ResearchSummary

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

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

This research summary, based on research led by Val Williams, Anna Marriott and Ruth Townsley at Norah Fry Research Centre, University of Bristol, on behalf of the NIHR Service Delivery and Organisation Programme (SDO), reports on a scoping review and consultation. Regional workshops for people with learning disabilities, families and professionals were held to identify the most important areas for progress. Following a literature review, research gaps were discussed with all stakeholders, to reach a consensus about the key priorities for learning disability research during 2008-2018.

This summary is for people with learning disabilities and their families, as well as practitioners, policy-makers and researchers. It helps to identify the future directions for social research in learning disability, as well as the type of research which will make a difference to practice and change. We hope it will provide the basis for continued discussion about the development of useful research in this field.

Key findings

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

Background

This research was commissioned at the same time as a renewal of learning disability policy in England, with 'Valuing People Now' (DH, 2007). Since 'Valuing People' (DH, 2001), we know that there has been some progress in the lives of people with learning disabilities. However, the research evidence reveals that most are still excluded from many areas of life. Over half live at home with parents into their adulthood, only some 10-17% have any form of paid employment, and there are major concerns with access to health care. The move out of institutions and into the community has not necessarily led to people being more active, and many people with learning disabilities still use special, segregated provision such as day centres. Most people do not have many friendships and close relationships.

The population of people with learning disabilities is set to increase by an estimated 1% per annum (DH, 2001) over the next 10 years, while currently this group forms some 2% of the general population, and there is a continued growth in the population of people with profound and multiple learning disabilities (PMLD). Additionally, social care and health services are set to change (DH, 2006), towards a service system which is more open, transparent and user-led. One of the main mechanisms for promoting social inclusion is individual budgets (IB) or self-directed support. These changes have major implications for the ways in which services are delivered to people with learning disabilities, who have traditionally been considered incapable of taking control over their own lives. There are two major thrusts:

a) People with learning disabilities should have greater control and autonomy, and a focus on their own person-centred needs and wishes.
b) People with learning disabilities are citizens. They should be able to use ordinary, mainstream community facilities and services.

At the same time, the Mental Capacity Act (2005) was implemented in 2007, and attempts to clarify the distinction between incapacity and capacity. One of the key principles of the Act is that people should get good support and information to make decisions, and should not be presumed to be incapable.

These policy and legal shifts represent a potential sea-change in the lives of people with learning disabilities and their families. Some people and families are embracing these changes, and taking control of their own lives. However, these changes require innovation and a certain pioneering spirit. The majority of people with learning disabilities may not have access to the support which is required.

In this context, the current scoping review set out to discuss key priorities for research with all the main stakeholders, and to reach a consensus. It aimed to listen to what people said was important in their lives, and to find out what research had to say about those things. The main aim was to identify research priorities, but this was not just about the important topic areas. It was also about establishing the types of research which will inform change, and be of practical value to people with learning disabilities and their families.

Practical findings

People with learning disabilities, family members, practitioners and policy makers, as well as researchers all agreed on the following:

a) Research needs to be better linked with changes in practice, and to achieve that we need a better understanding of the factors that lead to change.
b) The important areas for progress were health, support staff, relationships, housing, work and personal finance and inclusion in the community.
c) Research in all these areas needs to look to future changes in social care (such as individual budgets and self-directed support) as well as changes in the population of people with learning disabilities.

People with learning disabilities identified, by and large, issues in their lives which were about their aspirations, for instance to have a relationship, a job or housing. They tended not to talk about mechanisms to secure these things, which are high on the policy agenda at present. However, some of the other stakeholders pointed out the importance of mechanisms such as person centred planning (PCP) and individual budgets (IB), and we have included these as key aspects for future research priorities. Following our research review, we discussed with all stakeholders what the most important research gaps were. In all these areas, we need a research focus which prioritises people with high support needs and people from black and minority ethnic groups, who are under-represented in research. It is also possible that we need to know more about older people with learning disabilities. The following represents the key priority areas.

Access to health care

> ***"Professional health workers need to listen more. Doctors need better training about learning difficulties – doctors don't always ask the right questions. This training should be delivered by people with learning difficulties."***

People with learning disabilities are facing premature, preventable deaths because of failures in health care (Tyrer *et al*., 2007), and there is evidence that people with learning disabilities may be directly and indirectly discriminated against in terms of their health care (MENCAP, 2007). However, we know that targeted interventions, such as pre-admission appointments (Hannon, 2004), can improve hospital stays from all perspectives.

