

Shaping our Future

Research
priorities in
Learning
Disability
2008-2018

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.

Norah Fry Research Centre at the University of Bristol carried out a scoping review and consultation for the National Institute of Health Research. They held four regional workshops in the UK, to find out what was important for all the different groups of stakeholders. People with learning disabilities represented their own organizations at these workshops, which were also attended by family members, professionals and development workers. Following a systematic literature review in the key areas identified, research gaps were identified and discussed in a second round of workshops, as well as with a researchers' network.

Key findings

- 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 are increasing numbers of [people with profound and multiple learning disabilities](#), 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, both in primary care and in hospitals.
- We need to look at the provision of accessible information and support for medical decisions.
- Research should help us 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.

Getting good support

- Research should help us find out how support staff can shift from the 'Learning Disability' culture, to person-centred ways of working.
- People with learning disabilities need to tell us more about what they want from support staff, and research should focus more on the role of families in leading individual budgets.
- We should find out more about the skills needed to work with people with people with profound and multiple learning disabilities.

- 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

- We need research that can help us find out how people make and maintain friendships, particularly where they no longer have day centre support.

- We need more research about sexuality for people with learning disabilities.

- We need to know more about giving good support to families where the parents have a learning disability.

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

Housing options

- We need to know the numbers and experiences of people with learning disabilities who live in different situations.

- What good practice is there, in giving people real housing options, good information, and choice about who to live with?

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

- Family-led research should 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.

- We need to look at how people can manage their personal finances and get good advice from mainstream financial providers.

- How do we move more resources into supported employment, and support job seeking and career progression? Employers' needs should also be a focus for research.

- We need to consider more the role of FE in helping people 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.

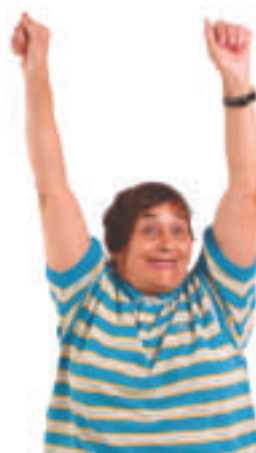
Inclusion in the community

- Action research about hate crime and bullying is a priority.

- Research should move outside the 'Learning Disability' box and look at the attitudes and needs of mainstream service providers and organisations.

- 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 new roles and 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 should be funded, in partnership with a range of stakeholders (people with learning disabilities, family members and practitioners). We need to 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.

How to get further information

The full report of this project is 'Shaping our Future: a scoping and consultation exercise to establish research priorities in Learning Disabilities for the next ten years'

The report will shortly be available on the following websites:

www.sdo.nihr.ac.uk

www.bristol.ac.uk/norahfry



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