

Disabled children & child poverty

Briefing paper by the Every Disabled Child Matters campaign

To end child poverty for families with disabled children, EDCM wants government to invest £4 billion in benefits and child tax credits, along with:

- A major take-up campaign on Disability Living Allowance (DLA)
- An increase in the childcare element of working tax credit for these families to £300 per week
- An increase in DLA to meet the real cost of caring for a disabled child

Every Disabled Child Matters (EDCM) is the campaign to get rights and justice for every disabled child. It has been set up by four leading organisations working with disabled children and their families – Contact a Family, the Council for Disabled Children, Mencap and the Special Education Consortium. EDCM is funded by the True Colours Trust.

Find out more and sign up to support the campaign at www.edcm.org.uk

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EDCM is a member of the Campaign to End Child Poverty. Sign up to the campaign at www.ecpc.org.uk

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The government's commitments to end child poverty by 2020 and cut it by 50 per cent from 1997 levels by 2010 are ambitious and highly commendable. It is also clear that these commitments are not going to be turned into a reality unless the government adopts new policies and makes a significant investment in existing policies to reach families living in poverty. Barnardo's suggests that on present policies, by 2010 there are projected to be nearly 30,000 more disabled children living in poverty than there were in 2004/05.¹

The government has already helped lift 800,000 families out of poverty since the commitments were made. But as time passes, the need increases to target future action at the specific drivers of poverty for certain key groups. This briefing paper, produced by the Every Disabled Child Matters campaign as a contribution to the Campaign to End Child Poverty, sets out the case for targeted measures to tackle poverty in families with disabled children.²

Disabled children and child poverty – the challenge

There are around 770,000 disabled children in the UK. Disabled children aged 0–16 are the fastest-growing group amongst the population of disabled people.³ This growing population contains proportionately more children with disabilities requiring input from a range of services, in particular children with autistic spectrum disorders and complex health needs.

Research demonstrates a strong relationship between low income, social exclusion and disability among families who have a disabled child.⁴ Families with disabled children remain disproportionately likely to be in poverty.⁵ They are more than twice as likely as other families to be unable to afford five or more everyday items.⁶ From a major survey of over 1,800 families with disabled children, only 6 per cent reported they were 'comfortably off' with 93 per cent reporting some form of financial difficulty.⁷

Using a standard income measure of poverty (60 per cent below the median income level after housing costs), government data from 1994–2005 shows that disabled children face a 30 per cent risk of poverty, compared with a 27 per cent risk across all households.⁸ A different measure of child poverty that took account of the additional costs that are associated with bringing up disabled children would be likely to show much higher rates of severe child poverty amongst these families.⁹

Childhood disability is frequently a 'trigger event' for poverty, as a result of additional costs, family break-up and unemployment that can follow the birth or diagnosis of a disabled child. Indeed, disability across the life cycle has a close association with poverty; although this paper focuses on disabled children, the presence of a disabled *parent* in the family increases the risk of poverty even further.¹⁰ Those families where one or both parents are disabled have additional needs. Disabled children in these families face a risk of over 37 per cent of living in poverty.¹¹

Certain types of families with disabled children are particularly at risk of poverty, not least because services are not currently designed to meet their needs.¹² Families from black and minority ethnic backgrounds in particular report a high level of unmet need.¹³ Data from the Family Fund points to a lower rate of benefits take-up among disabled families from minority ethnic groups. Having more than one disabled child places further strain on the family. It is estimated that ten per cent of families with disabled children care for more than one disabled child.¹⁴

Disabled children and child poverty – the drivers of poverty

Families with disabled children face two specific challenges in addition to those faced by all families, which taken together increase their risk of living in poverty:

- 1 Considerable additional and ongoing expenses – the **cost of care** for their disabled child
- 2 Barriers to entering and sustaining employment – the **income penalty**

The cost of care

Families with disabled children face considerable additional expenditure on heating, housing, clothing, equipment and other items compared with other families. It costs three times as much to bring up a disabled child as it does a non-disabled child.¹⁵ In 1998, this equated to an annual cost of £7,355 to bring up a disabled child, compared with £2,100 for other children.¹⁶ These extra costs associated with disability drive high levels of poverty among disabled children and their families.