There are many different issues affecting access to health care, including the quality of communication between people with learning disabilities and health care staff. Accessible information is essential but further research is needed to explore the most effective/appropriate formats (e.g. Tuffrey-Wijne *et al*., 2006) and training needs of health care staff. Further, the Mental Capacity Act (2005) requires medical professionals to give patients accessible information, so that they can make health choices.

Research has shown how annual health checks for people with learning disabilities can lead to sustained improvements for individuals (Cooper *et al*., 2006). However, there is a need for more knowledge about how Health Action Planning can best be provided. We also know about the risks of obesity (Melville *et al*., 2007) and lack of exercise amongst people with learning disabilities. However, little is understood about how people can be encouraged to change to a more healthy lifestyle.

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

Getting good support

> ***"How can we provide the support people want, and not what the job description stipulates? How do we keep fresh the 'ordinary' vision of a new support worker?"***

Support staff for people with learning disabilities are vital in their lives. Research has shown that staff practices are the single most important factor in quality of life for people with learning disabilities (Mansell *et al*., 2002). However, we know (Jingree *et al*., 2006) that staff often communicate with people in disempowering ways. This can sometimes amount to abuse (White *et al*., 2003) and official procedures for reporting abuse are not always followed, while certain forms of abuse (e.g. emotional abuse or neglect) are naturalised and overlooked in services. People with learning disabilities still have very few opportunities for choice and control in their dealings with support staff.

Hatton *et al*. (2006) and Williams *et al*. (2007) have started to explore what people with learning disabilities want from their support staff. Respect, choices and friendliness feature in this list. As we have noted above, the majority of people with learning disabilities live at home, with support from their families. However, there is a paucity of research which links family-based support with the issues for support workers. This is a major priority for future research, with the increasing role of families in leading the change towards individual budgets.

In general, positive attitudes amongst care staff are associated with a good team climate (Rose *et al*., 2006) and good organisational support, while frontline staff themselves most frequently request the chance to talk to colleagues and to have good supervision (Holloway, 2004). These matters will be important to review with the move towards individual budgets. How do organisations change, and how can people with learning disabilities and their families become involved in supervision and support for staff?

Skills for support staff are central in these arguments. There has been a wealth of research about staff training, and particularly about skills in working with people with challenging behaviour. However, surprisingly few studies since 2001 were revealed which examine workforce issues under the new IB systems. Some of the work in Leece and Bornat (2006) and ongoing development work by BILD about personal assistants is indicative, but many of the issues about active support, skills training and the supports needed by staff themselves are going to be key questions to pursue in the new contexts of individual budgets.

- The big challenge for research in this area is to move with the policy changes, and to find out how support staff can successfully move out of the traditional 'learning disability' culture, towards a more person-centred way of working.
- We need more research about staff practices under individual budgets and direct payments, to promote good practice and ensure safety of people with learning disabilities from possible abuse.
- We need more research from the point of view of people with learning disabilities and their families, so that they can say what skills they want from their support staff. Research should focus more on the role of families in leading individual budgets.
- The skills needed to work with people with people with profound and multiple learning disabilities are under-researched at present.
- Research should also focus on organisational change, and find out how we can effect the changes towards a new type of workforce.
- Alongside all these priorities, the rights, status and satisfaction of support workers and others working with people with learning disabilities are also an important focus for research; there is a need for research that engages with and empowers support workers, along with the people with learning disabilities they work for.

The right to relationships

> ***"A lot of things in life can be replaced but friends are irreplaceable."***

People with learning disabilities face many barriers in making and keeping friends and forming close relationships (Robertson *et al*., 2001). Their networks are mainly made up of staff, families and other people with learning disabilities (Forrester-Jones *et al*., 2006). We know that developing and maintaining friendships is virtually impossible without good support. Schemes such as relationship services seem to be well received but funding can be difficult to obtain, although paid work and person-centred planning may also help people make new friends.

People with learning disabilities say that close relationships, including sexual relationships, are the most important thing in their lives. However, we have very little knowledge about how to support people in matters to do with sex, and there is very little guidance and policy for staff in dealing with issues around sexuality (Parkes, 2006; Abbott & Howarth, 2007).

Parents with learning disabilities, and those taking up caring roles for other family members, are often not recognised as needing support. We know that parents with learning disabilities frequently have their children taken into care. However, Tarleton *et al*. (2006) showed how good support services can help people with learning disabilities to be good parents.

