

**Response to the analytical report: Improving the life chances of disabled people
July 2004**

Introduction

The Foundation for People with Learning Disabilities welcomes the opportunity to contribute to the discussion of the issues raised in the analytical report: Improving the life chances of disabled people, which resonates with the Foundation's mission statement:

We use research and projects to promote the rights of people with learning disabilities and their families. We do this by:

- *identifying work that is needed to overcome barriers to social inclusion and full citizenship*
- *communicating our knowledge to a wide range of people*
- *turning research into practical solutions that make a difference to people's lives, now and in the future.*

The Foundation welcomes the congruence between the priorities of the Strategy Unit and those of the Foundation especially around early intervention, transitions and working with older people. The Foundation is concerned that thinking about adulthood seems to be dominated by the world of work. Not everyone will be able to work, although there should be an opportunity for far more people to be employed. Throughout their lives people with learning disabilities need support to access a whole range of activities and this needs to be emphasised.

This paper discusses themes from the Foundation's current work and consultations.

The genetics agenda

The Foundation for People with Learning Disabilities is beginning an exploration of the way in which genetics research and screening impact on the lives of people with learning disabilities and their families.

Within a broader research programme, it proposes to examine the advice that is given to women being screened for example for Down's syndrome. Anecdotal evidence suggests that usually it is assumed they will seek a termination and that they are not necessarily presented with a balanced picture of life with a child with Down's syndrome. It wishes in partnership with other agencies to redress the balance.

While recognising that there is a range of views on abortion, the Foundation is gravely concerned about late termination on the grounds of disability. It is in agreement with the following statement issued by the Disability Rights Commission in August 2001:

'The Section [(1) (d) of the 1990 Abortion Act] is offensive to many people; it reinforces negative stereotypes of disability and there is substantial support for the view that to permit terminations at any point during a pregnancy on the grounds of the

risk of disability, while time limits apply to other grounds set out in the Abortion Act is incompatible with valuing disability and non-disability equally.’¹

Anecdotal evidence suggests this Section is deeply hurtful to most people with learning disabilities and upsetting for many of their families. As suggested in the analytical report, research is needed. We feel that a discussion of these issues, in the context of a paper on the life chances of disabled people, needs to be handled with great sensitivity and indeed question whether it is the right place for this discussion.

Discussion point: What is the impact on the life chances of people with learning disabilities of the current abortion law/screening programme?

The support for families, especially in the first 5 years of the lives of children with learning disabilities

The First Impressions Initiative is a small scoping study addressing the emotional needs of families from the time of the diagnosis to the age of five years. It coincides with a number of new initiatives in this area, for example Together from the Start², the Children’s National Service Framework that is being developed, and Scope’s Right from the Start.³

The findings from 22 interviews indicated that there is great variation in practice. For half the parents interviewed the disclosure of their child’s disability was handled sensitively, but for others, their experiences were less positive: The mother of a five-day-old baby was told: “*There’s no beating around the bush, he’s got Down’s Syndrome.*”

Following diagnosis the information and support offered was patchy. Some people were automatically referred to Special Educational Needs services and were introduced to Portage home visitors and similar services early on. Others did not receive any follow-up appointments and were on long waiting lists. It was clear that parents with access to supportive pre-school or early years provision reported more positive feedback. In areas where there was little or no access to such support, parents spoke of feelings of isolation and high levels of anxiety, with a number of mothers saying they had taken anti-depressant medication at this time. The parents provided us rich insight into the difficulties they encounter on a daily basis. Examples include finding an appropriate shopping trolley, using public transport, the impracticality of attending so many appointments, and not being able to go back to work. An information booklet for families will be one of the outputs of this project.

Discussion point: How can a minimum standard of support for families in early years be established?

