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

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)

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prepared by

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Executive summary

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

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

- The six most important areas of concern for people with learning disabilities were access to healthcare; getting good support; the right to relationships; housing; work and personal finance; inclusion in the community.

- There is a large volume of academic research in these areas, but people want more research about action, which helps us to understand how to make changes.

- We need clear evidence about the lives of people with learning disabilities and their families, so that government ensures there are resources to meet their needs.

- Research is needed about self-directed services, which affect every part of people’s lives.

- There is an increasing number of people with profound and multiple learning disabilities, who are an important focus for future research.

Access to health care

- Research is needed about health outcomes, inequalities and access to health services for people with learning disabilities.

- We need more research about how to improve communication and access to health care for people with learning disabilities, both in primary care and in hospitals.

- Research should follow the Mental Capacity Act (2005) in looking at the provision of accessible information and support for medical decisions.

- We need to undertake research which will enable us to plan for people with profound and multiple needs, who may be technology dependent.

- We need to analyse the health risks to people with learning disabilities who live with ‘supported living’ arrangements, and find out how to change patterns of obesity and lack of exercise, as well as obtain information on use of alcohol and smoking.
Getting good support

- The big challenge for research in this area is to move with the policy changes, and to find out how support staff can successfully move out of the traditional ‘Learning Disability’ culture, towards a more person-centred way of working.

- We need more research from the point of view of people with learning disabilities and their families. Research should focus more on the role of families in leading individual budgets.

- The skills needed to work with people with profound and multiple learning disabilities are under-researched at present.

- Research should also focus on organisational change, and find out how we can effect the changes towards a new type of workforce.

- There is a need for research that engages with and empowers support workers, along with the people with learning disabilities they work for.

The right to relationships

- Although research has already given us plenty of evidence about social isolation of people with learning disabilities, we need research that can help us find out how people make and maintain friendships.

- There is a particular need to carry out research about these issues for people living on their own, or who no longer have day centre support.

- We need more research about sexuality, and sex education for people with learning disabilities, particularly from their own point of view.

- There is a gap in our knowledge about families where the parents have a learning disability. We need to know more about giving good support to those families. Research should also document the views and experiences of children in those families, as well as attitudinal and structural changes in the legal and social care systems.

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

Housing options

- We need evidence about the numbers and experiences of people with learning disabilities who live in different situations (renting, supported living, shared ownership, ownership, as well as residential care homes).

- Research needs to highlight good practice in giving people real housing options, good information, and choice about who to live with.

- We particularly need more research about the support offered to people with learning disabilities who live in their own tenancies, and about places where young people can learn independence skills.

- Some research could be led by families, and particularly could look at the
outcomes for people who live near the parental home, or who move away.

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

**Jobs and personal finance**

- Research needs to focus on poverty amongst people with learning disabilities and their families.

- With the advent of the Mental Capacity Act, we need research to look at how people can manage their personal finances, get good advice from mainstream financial providers, and receive appropriate information about financial decision-making.

- There are still many gaps in our knowledge about how to move local authority resources from day services into supported employment, and how to support job seeking and career progression. Employers’ needs should also be a focus for research.

- Research is needed about the ways in which Further Education can help students with learning disabilities move into real jobs.

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

**Inclusion in the community**

- Research about hate crime and bullying is a priority. This should be action research, that not only seeks to understand attitudes, but also to find measures for action against hate crime and bullying.

- It is a priority for research to move outside the ‘Learning Disability’ box, and to look at the attitudes and needs of service providers and others who are outside the Learning Disability service world.

- Research should highlight the strategies which help people with learning disabilities go out and do the things they want to do. This will involve looking at support staff skills, as well as people and places in the community.

- We need research which will help us understand how people with learning disabilities can be equal citizens, and make contributions to society.

**Recommendations**

- The main research priority areas flagged up in this study should be used to inform the funding decisions of major research funders in a more coordinated way than at present.

- Further reviews should be funded, to cover specific areas of research
which this study was unable to cover (e.g. medical research about specific syndromes; neurological research; mental health needs).

- Action research in partnership with a range of stakeholders (people with learning disabilities, family members and practitioners) should be funded. These studies should be well-designed and robust, in order to help us understand how changes can happen, and how we can bridge the gap between policy and practice.

- There should be funding for targeted research which gives us evidence to argue for particular resources and commitments from government.

- Local action or demonstration sites are needed, which could enable us to learn from local good practice.

- Funders need to commission research which moves outside the ‘Learning Disability box’, and views the issues for people with learning disabilities in the context of the lives of other, non-disabled people.
Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health.

Addendum

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