Examples of additional costs received by MPs who led the Parliamentary Hearings on Services for Disabled Children ranged from a family whose daughter needed five nappies each day, but who only received three per day from social services, to a family trapped in a small flat with two children who had spent the equity in their home on their disabled child's therapies.¹⁷ Families also struggle to adapt their homes to meet their children's needs. The government has identified that as many as three-quarters of families with disabled children live

Miles driven to appointments about her needs – 11,004

in unsuitable housing.¹⁸

Benefit increases have not been based on these extra costs. The tax and benefits system does acknowledge that disabled children and their families incur additional costs, particularly through Disability Living Allowance and premiums to relevant tax credits. However, many have argued that the system fails to recognise the true cost to these families. Over half (55 per cent) of the parents submitting evidence to the Parliamentary Hearings described benefit levels for disabled children as poor.¹⁹ In a recent Carers UK survey, half of all carers end up subsidising the costs of the disability of the person they care for because of inadequate disability benefits.²⁰

The income penalty

Disabled children are also at a high risk of poverty as a result of low household incomes. Many parents of disabled children are unable to work because of care responsibilities and the lack of, or the cost of, appropriate childcare.

Income figures do not give a full picture of poverty levels because they do not take into account additional expenditure. However, they do shed some light on the earning capacity of households with disabled children. Recent DWP figures show that there are almost three times as many families with disabled children in the lowest income quintile as in the top quintile.²¹

The government views work as the prime guarantor of a reasonable level of household income. However, in 2003, families supporting a disabled child were 2.5 times more likely than other families to have no parent working for more than sixteen hours per week.²² Carers UK found that 86 per cent of those caring for disabled children under the age of 18 reported their earnings had been affected.²³

Just 16 per cent of mothers with disabled children work, compared with 61 per

our feelings of isolation from other families are sometimes overwhelming

cent of mothers with non-disabled children.²⁴ This is confirmed by analysis of Family Fund data from 2002.²⁵ Carers UK analysis of the 2001 census data found that only 38 per cent of families with a sick or disabled child contain two working adults, compared with 55 per cent of families generally.²⁶

Barriers to work are also created by the stress of caring unsupported for a disabled child and the pressure this can place on family relationships. Three in ten lone parents (29 per cent) have a sick or disabled child.²⁷ These families are particularly likely to have no adults in work.

A generic failure to provide co-ordinated, streamlined support for children contributes to trapping families in poverty. One parent's experience stands for a large number of families in a similar situation:

'My daughter Amy, aged seven, was diagnosed with a rare syndrome when she was five weeks old. She uses a wheelchair and has only a few words of speech. I had no idea what implications her diagnosis would have for our entire lives. I recorded just how much time and effort we've had to put into Amy's care since then:

- Meetings and contacts with professionals – 774
- Hours spent on appointments and phone calls about Amy's needs – 4,942
- Miles driven to appointments about her needs – 11,004.'

The consequences

Amy's mother sets out in stark terms the consequences of the unco-ordinated provision for her daughter:

'I've had to give up work, and as a result my husband and I have been unable to afford much of the special equipment and support Amy needs. The stress puts a lot of pressure on our relationship and our feelings of isolation from other families are sometimes overwhelming.'

As a consequence of additional costs and limited income, families with disabled children are faced with a stark choice – go into debt or go without. Sometimes there is no choice between these unpalatable alternatives. Families with disabled children are both 50 per cent more likely to be in debt and 50 per cent less likely to be able to afford holidays, new clothes, school outings or 'treats' for their children than other families.²⁸

A Family Fund study of the income and expenditure of families with a severely disabled child found that these families 'struggle on a daily basis to fulfil the needs of

their child and use a variety of methods, including credit, to overcome their immediate financial hurdles.²⁹ In the recent Carers UK survey, more than 1 in 5 families said they had to cut back on food as a result of the costs of bringing up their disabled child.³⁰

The Family Fund research also found that pension payments for families with disabled children averaged only £6.02 per week, compared with an average UK family expenditure on pensions of £21.20.³¹ This is the lowest expenditure of any group covered by the Office of National Statistics data, and demonstrates how the additional costs of bringing up disabled children are storing up poverty for families as parents get older.

