice in fundamental life areas such as where to live (5%), who to live with (9%), moving home in future (15%), day activity (37%), and employment (23%), suggesting that it is often environments and systems that may prevent a fuller expression of choice by limiting available options.

Person-centred planning is very much at the centre of seeking to place the person in control of their own lives and for services to respond to their dreams, wishes and aspirations. It should be remembered that the PCP study was effectively a ‘demonstration project’, since specialist trainers were involved in developing person-centred planning and providing training in the four research localities prior to data collection. As reported in the next chapter,
localities with a person-centred philosophy prior to implementation of person-centred planning, and those with trained facilitators, were likely to produce better outcomes.

In examining these ‘best case scenario’ outcomes the results are at first sight encouraging, with improved outcomes in relation to community involvement, contact with friends, contact with family and choice. Even more interesting was that the cost was not significantly higher than previous arrangements for service provision and support.

However, outcomes were not positive in all life areas. For example, what might be seen as strong markers of choice and inclusion such as larger social networks, employment and physical activity did not improve, and indeed produced worse, outcomes in relation to risk and physical health and in meeting emotional and behavioural needs. The study also found that those with emotional or behavioural problems, autism, those with more health problems and those with restricted mobility were less likely to have a plan, and that where they did, the outcomes varied. This finding is essential in that it tells us that special attention should be paid to those with higher support needs.

The PCP researchers suggest that person-centred planning should be seen as a ‘staging post’ to more individualised services. Where person-centred planning and individualised funding come together, there is a likelihood that well-being and choice will increase. However, brokerage will need to reflect a better linkage between PCP, service commissioning and freedom to choose services which will make a difference and move the person towards their goals. At the service level, leadership, a commitment to person-centred ways of working by first line managers and more effective ways for supporting facilitators to link innovative and successful PCP practice to organisational change would help suffuse services with the PCP values over time.

Suggestions for taking forward this agenda are outlined in Box 4.1.

Box 4.1: Further development of person-centred planning

- Monitoring the implementation and outcome of person-centred planning is required in different localities, with a focus on local facilitators and champions overseeing its implementation.

- The infrastructure and system architecture to support person-centred planning is essential to success. Investment in this activity is vital (see also Chapter 6).
The role of the Partnership Boards is crucial to extending choice in the services to which people might gain access, given their responsibility at local authority level to plan strategically and commission ‘comprehensive, integrated and inclusive services that provide a genuine choice of services to people in their local community’ (Department of Health 2001a, paragraph 9.7, p.108).

The experience of a previous national strategy in Wales indicates that linking the individual needs, interests and aspirations of people with learning disabilities to the development of services to respond to these needs is very difficult (Felce et al. 1998, Chapter 4). Among the potential difficulties additional to the inevitable funding issues are: insufficient personal plans to inform policy; insufficient population-based data to establish overall levels of provision; difficulties in managing the quick development of new and inclusive services; resistance to change within the sector; and lack of participation by people with learning disabilities and family carers in planning mechanisms.

In their consideration of the first Joint Investment Plans (JIPs) submitted by the Partnership Boards, the SFC study found that there was poor baseline information about the prevalence of learning disabilities locally, and only half of the JIPs considered the impacts of demographic changes. JIPs made reference to sub-groups of people with learning disabilities, such as people with mental health needs or challenging behaviour, but often without much elaboration as to the implications for local resources. There was much variation in the details provided about local services and expenditure. Similar problems were therefore being experienced to those experienced in Wales. Additionally, the relationship between care management and person-centred planning was found to complicate and obfuscate rather than clarify and support the link between people’s wish for services and choice around services options and their delivery.

In extending choice, the involvement of people with learning disabilities and carers on the Partnership Boards was seen as important. Though they were found in the SFC study to

Box 4.1: Further development of person-centred planning (continued)

- Integration and streamlining of practice around person-centred practice, health facilitation, care management and forms of self-directed care are essential to prevent confusion and to maintain seamless and co-ordinated support for people across the life course.

- More research and development work around improving the lives of those who benefit least from the person-centred planning model needs to be undertaken.
have a presence, it was not clear that their contributions were effective. People with learning disabilities, the SFC study concluded, have clear views about what needs to be done to secure their inclusion in planning for change at local level. Consultative arrangements need to be organised, spaced and paced to maximise the voice of people with learning disabilities. Though this means that decision-making cycles may be lengthy, it should ensure that the right decisions are reached about priorities and goals. In some senses this mechanism for the flow of information at local level reflects the wider contribution framework for the flow from local self-advocacy to Task Force levels.

There is much to be learned about extending choice but also about measuring whether such choice making has been a success. The BM study, as will be reported more fully in Chapter 5, makes an important contribution by proposing that too much emphasis has been placed on evaluating services on the assumption that they will inevitably lead to better choice and outcomes. The study emphasises that performance indicators and outcomes should be developed with people with learning disabilities and family carers and reflect the totality of lived experience rather than services or activities being undertaken.

**Box 4.2: Linking systems to improve choice making**

- More work is required in developing systems that can support population-based data, linked to aspirations expressed in person-centred plans.

- Data should not be exclusively about services. There needs to be data on outcomes collected on the basis of measures that are developed by both people with learning disabilities and family carers.

- Mechanisms for more meaningfully involving people with learning disabilities in the Partnership Board processes are required. Strengthening local self-advocacy is a starting point in this respect.

- Direct Payments may offer a better option for developing services in ways that respond to consumer demand. Here Partnership Boards and brokerage organisations will need to develop skills in responding to consumer demand rather than merely managing the market.

It is clear from the above that to extend choices around services requires a mechanism that translates personal choice into service provision. Choice is therefore limited by the opportunity structure provided by the services in place to respond to personal aspirations and
wishes. Choice, though, is also about everyday experiences and interactions. In the CC study it was found that within the context of sexual healthcare services:

… it is hard to escape the conclusion that negative attitudes, values and stereotypes about the reproductive capacity of women with learning disabilities influences decisions taken about their contraceptive needs. (CC study main report, p.70)

Without information about contraceptive choices, their advantages and disadvantages, and without seeing the links between the choice and their everyday lives, there remains a lack of control over reproductive choices. The overuse of Depo-Provera compared with the population as a whole, for example, seems to imply that the potential disadvantages are not spelled out to women, and that those prescribing are in some way controlling reproductive choices.

In the case of women with learning disabilities and their healthcare needs, the CC study identifies the importance of ‘responsible prescribing’, i.e. questioning the reasons for the prescription. The Mental Capacity Act 2005 also assumes competence, that all practicable steps must be taken to support people in their decision making, and that they should have information in simple formats as an aid to making those decisions. As a series of values underlying how best to approach and to facilitate choice, the model can be extraordinarily powerful. The findings of this study therefore have ramifications across people’s lives and not just in relation to sexual health. To maximise people’s choice making all efforts must be made to support the person to make their own decision and, in doing so, to make their choice out of all the potential options while understanding all potential outcomes.

Indeed, in the JP study, those job performance measures identified by people with learning disabilities themselves among their top 20 were listening to the person, doing things when it suits the person, letting the person get on with their own life, doing the things the person chooses and giving the person new ideas. However, there remain limitations in situations where the person’s choice remains unclear despite focused efforts. Even with a circle of support or other forms of supported decision making, such situations produce real difficulties in choice making and self-determination, and this may be one reason why some groups fare better under person-centred planning than others.

While choice and control are problematic at the interactional level, several of the studies suggest the conditions within which such choices are made. It is the context, environment and opportunity structure that place limits on the freedom to express choice.
Among examples of this are the findings of the HF project that family carers and people with learning disabilities neither understood the idea of health facilitation nor what a Health Action Plan was meant to accomplish. An additional example is the experience of people in black and minority ethnic populations trying with difficulty to make choices around information systems not designed for their needs and services that do not square with their cultural expectations.

Very much at the heart of all these examples is the assumption that if information is created in a way that people can understand then it will extend informed choice making. This is an objective of Valuing People and was the focus of the IFA project. This project was innovative. Instead of examining the academic literature to find out what worked, it took the novel approach of seeking advice about its recommendations from the people who would need to use information in different formats. The result is a series of guidance documents around different formats drawing on valued practice and based on evaluations by end users. The project also found that involving people from the target audience in developing accessible information, and in its production, were worthy approaches to describing ideas clearly and enhancing the likelihood of its use.

**Box 4.3: Clarifying the infrastructure to support choice making**

- Professionals likely to provide services to people with learning disabilities among their clientele have more knowledge about their rights, needs and interests.

- Environments, contexts and services have an implicit opportunity structure that simultaneously allows some choices while denying others. In the construction of structures, the limitations placed on choice making should be taken into account.

- Decision making that supports choice making requires information to be made available in formats that are understandable. This process has to begin early, i.e. in childhood. People should be supported to understand the options and to appraise these in light of the potential outcomes and effects.

- Person-centred planning and Health Action Planning may seem cumbersome and unreal to people unless such processes connect with people’s realities and have tangible benefits.

- Providing information about such planning in easy-read formats would potentially be very useful, but the information needs to be in the hands of people capable of explaining it in appropriate ways. Easy-read information is no substitute for valued interpersonal relationships as a conduit for information sharing.
Observations and conclusions

Establishing a relationship between choice and rights, particularly those rights set out in legislation such as the Human Rights Act, the Disability Discrimination Act and the Mental Capacity Act, will be crucial in years to come. In their report on the HRA study, the researchers argue that the effectiveness of the law in changing the way society acts is based on the ‘weight and focus of public policy on the issue’, the ‘compatibility of the law with existing values’, the ‘clarity’ of the law to the public, the ‘enforceability and diligence of enforcement of the law’ and ‘a visible victim who can prosecute a case’.

There have been some hugely significant changes in the development of advocacy, particularly self-advocacy, in the past six years. A structure supporting the flow of information from local level to government level is in place. It is possible to see from the publicly available minutes of Task Force and Regional Forum meetings how the information flows between levels and how it makes a difference at different levels. The effect is visible, accountable and in the public domain. However, at local level the systems do not operate with the same level of clarity; the visibility of local decision making is low, and therefore so is public knowledge and public concern.

For a community to accept people with learning disabilities, it will need convincing of the value of diversity and the benefit of welcoming and supporting people with learning disabilities. In other words, a system of values has to be managed, not only within services but also within communities. This has been demonstrated in the application of anti-social behaviour orders to people with learning disabilities, who are far more likely to have these applied than members of the general population (Ramcharan, McClimens and Roberts 2006).

This emergent evidence suggests that a substantial amount of work has to be undertaken with communities around Valuing People with learning disabilities. As the HRA researchers suggest, changing public attitudes will require a new relationship and link between people with learning disabilities and the communities in which they live. It is now time to consider how the links into those communities might be managed so as to place people with learning disabilities at the heart of them. This step would expand the role of Partnership Boards, which, while continuing to manage comprehensive choices in services, would seek to stimulate comprehensive rights of access to resources in the community.
Chapter 5: Independence

Some context

Five of the LDRI studies (SE, PCP, HF, SFC and BM) were particularly relevant to understanding how people with learning disabilities can be enabled to lead independent lives, so we concentrate on their findings here.

First of all there is an important observation to make about overall progress in achieving Valuing People's aims. Judged against its own milestones (Department of Health 2001a, Chapter 10), it is evident that some key targets were not met when intended. These included:

- the reprovision of the remaining long-stay hospitals to enable people to move to more appropriate accommodation to be completed by April 2004;
- the full range of employment and support service options to be in place by winter 2003;
- health facilitators to be identified by summer 2003;
- all people with a learning disability to be registered with a GP by June 2004;
- all people with a learning disability to be in receipt of a Health Action Plan by June 2005.

Despite the acknowledged challenges presented by the reforms envisaged by Valuing People and the tight timetable associated with these reforms, it is hard not to draw the conclusion that strides towards independence in the lives of people with learning disabilities are bound to be undermined if the necessary structures, resources, governance and supports are not in place. And they clearly are not in some cases, some considerable time after they were envisaged. We are talking here about basics: whether people are living in communities as opposed to long-stay hospital settings; whether they have access to primary care services and to the anticipated new ways of helping them to access mainstream and specialist health services; and whether they are enjoying productive, rewarding and income-generating activities during the day.

Policy implementation slippage, or the absence of an adequate policy response (Disability Rights Commission 2006), on this scale of course has longer-term consequences, and can quickly lead to disillusionment and distrust of official intent and competence, or at the very least to a realignment and lowering of hopes and expectations. We are reminded of very similar experiences in another national learning disability strategy 20 years ago, which is worth briefly summarising here.

When the All Wales Strategy (Welsh Office 1983) was launched it was trumpeted for its vision, its commitment to inclusive principles
and declarations about the rights of people with learning disabilities and their families. The promise to make consultation the bedrock of an inclusive approach to planning and strategic management at the local level was enthusiastically welcomed. The establishment of demonstration sites (Vanguard areas) where there would be an early concentration of resources to illustrate quick wins and to show the way forward created lots of interest, but also some cynicism. The cynics were proved right. Early on the practice of consultation was without guidelines and was too unfettered. County planning was held back by lack of adequate consultation with users and carers, the Welsh Office rightly exercising its veto powers in requiring local plans to be resubmitted in most cases. Resources therefore were not provided on schedule. All this generated a severe reality check and widespread disillusion, especially among people with learning disabilities and their families who were pinning their hopes on the much vaunted changes anticipated. This experience is written into a comprehensive evaluation of the All Wales Strategy (Felce et al. 1998) so it cannot be claimed that this was unknown or that the lessons were not available.

Messages about policy implementation milestones are summarised in Box 5.1.

**Box 5.1: Developing policy implementation milestones**

- Policy implementation milestones are useful in holding people to account, but the consequences of failing to meet them can lead to disillusionment among service users and their families at the very time when commitment all round is needed.
- Such policy failures can undermine the very ambitions they are seeking to fulfil, and this is nowhere more evident than in helping people to achieve independence.
- Policy lessons, perhaps because they are viewed as historical and therefore out of date, or because they were borne of experiences in other countries of the United Kingdom, can be too easily dismissed.
- It is important to establish a baseline from which to measure achievements.

**Establishing a baseline from which to measure achievement**

When it was published, *Valuing People* not only made very clear its principal objectives (see Chapter 1 of this report) but in an annex it also laid out its sub-objectives, targets and proposed performance indicators. However, not all of the objectives had performance indicators tied to them. *Valuing People* recognised that national data about the lives of people with
learning disabilities were underdeveloped and that decisions were yet to be made about what activities should be the subject of regular statistical returns. This led to the commissioning of the BM study. This study located and mapped national data sources relevant to services for people with learning disabilities, and involved wide-ranging consultations with different stakeholders about what information should be collected to assess the impact of Valuing People. We summarise the findings from this study here because they are relevant to a reconsideration of all of the main ambitions of Valuing People.

The first phase of the study provided confirmation of some long-standing difficulties with available databases:

- information in statistical returns often lags behind policy;
- there are quality and reliability problems with existing statistical returns;
- there are limitations in the types of information collected through statistical returns, largely because of the dependency on quantitative data and inconsistencies in working definitions, not least in the operationalisation of learning disabilities (also confirmed in the HF study);
- a lot of data are inaccessible, and some agencies make charges to make data available;
- a lack of joined-up working between government departments in the collection of statistical data makes processing it difficult;
- most of the data are collected at the level of services rather than at the level of the people using specialist and mainstream services;
- Valuing People objectives are broadly cast and do not capture all the necessary factors that usefully demarcate changes in people’s lives.