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

social care systems.

- We need to know more about the issues for people with learning disabilities who take on caring roles.

Housing options

> *"People want choice about where they live and who they live with."*

Where do people with learning disabilities live? Over half of people with learning disabilities still live at home with their parents, and of the others, 2/3 are in residential accommodation: these are mostly people with the highest levels of need (Emerson *et al*., 2005). However, this is not necessarily the cheapest option, and congregate settings lead to problems in social opportunities and community engagement (Emerson, 2004). Many people with complex needs are sent away, to live in places far from their home area (Beadle-Brown, 2006). We still need better information, however, about the numbers of people living in rented accommodation, or in properties they own.

Supported living should give greater community opportunities, but it does not always deliver on this (Fyson *et al*., 2007). We need to know why that is, and how to change the situation. It is important that people with learning disabilities can get safe, secure accommodation in their own local areas, as tenants or home owners. There are major gaps in research about housing stock and how to obtain good housing, from the point of view of people with learning disabilities. Most people have not chosen who they live with, and we need to create better choices for people with learning disabilities about where they live and about the people they live with.

- We need robust, clear evidence about the numbers and experiences of people with learning disabilities who live in different situations (renting, supported living, shared ownership, ownership, as well as residential care homes).
- Research needs to highlight good practice in giving people real housing options, good information, and choice about who to live with.
- We particularly need more research about the support offered to people with learning disabilities who live in their own tenancies, and about places where young people can learn independence skills.
- Some research could be led by families, and particularly could look at the outcomes for people who live near the parental home, or who move away.
- There are research priorities about housing for particular groups, including those in the criminal justice system; people with complex needs who are moved out-of-area; people with PMLD or other physical impairments.

Jobs and personal finance

> *"It was great getting to work, and having something to get up for in the morning. It was difficult to learn (on the job), but much easier than doing all those tests and paperwork."*

About 23% of people with learning disabilities are likely to be living in poverty (Emerson *et al*., 2005), and we know that families caring for a relative with learning disabilities face financial hardship because of loss of career opportunities. Further, access to financial services is difficult, because of lack of accessible information, and systems which discriminate against people with learning disabilities and over 50% of people with learning disabilities do not have control over their own money (Williams *et al*., 2007). There are concerns about vulnerability and financial abuse, but little hard data. However, financial decision making will come under a renewed spotlight with the implementation of the Mental Capacity Act (2005).

Between 10-17% of adults with learning disabilities are in paid employment, but most of these have part-time, low paid jobs (Beyer *et al*., 2004). The majority of adults with learning disabilities would like to work, but are restricted by a range of barriers, including attitudes, concerns over benefits, lack of coordinated support, information and education. We know that people with learning disabilities tend to stay in their jobs longer than most, and have a strong commitment to work, and that work can help to maintain social networks and offer a better quality of life.

Research has also explored the ways in which people get support to find and keep a job. We know a lot about the factors in supported employment schemes, for instance, which are effective. We also know that FE colleges have a key role in providing work preparation courses, and supporting students into paid work. It is hard for them to achieve results, but this is a fast developing area.

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

- We need more research about alternative forms of employment, including social firms, and the options for people with high support needs to have fulfilling lives.

Inclusion in the community

> ***"We need to educate more people who haven't got disabilities – the rest of the community… We are human beings so treat us like human beings."***

People with learning disabilities are still often separated from their own communities, and from ordinary activities. Many people with learning disabilities still predominantly take part in activities provided by learning disability services (Forrester-Jones *et al*., 2006). However, it is possible that practice is outstripping research in the area of community inclusion, and that there is good practice in certain pockets of the UK.

There are many factors which seem to stop people having active lives in their own communities (Abbott and McConkey, 2006). Negative attitudes, discrimination and hate crime (Perry, 2004) are major problems, but we need more research about how to tackle these problems.

There is a strong link between making choices and being more active in the community. We also know that paid employment in the daytime leads to better leisure in 'leisure time'. Good support can help people use community facilities. However, we need to understand better what skills support workers need in order to be successful in this task. There is a need for accessible information, and research has shown us what information really works well for people with learning disabilities (Rodgers *et al*., 2004). It is also possible that computers and new technologies could be used for people to find out what is going on in their local area.

