

Out of Reach: benefits for disabled children

Executive summary

Introduction

The Government's commitment to reducing child poverty, and improving the lives and life chances of disabled children is not in doubt. However, despite a plethora of initiatives aiming to reduce child poverty and improve support for disabled children, families that are affected by disability continue to experience high levels of poverty and social exclusion.

The problems faced by families with disabled children are clear. Incomes in such households are likely to be low because families experience considerable additional costs, face multiple barriers to employment, and experience problems accessing disability benefits. Current poverty statistics, which underestimate levels of poverty in households affected by disability, indicate that over a million children living in poverty are affected by disability. A quarter of all poor children have a disabled parent. Over half disabled children live on or near the margins of poverty. Half a million children live in households that contain both disabled adults and disabled children. The risk of poverty for these children is particularly high.

Drawing on comments from families, this report indicates that access to disability benefits – triggered by an award of disability living allowance (DLA) improves childhood experiences and life chances for disabled children. It argues that increasing take-up of DLA is an effective way of targeting support to the poorest families and enables parents to purchase essential preventive and support services for children who face significant barriers to education, training and employment. Improving take up would take the Government some way towards reaching its 2010 target to halve child poverty.

For the time being, however, the lack of information about DLA, the onerous nature of claiming and reassessments, and the stigma associated with being on benefits all have a negative impact on take-up. Furthermore, the constant reduction and removal of DLA and, more often than not, its reinstatement at appeal generates considerable financial uncertainty for families.

Much is made about the difficulties of ensuring that hard-to-reach families' access the services and support on offer. This report suggests, however, that

all too often it is the services, not the families that are inaccessible. For households affected by disability, poor service provision compounds problems on a daily basis, and generates high levels of stress and ill-health.

Outline of report

- **Chapter 1** provides a brief overview of child poverty, the political context and the legislative framework. It considers the situation when Labour came to power in 1997, contains an overview of the Government's strategy to reduce child poverty, and outlines the progress that has been made. It discusses the Government's failure to reach its target of reducing child poverty by a quarter by 2004/05, and outlines concerns about the most disadvantaged children who seem to have benefited least from government strategies to reduce child poverty.
- **Chapter 2** looks at the link between poverty and disability. It provides an overview of government statistics, but indicates that these should be viewed with caution because of their failure to take account of extra costs and/or low take-up of disability benefits. It includes a short statistical analysis of receipt of DLA by different income groups, which suggests that, although DLA is a non-means-tested benefit, increasing take-up would focus additional income on poorer families. It considers the sort of extra costs disabled adults and children are likely to incur, and reviews different ways of measuring them. It discusses how disability spans a number of different groups of children who face a high risk of living in poverty.
- **Chapter 3** considers the extent to which employment is a feasible and appropriate route out of poverty for families with disabled children, and considers whether the current benefit system – primarily DLA – safeguards families from living in poverty. It considers problems with the current system and the barriers families face when trying to access benefits. It concludes with a brief overview of service provision. It emphasises the important role played by welfare rights workers in supporting families and maximising income.
- **Appendix 1** contains an analysis of Contact a Family's recent survey about DLA with 461 families.
- **Appendix 2** outlines a number of successful take-up campaigns run by local authority welfare rights units aimed at low-income families with disabled children. Information from the survey is used throughout the report to illustrate problems with DLA.
- The report also contains two **case studies**: the first captures the experiences of a lone parent applying for DLA and reviews the impact receiving it had on her financial situation. The second records the written communications and evidence needed for an application for DLA and an appeal.