Based on the consultations with stakeholders and the direction of government policy towards self-directed, personalised support, the BM researchers developed five principles for the creation of future national statistics on people with learning disabilities (Box 5.2)

**Box 5.2: Principles for creation of national statistics**

- National statistics and performance indicators should place greater emphasis on outcomes (the life experiences of people with learning disabilities) rather than on resources or service activities.
- People with learning disabilities and family carers should have a central role in shaping the outcomes agenda, especially in relation to what types of information should be collected and the conditions surrounding their access and use.
Box 5.2: Principles for creation of national statistics (continued)

- Data collection should be based on the totality of the lived experience rather than being activity-based.
- National statistics should reflect government policies and their linked objectives.
- National statistics should have the capacity to document potential areas of inequality – between people with learning disabilities and the general population, and within the population of people with learning disabilities.

There are important assumptions in these principles that merit further discussion here. First, the outcomes focus is a reminder about who and what is important. As primary beneficiaries of the White Paper, people with learning disabilities, not services, need to be centre stage. Secondly, as people’s aspirations and circumstances never stand still there is a need to revisit on a regular basis the values and norms that underpin them as these are likely to provide important clues about quality standards. Thirdly, services for most people with learning disabilities represent only one domain of support in their lives – families, peer support networks and wider communities of interest can be other sources of support, added to which is self-care. In evaluating outcomes, therefore, services are only one of the important contributors. Finally, as is indicated elsewhere in this and subsequent chapters of this report, different kinds of inequality persist. These need to be monitored in their own right, if only to serve as a salutary reminder of the low starting point, even in 2007, from which changes and improvements in people’s lives are being gauged.

The Office for Disability Issues (2006) in its first annual report *Improving the Life Chances of Disabled People* is conscious that there is no ‘gold standard’ measure of disability, and that it is critical now to move forward the development of outcome-based indicators to measure progress towards the goal of achieving substantive equality for disabled people by 2025. In the interim, the intention is to involve stakeholders, including disabled people, in developing relevant measures, and in publishing these in future annual reports. The BM study findings make an important contribution to this task.

We now look more closely at the specific evidence from the LDRI studies to chart progress and challenges in helping people to lead independent lives.

**Early steps towards independence?**

Based on an analysis of the first years of seeking to make *Valuing People* work, the SFC study provided some early evidence about
steps towards independence based on the perspectives of local commissioners. Achieving change was seen to require a number of linked factors to be in place. First among these was the recognition that ‘without constant referral back to core principles, practice may be distorted by budgetary pressures or brought to a halt by the inertia of existing systems’ (SFC, p.53). Interviews with commissioners, however, highlighted that they were alert to the possibilities of engaging change in creative ways, but also aware of dilemmas that could be enduring. Examples are as follows:

**Person-centred planning**

- rolling out person-centred planning carefully and, if necessary, slowly so that it does not lose its radical, empowering essence (O’Brien and Towell 2004), while at the same time managing the equity implications;

- recognising the dependence of person-centred planning on having in place services or supports that allow a person-centred approach to be achieved – implying access to mainstream services and community resources and facilities;

- implementing person-centred planning while ensuring that it was locked into ways of informing local strategic and population planning;

- integrating person-centred planning with care management.

**Housing**

The SFC study describes commissioners as struggling to get housing right because of capacity issues and pressures on budgets. Funding was ‘locked up’ in existing provision; independent sector providers feared that changes would lead to a collapse of their viability; and there was a shortage of affordable housing in many parts of the country. But successes were noted with regard to securing improved understandings and partnerships with housing associations and councils so that people with learning disabilities were entitled to the same options as other citizens, and shared ownership developments were beginning to open up. On the other hand, securing change with new-build developments to establish options for people with learning disabilities seemed to be more difficult, and indeed experience of this was still rare at the time.

**Productive engagement in activity**

It was reported that, as in the case with housing, partnership work with employment agencies was ‘slowly beginning to develop’, but limits were being reached already in sustaining people in supported employment who still needed support. Resolving this was seen to require the active involvement of the DWP. The welfare benefits trap was recognised early on as an obstacle to supported employment. In the words of one commissioner interviewed:
If we can have major change around [welfare] benefits and other things like that, we’ll get a lot more people into work. That’s a big issue, it’s a national issue and unfortunately I don’t think that’s picked up properly but there’s not a lot I can do about that one. (SFC, p.67)

Most commissioners realised that Valuing People’s goals would require long-term effort on the part of all stakeholders. When asked what they would most like to change, commissioners:

... mentioned cultural change within organisations. Modernisation of day services came a close second, followed by a desire to expand job opportunities and improve options for young people at transition and, at a more fundamental level, to change attitudes towards people with learning disabilities in society at large. (SFC, p.71)

This early evidence in a sense confirms the scale and complexity of system change. Much will rest on interdependencies between partner organisations and on subjugating organisational self-interest in favour of a collective commitment to meeting the needs and aspirations of vulnerable citizens. The history of joint working in health and social care confirms, if confirmation were needed, that this implies a long haul movement towards positions based on mutual understanding, respect and trust between organisations (Hudson et al. 1999).

We now look in more detail at the relationships between some of the provisions of Valuing People and claims about independence.

**Planning for ‘person-centredness’**

It is tempting to place person-centred planning into a similar category as clinical interventions since it can be argued that both involve ways of working with people. However, person-centred planning is more correctly seen as a way of engaging with people with disabilities and their allies in personalising their supports. This means that there is as much interest in the influence of person-centred planning on the design and delivery of services such that services are more consistent with the principles of Valuing People. In short, person-centred planning is as much about change in service delivery as it is about change in people.

Drawing heavily on the PCP study, we comment here first on changes, or lack of them, in service delivery linked with person-centred planning, as these findings help to explain outcomes in individuals associated with person-centred planning, which we discuss later. The main observations about linked service delivery changes are summarised in Box 5.3.
Box 5.3: Embedding person-centred planning in the system

- Political and strategic leadership for person-centred planning was poor. Confirming the SFC study, there was limited evidence that person-centred planning was being used to inform strategy planning.

- There was a lack of clarity about what person-centred planning meant both in theory and in practice.

- Knowledge about what was happening locally in relation to implementation was uneven.

- First-tier managers were pivotal in either helping or hindering staff to pursue plans.

- High staff turnover in some organisations required continuous revisions to staff training and preparation for person-centred planning, but effecting the necessary change in culture towards person-centred thinking required the involvement of users and carers as well. This on its own is a substantial agenda.

- Person-centred planning and care management were insufficiently linked; there was tension between the informality of person-centred planning and the formality of statutory care management processes; and some care managers were unsure of their role in

Box 5.3: Embedding person-centred planning in the system (continued)

person-centred planning, meaning that person-centred planning may not lead seamlessly to changes in personalised services and support.

- A heavy burden was placed upon circles of support to deliver good outcomes for people, but they often felt that their powerlessness and lack of influence prevented them from doing so.

These findings were based on localities where there was commitment to staff development work to make things happen. A concern is the typicality of these experiences for the rest of England where comparable commitment cannot be presumed, though this of course does not preclude the possibility that other localities were better prepared. These findings do confirm that the guidance published about person-centred planning (Department of Health 2002b) was correct in asserting that person-centred planning cannot substitute for high-quality leadership, adequate resources efficiently used, skilled and energised staff, or service development work and system changes. Nevertheless, these findings suggest that structural and organisational factors were indeed holding back the full implementation of person-centred planning, leading to some uneven provision and practice. These important
‘contextual’ factors need to be borne in mind when examining the ‘harder’ evidence about outcomes for individuals associated with person-centred planning, for they suggest that practice as implemented did not reflect the theory in its intended form.

So what was that evidence? We comment here on access to person-centred planning, personal outcomes relevant to independence and factors associated with outcomes.

Access to person-centred planning

The PCP study demonstrated that there were ‘winners and losers’ in relation to whether or not people gained access to person-centred planning. Those less likely to gain access to person-centred planning included people with:

- mental health or emotional or behavioural problems;
- autism;
- more health problems;
- restricted mobility.

By implication, those more likely to be accessing person-centred planning were people with less evident signs of mental health problems, autism, other health problems and restricted mobility – in short, people with arguably less pressing needs. While this seems to represent a powerful inequality in the delivery of what is regarded as one of the core commitments of Valuing People, it will be recalled that Valuing People is silent vis-à-vis people with autism, people who offend and people with multiple impairments. From the data, it is not possible to gauge whether the roots of this inequality are tied to services seeking ‘quick wins’ where they could see immediate pay-offs for certain groups of people, or whether it is linked to the articulations and preferences of people with learning disabilities themselves about person-centred planning. The PCP study did demonstrate, however, that contextual factors were implicated in the likelihood of someone having a person-centred plan or not. Key factors here were:

- the existence of more person-centred ways of working prior to the introduction of person-centred planning;
- a facilitator with high personal commitment to person-centred planning;
- having a key worker;
- living nearer to one’s family.

These findings can be used to register concerns about wider inequalities in provision for people with learning disabilities.

Further evidence about inequalities was reported in the national sample survey of adults with learning disabilities by Emerson et al. (2005), which showed that, in relation to
inclusion in civil society, personal relationships, personal safety and control, people with high support needs, poor health and lower incomes fared worst of all. Another indication of what seems to be an underlying and serious inequality in this context is evidenced in the recent Mansell Report (2007), which shows that for people with learning disabilities who have challenging behaviour or mental health problems there is a high risk of services breaking down, with individuals being uprooted from their home communities and subject to expensive out-of-area placements that are less than effective. The consequences, therefore, of failing to find personalised solutions, beginning with person-centred plans, but requiring also improved and more comprehensive local services, can be very costly in personal and economic terms.

Person-centred planning outcomes relevant to independence

The PCP study set out to assess the possible links between person-centred planning and a range of personal outcomes. Person-centred planning was found to be associated with some important domains of quality of life, notably social relations (community involvement, contact with friends, contact with family) and also choice. At the same time, it had no apparent impact on other domains, such as more inclusive social networks, employment, physical activity and medication, and indeed there were three areas (risks, physical health, and emotional and behavioural needs) where the evidence of change was in a negative direction. Because the results are based largely on statistical analyses, causal links cannot and should not be imputed from these findings. The PCP researchers contemplated a number of possible reasons for these outcomes, before coming to the following conclusion:

*These results are consistent with the position taken in Planning for People (Department of Health 2002b), which argued that PCP would be helpful but not enough in itself to promote social inclusion and that additional action would be required to complement improved planning with individuals. Such action is likely to include, for example, positive action to remove barriers to employment and mainstream housing options and to encourage specialist services to play a stronger role in enabling more inclusive social networks.* (PCP report, p.105)

This conclusion is also consistent with the observations described earlier about the problems for *Valuing People* in meeting health and employment milestones, and also with the findings from the SFC study that highlighted particular challenges associated with the speed of development of housing and employment services. Perhaps the bigger message to take from this is that opportunities for people with learning disabilities to express their
indirect measures are unlikely to come about until whole systems change (Hudson 2006). The question that now has to be asked is: how long will people have to wait?

**Employment, productivity and independence**

It is fairly well accepted in western societies that paid work or engagement in purposeful activity is conducive to the achievement of self-worth, social integration and independence. Although there are competing theoretical perspectives about ways of understanding these connections (Hammell 2004, Dickie, Cutchin and Humphry 2006), there is growing convergence about the need to capture what this means as expressed by people through their chosen occupational experiences.

With still small numbers of people with learning disabilities in paid work (Emerson et al. 2005), the SE study concerned itself with exploring how supported employment initiatives were organised and what impacts they had on productivity and social inclusion. Here we summarise what the study had to say about productivity.

When other variables were taken into account, it was found that in relation to hours worked:

- disabled women worked fewer hours than disabled men;
- people with learning disabilities or mental health needs worked fewer hours than other disabled people;
- not being on benefits was associated with greater productivity for all disabled people;
- clients of employment officers who were shown to practise supported employment according to the theory worked longer hours;
- clients of employment officers in Jobcentre Plus settings worked longer hours on the whole than those in Workstep and supported employment settings.

There was therefore evidence suggesting the existence of inequalities in the workplace, associated with gender, disability label, being on benefits and the structure of supported employment itself. However, getting and keeping a job was not enough – people wanted career progression as well. In maintaining their current jobs, individuals named lots of people as sources of help and support – and it was important that this support was accessible to them. In over 80% of cases, supporters were judged to be easily contactable.

As the SE researchers summed up:

*The general picture of our respondents’ experience of working life is of task-based roles, following a routine, not doing particularly skilled work, and having low levels of autonomy and responsibility. All of the jobs are ‘entry level’, sometimes called secondary sector jobs, characterised by low wages, low skill levels, poor working conditions, little
job security, and few if any possibilities for advancement... We found that many people wanted more responsibility or more autonomy in work, which implies that training and job enhancement programmes should be put in place to achieve this progression. (SE study main report, p.23)

The SE researchers also confirmed evidence about structural barriers to employment. Notable among these were the attitudes and awareness of employers and the public, benefit rules that limit the number of hours people can work, time-limited funding for employment initiatives and lack of accessible qualifications for employment officers. These findings amplify and confirm what the SFC study had to say about employment. There were clearly successes in getting people into work and in supporting them in the workplace. In this respect, presence as physical integration in the workplace had been achieved, but many people had as yet unfulfilled aspirations for job security, advancement and recognition, not unlike the wider workforce. As will be seen in the next chapter on inclusion, this also raises important issues about feeling part of the workplace and having a future to look forward to.

Since the completion of the SE study in 2004, there has been continuing consultation and debate about these matters. By 2006, a working group report had been published on barriers to employment faced by people with learning disabilities, co-chaired by the Department of Health and the Department for Work and Pensions (Department for Work and Pensions 2006). The report makes sweeping recommendations to address the take-up, maintenance and quality of work and work preparation experiences of people with learning disabilities, embracing in the process many of the concerns expressed by the SE and SFC studies.

The working group report appears to adopt a very clear position about dealing with the long-standing structural barriers to employment for people with learning disabilities – especially through leadership and co-ordination of inter-agency and inter-governmental work on employment support, widened work experience opportunities, joint staff training, more flexible funding to help those ‘hardest to help’ into employment, and removal of barriers that prevent people working longer hours if they wish to. The BM study contains recommendations for collecting and disseminating accurate and integrated employment statistics for people with learning disabilities, with an emphasis on outcomes related to people’s experiences, something acknowledged and affirmed by the working group report.

The intention of the Department for Work and Pensions, declared in the working group report, to consider the need for research to understand better the current provision and distribution of supported employment services for people with learning disabilities in the UK will present a good opportunity to establish what further progress has been made with the above recommendations in mind.
In its recent annual report, the Learning Disability Task Force (2007) confirmed that many people with learning disabilities who want jobs cannot get them, that there should be systems and rules to help them get into and keep work, and that the recommendations of the working group report should be implemented. More recently, the Office for Disability Issues has set up a cross-government group to examine how best to address the report’s recommendations.

