

Families Matter

Supporting families in Northern Ireland

Comments by Mencap in Northern Ireland

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1.0 About Mencap

1.1 Mencap is a voluntary organisation which works alongside and represents the views and interests of people with a learning disability and their families.

1.2 We believe that everyone with a learning disability should have equal rights and opportunities. We believe that these should be available to everyone with a learning disability and that they and their families should get the support they need to live an equal life.

2.0 About learning disability

2.1 It is estimated that 2% of the population has a learning disability. The Bamford Review of Mental Health and Learning Disability stated that there were 8150 children and young people with a learning disability in Northern Ireland who were known to services. **Equal Lives**, the report from the Bamford Review on learning disability, drew attention to the inequalities experienced by children and young people with a learning disability and their families.

2.2 **Equal Lives** stated that there would be an increase in the numbers of children with a learning disability over the next 15 years including:

- Children who are technology dependent
- Children with a learning disability who also have an Autistic Spectrum Disorder
- Children with profound and multiple disabilities who require 24 hour personal care
- Children with a learning disability from minority ethnic communities

2.3 **Equal Lives** also drew attention to the increasing numbers of parents with a learning disability who may need additional support to enable them to meet their parenting responsibilities; and to the absence of residential and foster placements for children with a learning disability.

2.4 **Equal Lives** stated:

“All children have the potential to bring to families great joy and equivalent levels of stress. Families are important to all of us, more so to the person with a learning disability. Families of people with a learning disability provide care and support well beyond what is normally expected and over a longer period of time. Families of children with a learning disability will at times report experiencing increased family harmony and cohesion, and higher levels of empathy among family members. For many other families, however, there can be preponderance of more negative experiences that drain the parent’s or other main carer’s ability to function as both an individual and as a long-term carer”¹

2.5 **Equal Lives** stated that the risk of experiencing such negative emotions increased for families where the child had additional needs and at times of transition. It highlighted the key stages in a child’s life when intervention and support were particularly important:

- At the time of diagnosis
- Starting school
- Leaving school
- Transition into adulthood
- Leaving the family home

2.6 **Equal Lives** identified some of the roles that parents of children with a learning disability have to perform including “parent, educator, communication facilitator, behavioural specialist, emotional confidant, advocate”, adding that “few carers could innately possess such a range of skills and, as such, need support and opportunity to acquire such skills”

2.7 Mencap’s **Breaking Point** survey of families caring for children or adults with severe or profound learning disability about their use of short break services found that, in Northern Ireland:

- 8 out of 10 families have reached or come close to breaking point because of a lack of short break services
- 8 out of 10 families provide more than 15 hours of care every day
- 5 out of 10 families always provide care during the night
- 5 out of 10 family carers who are in poor physical health say it is because of the amount of care they provide
- 10 out of 10 family carers who are in poor mental health say that it is because of the amount of care they provide

¹ **Equal Lives**, Bamford Review of Mental Health and Learning Disability, DHSSPS 2005, p36)

3.0 General Comments

- 3.1 Mencap welcomes the government's commitment to improving the life chances for every child and young person.
- 3.2 We welcome, too, the commitment to working in partnership with all sectors and with parents. We welcome the recognition, given in the strategy, to the role played by the voluntary and community sector. We believe, however, that it is also important that the Department ensures that this work is valued and adequately resourced.
- 3.3 We suggest, however, that the strategy struggles with incorporating and reflecting the different approaches required when intervening to prevent abuse and protect a child and intervening to build the resilience of families to unexpected events, – strengthening the relationship between a child and their family, enhancing a family's ability to respond to their child's needs and reinforcing the natural supports that exist within the family.
- 3.4 We believe that the strategy must explicitly identify the distinct nature of the support that parents with a learning disability and families caring for disabled children need and the specific actions that will address those needs.
- 3.5 We note the points made in the draft strategy about **Every Child Matters**. We draw attention to the fact that the campaign "Every *Disabled* Child Matters" started in England because the government's policy did not adequately reflect the needs of disabled children and their families. We believe that the Department should ensure that the strategy for Northern Ireland is fully inclusive of the needs and interests of **all** children.

4.0 Vision, Principles, Outcomes

- 4.1 Mencap suggests that there should be explicit references in the vision statement, principles and outcomes listed - and in the explanatory texts which accompany these sections – to the inclusion of all children and to the role played by early intervention services.

We believe, too, that the explanatory text should include examples that are inclusive of the experiences and support needs of parents with a learning disability and families caring for and supporting disabled children.