The report highlights the need for a system that is more responsive to families' needs, and argues that this can be achieved without significant structural changes. It concludes with a number of **detailed**

recommendations about how the current system could be adapted and improved to ensure that the system provides greater financial security for families. It considers the following issues:

Take-up

Barriers to take-up

- **Lack of information.** Lack of information about DLA prevents families getting the support they need to care for their child. A holistic, family-friendly, co-ordinated approach to service delivery is essential. Informing service providers about the existence of DLA and the way in which it reduces stress, and enhances health and educational outcomes for children is crucial.
- **Complexity.** The benefit system must be improved so that it is less demanding, and better reflects and responds to families' needs. The administration of DLA should be informed by, and feed into, the ongoing programme of benefit simplification.³
- **Lack of statistics.** Lack of information about the number, location and needs of families with disabled children currently undermines take-up. It is important that national and local statistics capture the way in which disabled children span different 'at risk' groups to ensure that support is effectively targeted and culturally appropriate.
- **Stigma.** The stigma associated with living on benefits and being disabled detracts from take-up. The DWP needs to consider the terminology used to describe children with additional support needs within benefit regulations, guidance and publicity material.

Given the importance of independent support, improving take-up requires a well-financed local authority and independent advice sector that can provide long-term advice and support with applications, appeals and re-applications. The DWP should run and finance a national take-up campaign along the lines of the campaign for tax credits, but this must be linked to local targeted campaigns that can provide ongoing support with form-filling and tribunals, and outreach work.

Delivery

The way in which DLA is administered continues to pose major barriers to take-up. Complex forms, the need for extensive additional evidence, poor decision making and a high number of appeals prevent many families from receiving their full benefit entitlement. The frequent downrating and removal of DLA generates high levels of financial insecurity. Delivery should be improved to ensure that 'security for those who cannot work' becomes a reality for families with disabled children. The report provides guidance on how this might be achieved.

Decision makers

There are serious concerns about the quality of decision making – particularly with regard to 'invisible' and/or fluctuating conditions such as ADHD. In

particular addressing the following issues will improve both delivery and take-up.

- **Better training** is needed for assessing children's DLA claims, and consideration should be given to having specialist decision makers who take responsibility for determining child DLA forms. Jobcentre Plus outreach staff need better training and awareness to work in a holistic way with parents of disabled children, and take account of people's parenting responsibilities.⁴ Training should include disability awareness.
- **Length of awards.** Increasing the length of awards would reduce administrative costs and give families, some of whom have to start re-applying for DLA within six months of receiving an award, greater financial security. Children with long-term conditions that are unlikely to change need significantly longer awards.

Structure

Although access to additional support provides a welcome boost to family income, the current system is complex and 'cliff edges' generate considerable fluctuations in income. More effective data sharing between the DWP and HM Revenue and Customs would improve financial security and take some of the stress out of families' lives.

Adequacy

The reliability of DLA and associated benefits as a financial 'safety net' needs to be improved. The ability of DLA to meet extra costs should be reviewed. Families who choose to care for their disabled children themselves should be adequately supported in financial terms. An increase in levels of income support would ensure that families who do not receive DLA, or have it downrated or removed, are better protected. **The Government should review the rates of DLA. A significant increase in carer's allowance (CA) is long overdue.**

Notes

1 *Parliamentary Hearings on Services for Disabled Children*, October 2006, p14

2 See S Gooding, *A Jigsaw of Services: inspection of services to support disabled adults in their parenting role*, Social Services Inspectorate, 2000

3 See for example, Boag Associates and CLICSargent's paper 'Ways Forward: suggestions for how design can be used to improve the DLA claims form for under-16s', which can be downloaded from: <http://www.clicsargent.org.uk/>

Getinvolved/Campaignwithus/Cuttheredtape/Campaigninformation/main_content/boag_clic_s upplement_v2.pdf, and CLICSargent's 'Cut the Red Tape: keep it simple for kids with cancer', which makes a number of suggestions on how to simplify the system for children with cancer; many of the suggestions are relevant to other groups of children. This can be downloaded from: <http://www.clicsargent.org/>

4 L Harker, *Delivering on Child Poverty: what would it take?*, A report for the Department for Work and Pensions, The Stationery Office, 2006

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