

Review of Services for Disabled Children

1. Introduction

Barnardo's runs over 60 services specifically for disabled children and many of our other services include disabled children. We are the largest voluntary sector provider of short breaks in the UK, with some 30 services supporting families.

2. Structure of this response

The sections that follow draw on our experience working with disabled children and their families. It falls into four sections:

A – Children who use wheelchairs, who are especially vulnerable to social exclusion as they find it difficult to access specialist services and equipment.

B – Transitions to adulthood for disabled young people – at this key stage in their life they need extra help and support particularly with employment and training.

C – Short breaks – which can enable families to continue to care for a disabled child at home – which can often prevent a child going into residential care - but not all families can access such services they need when they need them.

D – Poverty and disability - about 55% of families with disabled children will experience poverty at some time.

3. Summary of Recommendations

Our recommendations are explained in the sections that follow. The key points are:

- Funding for wheelchair provision for children should be increased so that all wheelchair services can provide a comprehensive service, including accessories, training, replacement wheelchairs, maintenance and insurance.
- More support and training places are needed for disabled young people to meet current needs and to take account of the changing profile of disabled children.
- Government should work with employers to provide incentives to make available good quality work experience placements. Investment is needed to extend work experience, learning lessons from existing good practice, such as Supported Employment Scheme used by Barnardo's in Belfast (see below)
- In its drive to end child poverty, the Government should recognise the extra, essential costs of caring for a disabled child. Barnardo's supports the call for a minimum income standard to end child poverty.

A - Disabled children's experiences of wheelchair services in the UK

There are around 770,000 disabled children in the UK², about one in twenty children and it is estimated that at least 70,000 would benefit from wheelchair and mobility equipment that meets their physical and lifestyle needs³. On 31 May 2006, Barnardo's and Whizz-Kidz published *Don't push me around! Disabled children's experiences of wheelchair services in the UK.*¹ The key findings from that report are that:

- Disabled children are waiting for unacceptably long periods for assessments and for wheelchairs or replacement
- Wheelchairs are often unsuitable and lack essential accessories
- The social and other needs of the children and families, especially for training, maintenance and insurance, are often not met
- There are geographical inequalities in the provision of wheelchair services.

Most of these problems are caused by funding restrictions. Wheelchair service funding has not been reviewed since 1991, despite the increase in numbers of disabled children and improved wheelchair technology. Wheelchair services cater for the needs of both adults and children and under-funding has led to strict eligibility criteria which often discriminate against young children, leading to inadequate or no provision. The absence of targets for wheelchair services means that there is often little incentive or commitment for change at a strategic level or within budgeting and commissioning processes.

Many staff working in NHS wheelchair services recognise that an inadequate service is being provided to children but they are restricted by a lack of resources and insufficient funding and often advise families to apply for charitable funds instead.

These difficulties have been recognised before, not least in the Prime Minister's Strategy Unit's, *Improving the Life Chances of Disabled People* (2005) which made a number of recommendations relating to wheelchair provision. In addition, Standards 1-5 of the *National Service Framework for Children and Maternity Services* emphasise the importance of early intervention and child-centred services. It is now time to make funding available to implement the recommendations.

Recommendation for this Review

That this Spending Review examines funding specifically for wheelchairs for children. Funding to be sufficient to enable all wheelchair services to provide a comprehensive service, including accessories, training, replacement wheelchairs, maintenance and insurance.

Quotes in “Don’t push me around” from disabled children and their families

“Assessments need to happen much quicker as children grow really fast and an ill fitting wheelchair can be damaging and painful” (14-year-old from Wales, who has cerebral palsy and vision impairment and waited eight months)

“Why are the accessories that are needed so expensive and why do these have to be bought? Why can’t they be provided?” (Parent of a 6-year-old boy who has cerebral palsy)

“Maintenance is through a company contracted to do repairs for the wheelchair service. This contract is so poor and inflexible they are only available in the area for one day a week (Thursday). When the wheelchair needs repairing from the first visit to final repair, may be several weeks, from Thursday to Thursday...to Thursday...”(Parent of a disabled child, aged 12).

The following case studies show how the right chair for the child, taking into account the child’s preference, lifestyle and family needs can make a huge difference to their lives:

¹ A full copy of the report can be downloaded from www.whizz-kidz.org.uk or www.barnardos.org.uk
Hard copy is enclosed

² Department for Work and Pensions (2005) Households Below Average Income 1994/5-2003/4.
http://www.dwp.gov.uk/asd/hbai/hbai2004/pdf_files/chapters/chapter_3_hbai05.pdf

³ Social Policy Research Unit (SPRU) York University (1995) based on OPCS survey data 1984 and the Family Fund database

B - Transition into adulthood: support with training and employment

A good education is important for all children and young people, but particularly for those facing disadvantage, such as disabled children. An incomplete or sub-standard education means fewer qualifications and fewer job opportunities – disabled people are twice as likely as non-disabled people to have no qualification whatsoever, and only 50% of disabled people of working age are in employment compared to 31% of non-disabled people (Labour Force Survey, Winter 2001/2).