- 4.2 We draw attention to the actions identified in **Equal Lives**: that support should be "family directed", should continuously identify the needs and wishes of the family, empower staff to support families in a more family directed, purposeful way, and be able to direct resources in a flexible way. **Equal Lives** drew attention to evidence which indicates that "there are key elements of a Family Support model which are crucial to successfully helping families cope"²

² Ibid, pp36-40

- 4.3 We realise that the principles may not be listed in order of priority, but suggest that it would be helpful if the principles about promoting inclusion, empowering and promoting independence and enabling communities to help themselves were placed at the top rather than at the bottom of the list.

5.0 Scope

- 5.1 Mencap supports the scope of the strategy. We believe, however, that the strategy, in its principles, outcomes and actions must reflect both aspects of the strategy.

We believe that the scope, for example, should recognise that while there are stages when intervention is of particular importance, families of children with a learning disability have highlighted the need to continuously identify the needs and wishes of the family. It is important, we believe, that early intervention support respects the contribution and expertise of parents, listens to their views, works across professional boundaries and is family directed.

Families caring for or supporting a child with a learning disability are likely to need support at an early stage, preferably delivered in a planned way, rather than as a response to a crisis. This support may be required on a long term basis, and the type and amount of support may change as the child or family's needs and circumstances change.

6.0 Priority theme – parental support

- 6.1 Mencap believes that the actions outlined in this section have not reflected the distinct circumstances and needs of families caring for and supporting disabled children.

We believe that there should be separate actions which reflect the additional skills and knowledge parents of disabled children need to respond to their child's condition or disability. We also believe that there should be specific actions reflecting the importance of early intervention services for children with a learning disability and their families.

We believe that there should be specific actions which acknowledge the additional support that parents with a learning disability may need to fulfil their parenting responsibilities.

- 6.2 We believe, too, that the strategy should identify actions which ensure that mainstream, universal services or projects are accessible to all children and their families.
- 6.3 Mencap believes that the role of health visitors in supporting families with a baby or child with a disability should be included. We suggest, too, that there may be other professionals involved in supporting the child and family at this time who should be included in this strategy.

6.4 Mencap notes the points made about Sure Start. We understand the importance of Sure Start to the government's policy of reaching families and young children. We believe, however, that the strategy should highlight the need for targeted initiatives which help ensure that all children benefit from family support in the early years, particularly children with a disability who may access specialist services.

6.5 Mencap is surprised and disappointed at the lack of information or actions in the strategy around supporting young people with a disability and their families, particularly as they move from children to adult services and as they get ready to leave school.

7.0 Priority theme two – access to information

7.1 **Equal Lives** highlighted the need for information by families caring for or supporting people with a learning disability. Research has indicated that families of disabled children prefer a range of methods for accessing information, and value face to face contact and the availability of support while they make decisions about what to do.

7.2 Evidence also suggests that disabled people and their families rely heavily on the health, education and social care professionals for the information they receive. An evaluation of Mencap's Family Adviser Service indicated that Mencap was the organisation families were likely to contact after statutory services.

7.3 Mencap's experience of providing information to people with a learning disability and their families indicates that they want information at key stages about entitlement to services, services available and some help with understanding the possible impacts or issues for them and the person they care for.

7.4 Mencap's experience of working with parents with a learning disability indicates the need for accessible information delivered through face to face contact and support.

7.5 We believe that the actions should reflect the fact that some groups will need a targeted approach if they are to access the information they need.

7.6 We suggest, too, that there should be a specific action reflecting the distinct needs of parents with a learning disability.

8.0 Priority theme three - Assessment

8.1 Mencap supports the action outlined in this section. We believe that these assessments should reflect a holistic assessment of the child and their family's needs and should reflect a child-centred approach.

We believe that families should be involved in the design of these assessment tools.

9.0 Priority theme four – information sharing

9.1 Mencap supports the development of protocols around the sharing of information. We believe that families, and disabled young people, should be involved in the development of these protocols.

9.2 We suggest that there should be an additional action on the need for professionals to better co-ordinate their activities when supporting families.

10.0 Priority theme five – integration and multi-agency working

10.1 Mencap draws attention to the Wraparound project in the SHSSB area as an example of successful multi-agency, intersectoral working. We suggest that the strategy includes this as a model of good practice.

10.2 **Equal Lives** called for “multi-agency centres” to be developed which would act as a focus for both generic and specific services. The goal, it said, was to create a “hub” for supporting families so that help could be wrapped around the child and the family.³

10.3 Mencap believes that families caring for or supporting children and young people with a learning disability should be involved in the design and development of such services.

10.4 We believe that the strategy should include an action about ensuring that the new children's centres are fully accessible to children with a learning disability and to parents with a learning disability and that they incorporate services which they use and rely on.

³ **ibid**, p39