

CONSULTATION QUESTIONS

Progress and Challenges

Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carer?

Yes No

Please provide any comments, evidence and/or examples here

We do not think they really say how tough life can be for some parents with learning difficulties and how the rights of our families are not upheld and we are not treated equally.

Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you?*

Please provide any comments and/or examples here

Most long stay hospitals are now closed.

We now have Good Practice Guidelines on Supporting Parents with learning disabilities.

More information is available in easy read formats such as the CHANGE books for parents with learning difficulties. (A lot of parents are still not getting these though).

Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?

Please provide any comments and/or examples here

Families where there is a parent with learning difficulties are still not getting their rights to an equal chance of family life and to marry, found and family and not to be separated because of disability (European Convention on Human Rights Article 8 and UN Convention on the Rights of Persons with Disabilities Article 23).

The issues for parents with learning difficulties are:

- Getting the right support right from the start not just after a crisis
- Acceptance of the idea of supported parenting and the availability of ongoing, flexible support, one to one, in our own home. We think we need to learn from Australia where they have a national Supported Parenting approach.
- Eligibility criteria need to change so being a parent with learning difficulties is enough to qualify for support.
- More needs to be done to put the Good Practice Guidelines into practice
- Care Inspectorate needs to record how many parents with learning difficulties there are in each area, what support they are offered, how many children are taken into care from these families and how well the good practice guidelines are being implemented when they carry out inspections
- More support when our children get older
- Accessible information - reports and children's' plans need to be written in a way that we can understand, there needs to be accessible information about looking after children aged over 5 and teenagers
- Communication – professionals need to break things down, to go at our pace, to take time, to not use jargon, to show us how to do things rather than tell us, to be prepared to repeat things until we get it
- Attitudes need to change so that the discrimination which research evidence has highlighted does not continue. Professionals need to listen to us, to see that we can learn, and that it's OK to need support to do some things. They need to not use this against us. They need to uphold our rights.
- Professionals need to take time to build up trust with parents. Many of us have good reasons for not trusting professionals.
- There needs to be more training for professionals, including midwives and health visitors, about the issues for families where one parent has learning difficulties – run by parents with learning difficulties.
- Provide support for the whole family not just the child.
- Services need to work together better so we don't fall down the gap between children and adult services
- We need accessible parenting classes – for parents with learning difficulties. These should include parenting teenagers. They should include follow up work in our own homes.

- We need support to link with schools, to understand letters, to go to meetings and parents consultations and to help our children with their homework. Schools need to get better at producing information in ways that we can understand.

Good Practice – Organisations

Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?

Please provide any comments and/or examples here

We set up the People First Parents' Group. The group has provided support to around 30 parents with learning difficulties. It helps us grow in confidence, learn new skills, support each other, and we work together to make life better for families where there is a parent with learning difficulties.

We have:

- Run training sessions for professionals, students
- Spoken at conferences, at events in Parliament and run workshops,
- Campaigned for the CHANGE books to be provided free of charge by NHS Health Scotland to parents as an easy read alternative to Ready Steady Baby and Ready Steady Toddler
- Carried out part of an evaluation of the accessibility of the CHANGE resources for NHS Health Scotland
- Represented the voice of parents with learning difficulties on local and national strategic planning groups
- Helped to produce the Scottish Good Practice Guidelines on supporting parents with learning difficulties and run training sessions on the guidelines.
- Given input on various Scottish Government consultations
- Helped produce a DVD on Children's Hearings

Good Practice - Individuals

Q.5 What have you done, as an individual, to make positive changes within your local area?

Please provide any comments and/or examples here

Future Priorities - Healthcare

Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?

Please provide any comments and/or examples here

Health visitors, midwives and GPs don't always understand the needs of people with learning difficulties. They need to have more training by parents with learning difficulties. They don't always have the time to provide us with the right ongoing support, at our own pace.

There needs to be accessible information about bringing up children over five and teenagers, like the CHANGE resources.

Health professionals need to listen to us, give us enough time and take us seriously.

Future Priorities - Education

Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?

Please provide any comments and/or examples here

Some parents with learning difficulties also have children with learning difficulties. Schools need to get better at meeting our needs as parents so we can support our children better. They need to provide letters and information in easy read formats. We need support to attend meetings at school like parents consultations. Our children will often need support with their homework.

If we get the support we need as parents we might be able to go out to college and continue our education.

Future Priorities – Independent Living

Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?

Please provide any comments and/or examples here

Better support for parents with learning difficulties and our families is about independent living (see Q.3)

Other things we need to change are:

- Support to manage SDS needs to be more geared to the needs of people with learning difficulties so we can take up SDS options
- Person centred planning needs to be available to everyone
- There needs to be more independent advocacy. Advocacy doesn't really work if you don't have a trusting relationship. Half an hour before a meeting isn't what we need.

Future Priorities – Employment

Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?

Please provide any comments and/or examples here

There need to be more supported employment projects.

People with learning difficulties need more support at school and college for adult life including getting a job. We need to be able to get proper training and qualifications.

Attitudes of employers need to change.

Future Priorities

**Q.10 What other future priorities do we need to focus on?
(Please list these in order of importance with the most important first)**

Please provide any comments and/or examples here

Parents with learning difficulties.

Criminal justice.