New contexts are arising that perhaps permit a broader view to be taken of what employment and productivity mean for many people with learning disabilities. It has been suggested, for example, that:

*The definition of work should include those activities that people with disabilities undertake in the management of daily living, including the employment of personal assistants, and the creation of employment opportunities for others.* (Pavey 2006, p.226)

This broader definition, which incorporates the application of entrepreneurial spirit, could for Pavey.

*Also include recognition of disabled people’s power and status as consumers and as direct and indirect employers, and for young people with disabilities or learning difficulties, the development of skills to be managers of the enterprise of their own lives.* (p.227)

The intention to roll out Direct Payments and Individual Budgets to more people with learning disabilities, coupled with the emphasis in health and social care policy on self-management (Department of Health 2006), would suggest that this broader view of work has important implications for the implementation and monitoring of employment policy.

**Observations and conclusions**

Several messages emerge from reviewing evidence about steps towards independence. These seem to revolve around five issues.

**Balancing ideals against pragmatism**

There are indisputable advantages in having a strategy with high ideals, as these inspire, give hope and galvanise people to action. This has been apparent in other similar national policy initiatives for people with learning disabilities (Welsh Office 1983). Further, the publishing of milestones for strategy implementation is a useful device for charting progress and holding everyone to account. At the same time, when several key milestones are neither met nor even nearly met, the consequences can be demotivating. When those milestones signal requirements that can make a difference to people achieving independence, then the situation becomes even more serious. The failure then to achieve the intended milestones for employment and mainstream health provision has frustrated the achievement of goals for independence and has undermined...
the potential of person-centred planning to achieve its ambitions in this regard. Person-centred planning cannot achieve its ambitions alone, as the PCP researchers acknowledge, without the structures and resources to help people being in place.

**Processes versus outcomes**

Current database systems are riddled with incompatibilities that complicate or make impossible the harmonisation of intelligence systems between health services, local and national government. Added to this are quality and reliability problems. The design of these systems is outmoded in two main respects: the present focus is on inputs and processes rather than outcomes and user experiences, and on services rather than on the people who use them. This severely compromises efforts to monitor steps towards independence, or indeed any of the other main *Valuing People* ambitions, and to develop an understanding of the mediating factors involved.

**Inequities in personalising support**

There appear to be ‘winners and losers’ in terms of who gains access to person-centred planning and also who benefits. The benefits were also unequally distributed across outcome domains, and some outcome domains – such as employment, physical activity, risks, physical health and emotional and behavioural needs were poorly served – by person-centred planning. Follow-up work will be required to establish whether and how, as hinted above, this is related to the lack of development of structures and resources.

**The persistence of structural barriers**

It was shown in the SFC and SE studies that long-standing structural factors seemed to be impeding employment and improved pay for individuals. Career ambitions were far from being fulfilled. The Learning Disability Task Force and the Office for Disability Issues have been looking into these issues to see how they can be addressed.

**Employment and the entrepreneurial spirit**

The advent of Direct Payments and Individual Budgets is beginning to change the meaning of employment and productivity, as people with learning disabilities become employers and commissioners who have a direct influence on the labour market, and correspondingly on the ways in which social capital is reproduced. This is likely to change how we come to understand what independence means to people. Although this issue was not the subject of study in the LDRI, it is bound to have some bearing on a refreshed *Valuing People*, as is consideration of inclusion, the fourth of the *Valuing People* principles discussed in the following chapter.
Chapter 6: Inclusion

Background

As highlighted in Chapter 2, the social model of disability embraced by Valuing People has the merit of proposing, with considerable justification, that the institutions of civil society and even services themselves can be major barriers preventing people with learning disabilities from participating fully in society. However, in their attempt at decoding Valuing People, Burton and Kagan (2006) suggest that it represents an uneasy amalgam of the progressive and the neoliberal, the romantic and the practical.

Pointing to characteristics of a locally typical population of people with learning disabilities, they suggest that:

if inclusion is to happen, there needs to be a realistic assessment both of the level and types of supports that are required, and of the long haul involved in such a social transformation that has to work against disablist ideology, the legacy of discrimination, abuse and continuing physical and social disadvantage. Failure to do this risks cynicism and a return to negative expectations. (p.306)

This last observation captures a critical point in the debates surrounding inclusion. Without wishing to become tied up with too much theorising on this issue, it is important to draw a distinction between social inclusion as a ‘means of ensuring that people with learning disabilities have full and fair access to activities, social roles and relationships directly alongside non-disabled citizens’ (Bates and Davis 2004, p.196) as opposed to social capital which, following the influences of Bourdieu (1986), Putnam (2000), McKenzie and Harpham (2005) and others, emphasises the importance of social networks, trust, contributions, reciprocity and power. Contrasting the two approaches, summaries might point to different views of inclusion:

- Social inclusion emphasises:
  - engagement in activities
  - social roles and identities
  - social contacts – frequency, intensity, functions.

- Social capital emphasises:
  - social networks as conduits for making contributions and connections
  - valued qualities of relationships
  - reciprocities among individuals, groups and facilities
  - a distributed series of relationships based on trust as a source of empowerment.

It would be wrong to over-emphasise the differences between these perspectives as there are points of convergence, so they are best regarded as complementary to each other. The
In addition to the above, there was some evidence suggesting that person-centred planning enhanced opportunities for people with learning disabilities to engage mainstream health, social care and community services including advocacy, dentistry and chiropody, and also specialist services such as occupational, art, drama or music therapy. Although these changes were in the right direction they were statistically non-significant. This evidence points to measured gains on the social inclusion agenda rather than the social capital agenda, though it should be said that this may have been due to the way the research operationalised its questions and outcomes. Social capital foci lay largely outside the PCP study, so we cannot say for the moment whether or not social capital gains also occur. However, part of social capital theory is that social networks and social contacts represent a kind of ‘opportunity structure’ for more enduring, trusting and reciprocal relationships to develop. These conditions and outcomes may already be in place but they were not measured by the study, so prospective or follow-up studies are needed to establish whether social capital gains flow from improvements in social inclusion.

These positive impacts on social inclusion outcomes were not pervasive, however. For example, people with mental health or behavioural problems who had person-centred plans were found to be much less likely to
benefit in social inclusion terms. Bearing in mind that this is a group of people who are less likely to be part of a person-centred plan in the first place, this once again reminds us of the difficulties of securing good coverage of PCP not only in terms of its implementation across its intended community of interest but also in terms of its outcomes. In this it seems to bear out what Burton and Kagan (2006) had asserted about the ease with which the conditions of people with significant impairments can be glossed over. Issues of equity that arise from this were recognised by the PCP researchers and we return to these in Chapter 9.

In relation to securing access to and use of mainstream healthcare, an important part of the inclusion agenda, the HF and CC studies charted a number of challenges. The HF study showed that implementation of health facilitation was hampered by systemic difficulties, prime examples being lack of capacity within primary care teams to deal with the requirements of health facilitation, intransigence and apathy on the part of GPs who questioned the evidence base for health facilitation, and even confusion about the health facilitation role itself. Similarly, in the CC study GPs appeared to adopt an overriding 'safety first' approach when advising women about contraception and HRT, leading to an over-reliance on the contraceptive pill and Depo-Provera. Consultation styles of GPs did little to enhance the sense of personal agency in women with learning disabilities, reinforcing dependency on their families or support workers as spokespersons. The CC study also provided independent evidence about the lack of availability of health facilitation and Health Action Plans (HAPs).

Key messages about inclusion emerge here (Box 6.1).

**Box 6.1: Tackling the roots of inequalities in social inclusion**

- There are clear signs that progress has been made towards inclusion of people with learning disabilities in personal networks and community activities, and that to some extent there have been improvements in their access to mainstream health services, but there is less certainty about the social capital gains. This needs to be investigated further.
- As with gains related to independence, inclusion was not equally distributed across all people with learning disabilities. The system-induced inequalities in this regard need to be tackled.
- In relation to accessing community health services, problems of supply, style of delivery and even confusions about new roles were hampering progress. Issues of resources, structure and professional education need to be addressed to correct these systemic problems.
Inclusion and Partnership Boards

Part of the remit of the SFC study was to examine the early experiences of people with learning disabilities and family carers on Partnership Boards, the primary vehicle at the local level for planning and delivering the right services. Family carers, like some of the other stakeholders, while energised by the prospects of being drawn into consultation, were less than happy with the lack of executive responsibility held by Partnership Boards. This led to a tension between a focus on involvement and debate on the one hand and action on the other.

Issues (which were not fully resolved in the early years of Partnership Boards) arose about statistical versus democratic representation – in other words whether stakeholders, particularly service users and family carers, were supposed to reflect the wider interests of their constituencies in a demographic sense, whether they were elected or appointed to Partnership Boards with a mandate to speak on behalf of their constituencies, or indeed whether they were present in their own right. It appears from other experiences of integrated working and governance that the outcomes of these different arrangements for representation are less well evidenced (Glasby and Peck 2004). As Edwards (2006, p.21) has also commented in her discussion of service user and carer involvement in partnership work:

There is little if any research focus on change not sustained, initiatives that fail or groups that collapse, so we may be missing opportunities to learn from mistakes. Partner organisations could benefit from reviewing their respective histories of service user and carer involvement to avoid repeating mistakes and identify what worked.

The SFC study raised some further dilemmas about the operation of Partnership Boards. On the one hand there was evidence of much creative work in producing accessible or easy-read information to optimise the involvement of people with learning disabilities; but at the same time other stakeholder groups, for example, family carers, found this information less helpful. There were signs that more action was enabled when partner agencies such as housing departments and organisations representing wider community interests were on board. Years later these were still issues to be addressed, and though there are clear signs that the performance of Partnership Boards varies considerably, there are lots of success stories (Snell 2007).

In microcosm, Partnership Boards can be seen as an attempt to operationalise whole-system working. As Hudson (2006, p.21) has suggested, this:
offers no simple solution and is difficult to achieve... Much more will be heard about whole system working over the next few years, and much more will be demanded of those managing and working in inter-dependent domains. Doing nothing will not be an option.

The implications are summarised in Box 6.2.

**Box 6.2: Service user inclusion in governance**

- The conflict of interest between service user inclusion in planning and the need to maintain efficiency of consultation dedicated to decision making needs fuller recognition. The publishing of ‘success stories’ by Partnership Boards is likely to be helpful in illustrating how this tension can be addressed.

- Attention needs to shift from describing how service user inclusion in planning works, to what outcomes follow.

- Maintaining a focus on effective Partnership Board functioning will be important in highlighting ‘joint systems thinking’ in action, and as such will benefit the wider health and social care policy community.

### Transitioning and inclusion

Valuing People recognised that continuity of care and support is essential for young people with learning disabilities to move into adulthood. It also emphasised a commitment to equality of opportunity to enable as many disabled young people as possible to participate in education, training or employment. To this end, the Connexions service was to be rolled out to provide all 13–19-year-olds with access to advice, guidance and support through the creation of a network of personal advisers. Advisers were charged with identifying young people with learning disabilities, attending annual reviews of all year 9 pupils with statements of Special Educational Needs, and working with schools and other agencies to draw up transition plans. The Connexions service was also to have responsibility for arranging with the local Learning and Skills Council and the employment service a review for each young person in their 19th year so as to agree transition arrangements. These arrangements could be extended until the young people were aged 25.

It was also expected that local agencies would have introduced person-centred plans for all young people moving from children’s to adult services by 2003. Continuity of health planning was to be assured through the new HAP system, with social care requirements being driven by the Social Care Quality Framework.
In publishing the Green Paper *Every Child Matters*, the Department for Education and Skills (DfES) (2003) emphasised five outcomes that were central to maintaining integrated support for children and young people. These were to form the basis of a common assessment framework:

- being healthy – enjoying good physical and mental health and living a healthy lifestyle;
- staying safe – being protected from harm and neglect;
- enjoyment and achievement – getting the most out of life and developing the skills for adulthood;
- making a positive contribution – being involved with the community and society and not engaging in anti-social or offending behaviour;
- achieving economic well-being – not being prevented by economic disadvantage from achieving full potential in life.

The subsequent Children Act 2004 provided the legislative framework to take forward *Every Child Matters*, and Ofsted (2005) published a framework for the inspection of children’s services based largely on the five outcomes.

Early evidence from other research showed that young people are not directly involved in transition planning (Ward et al. 2003). Heslop et al. (2002) have reported that a fifth of young people with learning disabilities in their study left school without a transition plan, while Hatton et al. (2004b) described none of the South Asian parents of severely disabled children in their UK study as having any knowledge of transition plans for their children. These reports back up a large number of other early commentaries, many headlined in the national press, suggesting that schools were indeed slow to embrace the broad agenda set out by the Green Paper.

We now examine what the SL study found, concentrating as it did on the experiences of school leavers with learning disabilities with respect to its special focus on ethnicity.

**Young people, transition and inclusion**

The SL study was the first of its kind to provide first-person accounts of transition experiences by young minority ethnic people with learning disabilities and their families, although the study also involved white families from the same localities. It is worth comparing the views and experiences of the young people and their families (see p83), as some important differences arose.

For the young people:

- the immediate family (mostly parents and siblings) was the most constant source of practical and emotional support;
• friendships were limited; they were even less in evidence among young people with high support needs;
• instances of bullying were reportedly quite rare;
• South Asian youngsters were less likely to be involved in community leisure pursuits than non-South Asian youngsters.

Regarding transition outcomes:
• placements were far from meeting young people’s aspirations in regard to activity or work preferences;
• loss of friendships was common during transitions, but family support remained constant;
• transition options from school for young people with high support needs were more restricted, with a dependency on day centres;
• transitions from college were problematic, with apparently fewer viable options and histories of placement breakdowns.

From these findings, albeit based on a relatively small sample of young people, it is evident that social life is heavily circumscribed by dependencies on families. Friendships, another source of bonding social capital given relations based on trust and reciprocity, were limited, and all the more so for young people with high support needs. Further, friendships were often lost during transitions. The SL research did not set out to assess the consequences of these variations and changes in patterns of friendships, but it does allow us to raise questions for others to pursue about the potential threats to identity formation and social capital building for the young people involved.

Families, transition and inclusion

Less than half the parents interviewed had knowledge of a transition plan, despite the fact that their sons or daughters only had 12–18 months left at school. Lack of knowledge and degrees of confusion about transition procedures typified parents’ experiences, and were more pronounced in South Asian families where lack of attention by education, health and social care agencies to linguistic and cultural factors impeded communication. There was too little evidence to establish whether socio-economic factors were also implicated here.

As a result of this lack of knowledge, it was difficult for families to envisage futures. They were, on the whole, keen for their sons and daughters to become more involved in different kinds of community activity, but the practicalities of transportation and perceptions of unresponsiveness from community organisations were cited as barriers.
There were cultural dimensions to some of the observations families made about fuller community inclusion, and these seemed likely to shape behaviour. Three typical quotes from families make this point forcibly:

- ‘if there’s loads of other Muslims there [supported accommodation] and depending on what kind of environment, Halal food, then maybe. But if there is drinking, going out with girls, I don’t want him, I wouldn’t want to think that was normal, to drink or whatever.’ (British Pakistani mother);

- ‘i stopped her going swimming because we’re Muslims and because it’s a mixed group, and the teacher is quite understanding of that.’ (Pakistani father);

- ‘there’s a few people that are saying ‘why’s he coming here [to the mosque]?’, which is really horrible, I think. Certain people that come to pray. I think they have images that he is different and they have made some rude comments.’ (British Pakistani mother).