¹ BBC News Online (21 August 2001) *Abortion Act ‘Discriminatory’*, UK www.news.bbc.co.uk/1/hi/health/1502827.stm

² DfES (May 2003) *Together From The Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families*, Nottingham: The Stationery Office

³ Scope (2003) *Right From the Start*, London: DoH

The transition of young people with learning disabilities from full time education to children's services to adult services and opportunities

a) The policy direction and organisational change in children's services: the potential impact on young disabled people

The Foundation has concerns that the plans in the Green Paper, *Every Child Matters*⁴ and in the Children's Bill to include the Connexions service within Children's Trusts may undermine the independence of the Connexions service and its ability to advocate on behalf of disabled young people in a complex multi-agency environment dominated by scarce resources and understaffing. It needs to be able to create an effective bridge to a range of community and support opportunities for adults (including education and work).⁵

It was reassuring to hear the DfES response to the Foundation for People with Learning Disabilities, *Developing Connexions Report*: that the value of the role of Personal Advisers was recognised and this aspect of the service would be maintained.

The importance of support in advocating for oneself is identified by both young people and by those supporting them. Any future arrangements must acknowledge this and provide appropriate support to young people.

b) 14-19 education reform and implications for young disabled people

While welcoming the thrust of 14-19: Opportunity and Excellence and specifically suggestions being made about the new Entry Level Diploma, the Foundation believes that it will be crucial to meet the specific needs of all young people with learning disabilities and not only those with the ability to move on to a foundation level diploma as appears to be case in present draft versions. The link with training providers, employment, and increased opportunity for work experience is welcomed. However the diploma must include learning that addresses the future for the individual young person. At present it would appear that those with more complex support needs or impairments are going to miss out on the chance to attain a recognisable and valued qualification at the end of the diploma. The Foundation would urge most strongly that this is rectified.

c) The needs of young people with learning disabilities and mental health problems

The *Count Us In Inquiry*⁶ and Research Programme on meeting the mental health needs of young people with learning disabilities have demonstrated the level of vulnerability to mental health difficulties. It is estimated that 1 in 4 young people with learning disabilities have diagnosable mental health problems at any one time, compared with 1 in 10 in the general population of young people. There is a strong

⁴ DfES (September 2003) *Every Child Matters*, London: The Stationery Office

⁵ The Foundation for People with Learning Disabilities (2004) *Developing Connexions*, London: The Mental Health Foundation, www.learningdisabilities.org.uk

⁶ The Foundation for People with Learning Disabilities (2002) *Count Us In: Meeting the mental health needs of young people with learning disabilities*, London: Mental Health Foundation

link with poverty with 57% of young people with learning disabilities and mental health problems living in poverty compared with 30% of the general population.⁷

Although some conditions such as Fragile X and autistic spectrum disorders may predispose young people to anxiety or depression, problems also arise from the environment in which these young people are making the transition to adulthood, which underlines why the points made in a) and b) are so important.

Where young people experience mental health problems, the evidence to the Inquiry suggests that they often lack suitable treatment and services, while care pathways are unclear. The committee recommended:

Young people with learning disabilities and mental health problems should have full access to local mental health services. These services should be made available to the same service standard as those available to other members of the community.

Specialist learning disabilities services should be retained and developed both as a resource to mainstream health services and to support young people with the most complex needs.

The Count Us In project in Bradford looking at the needs of young people from the South Asian community who experience mental health problems is demonstrating a particular difficulty in accessing services and the need for a liaison worker to help to access appropriate services. The research indicates that barriers to accessing services include language barriers, non-culturally sensitive services, the stigma associated with mental health issues and self-reliance.

Discussion point: How can the transition process be improved to ensure that the needs and aspirations of young people with learning disabilities are addressed?

Person centred planning

The Foundation believes that sound person centred planning and implementation has the potential significantly to improve the life chances of people with learning disabilities.

The Foundation's research on Person Centred Planning (PCP) in partnership with the University of Lancaster has highlighted the importance of:

- a power shift so that family, friends and people with learning disabilities can be actively engaged
- training for the workforce and especially frontline staff in PCP and its implementation.

PCP is likely to alter significantly what support is offered to individuals and how it is provided. It will highlight different priorities from those of traditional services and will make demands upon support staff to work in creative and flexible ways.

⁷ Emerson, E. (2003) *Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability*, London: Journal of Intellectual Disability Research, 47, 1

In order for PCP to become rooted in local government a significant culture change is required. The changing role of Social Services and reduced input into providing services may move PCP into the voluntary sector.

The Foundation's work in Transition Planning with young people entering adulthood has shown that many parents and family members are keen and more than able to lead in planning and delivery of person centred plans.