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

Conclusions

People we met during this consultation were frustrated by the lack of action springing from research, and said that they wanted practical research which engaged with people who could change practice:

> ***"Why is research not implemented? What helps this change? Why can't we do something out of the research – for instance, make sure that families can make a difference?"***

New models of research are developing rapidly in the world of practice, amongst people with learning disabilities and their families, and within organisations campaigning for change. One of the strongest ways to take hold of knowledge is to be involved in generating it for yourself. People with learning disabilities, their supporters and families all wanted to take leading roles in research. The strongest message from this review was that research needs to be tied in more closely with the real concerns of all the major stakeholders, and to seek engagement from all parties. It is engagement which will make for relevance.

- **The implication for practitioners, researchers and for people with learning disabilities and their families is to form partnerships for research. People with learning disabilities can take a leading role, and practitioners can also benefit from getting involved in finding answers to questions which concern them.**

One of the most important roles for future research is to provide clear evidence of what is happening in the lives of people with learning disabilities. It is essential to keep public attention focused on the disparities between people with learning disabilities and other, non-disabled citizens. It is equally important to find ways of doing research which link more closely with action and practice. A wide range of good quality research already exists about the lives of people with learning disabilities. It is vital that research efforts are not lost, and that research summaries can be provided in accessible ways to practitioners, to families and to people with learning disabilities themselves.

- **Policy makers and those in government need to pay attention to the findings of research that tell us about the facts in the lives of people with learning disabilities and their families.**
- **Funding for research needs to include funding for dissemination and action.**

Over the following decade, more people with high support needs, who may be technology dependent, will survive into adulthood. The needs of children and adults with profound and multiple learning disabilities are vitally important. There are also changes envisaged in the social care system, and self-directed support will imply a whole range of new issues for people with learning disabilities. Research needs to help us understand how local authorities should make changes, and the new roles involved in social care. We should analyse the skills needed by support workers, as well as the role of families in leading change. More than anything, we need to grasp the opportunity for person-centred approaches, and to be able to extend these to all people with learning disabilities, including those with the highest support needs. It is important that our research knowledge leads the way towards inclusion in communities, and gets outside the 'learning disability box'. There are many exciting opportunities for research over the next decade.

- **Researchers working in the learning disability field need to make links with research outside their field. Equally, researchers and practitioners need to focus on issues and settings outside the world of learning disability.**

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

About the study

- This study was carried out by academic researchers, with the involvement of people with learning disabilities who represented two local self-advocacy groups. They were the 'Ideas Group' for Norah Fry Research Centre, and they helped to run the consultation workshops.
- The design of this study involved a combination of consultation and literature appraisal. The first phase of the consultation was conducted in four regional workshops in different areas of the country. The aim was to listen to what people with learning disabilities, their families, practitioners and policy makers said about the most important things for the lives of people with learning disabilities. Discussions were recorded and analysed thematically.
- We then took the themes from what people had said, and carried out a systematic review and appraisal of research which had been done since 2001 in the six main priority areas.
- We were able to identify some of the main gaps in research knowledge, and took those back to the groups we had consulted with, in a second round of workshops. We discussed the main research gaps with them, and listened to their views about the priorities and about what kind of research is needed.
- We also talked with researchers, government policy makers and a range of other interested parties, and we sent out a questionnaire to leading development organisations to ask their opinions of the research questions suggested in the workshops.
- The research included a continuous process of checking with all stakeholders, so that we could ensure that we reached some useful conclusions about the future role of research in learning disability.

Members of the research team

Val Williams, Anna Marriott and Ruth Townsley (Norah Fry Research Centre, University of Bristol); with members of the Norah Fry Research Centre Ideas Group: Chris Schuhmacher, Sian Packer, Kim Norman and Patricia Spry.

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Further information

The full report, this research summary and details of current SDO research in the field can be downloaded at: www.sdo.nihr.ac.uk

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Feedback

The SDO Programme welcomes your feedback on this research summary. To tell us your views, please complete our online survey, available at: www.sdo.nihr.ac.uk/researchsummaries.html

About the SDO Programme

The Service Delivery and Organisation Programme (SDO) is part of the National Institute for Health Research (NIHR). The NIHR SDO Programme is funded by the Department of Health.

The NIHR SDO Programme improves health outcomes for people by:

- commissioning research and producing research evidence that improves practice in relation to the organisation and delivery of health care; and
- building capacity to carry out research amongst those who manage, organise and deliver services and improve their understanding of research literature and how to use research evidence.

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Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.