These comments are interesting for several reasons. The first and second quotes can be used to make a case for the primacy of bonding social capital (Putnam 2000), meaning that families would really only be prepared to contemplate inclusion with their own community of interest where culturally congruent practices can be enacted. In this context bridging social capital, which brings diverse groups together, is interpreted as unacceptable. By contrast the third quote illustrates the opposite view, in which bonding social capital is seen as negative or unhelpful. Other researchers studying the lives of South Asian families with disabled children have similarly reported support from religious organisations to be variable (Hatton et al. 2004b). This leaves a dilemma as to what the approach to community inclusion should be in these contrasting situations:

- leave the situation as it is (which seems unacceptable)?;

- focus on persuading the community of interest to be more accommodating, but by dint of doing so run the risk of separating individuals and families from the wider community and reinforcing difference between communities of interest?

There would appear to be no easy answer. It may be that a diversity of approaches when tested may produce a range of preferred options.

Families seemed to have different perceptions of the young people’s friendships to those of the young people themselves, characterising them more as acquaintances than relationships based on reciprocities. Families also reported teasing and bullying as occurring more frequently in the lives of their sons and daughters than did the young people themselves. It is difficult to gauge from the available data whose perspectives were most trustworthy or authentic.
Less than half the families were happy with transition outcomes, largely because of the lack of ‘fit’ between the person’s circumstances, needs and aspirations and what provision was available. Most families remained unaware of the work of the new Connexions service.

As the SL researchers have suggested earlier, the complex dynamics involved in moving young people with learning disabilities to independence are mediated by risk, relationships, structural problems with services and their own constructions of self-identity (Small et al. 2003). In modern societies the contrast between young learning-disabled adults and mainstream youth is vast. The interaction between their ‘place’ and their personal histories leaves those with learning disabilities looking very isolated, despite the best efforts of contemporary policy. Implications stemming from the experience of transitioning are summarised in Box 6.3.

**Box 6.3: Inclusion and transition**

- Transition experiences of young people and their families are marked by incomplete transition plans and, in some cases, a lack of awareness of such plans. Better information, awareness and provision need to be promoted.

- Placement options in their present form do not suit all young people. Coupled with the fact that transitioning often leads to a depletion of their social capital, especially friendships, the picture is rather bleak.

- The work of the Connexions service needs to focus on the five core outcomes of *Every Child Matters* (DfES 2003) to ensure integrated support for young people.

- Bridging and bonding social capital prospects are perceived by some Asian families as being unacceptable. This leaves a policy dilemma, with the public intent of the social inclusion agenda and the private aspirations of families being on a collision course. Further debate is required about this.
Inclusion and employment

One of the commissioners interviewed in the SFC study makes the point about inclusion well:

*What we say about supported employment is it's not about earning a wage, it's about achieving inclusion. Although people must have an equal wage to somebody else in the organisation – that is one of our strict rules – but the real benefits are far beyond.* (SFC study, p.67)

Earlier it was argued that independence and inclusion were closely related, and that it is difficult to envisage one being accomplished without the other. This was clearly evidenced in the SE study. In about half of the sample of employed people who were interviewed, there was integration with work colleagues, but others worked mainly on their own. Most of those interviewed appeared to get on well with their work colleagues but 40% did not have what they regarded as close friends at work. Some felt isolated, bullied and unhappy at times. This was shown to be more common where they felt they had little control over their job, lacked adequate supervision or had few natural supports.

Some of these experiences appeared to be linked to the type of work those interviewed had taken on, much of which was depicted as ‘menial’, and included experiences such as standing all day, sweeping up, quiet days, having too much work to do or too much discipline. It was evident that the interviewees did not like these experiences. This seemed to breed further problems, such as worrying about doing things wrong or perhaps not fully realising what to do if unreasonable demands were being made.

Environmental and structural factors that defined the workplace seemed therefore to have a hand in constraining both bridging and bonding social capital. People were often physically isolated from colleagues or given boring or menial jobs to do that did not require social interaction, and these factors were largely beyond their control.

However, over three-quarters of those interviewed thought they were doing a good job, as evidenced by indications of being acknowledged, thanked and valued.

It was suggested that a person can be judged to have a good-quality job and be satisfied if they:

- have close friends at work;
- socialise with colleagues;
- feel respected at work;
- feel valued by their supervisor;
- feel fulfilled at work;
- are treated the same as other workers;
are satisfied with the status of the job;
• have work aspirations that are met.

Interestingly, these criteria embrace both bridging and bonding expressions of social capital, thereby suggesting interdependencies between these two forms of capital.

The SE researchers applied the above criteria in testing a model to see what factors – personal, environmental and employment officer roles – were related to social inclusion in the workplace. The results indicated that there were several areas that employment officers could address to improve social inclusion in the workplace (Box 6.4).

The overall picture of social integration in the workplace is therefore very mixed, with much development work still required to enable more people with learning disabilities to feel an integral part of the workplace. This confirms earlier research findings about supported employment (Beyer, Goodere and Kilsby 1996). As the SE researchers state:

The target for people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships does seem to be attainable in some work contexts. However, this possibility is not universal. (SE study, p.23).

Box 6.4: What employment officers can do to improve social inclusion in the workplace

• Working with employers to promote acceptance and, where applicable, informal supports.
• Developing the ethos of the company around employing disabled staff.
• Dealing with clients’ difficulties in getting on with people at work.
• Encouraging social interaction at work.
• Investigating clients’ fulfilment, satisfaction with income and sense of status.
• Helping to ensure equality of treatment in the workplace, including being valued by employers and respected by work peers.
Judging by this evidence, the identity-affirming consequences of ordinary social relationships, whether these are associated with families and social support networks (Gourash 1978) or, in this case, with employers and colleagues, are far from being maximised.

The Office for Disability Issues (2006) has laid out ambitious reforming plans to improve the employability of all disabled people, recognising that people with learning disabilities or mental health conditions have the lowest employment rates. However, it is not clear from the ODI proposals whether the social integration dimensions of purposeful employment have been taken into account.

**Inclusion and standards of staff performance**

The JP study provided a different perspective on inclusion. By involving people with learning disabilities and families in panels about what makes a good housing support worker, it was found that they emphasised core competencies that professionals downplayed, especially good interpersonal skills, and relationships between service users and support staff. These aspects of support worker roles were not at the time emphasised in common vocational qualification frameworks such as National Vocational Qualifications and the Learning Disability Awards Framework. In addition it was considered that these core competencies might not require extensive training before support staff begin such work. What this points to is a virtuous circle in which the inclusion of people with learning disabilities in the development of competency-based staff measures for support workers leads to recruitment and training of people with the relevant attributes and competencies, and the consequent achievement of the kinds of personalisation in support arrangements that address service user and family needs in effective ways.

As the JP researchers suggest, there is likely to be merit in testing this procedure out in different contexts and across different groups of service users, though it will be important to take account of extrinsic factors such as pay, working conditions, supervision and organisational culture that also shape staff performance. Methods for evaluating the contributions of these different influences have been well rehearsed elsewhere (Hatton et al. 2004a).
Observations and conclusions

Perhaps wisely, Valuing People does not offer a tight definition of inclusion, though what it does suggest in talking about people ‘doing ordinary things’, ‘looking after families’, ‘using transport’ and so on is an interpretation that emphasises being in the mainstream and participating in the things that matter in life. As such this is an interpretation that emphasises being involved rather than necessarily feeling involved. Put another way, it brings out the distinction made in this section of the report between social inclusion and social capital. The LDRI studies touched on both of these dimensions of inclusion.

Planning for inclusion

It was demonstrated that person-centred planning had a strong influence on the ability of people to develop their ties with family and friends and to experience improved engagement with some mainstream services. This evidence clearly validates one of Valuing People’s main goals. To this extent it shows that significant strides can be made in fulfilling ambitions for social inclusion. Data were not collected about the social capital gains of person-centred planning, so it should not be assumed that gains in relation to trust, reciprocity and contributions did not occur. This needs to be investigated in future studies.

The HF and CC studies provided evidence suggesting that structural barriers tied to the capacity and resources of primary care teams, the working practices of GPs and the modest roll-out of health facilitation and HAPs were preventing many people with learning disabilities from accessing and using mainstream community health services.

Young people, transition and inclusion

The experiences of young people and their families in the SL study suggested that transition planning arrangements were not well developed. The young people’s social networks were found to be rather impoverished. Friendships were limited and less in evidence among youngsters with high support needs. It was common for friendships to be lost during transitioning. Hence an important potential source of social capital appears to be compromised by this experience, coming as it does at a time when young people are forming adult identities where there is a premium on enduring and meaningful relationships.

Culture, families, young people and inclusion

Culturally embedded norms appeared to shape the views of parents from the South Asian community about what kinds of community activities and social arrangements were acceptable. Views were expressed suggesting that bonding social capital could be as negative as it could be attractive, leaving a dilemma as
to the approach to be taken in setting social inclusion goals for young people and families from South Asian communities. **Bridging** social capital with other communities of interest was also problematic, but for other reasons. This matter requires further exploration and debate. Parents and young people had different perceptions of young people’s friendship patterns and also of their experiences of bullying, suggesting that different constructions of relationships and risks may be operating, adding to the complexities of the experience of inclusion during the transition period.

**Inclusion, the workplace and adulthood**

Progress in securing employment for some people was not necessarily matched by achieving inclusion in the workplace. Isolation was not uncommon and even bullying was reported by some people, with the strong suggestion that these experiences were often the product of the structure of the workplace itself. In the testing of a supported employment model it was found that both **social inclusion** and **social capital** measures were important in the judgement of what counted as success.

**Inclusion and staff performance**

A methodology was developed by JP researchers demonstrating the utility of an inclusive approach to establishing core competencies in a group of housing support staff. This seems to have potential in addressing part of the personalisation agenda in frontline practice where there is a premium on maintaining and benefiting from long-term relationships. The approach could now be usefully tested in other service contexts and with other categories of service users, especially those with high support needs and those from black and minority ethnic communities.
3 The wider contributions of the LDRI
Chapter 7: The wider contributions of the LDRI to policy

Introduction

With the publication of the White Paper *Our Health, Our Care, Our Say* (Department of Health 2006), the Government set a new direction for community services, premising many of its reforms on aspirations that parallel or consolidate those in *Valuing People*. It therefore seems sensible to re-evaluate evidence from the LDRI studies in the light of the White Paper’s aspirations. This helps to serve two important functions, one negative and one positive. First, it helps to avoid the risk that the LDRI will be viewed as a free-standing silo, relevant to only one group of people who happen to share a particular label, or to one strategic imperative, *Valuing People*. It would be a disservice to everyone involved in commissioning, managing, advising or implementing the LDRI studies for this body of work to be constrained in that way. Secondly, given the evidence from the LDRI studies and the themes they address, they can be seen as contributing knowledge to the Government’s reforming agenda for adult community services.

In this section of the report we therefore identify the aspirations in the White Paper and then distil what we think are the main messages from the LDRI studies that are relevant to the fulfilment of these aspirations.

*Our Health, Our Care, Our Say* promises a radical and sustained shift in the way services are delivered – ensuring that they are more personalised and that they fit into people’s busy lives. We will give people a stronger voice so that they are the major drivers of service improvement. (Department of Health 2006, pp.6–7.) Four connected main goals are identified, with an emphasis on:

- prevention and early intervention;
- more choice and voice for service users;
- tackling of inequalities;
- more targeted support for people with long-term conditions.

We now discuss each of these in turn.

Prevention with earlier intervention

It is expected that GP practices and primary care trusts will work much more closely with local government to ensure that there is early support for prevention, meaning that more must be done for groups such as people with learning disabilities to improve access to primary care, especially in poorly served areas, with greater control given to service users to register with a practice of their choice. Better information for service users about local primary care provision is required to make this work, including fuller use of the...
internet. More NHS walk-in centres will be
developed to give people with busy lives more
options. The intention is for people to have
the ability to get fast access when they need
it and the opportunity to book appointments
ahead. More will be done to support efforts to
maintain mental health and emotional well-
being, the neglect of which costs the nation
dearly in terms of long-term sickness, days
lost at work and attendant losses of work and
occupational skills.

Several of the LDRI studies directly or indirectly
provide evidence about these ambitions, with
insights about the likelihood of their being
realised.

The HF study, for example, illustrated that GPs
were resistant to change. They questioned the
evidence base for health facilitation and yet
also demonstrated confusion about the health
facilitation role. There was also an acknowledged
lack of capacity within primary care teams
to deal with the requirements of health
facilitation. Convictions, values and capacities
all emerged as barriers to be dealt with here.

The HF study also demonstrated that barely
two-fifths of people with learning disabilities
were captured in GP lists in the study area.
Preventive work in primary care evidently
cannot happen without people being registered
on practice lists. Efforts to put in place a
database of people with learning disabilities
threw into relief the absence of information-
sharing requirements between local agencies
and confusion about data protection legislation.
These are likely to remain as obstacles both to
local population planning and to proposals set
out in the White Paper for the development of
integrated health and social care records.

Findings from the CC study provided
evidence to show that women with learning
disabilities did not receive the same advice
about contraception or treatment from GPs as
other women. The personal agency and sense
of control of the women was shown to be
undermined by the way they were treated by
GPs, as illustrated by short appointment times,
lack of accessible information about sexual
health and the interactional styles adopted
by some GPs who avoided direct dialogue
with the women. A significant educational
agenda for primary care and health promotion
professionals is indicated.

The CC study also showed that the use of
Depo-Provera, which can have serious side
effects like weight gain, irregular breakthrough
bleeding and mood disturbances, was
disproportionately high when compared with
its use by women in the general population,
where few women are reported to use it
(Office for National Statistics 2005). As the
report goes on to say:
This leads to the suspicion that the potential disadvantages are not being spelled out to women with learning disabilities quite as clearly as they might be. This is a serious matter and not confined to women with learning disabilities. (p.70)

Coupled with the fact that, when interviewed, the women seemed poorly informed about alternative forms of contraception and their side effects, it is difficult not to draw the conclusion that GPs are taking the ‘easy’ option because Depo-Provera is judged to be safe, despite the knowledge that side effects can last as long as its primary preventive benefits, ie three months. That it was common for the women to be accompanied to their GP by a third party suggests that a premium was being placed on convenience for professionals and/or families rather than for the women themselves.

The CC study provided further evidence about under-provision of Health Action Plans and health facilitation.

More choice and a louder voice

The measures for preventive community health outlined in Our Health, Our Care, Our Say may go some way towards giving people more choice and voice. In social care it is intended that new legislation will be introduced to increase the take-up of Direct Payments to currently excluded groups. Piloting of Individual Budgets will be extended. A risk management framework will be developed to enable people using services to take greater control over decisions about how they want to live their lives.

Amidst the ambitions to create a better, more responsive health and social care system that works in partnership with service users, it would be churlish to challenge the need for more choice and voice for them. The LDRI studies raise some questions and challenges about the likely winners and the possible losers.

Several of the studies (PCP, HF and CC, for example) that focused on front-line service delivery showed that experience was very uneven, and in too many cases it was unacceptable. All three studies demonstrated that there were pressing problems for people in securing access to services and support designed to help them. In the PCP study, a number of high-risk groups did not have access to person-centred planning arrangements. In the HF study, large numbers of people were still not on GP registers. In the CC study, the women concerned were arguably not getting the appropriate guidance and treatment in regard to their sexual health needs. The point about this is that without access there is no prospect of exercising choice, and even when there is access, with choices to be made, the voice of the person with learning disabilities is still too easy to ignore, as was seen in the CC study.