Many parents are however fearful and poorly informed about the options and choices available to their son or daughter. It has proved helpful to offer regular sessions to groups of parents and young people during the last year of the young person's schooling. The sessions that are most beneficial are supported living, supported employment, going to college and the transfer to adult services and how to get the best from this shift. Parents can be supported to assist their son or daughter with a person centred plan. A significant investment is needed in those who specialise in transition work.

Discussion point: What steps are needed to ensure person centred planning is implemented in such a way as to improve the life chances of people with learning disabilities?

Direct payments

One of the ways to give people more power and control over implementation of their person centred plans is to give them direct payments. Uptake has been slow amongst people with learning disabilities and there appear to be several contributing factors:

- lack of information reaching people about direct payments and how to use them (this is particularly reported by people from minority ethnic communities)
- lack of creativity and confidence amongst care managers (and in some cases downright reluctance)
- lack of supports geared to the needs of people with learning disabilities and their families (many direct payment support services have been set up for people with physical impairments)
- overly bureaucratic systems that some councils have put in place
- rigid approaches to questions of capacity to consent.

Direct payments are only one way to offer people more control and naturally not everyone wants them. Making them easier to use, and looking beyond the narrow definition to wider approaches incorporating a variety of means of individualising funding may encourage more people to try this. The 'In Control' project sponsored by the Valuing People Support Team and Mencap is expected to yield very useful lessons.

Discussion point: What further changes to individualised funding would bring greater control for people with learning disabilities over their lives?

People with learning disabilities living with older family carers

People with learning disabilities do not have the same chances as others to live independently in adulthood. Some would welcome this opportunity as young adults and it needs to be first considered in transition plans. Some will choose to remain with their families, but plans need to be made to avoid a future crisis when the family is no longer able to care. Then last minute and possibly inappropriate solutions will be avoided. Research at the Foundation⁸ has indicated that those from a family home are more likely to be misplaced in an older people's residential home or nursing home.⁹

It is estimated that one third of people with learning disabilities live with a family carer aged 70 or above. *Valuing People* estimates that up to 25% of people with learning disabilities living at home with a family carer aged 70 or above do not become known to services until their family carer is too frail to continue looking after them. The Older Family Carers Initiative (OFCI) is led by the Foundation for People with Learning Disabilities. Its survey with Partnership Boards highlighted the need for local areas to focus on developing their systems for identifying older families, repair and develop better relationships with older families and coordinate their work on planning for the future through their various strategies and practice.¹⁰

People with learning disabilities in their turn may become carers, which impacts on their own life chances. Although they may find fulfilment in this role it is important to ensure that they have the recognition and support they need. There are few examples of support being offered through Carers Assessments, but in places like Shropshire, (where they have specific carers assessment forms for this group), the benefits to the individual have been high, with additional support provided to the ageing parent to give the person with learning disabilities a break.

Supporting people with learning disabilities and their older family carers requires services to work in close partnership. The partnership between services for older people, learning disability and generic carers' services from the statutory and voluntary sector need to be further explored and developed to ensure joined up support to older families. This may help avoid crises in the future and improve the life chances of people with learning disabilities who have lived with their families as they approach old age.

Discussion point: What are the key priorities in improving the life chances of people with learning disabilities living with older family carers?

Social inclusion

-within faith communities

⁸ Foundation for People with Learning Disabilities (October 2001) *Misplaced and Forgotten: The Mental Health Foundation*, www.learningdisabilities.org.uk

⁹ Foundation for People with Learning Disabilities (October 2002) *Today and Tomorrow. The Report of the growing older with learning disabilities programme*, London: The Mental Health Foundation

¹⁰ Foundation for People with Learning Disabilities (2003) *Planning for Tomorrow*, London: The Mental Health Foundation, www.learningdisabilities.org.uk

Research conducted by Professor Chris Hatton of Lancaster University¹¹ and Professor John Swinton of Aberdeen University¹² on behalf of the Foundation on meeting the religious and spiritual needs of people with learning disabilities respectively has demonstrated the importance of faith to many people with learning disabilities and the role that faith communities can play in improving the life chances of some people with learning disabilities.

