

Helter Skelter

Families, disabled children and the benefit system

By Gabrielle Preston

Findings and recommendations

In-depth semi-structured interviews were carried out during 2004 with 20 families who had one or more disabled children. Families were asked about their experiences of claiming disability benefits for their child and about the extra costs they incurred in relation to their child's disability.

The report examines the effect of additional income from benefits on families and the impact of the loss of benefit income. Families were asked about their attitudes to paid employment and to the Government's welfare to work strategy. The research also looked at the difficulties created for families by the fragmented nature of statutory services.

The benefit system

The Government recognises that disability is both a cause and a consequence of poverty. It has introduced a number of significant improvements to disability benefits for children in order to avoid them being sucked into an often intractable cycle of disability, social exclusion and poverty. When the system works, additional financial support does make a real difference to families' lives. A rise in income reduces stress levels, and enables families and their children to be more active participants in society.

If Government initiatives on the reduction of child poverty are to be successful, it is clearly important that families with disabled children access the benefits to which they are entitled. However, flaws within the system prevent families accessing benefits, and actively undermine policy initiatives to reduce high levels of poverty amongst disabled children. Caring for one – or sometimes two or more – disabled children without adequate support exacts a huge financial and social toll on parent-carer's (and

indeed their disabled and non-disabled children's) physical and psychological well-being.

Families whose child is awarded DLA report that it is frequently downrated or removed, resulting in fluctuating incomes. Families are perplexed when their child's DLA award changes, but their child's care needs (and their costs) have not. Far from providing financial security for families, the current system renders families with disabled children extremely vulnerable to high levels of poverty and social exclusion. The provision of reliable, long-term financial support is essential if 'security for those who cannot work' is to become a reality.

Additional disability-related costs sap income whether or not a family is receiving their full benefit entitlement, and yet families who are most vulnerable to poverty are the least likely to apply for DLA (Chamba et al, 1999). Although an award of DLA is clearly enormously helpful, for low-income families who have been struggling for some years with disability-related costs without additional financial support, it may do little more than pay off debts.

As a consequence, DLA may simply bring family finances up to income support levels, which the Government acknowledges are not sufficient to cover the extra costs of disability (hence the introduction of additional disabled child and carer's premiums within income support).

Although DLA is back-dated to the date of the original application, there is no acknowledgement that low-income families, who may have struggled for many years without extra financial support, need to 'catch up' financially before DLA can effectively meet extra costs.

Families highlight a number of specific issues that must be addressed if the Government's hopes of eradicating child poverty are to be realised:

Failure to receive DLA and associated benefits renders low-income families with disabled children vulnerable to high levels of poverty and social exclusion. Maximising take-up is a priority. Given the shortcomings of information and advice emanating from the DWP, improving take-up requires a well-financed local authority and independent advice sector which can provide long term advice and support with applications, appeals and re-applications.

Publicising information about benefit entitlement in schools, as part of a local authority take up strategy, would be an effective way of alerting parents to their child's potential entitlements, and would ensure that the educational establishment is better informed about disability benefits.

A number of families who receive DLA for their child do not realise that they are entitled to carer's allowance and/or disabled child and carer's premium within income support. They therefore miss out on crucial forms of additional support.

Currently people are expected to make separate applications for benefits such as carer's allowance or to know they need to notify the DWP so that additional premiums within income support can be paid. There is no reason why an award of DLA should not trigger these payments automatically.

There are serious concerns about the quality of decision making – particularly with regard to 'invisible' and/or fluctuating conditions such as ADHD. Although the Disability and Carers Service is piloting two training modules for decision makers on ADHD and children's mental health services, it remains to be seen whether these will improve the quality and consistency of awards.

Meanwhile, the increase in the number of short term awards made for DLA has widened the scope for conflicting and contradictory decisions.