The further development of Direct Payments and piloting of Individual Budgets is a natural
hierarchy that leaves those without capacity or those with mental health, emotional or behavioural problems, autism, more health problems or restricted mobility at the end of the queue in exercising control over their lives. This is an enduring problem.

The evidence reported in the Modernisation of Adult Social Care (MASC) Report about Direct Payments appears at the moment to be rather mixed. Challenges have been reported in relation to take-up, the transition from pilot/innovation stages to national programme status, the supply of personal assistants (see also Flynn 2005), risks in the assessment process, and inconsistent benefits across client groups, with mental health service users and people with learning disabilities benefiting least of all (Newman and Hughes 2007). The same report suggests that it is too early as yet to make a judgement about the effects of Individual Budgets because the associated research is still at an early stage.

Authors of the PCP report suggest that:

For all to benefit, however, we believe that person-centred planning and individualised budgets will need to be complemented by the kinds of support brokerage assistance upon which the Green Paper (Independence, Wellbeing and Choice) invites consultation. Attention will also need to be paid to developments in commissioning and
provider services to ensure that they become increasingly responsive to what person-centred planning tells us about people’s preferences. We recommend that the new guidance suggested above includes advice on better linkage between person-centred planning and service commissioning and delivery systems, both micro and strategic. (p.110)

The very last point made by these authors seems to underlie a hard-won lesson, for essentially the same point was made almost 10 years ago when conclusions were drawn from the outcomes of the All Wales Strategy (Felce et al. 1998) in regard to the connections, or lack of them, between individual and strategic planning.

Possibilities for exercising choice and control were extended to people with learning disabilities through their participation in local Partnership Boards. Evidence from the SFC study showed that there had been positive initiatives in making information available for people in accessible formats, but that in other respects the infrastructure for making service user involvement a reality in Partnership Boards was less developed. Arrangements for financial support to underpin the involvement of service users, including travel costs, costs of support workers and payments in lieu of loss of earnings, were poorly developed in many authorities and non-existent in some. Service user influence on decision making in this context was not obvious. It was observed that most learning disabled Partnership Board members were white, able-bodied men with mild impairments; people from black and minority ethnic (BME) communities, women and those with physical or communication difficulties were under-represented.

**Tackling inequalities and improving access to community services**

Health and social care commissioners are expected to work together to understand and address local inequalities, with a clear focus on those with ‘ongoing needs’. It is stated that ‘... we will ensure that people with particular needs get the services they require – young people, mothers, ethnic minorities, people with disabilities, people at the end of their lives, offenders, and others.’ (Department of Health 2006, p.8.) People with learning disabilities fit into all these categories. It is likely to take investment on a large scale to make this happen, to correct the long history of under-provision for people with learning disabilities and to achieve comprehensive service coverage, as other national policy initiatives like the All Wales Strategy have amply demonstrated (Felce et al. 1998).

The relative disadvantages faced by people with learning disabilities were graphically portrayed in the findings from the first national sample survey of 2,898 adults with learning difficulties in England (Emerson et al. 2005). Headline findings can be used to summarise the situation:
– 54% said someone else decided how much money they could spend each week;

– 54% had an independent advocate.

These, of course, are only averages and conceal considerable variation in personal experience. Disadvantages were even worse for people who were poor or lived in poor areas, people from BME communities, people with higher support needs and people with poor health. The position was rather more mixed when gender and age were taken into account.

Addressing these issues will take very concerted efforts, given that people with learning disabilities are clearly starting from a very low position when compared with norms and expectations for other citizens. However, some of the LDRI studies make contributions to steps that can be made, even if they also illustrate challenges for implementation.

Together, the SA, CC, PCP and CBT studies show that the promotion of independence and the assurance of personal safety need to be kept in balance. An unfettered focus on independence and autonomy may expose individuals to unacceptable personal risks; on the other hand, an undue focus on personal safety may compound conservative practices and consign people to roles in which they are unable to fully contribute as citizens. This is an enduring and familiar dilemma for public policy.
As demonstrated in the SA study, personal safety issues can remain undetected for a long time and vulnerable people can suffer in silence without even their loved ones knowing. Yet symptoms of post-traumatic stress disorder can be detected in some cases. Parents and carers can become confused by not knowing what may have triggered such changes and they may consequently delay accessing help and advice. When seeking to access such help, parents reported that provision of therapeutic help for their sons and daughters was patchy, and there were sometimes delays even after lots of lobbying. Parents themselves were rarely offered help, let alone therapy, to deal with the trauma and self-blame that can occur in these situations, leaving them distrustful of services.

The SFC, SL and IFA studies have shown that new technologies and improvements in making information accessible and able to be used by people with learning disabilities can make a difference in the drive towards making choices. The JP study, however, has demonstrated that people with learning disabilities have clear views about the desirable qualities of support workers, suggesting that good and accessible information, if not in the right hands, may be of little use.

The PCP study has shown that, while person-centred approaches can help achieve some ambitions for inclusion and productive engagement, they do not and cannot address all of them without other factors being in place.

The influence of structural factors, such as low income or poverty and under-employment, which are both related and widespread within this population, continues to be overbearing. Added to this, the bullying that people report is likely to require a widespread and concerted approach, as has been highlighted by Mencap’s anti-bullying campaign.

**More support for people with long-term needs**

It is intended that people with long-term conditions will be supported to manage their conditions themselves, with the right help from health and social care services. Research shows that half the people with long-term conditions are not aware of support or treatment options and do not have a clear plan that sets out what they can do for themselves to manage their condition better. The assumption is that if people can be enabled to do this they are more likely to take control themselves. In support of this, the Government has set out to treble investment in the Expert Patient Programme, and to develop assistive technologies to support people in their own homes. Recognising that people have multiple and often complex needs, there will be a more integrated approach in the development of personal health and social care plans and linked health and social care records. Joint health and social care teams will be developed to support people with ongoing and complex needs. Finally, carers will be given more support.
By definition, people with learning disabilities have not only long-term but life-long conditions. This means that they need life-long support, and policies that reinforce this commitment. Some of the LDRI studies (SE and SL) have focused on people at particular life stages; in these cases, respectively, adults of working age and young people going through transitions to adulthood and adult services. Other LDRI studies (CBT, HF and PCP) have examined particular ways of intervening in people’s lives or of approaching how best to help them over time, thus bringing to bear a temporal perspective in ways that allow effects and impacts to be assessed prospectively. However, to assess fully how the White Paper might make a difference to the lives of people with learning disabilities, a life course perspective is probably required that can take account of the effects of:

- service transitions;
- shifts and changes in family support;
- changes in patterns of activity and occupation by individuals;
- the development of impairments and their consequences;
- changes in community attitudes and behaviour.

It will not be easy to accomplish this. The population planning required to make provision for people across their life course will take a strong commitment to outcome-focused data collection with consistent and clear definitions across all the relevant government departments, a means of rolling this out across government departments and inspectorates, and an integrated system for supporting people throughout their lives (BM). This will require seismic changes nationally and locally in the ways in which different arms of public services engage with one another.

The HF and PCP studies have shown that efforts to personalise support have made some strides, but there are huge obstacles to engaging primary healthcare in this process, not least because of professional attitudes and the smokescreen of confidentiality. The proposals, therefore, for personal health and social care plans and integrated health and social care records, while welcome, would seem to face major practical challenges to their successful implementation.

LDRI studies have also demonstrated, if more evidence were needed, that families need more support (SA and SL). It would appear that even with the panoply of legislative and policy changes in the last dozen years, which has brought more attention to carers’ issues (for example the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act
2004), family carers are still too often neglected or even scapegoated. The SA and SL studies have once again demonstrated the need to view family carers’ interests and concerns as being fully integrated into a systemic view of the ‘family’, where mutual interests, contributions and interdependencies between service users and family carers can be fully taken into account.

The proposal that joint health and social care teams will be developed to support people with ongoing and complex needs is a reminder that we should not neglect the history of experience about multi-disciplinary teamworking in this context (McGrath 1990, Brown and Wistow 1990, Felce et al. 1998), as there are clear lessons – bad experiences that need to be avoided, and good experiences that have long been neglected – that could be helpful in moving things forward. One of the MASC studies explored service user experiences of health and social care partnerships, reporting that quality of life outcomes were most valued by service users but least often delivered through partnerships, and that choice and having a say were process outcomes valued by all groups, especially by people with learning disabilities and mental health service users. Operational features of partnership working associated with the outcomes valued by service users included co-location, multi-disciplinary teams, user group-specific partnerships that were able to deliver more non-discriminatory care and, finally, extended partnerships. It was striking that staffing shortages and resource limits were reported to be most evident in services for people with learning disabilities (Newman and Hughes 2007, pp.64–5).

Observations and conclusions

The LDRI studies clearly have important contributions to make, not only to a refreshed Valuing People but also to health and social care policy for the general population. This can also be discerned from the Prime Minister’s speech at the Labour Party annual conference in September 2007, in which he stressed commitments to strengthen personalisation in healthcare, self-management, targeting of more vulnerable populations and active listening.

Taken as a whole, the LDRI studies demonstrate the persistence of inequalities, and more particularly how structural factors sustain these. Perversely, these inequalities impact most severely on those most at risk and those least able to speak for themselves. Mainstream provisions to strengthen self-directed or self-managed care will not touch these more vulnerable groups.
Chapter 8: Lessons about user involvement in research

In this chapter we comment on the experience of user involvement in three domains: (i) the planning and commissioning of the LDRI, (ii) the management of the LDRI and (iii) the implementation of individual studies. Data for (i) and (ii) come from sources including notes of meetings, observations in meetings and interviews by one of us (PR) with ‘experts by experience’ who were members of the commissioning and reference groups or who were independent reviewers. The data for (iii) were drawn from the LMI study, from accounts produced by the research teams themselves where there was an obvious user involvement element, and also from notes made by the academic co-ordinators from their engagement with all parties.

Planning and commissioning the LDRI

Some context

As mentioned in Chapter 1, an early decision was taken to adopt an inclusive stance in the planning and commissioning of the LDRI. There were several reasons for this. First of all, within the disability community there had been growing calls for over a decade for research that was not only more inclusive of people with different kinds of disability but also transformative of the relations between the researcher and ‘the researched’ (Barnes 2003, Walmsley 2001, Rodgers 1999, Oliver 1992). Secondly, the values and philosophy of Valuing People embodied a strong commitment to inclusion, so it would have been incongruous not to have reflected this commitment in the arrangements for commissioning a programme of linked research. Thirdly, major charitable trusts such as the Joseph Rowntree Foundation and the Big Lottery (formerly National Lottery Charities Board) had earlier shown that it was not only possible but also of benefit to fund research that was informed or led by service user opinion.

The Department was sufficiently convinced of its stance on inclusion that it was also decided to continue this commitment through to the implementation of the commissioned programme.

It is important to recognise that this values-led commitment was being adopted more broadly across health and social care research, as witnessed by the emergence of INVOLVE, supported by funding from the Department of Health. The benefits of user involvement in research have been usefully summarised by INVOLVE (2004). People using services can:

- offer different perspectives;
- help to ensure that research priorities are important and relevant to them;
- measure outcomes important to them;
- help to recruit their peers for research projects;
• help access hard-to-reach groups;
• assist or control dissemination and use of findings;
• become empowered through taking part;
• become engaged in the politics of service change.

These perceived benefits imply a wide-ranging agenda for change. However, very few of these benefits were evidenced by hard experience of inclusive research commissioning, so the LDRI represented an opportunity to do something about this. The main question then was exactly how?

Operationalising the planning and commissioning of the LDRI

Several measures were taken to put inclusive research commissioning principles into practice:

• two people with learning disabilities, one with their personal supporter, were appointed as members of the Department of Health LDRI commissioning group. In this role they worked alongside other expert people (academics, service providers and policy leads) in short-listing and eventually deciding the final studies to be funded;
• additional people with learning disabilities, and their personal supporters, were appointed as members of a virtual panel that provided independent reviews of proposals;
• in these expert roles, or as ‘experts by experience’, people with learning disabilities were reimbursed in the same way as other people working in advisory and consultancy roles with the Department of Health;
• it was decided to invite these ‘experts by experience’ to offer comments on two dimensions of the submitted proposals – (i) the arrangements for including people with learning disabilities in the research and (ii) how the research might benefit the lives of people with learning disabilities;
• individuals or teams submitting proposals were expected to provide accessible summaries of their proposals so that ‘experts by experience’ who were co-commissioners or reviewers could more quickly form their evaluations.

It was accepted that these arrangements were likely to be more labour-intensive and time-consuming, not only for commissioners and reviewers, but also for applicants.

It is important to stress, however, that when the research tender for the LDRI was published it was made clear that user involvement in research was required only where this fitted research goals. There was no intention to usurp already well-established and robust research that met the canons of science, good ethics and policy relevance without the direct inclusion of service users. Rather, a pragmatic
stance was taken in which ‘fitness for purpose’ was the overarching principle; this was applied not only to consideration of research methods but also to the arrangements for involving people with learning disabilities in individual studies. As things turned out, there was a good balance of applications reflecting a diversity of epistemological and methodological traditions, and with varying degrees of emphasis on user involvement in research.

Given the polarisation of views in the disability community about the ‘genuineness’ of inclusive research, and about whether participatory approaches in particular are merely paying lip service to user involvement as compared to emancipatory approaches (Lowes and Hulatt 2005, Ramcharan, Grant and Flynn 2004), it was recognised that the LDRI was entering a politically charged arena.

Having been propelled by the belief that this was the desirable thing to do, the Department was nevertheless alive to the fact that there were neither standards nor guidelines for judging the suitability of arrangements for involving service users in research, let alone people with learning disabilities. Although some Delphi-based research by Telford et al. (2004) had attempted to establish consensus around the principles and values of inclusive research, this was based on the views and experiences of academic and professional experts, not service users.

Even now, six years after the first LDRI studies were commissioned, there remains a lack of standards for gauging the suitability of arrangements for user involvement in research. At the time, therefore, we did not underestimate the challenges this presented for research commissioners, and especially research commissioners with learning disabilities.

What were the lessons about inclusive research commissioning?

Preparatory work

As academic co-ordinators we kept in close contact with the ‘experts by experience’ in the commissioning group. In one particular case this meant devoting time to working with one expert on a one-to-one basis in advance of meetings to provide fuller briefings about the agenda and papers, albeit concentrating on those proposals for which we had invited his expert comments. As it turned out he was unable to attend one of the commissioning group meetings but the preparatory work meant that his views were still able to be fed into the meetings as a contribution towards decision making. The unintended consequence of this preparatory work, therefore, was that an absent voice was able to be heard. This benefited the meeting, and was also appreciated and valued by the individual concerned.

This experience was repeated over a cycle of three meetings. However, without the input
from one of the academic co-ordinators (the 'expert by experience' involved did not have or want a personal supporter), this person's contribution would have been lost to the decision-making process.

Voices of experience

There were numerous occasions over the course of the commissioning process where the presence of 'experts by experience' made a marked difference to the course and also the outcomes of discussion.