The changing profile of disabled children poses a challenge for Government. The overwhelming evidence from Barnardo’s practitioners is that they have experienced a significant increase in the number of children with Autistic Spectrum Disorders as well

as an increase in the number of children with complex medical needs. Furthermore, the life expectancy of many disabled people has changed and improved over the past decade. For example, most people with Down's syndrome can now expect to live a normal life span. Improved life expectancy has considerable implications for services, especially training and employment. If the present cohort of disabled children and young people are to be fully integrated into society and become financially independent, then it is imperative that the Government plans for a range of training places on both a short and longer-term basis and that young people have adequate financial support while they are on training programmes.

Barnardo's has a number of approved training services: two of which work predominantly with disabled young people who have been referred by a variety of agencies. The experience of these services is that to enable more disabled young people to access training and enter employment we need:

- A commitment to expand the number of training places and to provide more personalised services and greater incentives for employers to provide placements for disabled young people.

4. Need for more training places

Barnardo's has two projects, Palmersville¹ in the North-East and Dr B's Kitchen in Harrogate, which provide work-based learning funded by the local Learning and Skills Council (LSC). The experience of both these services is that there is more local demand than they can meet.

At Palmersville the total cost of training an apprentice is £9,000 and an E2E student £3,000. Approximately 58 per cent of trainees, which is the average for the North-East, progress positively into employment or further training: they are tracked for 3 months and after this time 80% have maintained their chosen route.

These costs compare well to the alternative of long term dependency on benefits - the long term incapacity benefit for someone under 45 is £95 a week or a total of £133,380 from the age of 18 to 45.

Recommendation for this Review

We would like Government: to increase the number of training places to meet current need: to undertake planning for longer-term need to take account of the changing profile of disabled children and to increase the current level of funding available to Learning and Skills Council and to providers of registered training programmes.

¹ Barnardo's Palmersville Training, which began in 1983, offers off-the-job training and work placements to young people who have social, emotional and academic barriers to learning. They work with approximately 400 young people each year and about 90 per cent of these have some form of learning disability. Learners are trained for work in a wide range of occupations, including catering and hospitality, landscape gardening, retail, painting and decorating and office work.

5. Greater incentives for employers

Finding suitable placements for disabled young people is a challenge. Greater incentives are needed for employers and models of good practice built on. The results achieved by Dr B's Kitchen² in Belfast are instructive. Whilst open employment has been found by a small number of trainees in the past, Supported Employment is a more appropriate option.

Under the Supported Employment scheme, administered by a local disability charity, an assessment is carried out by the Training and Employment Agency to determine the productivity of the trainee in rough percentage terms. The employer pays the agreed percentage at the going rate for the job, with the remainder of the wage made up from the scheme allowing the employee with a disability to earn the same rate for the job as other employees in a similar post. The scheme supports both employee and employer, flexibly and agreed on need. There are currently about 20 trainees and about 69 per cent find employment with another 18 per cent going into further training.

Recommendation for this Review

That the Government works with employers to ensure that they have incentives to make available good quality work experience placements and that there is investment to build further services by learning lessons from existing good practice, such as the Supported Employment Scheme described above.

C - Short breaks

Barnardo's is the largest provider of short-breaks in the UK with over 30 services providing a spectrum of services for children and families, including playschemes and clubs, home sitting services and regular short stays with foster carers or in residential settings. Such schemes enable children to develop experience and social contacts beyond their own families, while giving parents time out.

We are concerned that short break services cannot meet demand and that short-break carers are not rewarded adequately. Barnardo's is a member of the Shared Care Network and we support the submission to the Review from Shared Care Network.

D - Poverty and Disability

In 2002 Barnardo's published a report '*Still missing out? Ending poverty and social exclusion: messages to government from families with disabled children*'. (Copy enclosed)

The families interviewed for the report all highlighted the extra costs of bringing up a disabled child. It costs on average three times as much to bring up a disabled child than

² This project works with young people with a range of learning disabilities aged between 16-23. The main focus of the work is to develop their skills, knowledge and practical experience enabling them to compete for and hold down employment in the catering industry. The project was started in 1990 with funding from the European Social Fund and assistance from Gardner Merchant with catering expertise.

a non-disabled child.³ The increases in benefits (before 2002) were welcomed but these had not made any real difference to their lives: they were still living in poverty and felt socially excluded.

Recommendations for this Review

- Government should establish a minimum income standard which includes targeted support to meet the extra, essential costs of caring for a disabled child and conduct an economic analysis of the investment required to ensure that programmes aimed at lifting children out of poverty also reach disabled children.
- Government should review how current policies, such as the childcare strategy and tax credits, are working for families with disabled children, including regional variations and make informed decisions about the direction of future policy.

³ B.Dobson, S.Middleton (1998) *Paying to Care: The cost of Childhood Disability*. Joseph Rowntree Foundation, York