DLA and associated benefits' reliability as a financial 'safety net' needs to be improved. A DLA run-on (for example, for three months, or until the person has lodged an appeal) would protect those families whose child's DLA has been subjected to an inappropriate decision from an overnight loss of income, and would provide financial breathing space for families whose child's needs have changed.

The ability of DLA to meet extra costs needs to be reviewed in the light of woefully inadequate income support levels and families' starting point income-wise.

The sudden loss of carer's allowance and disabled child and carer's premiums within income support can be devastating. An extension of entitlement to carer's allowance/carer's premium and the disabled child elements in child tax credit, housing benefit and council tax benefit for up to three months or until an appeal has been lodged would prevent sudden drops in income. (Although the transfer of financial support for children from income support to tax credits may prevent sudden drops of income, the loss of DLA will remain a problem.)

Families who choose to care for their disabled children themselves should be adequately supported in financial terms – for example, by a significant increase in carer's allowance – and by the provision of appropriate and affordable support services. Any parent-carer who cares for more than one disabled person (children and/or adults) should receive additional financial support whether they are lone parents, or part of a couple.

Childcare tax credit is rarely accessed by families with disabled children because they are unlikely to be in paid employment. The provision of specialist, high quality childcare for disabled children, irrespective of their parents' work status, would reduce stress levels, improve parental health and acknowledge the important role full time carers play. It would enhance the quality of life for disabled children and would render the long term prospect of employment for their parents more realistic.

Employment

Families with disabled children report that employment remains a difficult and unreliable route out of poverty. The main barriers to employment are inflexible employers, expensive childcare, worries about losing benefit, and the fact that parents are often advised to give up their jobs by professionals who represent their children's needs. Families raise a number of issues that have implications for the Government's 'welfare to work' policy:

Parents are grateful for additional financial support (such as income support and DLA), but they feel marginalised by the 'welfare to work' focus of New Labour's strategy which seems to stigmatise them because they are financially reliant upon benefits that are designed to help them cope.

Some mothers express the desire to use the expertise and knowledge they have acquired caring for their child to develop their careers. However, there is very little support (for example, with childcare) if they wish to undertake voluntary work, attend lectures, or study at home.

Some parents want to care for their disabled children themselves. Reducing benefit does not constitute an inducement for such parents to access employment, it merely renders life significantly worse for parent and child.

Some mothers (particularly those with two or more disabled children) report that they would rather have their partners at home helping to care for the children than have them out at work all day, even if this means living on a lower income.

When their partner shares caring responsibilities, mothers report an improvement in family relationships and a reduction in stress levels, which improves outcomes for all the family. However, fathers worry that even a short gap in employment due to caring responsibilities will be viewed as unacceptable by prospective employers. Differing priorities may contribute to stress and breakdown of relationships.

Improving financial support for carers would enhance the status of people who choose or have to give up employment to care for their disabled children, and may improve their long term chances of accessing employment.

Services

Families' reliance upon statutory services renders them particularly susceptible to unreliable and inadequate provision. Much more needs to be done to ensure that 'seamless' and holistic services are adapted to the needs of disabled children and their family. Differing priorities and a culture of blame hinder 'joined up thinking'. Poor services result in families being forced to use benefit income, which is supposed to help with the extra costs associated with their disabled child's particular needs, to pay for additional services.

Social exclusion

Individual members of the families experience social exclusion in different ways. Little is known about the perceptions of social exclusion amongst disabled children themselves, their non-disabled siblings, and their fathers. Further research is essential.

This report was researched and written by Gabrielle Preston, when she was Policy and Information officer at Disability Alliance, and on secondment to CASE as a User Fellow.

Copies of the full report CASEpaper 92 February 2005 are available to download free of charge from:

www.disabilityalliance.org or
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Report summary
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Disability Alliance is a national charity which seeks to promote a wider understanding of the needs of disabled people, particularly in relation to income and social security.

Our principal aim is to relieve the poverty and improve the living standards of disabled people. Our aspiration is to break the link between poverty and disability.

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