Course of discussion

Bearing in mind the large number of outline proposals (144) that needed to be shortlisted, the commissioning meetings were typically very lengthy – from a half to a full day on each occasion. Maintaining a focus was a key for everyone in the interests of ensuring fairness, transparency and rigour in how proposals were processed. It was also a major challenge for everyone's concentration. Of particular value then were the constant reminders from 'experts by experience' in the group about how proposals, irrespective of their science, policy relevance or value for money, were going to benefit the community of people with learning disabilities. Important though science, value for money and policy relevance were, what were being raised here were specific and challenging questions about how proposals were 'going to make a real difference' to people's lives. Evaluating the likely or real impacts of research is difficult at the best of times (Grant et al. 2006) so the challenges that were laid here most definitely helped the commissioning group to be mindful of its brief, constantly aware of the scope of the LDRI tender and its intended beneficiaries.

There was an expressed view that people's opinions were being respected, and acted upon. As one 'expert by experience' summed it up:

I really do think people listened to what I said. It made a real difference.

As another subjective marker of whether the experience was judged to be worthwhile, all three 'experts by experience' in the commissioning group said that they would participate again if they were to be approached.

Outcomes of discussion

It is not easy to gauge the extent to which the presence and contributions of people with learning disabilities made a difference to the outcomes of decisions any more than it is in the case of the others in the commissioning group. The signs were that it did make a difference. The commissioning group was constantly reminded by these experts of the importance of research that in particular tapped service user experience, that addressed the needs of BME communities and that attempted to engage hard-to-reach groups. And all the time the group was being asked to think about the likely benefits to the service user constituency.
All three ‘experts by experience’ had excellent occupational and organisational networks and were able many times to speak from that wider experience and understanding to reinforce their claims about the importance of different research proposals. There were definitely key moments, even turning points, in the discussions where these interventions were influential in shaping decision outcomes.

Independent reviews of proposals

As mentioned earlier, all proposals went through an independent review process with two or more reviewers. Independent reviewers included people with learning disabilities and their personal supporters or support workers. There were some mixed feelings about how well this process worked from the perspective of people with learning disabilities. On the positive side they expressed the view that they had undertaken valuable work, and were pleased to have taken part. On the other hand, the variability of plain language summaries of proposals meant that some reviewers with learning disabilities struggled with the content of proposals, leaving them in some instances to rely on their supporters to make sense of it. This was not always satisfactory since personal supporters or support workers were not necessarily well-equipped to comment on the complexities of research.

Here are some typical comments about support from ‘experts by experience’:

- I could not have done the work without my support worker.
- I think we could have done with some training about research.
- I would have liked a day to tell me about what I had to do, with trainers going through it.

The organisation of the review work also drew comments:

- I have done some work with easier ways to score things before.
- They sent me proposals and wanted me to do it in a week. And I was busy that week. My support worker doesn’t work nights, you know. And it took us an hour for each one, and then three quarters of an hour to give a mark.

One person also commented on the anxiety aroused by review work:

- I was a bit worried because nobody said if my name would be sent to the researchers (who wrote the proposal under review). I’d like to feel safe.

This last comment draws attention to an issue not often discussed with respect to research commissioning, namely ethics, and the proper
protection and support of peer reviewers for whom this may well be a new and unfamiliar role. Unlike in the case of academics used to the manner of their selection and to the anonymity of review procedures, it was necessary to explain these issues to people and not assume their prior knowledge. With hindsight, the procedures put in place to make transparent the guarantee of anonymity were insufficient in this particular instance to assuage concerns about personal safety.

Post-review, it became apparent that those who had helped with the reviewing of proposals had not received any feedback about which proposals had been funded. All said that it would have been ‘nice’ or ‘polite’ for proper feedback to have been given, not only as a matter of courtesy but also as a way of acknowledging the contributions they had made. As succinctly stated by one person:

Nobody ever wrote to thank me. I’d like to know where the money went.

We also became aware, when following up reviewers with learning disabilities, that the Department was taking an exceptionally long time in some instances to reimburse them for the work they had done. This inevitably cast a shadow over their experience.

Indispensable role of personal supporters

Two ‘experts by experience’ on the commissioning group had personal supporters who attended meetings with them. These played an invaluable role in ensuring that there was plenty of opportunity to go through all the paperwork in advance of meetings, that there was time for their partners to form prior views about proposals, and that they had the confidence to speak up at meetings. One ‘expert by experience’ said that she would not have been able to contribute to the meetings had her personal supporter not been able to go through things with her before the meeting.

That the personal supporters concerned each had long-standing and well-developed relationships with their partners was undoubtedly a key to the success of the enterprise.

Despite this support, there remained feelings that the representation was rather tokenistic, with only two people with learning disabilities in what were rather large meetings of 12–15 people. For these individuals, it made speaking up more difficult when others slipped into using jargon words.

Plain language proposals – what value?

When constructing the research brief, the decision was made that applicants should produce an easy-read or accessible version of their full proposals. There were two main reasons for this. Firstly, it was thought to be a useful test of how well prepared researchers were to engage in a research programme like
the LDRI where there were expectations about disseminating findings in a variety of forms, and especially in forms that communicated more directly to people with learning disabilities. Secondly, there was the practical value of having an accessible summary that could be particularly useful to ‘experts by experience’ in the commissioning and review groups. As will now be evident, the capacity of the research community to produce easy-read or accessible summaries was sorely tested.

At first sight this might appear rather surprising given prevailing expertise and technology. However, six years ago there were neither standards for judging what ‘easy-read’ or ‘accessible’ meant, nor a means for gauging whether the idea of standards or norms could be applied to diverse populations. Years later, and even with the guidance from one of the LDRI projects, IFA, and websites (http://easyinfo.org.uk) that promote good practice in this connection, it remains a significant challenge. With hindsight, it might have been expected that we should find this variability in the perceived quality of easy-read versions of applications.

More recent research continues to demonstrate that information intended to be accessible to people with learning disabilities is not necessarily effective. In their study of the addition of symbols to simple texts Poncelas and Murphy (2007) showed that this did not necessarily improve people’s understanding.

They concluded that further empirical research is required into the effectiveness of symbol support for written information and, importantly, methods of teaching symbol understanding.

Given present guidance about easy-read materials, and with growing experience to work from, it ought to be more straightforward now to produce broad guidelines or frameworks to help researchers to generate such materials, whether their easy-read proposals or indeed accessible research outputs. However, further research is also required to evaluate improvements in understanding due to accessible information across diverse populations of people with learning disabilities.

Starting inclusion too late

In the pre-commissioning period there was considerable pressure to generate the research tender quickly in anticipation of the publication of Valuing People in 2001, because it was recognised that getting a programme of research commissioned can take a considerable time. And so it did. One of the sacrifices in this process was the failure to consult people with learning disabilities about the tender, so that they were not directly involved in shaping its content and scope. It could be claimed that they were involved indirectly, as they were given access to papers that informed the contents of Valuing People.
One ‘expert by experience’ said that although she had an understanding of the LDRI, she would have liked more details, perhaps on an audiotape or CD-ROM.

The main lessons are summarised in Box 8.1.

**Box 8.1: Summary of main lessons from inclusive research commissioning**

- Despite guidelines about doing inclusive research, there are no validated standards or norms, anchored against the experiences of stakeholders, for judging the quality of such research. Further development work is indicated here.

- A ‘fitness for purpose’ stance on user involvement in research may be helpful in giving researchers freedom to decide their stance, but it can perhaps lead too many to ignore the commitment to user involvement altogether. Future funding calls need to be clear about adopting a prescriptive or a discretionary position about the requirements of inclusive research. In the end the main determinant is likely to be what ‘added value’ is brought by a requirement for inclusive research.

- More attention needs to be paid to consulting with service users about the design brief (research tender) in the pre-commissioning stages.

- Briefing and support for service user research commissioners are required at all stages, and need to be individually customised.

- ‘Experts by experience’ are able to make contributions to the course and outcomes of decision making.

- More work is needed to improve support to ‘experts by experience’ in their role as peer reviewers. Associated ethical issues need to be addressed to assure these individuals of their safety and protection as reviewers. More responsive reimbursement arrangements need to be in place.

- Where involved, personal supporters can play an indispensable role in helping ‘experts by experience’.

- Commissioning meetings work best for ‘experts by experience’ when there is a minimum of two representatives from their community of interest. This helps to avoid isolation and at the same time to increase their self-confidence in speaking up.
Box 8.1: Summary of main lessons from inclusive research commissioning (continued)

- The requirement for applicants to produce easy-read proposals was far from met. Building on more recent experience, not least the IFA study, it should now be easier to produce more tailored guidance about easy-read requirements for future research programmes.

Managing the LDRI

Following the commissioning of the LDRI studies it was intended to put in place arrangements to co-ordinate the work as a programme, and to help the studies to disseminate their experiences and findings from an early stage. With this in mind a number of steps were taken:

- a reference group was established to take over the work of the LDRI research commissioning group. It was constituted in a similar way, with representation from service users and their personal supporters, family carers, academics, policy leads and service managers. Its main purpose was to oversee and advise on the implementation of the LDRI, and exploit ways of disseminating important messages from the research programme. It met on a six-monthly basis. Reports from research teams and from the academic co-ordinators were brought to the reference group;

- over a period of three years, annual LDRI newsletters were published that brought together the interim and final results of the commissioned studies. The newsletters were reproduced in technical and easy-read formats. They were widely disseminated using mailing lists of the Valuing People Support Team;

- three annual LDRI seminars were held with the aim of stimulating discussion and debate between research teams, people with learning disabilities, the Valuing People Support Team, policy leads and the LDRI reference group. The focus of the seminars was the appraisal of emergent knowledge from the studies, its relevance to the implementation of Valuing People, and its wider dissemination and applications;

- a special edition of the British Journal of Learning Disabilities was published in 2003, themed on Valuing People and research. Edited by the academic co-ordinators, it brought together interim findings from a number of studies and raised some challenging issues about the operation of the research ethics system;

- towards the final stages of the LDRI, stands about the Initiative were taken to major exhibitions and conferences, including
the Learning Disability Today exhibition in London, and the national social services conference in Birmingham. These events provided excellent opportunities to disseminate key findings from the studies to large and diverse audiences.

Feedback from the two people with learning disabilities on the reference group reinforced many of the messages from the commissioning group experience. However, by this stage some lessons had been learned about the usefulness of easy-read notes of meetings, so these were always produced alongside more traditional minutes. Wherever possible, syntheses or summaries of key documents for discussion were produced in plain language, including for example a report on one of the annual seminars and a write-up of user experiences in the commissioning stages of the research. These efforts were appreciated, their flaws unwaveringly identified by ‘experts by experience’ in the group. Over time we would like to think that practice improved, though it was still less than perfect.

The LDRI newsletters were an attempt to keep wider audiences, including people with learning disabilities, informed about the commissioned studies and their findings. The feedback about the newsletters was that their mixed format – easy-read and conventional research summaries – was welcome, but that sometimes the easy-read versions did not work. The absence of accepted standards and norms for easy-read material mentioned earlier did not help. Neither, sometimes, did the production process. In the main, research teams produced their own easy-read summaries set within broad guidelines produced by the academic co-ordinators, but occasionally sheer pressure of work on teams meant that this task was taken on by the co-ordinators or abandoned altogether. The main lesson to be drawn from this is that distilling clear and digestible messages from complex research for communication to diverse audiences in easy-read formats is intellectually and logistically challenging, but that if it is considered worth doing then it is an activity to be fully costed into proposals.

The annual research seminars were helpful in cementing relations between the research teams and in generating discussion and debate about the relationship between Valuing People and the emerging research evidence from the LDRI. Though based on a conventional symposium model, the seminars afforded opportunities for some creative ways of sharing messages. The LMI study, for example, used drama on two occasions to convey lessons from its research, while the SL study commissioned a drama presentation from Mind the Gap, a theatre company that employed disabled people, for a dress rehearsal of a performance about the experiences of young disabled school-leavers from the Asian community. These performances showed that, when
executed well, the effects of performance arts on audiences can be transformative. This we already know from published research (Goodley and Moore 2002), but it is a message worth reiterating given the prevailing emphasis by academic researchers on dissemination of findings rather than on the potential transformative effects of their research.

We consider that, taken together, these measures helped to give an identity to the LDRI as a discrete programme of work. User researchers told us that they looked forward to the annual seminars, and they were quick to let us know if they thought that outputs, including presentations, from the research teams were not comprehensible. Their capacity to pose the questions that others were reluctant to ask, such as ‘So what are you going to do about things now?’ or ‘Tell me again how this is going to help people with learning disabilities?’ were constant reminders of the drivers behind the LDRI, as well as a uniting force in sustaining an esprit de corps.

The main lessons are summarised in Box 8.2.

Box 8.2: Summary of main lessons from inclusive research management of the LDRI (continued)

- The intellectual, logistical and economic factors involved in producing easy-read research outputs need fuller consideration. Improved guidelines now make the production of the easy-read outputs easier than before.

- The potential for more creative methods of research dissemination through performance arts and community publishing needs further exploration and evaluation, especially in relation to the transformational effects of these methods. This is perhaps more than ever important given the numbing effect of information overload stemming from the ease of data retrieval from the internet.

- LDRI newsletters proved to be a useful way of disseminating messages to wider audiences. They were particularly useful at large conferences and exhibitions.

- Annual or regular seminars can be helpful in creating a sense of common identity around research programmes, in enabling researchers to test their ideas on their peers and in weighing emerging evidence against the pressing need for intelligence relevant to policy. ‘Experts by experience’ can make valuable contributions to these processes.
**User involvement in the commissioned studies**

In this section we offer reflections on the experience of user inclusion in the individual studies. For this we draw on the LMI study and also our own analysis of the LDRI studies. When the last of the 13 studies came to an end, we checked what arrangements had been made to embrace the inclusion agenda with each of the teams. Table 8.1 overleaf contains data reported by each team.

From this table several features become evident. Firstly, despite the call for studies that were inclusive of service users in the relevant phases of the research, the response was far from uniform. In this the funded studies mirrored the 144 applications from which they were drawn. This outcome was perhaps predictable given the discretion teams had to decide what arrangements were fit for purpose. Some studies, such as the SA and PCP studies, did not require a strong commitment to user involvement principles given their goals and methods of choice. Others, such as the IFA, HRA, HF and CC studies, depended much more heavily on service user inclusion in the research process. Secondly, inclusion was typically selective, ie limited to particular tasks, especially those tasks where consultation with service users was necessary. Inclusion was most commonly expressed through involvement of users in advisory committees, as conduits for recruiting other service users, as data analysts, as supporters or advocates of other service users, or finally as agents of change in dissemination work. Areas where other controls can be placed on the research process by service users, for example as research managers, co-researchers, co-authors or advisers at the pre-protocol stage, were less in evidence.
Table 8.1: User involvement by study

<table>
<thead>
<tr>
<th>Task/function</th>
<th>SA</th>
<th>BM</th>
<th>JP</th>
<th>CBT</th>
<th>CC</th>
<th>HF</th>
<th>HRA</th>
<th>IFA</th>
<th>LMI</th>
<th>PCP</th>
<th>SL</th>
<th>SFC</th>
<th>SE</th>
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<td>Adviser at pre-protocol stage</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
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<tr>
<td>Member of project advisory group</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
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<td>✓</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Conduit for recruitment of users to study</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
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<td>✓</td>
</tr>
<tr>
<td>Fieldworker or research assistant</td>
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<td>✓</td>
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</tr>
<tr>
<td>Supporter/advocate of other service users</td>
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<td>✓</td>
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<td>✓</td>
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</tr>
<tr>
<td>Co-author</td>
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<td>✓</td>
</tr>
<tr>
<td>Change agent in dissemination work</td>
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</table>
worked on its own research proposal and set about visiting the other teams, where team members interviewed paid researchers, advisers and participants, 164 people in total.