-supporting those with complex needs within their localities

The Count Us In Inquiry demonstrated the distress experienced by young people and their families when the only way of meeting a young person's needs is through an out of county or out of borough placement. Localised services need to be developed.

The Choice Initiative, five service development projects funded by the Foundation¹³ to enable adults with high support needs to express their wishes and access community activities, demonstrated the intensive support that is needed if people are going to lead lives of their choice and not be confined within segregated settings. At the heart of the projects was the need to find ways of communicating with those who have little or no verbal communication. In order to enhance their life chances much greater emphasis is needed to establish individual ways of communicating. A communication passport may be one way forward. Owned by the person with high support needs it enables those who come into contact with them to understand their preferred means of communicating and their likes and dislikes.

A recurring theme in the recent research and projects at the Foundation has been the need to be able to make and retain friends. In supporting people with learning disabilities far more attention should be paid to this aspect of their lives as Valuing People recognises.

The Foundation welcomes the shift towards better sport and leisure provision mentioned on p 71. However, the evidence received by the Foundation suggests that short term breaks are a lifeline for families particularly where a person has complex needs. The Foundation urges that families continue to be offered these breaks and indeed that they are developed using a variety of models: family based, in units in the community, within the family home. It would agree that the term respite is unfortunate and that any breaks should equally be advantageous to the person with learning disabilities expanding on their opportunities and enabling them to make new friends.

Discussion point: How can all people with learning disabilities be supported to engage in life in their communities?

¹¹ Hatton, C. Shah, and R. Turner, S. (2004) *What About Faith? A good practice guide for services on meeting the religious needs of people with learning disabilities*, London: The Mental Health Foundation

¹² Swinton, J. and Powrie, E (2004) *Why Are We Here? Meeting the spiritual needs of people with learning disabilities*, London: The Mental Health Foundation

¹³ Foundation for People with Learning Disabilities (2000) *Everyday Lives, Everyday Choices for people with learning disabilities and high support needs*, London: Mental Health Foundation

Building the capacity of people with learning disabilities and their families to be involved in policy and service development

The process of developing the White Paper 'Valuing People' demonstrated the strong contributions that people with learning disabilities and family carers can make to policy and service development. These contributions have been developed further as more and more people have got involved through Partnership Boards and their sub-groups, the National Forum, and related activities. However, in many areas it is clear that the same few people are being asked to spread themselves ever thinner and it has proved more difficult to engage a wider range of people with learning disabilities and family carers. Furthermore, the contributions that people are making are often to the groups and forums that are set up within the learning disability 'world', rather than the wider community involvement initiatives under the aegis of Local Strategic Partnerships. One way of addressing these twin issues could be to support the development of leadership capacity amongst both people with learning disabilities and family carers; some programmes are already running successfully, but more and a greater variety are needed to reach out to more of those who are not currently engaged (including people from minority ethnic communities).

Discussion point: How can imaginative ways be established to engage with people with learning disabilities and their families in developing policy and planning services?

Partnership working

Since 1997 the Government has placed great emphasis upon the development of local partnerships to implement central policy and to deliver services. This is reflected in the work that the Foundation is commissioned to carry out: helping agencies either to establish or to review s31 Health Act flexibilities, supporting Partnership Boards, reviewing community teams and through our portfolio of work relating to Person-Centred Planning. Whilst the Foundation is supportive of the Government's policy objective in this area, our experience suggests that local arrangements are geared more towards the process of establishing and maintaining partnerships structures rather than demonstrating whether and how partnership working produces outcomes that are desired by the users of services. This echoes a recent review of the literature about evaluations of partnership working¹⁴ which found a very heavy bias in favour of process related measures compared to outcome related ones. The Foundation is also concerned at the dogmatic way that models of partnership working are pursued when local needs might be met more effectively by adopting a pragmatic approach.

At a national level development agencies could work with government and other agencies in pursuing changes in strategy to improve the life chances of people with learning disabilities.

Discussion point: What are the ingredients of successful partnership working?

¹⁴ Dowling, B., Powell, M. and Glendinning, C (2004) *Conceptualising Successful Partnerships* Health and Social Care in the Community 12 (4) 309-317

