

Building Expectations - Three Years On

Opportunities and services for adults with a learning disability

SUMMARY

In 1996, the Foundation published a report entitled *Building Expectations*. This report was the result of an expert Inquiry into opportunities and services for adults with a learning disability.

Three years on this report has been reviewed to consider to what extent the key recommendations have been taken forward. The major themes of *Building Expectations* were reaffirmed. People with learning disabilities seek:

- recognition that they are individuals, with their own strengths and weaknesses, which may change over time
- opportunities to develop their abilities and interests and to contribute to others
- a place to live of their own choice, including choice of who they live with
- good health care, appropriate to their particular needs and circumstances
- a wide variety of relationships and a recognition of their importance
- a right to participate in all decisions which affect their daily lives
- back-up support for everyday living.

This review has important implications for the development of the Government's Learning Disability Strategy, which will guide policy and practice for the next few years.

BACKGROUND

The *Building Expectations* review looked at recent Government initiatives and other key policy documents and reports, as well as consulting with people with learning disabilities and the Foundation's networks of academics and service providers.

Lessons were also drawn from the Foundation's programmes and projects, including:

- the **Choice Initiative** (1997-2000) exploring how people with severe, profound and multiple disabilities can communicate their wishes and bring changes to their lives
- the **GOLD Programme** (1998-2002) examining the needs of people with learning disabilities as they grow older.

THE REVIEW

Choice and opportunity

The consultations suggested that services are unable to fulfil this aim for many people with learning disabilities due to several factors.

- There is a shortage of financial resources in the service delivery agencies providing day opportunities and housing.
- The tightening of eligibility criteria means that some people are unable to access services. Those who are likely to meet the criteria feel that they need to stress their dependence.
- There is an expectation that people will fit into existing services rather than have services personally designed to enhance their lives.
- Many agencies promoting supported employment, advocacy, community activities or friendships are financially vulnerable.
- There is an increased emphasis by service providers on safety rather than a balanced view of risk taking. (See, for example, the report, *Empowerment and Protection*).
- Lack of transport and support for travel can prevent people from engaging in community activities.

Recognition of individuality

- *Public awareness* - much still needs to be done to combat the discrimination faced by people with learning disabilities.
- *Schools* - it is important that staff in mainstream schools and colleges, are aware of the issues in the lives of students with learning disabilities and are able to support them.

Opportunities to develop

The Government's policies of welfare to work and lifelong learning need to address specific issues if they are going to be effective for people with learning disabilities.

- *Education* - progress towards the greater integration of children and young people with a learning disability into mainstream education is slow.
- *Employment* - paid employment remains a goal for many people with learning disabilities. There is evidence that this is achievable given the right models and financial support. The social security system also needs to change further.
- *The alternative to day centres - Building Expectations* set out the hope that there will be a decreasing reliance on the day centre. Services appear to be moving in this direction, but there is a danger that day services will be reduced before alternatives are in place.
- *The needs of older people* - there is evidence that older people with learning disabilities are disadvantaged with regard to day services.

Housing needs and choice

Building Expectations emphasised that people with learning disabilities need a place to live of their own choice, including a choice of whom they should live with.

A number of practical steps could be taken to help. These include better information on need and demand; the safeguarding of resources transferred from the health service to community based services; better advice and information services for people with learning disabilities and their carers on housing options.

Health Care

People with learning disabilities need good health care, appropriate to their particular needs and circumstances. They often face significant discrimination in terms of access to mainstream health services.

- *General Practitioners (GPs)* - GPs should keep a register of patients with learning disabilities and should offer annual health checks.
- *Health care and the ageing process* - people with learning disabilities face the same age related changes as the general population and appropriate services need to be provided.
- *Hospital care* - there is a need to anticipate the needs of people with learning disabilities in hospitals, including the possibility of using health advocates to ensure that there is good communication about treatment.
- *Developing role of Primary Care Groups* - there is concern as to whether the Primary Care Groups have sufficient in-depth expertise to commission services to meet fully the health needs of people with learning disabilities.

The need for a variety of relationships

Building Expectations identified that people with learning disabilities need a variety of relationships.

- *Building communication* - the fundamental importance of the right of each person to communicate in the way that is appropriate to them needs to be recognised.
- *The particular needs of older people* - older people with learning disabilities often have particularly impoverished social networks and support services need to be particularly sensitive to this.
- *Parents with a learning disability* - the particular needs of a parent with a learning disability and their children need to be better recognised.
- *Sexual relationships* - the Home Office's review of sexual offences legislation provides an opportunity to recognise the right of people with learning disabilities to have sexual relationships whilst recognising their particular vulnerabilities to sexual abuse.

Decision making

People with learning disabilities should have the right to participate in all decisions that affect their lives.

Advocates could have an important role to play in the lives of people with learning disabilities. There continues to be concern that advocacy services are so fragmentary and fragile.

IMPLICATIONS

From this review, the Foundation has identified 4 key issues of particular relevance to the Government's learning disability strategy:

- local authorities should quantify the need for homes and daytime opportunities, so that appropriate funding can be made available and planning can take place.
- mechanisms should be in place to monitor and evaluate the quality of daytime activities for people with learning disabilities
- consideration of the friendships and relationships of people with learning disabilities should be a key factor in making plans with them, whether about a place to live or daytime activities
- priority should be given to working with older family carers (over 60 years of age) and their sons or daughters, to enable them to plan for the future.

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Series editor: Lisa Bird

This Update was written by Nigel Duerdoth, Director of Programmes at the Mental Health Foundation and Hazel Morgan, Programmes Manager for the Foundation for People with Learning Disabilities.

For information on subscribing to *Updates*, please call 020 7802 0300

The Mental Health Foundation
7th Floor, 83 Victoria Street, London SW1H 0HW
Tel: 020 7802 0300 Fax: 020 7802 0301

The Mental Health Foundation Scotland
24 George Square, Glasgow G2 1EG
Tel: 0141 572 0125 Fax: 0141 572 0246

E-mail: mhf@mhf.org.uk
Website: <http://www.mentalhealth.org.uk>

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