However, the LMI report also describes how the team prepared for and went about its task. We consider this first.

The LMI team’s experiences of undertaking the research

Group work aspects of the experience were important. The team met for two days in London each month. Team members shared and recorded stories each time they met as a group. In retrospect, the team felt that the things they did outside the formal meeting – like eating together in the evening, staying in the same hotel, going on a visit together and getting to know each other as people – were important in bonding and in developing relations based on trust. The team became important to individuals in managing personal crises that happened during the life of the project, such as bereavement and serious illness. This commitment to each other was crucial in helping to overcome occasional disagreements and upsets.

Data analysis was the hardest stage in the process. It required a lot of time, practice and creativity. The team was dealing with qualitative data in the main. The process of recognising when anecdotes and stories...
became part of a pattern, revealing deeper, more important issues, is challenging for all qualitative researchers. The combination of interviewing, diaries and group work helped this process, facilitated by VIA staff experienced in inclusive qualitative research.

Personal supporters once again had indispensable roles, here working as team members where they had an input in their own right. It was clear that only team members with learning difficulties had the right to ‘vote’ on decisions, but they made the decision early on to include supporters as team members, with a right to share in discussions. This also helped create a good team atmosphere, with members with and without learning difficulties supporting each other.

Team members agreed rates of pay for themselves and their supporters. Because of differences in individual circumstances, some team members arranged for money to go to organisations they worked for, where it was added to their salary. Others made arrangements with local benefit offices to receive the money in equal monthly or weekly amounts that did not affect their welfare benefits. The key here was flexibility to fit personal circumstances.

Some team members were confronted with unanticipated ethical challenges as they worked in project sites that created extra stress and upset. Practical and emotional help from supporters and the team as a whole was invaluable when this happened. This confirmed the value of pairing people with supporters and drew on the overall team trust that had been developed. In one case the effects of upset were long-lasting, which is a cause for concern.

Two members of the team were black, one with a learning disability and one supporter. Their involvement was important in helping black and Asian participants feel comfortable about getting involved in the research. In one instance it led a mother being interviewed to say that it was inspiring to meet a black person with learning disabilities as it gave her hope for her child’s future.

Experiences of inclusion in the 12 projects

Of the 12 projects, only two employed a person with learning disabilities as a paid worker. The team concluded that people with learning disabilities need to be involved as projects are developed, before they receive funding, for people to be included at the core of research. Although this has cost implications, the team also concluded that it is as much a question of planning and approach as money.

Some people with learning disabilities were involved in project advisory groups. It was reported that these groups were better at working together when they:

- met regularly;
- were personal and friendly;
Box 8.3: Messages about user inclusion in research, drawing from individual LDRI studies

• Pre-protocol work is important so that service users are involved in setting the research agenda and questions. The question as to who funds this pre-protocol work, specifically for inclusive research and for service users, requires debate and resolution.

• Good support during the research was important to make sure that people were fully involved and in charge during the research. From a service user perspective, this meant:
  – being able to work in pairs with other service users
  – being able to call on personal supporters
  – having access to group work for de-briefing and data analysis
  – opportunities to promote bonding
  – clear plans to deal with unanticipated challenges during research that can and do have personal consequences for service users.

• Developing a code of good practice about engaging in inclusive research with people with learning disabilities would be valuable, based on recognition of the different types of contributions people are being called on to make.

• had some social time together;
• included more people with learning difficulties;
• paid people;
• found more creative ways of discussing issues.

However, almost all people with learning disabilities on project advisory groups felt they had acquired some new skills. Concrete examples of contributions were in evidence.

One team considered that including people with learning disabilities as researchers or advisers was inappropriate because the research involved interviewing family carers about very stressful past events for a person with a learning disability. It was not clear whether family carers would ever have agreed to this. This raises challenging ethical and methodological issues about involvement in research contexts where sensitivities and vulnerabilities may be exposed.

Projects that used more creative ways to invite people with learning difficulties to take part – personal networks, an organised day out or a video – were better at including people than those issuing a traditional invitation letter, for example.

We summarise the main lessons about user involvement in the individual LDRI studies below.
Observations and conclusions

Inclusive research is still in its infancy and it would be wrong to draw premature conclusions about the knowledge claims. However, there seems to be sufficient prima facie evidence to suggest value in continuing with an inclusive research agenda as part of the overriding commitment to supporting people with learning disabilities to realise ambitions for inclusion and, in the longer term, for emancipation through the exploitation of research-based knowledge that they have had some part in producing. It is clear from the experience so far that considerable ontological, methodological and ethical challenges remain in the development of more robust forms of inclusive research that meet scientific as well as experiential expectations and standards.

Box 8.3: Messages about user inclusion in research, drawing from individual LDRI studies (continued)

• Contributions people with learning disabilities make in their different research roles – as co-researchers, individual consultants or advisers – need continuing but more systematic study at a national level.

• The economic and non-economic costs to service users of engaging in research similarly needs closer study to make sure that research is not exploitative, either to people with learning disabilities or to academic researchers, and to ensure equity and respect for individual rights.

• The ethics relating to expectations placed on user researchers need closer attention to avoid or mitigate the effects of unanticipated challenges that can go unnoticed for long periods of time, and that may deter individuals from contemplating research again.

• There now needs to be more study about the invaluable range of knowledge, expertise and perspectives service users can contribute to research and the difference this can make to policy and practice.
Chapter 9: Building on the knowledge base

In this final chapter we offer some brief comments about the LDRI as a programme of research, the types and quality of knowledge that it contributes, and what can be done to build on this body of evidence in the future.

The LDRI as a research programme

We suggest on the basis of this report that the importance of the 13 LDRI studies to the implementation of Valuing People is more than a sum of their parts. By integrating the findings of the studies and linking them not only to Valuing People’s aspirations but also to other significant policy arenas, we have tried to bring out the value of this evidence base as a whole to improve understanding of policy implementation, policy effects and outcomes.

As was outlined in Chapter 1, five linked criteria were used to assess the proposals submitted in response to the research tender for the LDRI: scientific quality, fit to research tender, policy relevance, value for money and user inclusion. These were all important, none being more important than the others. In retrospect, was this right? This is a debatable point. As with most commissioning processes, there were often long discussions about whether or not to trade scientific quality against securing a better fit between the commissioned studies and the research tender, or against studies profiling user inclusion in the research. Equally, the commissioning group needed to keep an eye on ensuring that there was adequate coverage in the research programme of the principal objectives of Valuing People’s portfolio. As was described earlier in this report, this was not achieved initially and led to a further call for proposals on themed issues.

Understandably, the importance of policy interests driving research was therefore a key factor in decision making. The LDRI studies can therefore best be described as ‘fit for their intended purpose’ and as constituting a research programme closely allied to linked policy interests, and we hope that their coherence as a programme can be appreciated on these terms. Like any other research studies, the LDRI studies also have their natural limits.

Products of their time

The studies were all commissioned at about the same time as the publication of Valuing People and are therefore associated with the early years of policy implementation. Data collection for three of the studies (SA, SE and SFC) had been completed as early as 2004, and therefore these are most closely associated with the developmental stages of Valuing People, before emergent practices had had a chance to bed down. This does not diminish the value of these studies. It is important to be able to offer perspectives about all stages of policy implementation so that the necessary lessons can be learned. This was amply demonstrated with the All Wales Strategy (Felce et al. 1998), where user and carer experiences of involvement in planning were shaped by different stages of strategy implementation
and cumulative experience around policy and research findings.

**Process versus outcome focus**

Some of the studies were more clearly dedicated to analysing particular policy implementation foci (SFC, JP, HRA and IFA), some were able to examine both policy processes and user-referenced outcomes (SE, SL, CC, HF, BM and PCP), other studies (SA and CBT) concerned issues of overarching importance (abuse, people at risk of offending) relevant to *Valuing People*’s commitments to rights and safety, while one study (LMI) was expressly commissioned to look at inclusive research in action.

**Cross-sectional versus follow-up designs**

The majority of the LDRI studies employed cross-sectional designs. These are good when a ‘snapshot’ is required or if there is thought to be value in obtaining retrospective views and experiences. They are also very common when time is short, as in a time-limited research programme such as the present one. Exceptions were the SA, CBT and PCP studies, each of which had some follow-up element. Follow-up designs are much more powerful in demonstrating the direction of effects, or even in predicting or explaining change. Even so, the timescales involved in all of the studies was correspondingly short. This means that, without further follow-up research, the LDRI studies cannot contribute very much to debates about sustaining change in the longer term.

**Locating hard-to-reach groups**

In some studies samples were squeezed because groups were ‘hard to reach’. The SA study struggled to find people who had been subjected to abuse and whose families had agreed to be interviewed, while the SL study had difficulties in securing information about young people with learning disabilities from mainstream schools, and the CC study found that sensitivities relating to the subject matter of interviews were a deterrent to some people. As more research is carried out with such populations to redress the impoverished evidence base relating to their status, circumstances and needs, creative solutions will have to be found to the challenges of securing the involvement of hard-to-reach groups in research.

**Coverage**

We mapped the studies against the *Valuing People* objectives in Chapter 2, from which it can be seen that, while there is good coverage, it is less than perfect. Gaps were inevitable, and at the commissioning stage educated guesses had to be made as to whether these were acceptable or not. This is another way of saying that the LDRI studies do not provide a ‘comprehensive’ evaluation of *Valuing People*. Rather, we would suggest that their coverage is ‘sufficient’, given the level of funding and balance of interests represented.
Gaps do remain, however. **Thematically**, better coverage of research relating to forensics, personal identities and person-centredness, safety, integration into the community and social networks, inequality and disadvantage, diversity, dual diagnosis, life course, family care, partnerships and whole system designs, creating better outcomes for those with the highest support needs and the educational preparation of staff would have added significantly to highlighting other ambitions in *Valuing People*. **Methodologically**, a greater number of studies evaluating service health and social care interventions that are efficient and effective for people with learning disabilities might have contributed to the still poor evidence base in these areas. **Sources of experience**, while reasonably comprehensive when viewing the LDRI studies as a whole, would have benefited from a greater emphasis on the voices of people with high support needs, families and support workers, raising very real additional questions about how in the new era of involvement these voices do not become stifled.

Then again, the LDRI forms only one part of the wider evidence base relevant to an appreciation of *Valuing People*.

**Types and quality of knowledge**

Weighing the quality of knowledge in health and social care research continues to be a vexed question. Despite the existence of typologies of supporting evidence used in National Service Frameworks (Department of Health 2001b, 1999) that place a 'gold standard' on systematic reviews, with expert opinion including the opinion of service users and carers at the margins, these typologies have been criticised for being unduly hierarchical. The genesis of such hierarchies is of course linked to the ways in which 'clinical effectiveness' has been defined over the years, but by doing so it reinforces professional hegemonies that are hard to reconcile with the participative research framework envisaged in the LDRI initiative.

Hierarchical typologies do not have such a history in social care, but in this arena the evidence base is arguably less developed, as are the means for weighing the quality of evidence. This makes all the more important the Social Care Institute for Excellence’s (SCIE’s) publication (Pawson et al. 2003) about types and quality of knowledge in social care, which went some way to addressing this gap. Recognising that social care knowledge has a multiplicity of sources and standards, the SCIE report produced a taxonomy rather than a hierarchy of social care knowledge. This was based on two main dimensions: sources of knowledge identified as organisational knowledge, practitioner knowledge, user knowledge, research knowledge and policy community knowledge; and generic standards about any piece of knowledge, comprising:
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- descriptive and other research or evaluation studies (not randomised controlled trials) (BM, SFC, LMI, IFA, HRA and SL).

The LDRI studies represent knowledge production that is in the mid-range of the implied hierarchy of evidence. They are also reasonably typical of the types of studies that populate the learning disability literature with respect to health and social care rather than biomedical research.

It is more difficult to apply the SCIE taxonomy because, with data that are grounded in experience and that have been generated using qualitative research methods, there are still disputes about the criteria for judging standards, authenticity and trustworthiness (Lincoln and Guba 2000). So, while the taxonomy looks very appealing, its practical application is far from straightforward. What it does do, however, is to suggest the need for an interweaving of different knowledge sources in the development of standards. For example, the principle of inclusion has permeated from the user and carer domain across to the practitioner domain (for example, see Marsh et al. 2005), while standards to do with propriety (governance, ethics and legal requirements) are increasingly applicable across all domains.

There is a further possibility in applying some judgement about the LDRI and other initiatives of a similar kind. SCIE’s approach to knowledge review places an emphasis on the researcher to

- transparency – is it open to scrutiny?
- accuracy – is it well grounded?
- ‘purposivity’ – is it fit for purpose?
- utility – is it fit for use?
- propriety – is it legal and ethical?
- accessibility – is it intelligible?

At the time of writing these two very contrasting approaches to weighing knowledge have not been reconciled. With the LDRI studies straddling health and social care foci and research traditions, we therefore have a problem in deciding how best to apply these different approaches. For readers interested in evaluating the knowledge contributions of the LDRI studies, we suggest that the final reports are read first with the hierarchical approach and then with the SCIE taxonomy in mind.

Our own reading of the LDRI studies would lead us to suggest that, with the typology of supporting evidence framework, they would be characterised as a mix of:

- individual, non-randomised, experimental/intervention studies (CBT and PCP);
- individual, well-designed, non-experimental studies, controlled statistically if appropriate (HF, SA, SE, JP and CC);
disseminate information in ways that fit with the criteria relating to transparency, accuracy, ‘purposivity’, utility, propriety, accessibility and specificity. As part of our role as co-ordinators, we were encouraged by the LDRI reference group to disseminate research more quickly and to do so in ways that were digestible and usable by different populations.

In order to do this, three newsletters were written using easy to understand words and pictures as well as technical language, and three annual conferences were organised to bring findings and emergent findings into plain view. The support of the Valuing People Support Team and publication of reports on their website have further added to bringing the knowledge closer to those who might wish to know about it, to use it and to apply it in their practices. There seems merit in thinking in future about the ways in which dissemination and the co-ordination of research programmes provide opportunities for building transparency, ‘purposivity’, usefulness and accessibility. While there will always be debate around accuracy, and important prior considerations about ethics, some parts of the creation of applicable knowledge can be managed as part of a research initiative. This implies a rather different approach to funding research and to the balance between data collection and analysis versus this ‘product quality’ approach. The LDRI has only begun this process, but it certainly seems worth further investigation and seems to be a process that will begin to resolve the gap between theory and practice.

Building on the evidence

Finally, we provide an outline of the kinds of questions that now need to be asked to advance the knowledge base from the LDRI studies.

Linking the structural to the individual

Overall, the findings of the LDRI studies, broad as they are, clearly demonstrate that it is possible to begin to fill gaps between structures that impose limitations upon individuals and individual wishes, aspirations, needs and desires. Within existing structural constraints, the LDRI evidence base can point to the following in this regard (see Box 9.1)

Box 9.1: Linking the structural to the individual

- If it is possible to implement person-centred planning universally, such plans are likely to produce better outcomes for at least some people with learning disabilities in some areas of their lives.
Box 9.1: Linking the structural to the individual (continued)

• Employment officers or employment services need a better strategy and better training and information to support people with learning disabilities into work where these options are chosen. The link between employment markets and a learning disability workforce remains to be established, leading to concerns that the structure for supporting employment will itself prove impossible to break down.

• Improved identification and recording of people with learning disabilities in primary care is required to make primary care accessible (Disability Rights Commission 2006).

• Establishing an interest in and a response to health facilitation from GP practices or from specialist health facilitation units is required to make this service structure feasible and accessible.

• Providing policies that comply with the Human Rights Act within public services and helping staff to understand these is vital if public authorities are to develop systemic approaches that are in kind with the legislation.

• Too many organisations in society make their information inaccessible, creating a dependency relationship where none is necessary, except by choice. This relates to community organisations as well as to services and other organisations and applies to people with different communication needs, including those from black and minority ethnic (BME) populations.

• The existence of evaluative, monitoring and recording systems that are at odds with each other means that data are lost and a focus on services by such systems can ignore important information on outcomes for people and how these change over time.

• Structural factors within work environments that measure and evaluate change based on a model of personal change among clients miss a range of additional competencies that support staff should have relating to interest, willingness and values.

• Service structures, for example in relation to transition, can be organised in ways that do not fit with some populations, for example people from BME backgrounds. Adapting such structures to be more responsive is highly important.
In stark contrast to LDRI evidence relating to structural constraints is evidence relating to interactional processes and personal values. The LDRI can claim to have demonstrated a number of links in this connection (Box 9.2).

**Box 9.2: Relationships, personal values and the individual**

- Deep-seated prejudices and values are hard to challenge, for example in relation to decision making around sexuality and reproduction.

- Excessive differences in value systems can often mean that people’s voices are not heard.

- The result is that no appropriate service system response is available, for example for those from BME communities or those groups identified in the PCP study as not benefiting from the person-centred planning approach as it presently stands.

- There are too many hard-to-reach and invisible people with learning disabilities whose interests are never addressed. The LDRI studies point to people who have been abused and their carers, people with autism and significant challenging behaviours, and those from disadvantaged and BME communities.

- The community is yet to become wholly welcoming to people with learning disabilities, as evidenced by the only partially successful experiences of people with learning disabilities in widening their social networks in mainstream employment.

- It is possible to change the values of people. It was shown that men at risk of sexual offending can change their understanding of acceptable behaviour and their empathy with others.

- The LDRI has produced substantial evidence that frameworks for inclusion in research can be manufactured, and that these can bring added benefit to research studies and to the understanding of academic researchers themselves.

The traditional structure/process/outcome model posited many years ago to evaluate services misses a vitally important point, which both Valuing People and the LDRI studies indicate very strongly. This reasoning is exemplified by the BM study’s proposition that too much attention has been placed on evaluating services. On this basis, the service is evaluated and not people’s lives. The service is changed and, similarly and all too often, not
people’s lives. What Valuing People seems to have accomplished, albeit in a nascent form, is a capacity to generate some synergy between processes and outcomes. The glue that seemingly ties the two together and drives the system of change is the views and aspirations of people with learning disabilities themselves.

Along with the flow of issues from the advocacy sector, from local through to governmental level, the LDRI points to further possibilities for extending involvement for service users (Box 9.3).

**Box 9.3: Possibilities for extending service user involvement**

- Being at the centre of person-centred planning, and planning during critical times in their lives.
- Being known and heard when their rights are challenged by abuse, victimisation or neglect.
- Being able to contribute to making their judgements about the services they receive, whether by contributing to the development of core competencies for evaluating staff or through Direct Payments.
- Having a voice in local planning mechanisms such as Partnership Boards, but also in developing services that reflect their wishes and needs.

The BM study has given a clear steer in the direction of outcome measures that really do reflect people’s lives and experiences. By creating synergies through involvement, structures and services that are not at present fit for purpose will have to adapt and accommodate the known preferences of people with learning disabilities. It may be that over time this offers a highly important recipe for improving the lives of people with learning disabilities.

**Sustaining and consolidating change**

Some of the LDRI studies, and also the national sample survey of people with learning disabilities (Emerson et al. 2005), could be used as baselines from which to measure longer-term changes in service delivery or outcomes.

The BM study is a good example of research that has extensively mapped databases designed to inform us about the lives of
people with learning disabilities and has made suggestions about the scope and viability of integrating them, and of changing their foci and modes of use. It points to nothing less than wholesale re-engineering of information systems, so that in the future these will be the repositories of intelligence that tells us what contributions services are making to securing the rights, choices, independence and inclusion of people with learning disabilities. Steps in this direction will lead to more efficient and effective routine monitoring of services and their relationships to outcomes at a whole-system level, and will remove the need for some forms of expensive outcome evaluation otherwise used to plug gaps in information systems.

The PCP study provides promising evidence of the capacity of person-centred planning in delivering outcomes relating to independence and inclusion. Follow-up studies are needed to establish whether these changes can be sustained and whether inequalities relating to access and benefits can be removed.

Inequality and disadvantage

Supported by the wider literature, the LDRI studies provided evidence about distinctive groups of people with learning disabilities for whom access to and effective help from the resources of both mainstream and specialist services were found lacking. Familiar groups cropped up time after time – people with high support needs, people from BME communities, people with challenging behaviour, people with autism, people who were abuse victims and perpetrators of abuse. Some families were not exempt from lack of help, even at times when they were experiencing crises, as demonstrated by the SA study, where symptoms of abuse in their relative had been noted. Audits are required to maintain some vigilance of these concerns. More importantly, better targeting of resources is required to improve access to proper and sustained help for hard-to-reach groups, but the effectiveness of such targeting strategies needs evaluation.

Structural factors implicated in inequalities that cropped up in the LDRI studies and the national sample survey (Emerson et al. 2005) – under-provision of services, social deprivation, relative poverty and ethnicity – need to be factored into the equation when considering studies of persistent inequality in people’s lives and how to address them.

The persistence of attitudes and behaviours in GPs who too readily assume that people with learning disabilities lack personal agency, as reported in the CC and HF studies, is a concern, especially in light of the Mental Capacity Act 2005 and the Human Rights Act 1998. This seems to indicate, once again, that a substantial educational agenda is required to orientate primary care teams to perspectives based on Valuing People’s core principles of rights, choice, independence and inclusion in decision-


making contexts. It also seems to suggest the need for urgent reappraisal and updating of professional communicative competence, and for targeted educational interventions with GP practices in particular, which can be subject to evaluation with raised communicative competencies in mind.

Social inclusion

The national sample survey findings were a salutary reminder of just how marginalised people with learning disabilities continue to be, relative to the general population, with respect to their inclusion in civil society, personal relationships, personal safety and control.

If the Government is to deliver on its equality agenda, the indicators used in this survey will need to be repeated in comparable surveys from time to time. A Learning Disability Observatory would be a useful way of ensuring that this important task is not neglected.

The LDRI studies suggested that there had been inroads in fostering social inclusion and in engaging mainstream services, person-centred planning being instrumental in this. However, structural factors are once again implicated in the delimiting of social inclusion opportunities, both in the workplace and in the community. These include: the social construction of what constitutes purposeful employment and activity; the physical location of work; employee attitudes; welfare benefit rules on earnings limits; lack of career progression prospects; and ‘toxic’ social capital.

Research is now required that can demonstrate how the negative effects of these structural factors can be mitigated or removed in advancing opportunities for social inclusion and social capital.

The quality of the service experience

The CC, JP, SA and SL studies provided different types of evidence about the qualities of front-line staff that were valued or not valued. There are some clear messages here that point to the importance of the nature of interactional styles and direct engagement with service users and families for understanding how services are perceived and evaluated. This seems to require a greater appreciation of what some commentators have termed ‘relationship-centredness’ (Nolan et al. 2003, Department of Health/Department for Education and Skills 2006), underpinned by a sensitivity to types of knowledge that allow this appreciation to be gained.

It has been argued that ‘getting closer to people’ in relationship-centred terms requires not only good case knowledge and system knowledge, but also:

- biographic knowledge – personal histories and circumstances, and how life patterns are governed by developmental, social and cultural clocks;
• **communicative knowledge** – how people convey intent, meaning and understanding, ie how they express personal agency. For people with high support needs this may lead to an emphasis on non-verbal communication, assistive communication technologies and also allies and advocates as facilitators and interpreters;

• **community knowledge** – how individuals relate to physical, social and political environments. (Grant and Ramcharan 2007, p.135).

Further research would be useful to test and evaluate the use of these types of knowledge in everyday practice for their effects on improving the quality of the service experience. Lying behind this are further questions about how best to sensitise staff to these requirements, and how to put them into practice.

**Accessible information**

The guidelines produced by the IFA study and the experience of the LDRI studies as a whole suggest that accessible information has potential value. Research is now required that examines the effectiveness of different types of accessible or easy-read information in everyday use, for different people, and in different contexts. The importance of context is important here because the devil is likely to be in the detail – support workers, personal assistants, advocates, families and others in daily contact with people with learning disabilities mediate access to resources, including easy-read materials, in everyday life, so they are likely to have a significant influence on how such materials are used.

**The health of health services**

The SA, CC and HF studies all showed that there are significant developmental challenges in the design, structure and culture of both specialist and mainstream health services. Within specialist health services, specialist counselling for people with learning disabilities and their families was patchy and slow to respond in the wake of suspected or actual abuse. Within mainstream health services, GP practices did not have all people with learning disabilities in their catchments registered with them, health facilitation was underdeveloped and the experience of consultations with GPs left a lot to be desired. In short, the very services designed to deal with people’s health needs were part of the problem. Underlying these challenges are issues to do with lack of investment in services, perverse incentives surrounding GP contracts and staff education. Addressing these challenges seems likely to require a sustained agenda for change, supported by focused monitoring and evaluation.

**Joining things up for individuals and families**

At several stages throughout this report there have been clear signals about not only
Research is now needed that raises challenging questions about the outcomes of inclusive research, the types and standards of knowledge generated, the fitness of that knowledge for different audiences and uses, the individual and social capital gains that emerge through inclusive research, and the partnerships that make this work. Some interrogation of how different research stakeholders evaluate knowledge generated by inclusive research would be useful in exploring the grounds for convergence that may be helpful in establishing standards by which inclusive research can be judged. This would fit well with SCIE's knowledge review agenda.

Observations and conclusions

What has been outlined here is a heady agenda. It confirms what Valuing People itself concluded:

*We do not underestimate the difficulties involved in delivering our ambitious new vision for people with learning disabilities. The principles of rights, independence, choice and inclusion we put forward are challenging and have far reaching implication for all those agencies – public, independent and voluntary – who work with people with learning disabilities.* (Department of Health 2001a, p.119)

Inclusive research

At its inception, the LDRI represented a step change towards inclusive research commissioning and research management. Valuable lessons have been learned from this experience. With regard to the practice of inclusive research at project level, lessons have emerged about helpful processes that seem to reinforce those from the wider literature (Nolan et al. 2007, Lowes and Hulatt 2005).
A refreshed *Valuing People* seems bound to have to tackle what has been outlined in the pages of this report. It is to be hoped that opportunities to contribute to the advancement of knowledge will be possible through further research.

Finally, funding for the LDRI was ring-fenced but time-limited. There is a danger that government funding for learning disability research may fall into the interstices between research priorities linked to the National Service Frameworks and the national clinical research networks. A refreshed *Valuing People* hopefully provides a stimulus to ensure that the learning disability research community can make a significant contribution to the production of knowledge and the evaluation of innovative policies that will benefit people long into the future.
References


Appendix
Appendix 1: List of LDRI study main reports and contacts


The Learning Difficulties Research Team with assistance from Catherine Bewley and Linsay McCulloch (2006) Let Me In – I’m a Researcher. London: Department of Health. (contact PinkCat63@aol.com)

McCarthy, M. (2006) Exercising Choice and Control: Women with learning disabilities and their reproductive health needs. Tizard Centre, University of Kent. (contact M.McCarthy@kent.ac.uk)

Schneider, J. and Wistow, R. (2003) Supported Employment in the UK: A profile of providers and service users. University of Durham. (contact Justine.Schneider@nottingham.ac.uk)


O’Callaghan, A., Murphy, G. and Clare, I. (2004) Symptoms of Abuse in Adults with Severe or Profound Learning Disabilities. Tizard Centre, University of Kent. (contact g.h.murphy@kent.ac.uk)

Murphy, G., Sinclair, N., Hays, S.-J. and Heaton, K. (2007) Effectiveness of Group Cognitive-Behavioural Treatment for Men at Risk of Sexual Offending. Tizard Centre, University of Kent. (contact g.h.murphy@kent.ac.uk)

Raghavan, R., Small, N. and Pawson, N. (2006) Evaluating Support Services for School Leavers with Learning Disabilities with Special Reference to Ethnicity. School of Health Studies, University of Bradford. (contact raghu.raghavan@northumbria.ac.uk)

Rodgers, J. (2005) Information for All: Evidence-based guidance on producing accessible information for people with learning disabilities. Norah Fry Research Centre, University of Bristol. (contact val.williams@bristol.ac.uk)

Further publications based on these main reports are available from the research teams.
Appendix 2: **LDRI research commissioning group**

**Members**

Gordon Grant, academic co-ordinator, University of Sheffield (now Sheffield Hallam University)

Paul Ramcharan, academic co-ordinator, University of Sheffield (now RMIT, Melbourne, Australia)

Cathy Baines, Department of Health

Annette Boaz, Department of Health

Andrew Bright, self-advocate

Sally Ann Cooper, University of Glasgow

Carolyn Davies, Department of Health

David Ellis, Department of Health

Margaret Flynn, National Development Team and family carer

Ann Gross, Department of Health

James Hogg, University of Dundee

Andres Holman, supporter to Eve Rank Petruzziello

Mary Lyndsey, Learning Disability Directorate, Department of Health

Eve Rank Petruzziello, self-advocate

Stefano Pozzi, Department for Education and Employment

Oliver Russell, University of Bristol and Department of Health

Patricia Walsh, University College Dublin
Appendix 3: **LDRI reference group**

**Members**

David Congdon, Mencap

Jackie Downer, self-advocate

David Ellis, Social Care Institute for Excellence and Department of Health

Lynette Farquarson, supporter to Jackie Downer

Margaret Flynn, National Development Team and family carer

Rob Greig, Director, Valuing People

John Harris, British Institute of Learning Disabilities (later Barnardo’s)

Pauline Heather, Department for Work and Pensions

Sheila Hollins, St George’s Hospital Medical School and Department of Health

Andrew Holman, supporter to Eve Rank Petruzziello

Geraldine Holt, University College London and Department of Health

Sharmila Kaduskar, Department of Health

Carol Lupton, Department of Health

Richard Parnell, SCOPE

Eve Rank Petruzziello, self-advocate

Patricia Walsh, University College Dublin

Juliet Whitworth, Local Government Association

Gordon Grant, academic co-ordinator, University of Sheffield (now Sheffield Hallam University)

Paul Ramcharan, academic co-ordinator, University of Sheffield (now RMIT, Melbourne, Australia)

A number of other individuals participated in reference group meetings for short periods.