With regard to debt, in the Carers UK survey already referenced, half of those caring for disabled children under 18 were in debt, a higher percentage than other groups of carers.³² Of over 1,800 families with disabled children surveyed by Contact a Family and the Family Fund in 2004, most owed between £500 and £10,000 (52 per cent), with the largest group of families owing between £1,500 and £5,000 (23 per cent). Only 16 per cent said that they had no debt. However, an equal proportion reported debts in excess of £10,000 (excluding mortgage payments).³³ This is four times the rate of serious indebtedness found amongst other families.³⁴

Disabled children and child poverty – the solutions

Investment in benefits and tax credits

EDCM fully supports the Campaign to End Child Poverty in its call for **government to spend the £4 billion needed on benefits and child tax credits to reach the 2010 target of halving child poverty.**³⁵ Barnardo's estimates that with this significant investment, by 2010 there would be 140,000 fewer disabled children living in poverty compared to 2004/05.

Childcare

The government needs to act to support parents of disabled children to meet the cost of childcare. A particular priority is to close the gap between tax credit support for childcare costs and what parents of disabled children actually pay. A previous EDCM briefing showed that parents of disabled children are paying around five times as much towards childcare costs as parents of non-disabled children.³⁶ To address this, **HM Revenue and Customs should increase the upper limit of eligible childcare costs under Working Tax Credits for families with a disabled child to £300 per week.**

The government has recognised the need to provide more accessible high quality childcare places for disabled children. The recent government review, *Aiming High for Disabled Children*, committed £35 million over the period 2008–11 to fund accessible childcare pilots.³⁷ The Childcare Act 2006 introduces new duties on local authorities to

provide a sufficient supply of childcare in their area. Pending the results of the accessibility pilots, **the next spending review should invest significant new resources in supporting childcare providers to increase access for disabled children, particularly those with high support needs and older disabled children and young people.**

Flexible working

The Employment Act 2002 gave parents with a disabled child under eighteen the right to request flexible working arrangements which may enable more parents to more easily balance paid work and care. Flexible working is an essential pre-condition of work for many parents of disabled children faced with a system that is not designed to help them work 'nine to five'. One parent told the Parliamentary Hearings:

*'I can in fact only work on a very ad hoc basis due to all the appointments and other commitments I now have for my daughter and I am not sure how much longer my employer will need me as I cannot work in school holidays at all.'*³⁸

I am not sure how much longer my employer will need me as I cannot work in school holidays at all

In recognition of this, **the Government should develop the Employment Act 2002 by creating a right to insist on flexible working arrangements unless a clear business case exists to reject such a request. This right should not be subject to any qualifying period of employment, as is currently the case.**

Benefits

The key benefit designed to meet some of the additional costs faced by families with disabled children is Disability Living Allowance (DLA). In the five years to February 2004, the number of children receiving DLA increased by 30 per cent.³⁹ Yet in August 2004, still only 271,000 children under the age of 16 were receiving some level of DLA.⁴⁰ In February 2006, this had increased to about 327,000 children – still well under half of the total population of disabled children in the UK.⁴¹ **To promote take-up of DLA, DWP should invest in a major advertising campaign, based on the model used for tax credits.**

The need for such a take-up campaign has been recognised by DWP. A recent research report stated:

'it is common for customers to only have learned of relevant disability benefits by chance, it is inevitable that eligible individuals exist who are unaware of benefits. We propose that additional ways of alerting potential claimants of the benefits should be sought, both by DCS itself and in partnership with relevant bodies' (emphasis added).⁴²

Even with enhanced take-up, DLA may not currently be enough to help the government meet its 2010 poverty target. The rates of DLA in recent years have been rising at a rate of around 2.5 per cent, barely in line with inflation. **DWP should**

consider again whether to uplift DLA significantly to come closer to meeting the real additional costs of bringing up a disabled child. Disability Alliance have estimated that an uplift in the region of 30–50 per cent would come close to achieving this aim.

Significant operational barriers exist within the system to prevent some families from receiving the benefit to which they would be entitled. First among these is the length and complexity of the DLA claim form. **DWP should proceed as quickly as possible to introduce the new claim form, which is intended to simplify the process for families.**

A significant grievance felt by families whose children have long-term conditions and lifelong disabilities is the requirement to fill in further DLA forms on an annual basis. **DWP should consider awarding DLA for longer periods where children have disabilities where the variation in the level of need is likely to be marginal.** This would be particularly applicable to many children who are in receipt of higher-rate care component, as their care needs are only likely to increase with age.

This recommendation was also made by the Parliamentary Hearings on Services for Disabled Children.

A further recommendation made by MPs in the Parliamentary Hearings report, and one that we endorse, was that **the government should give serious consideration to extending winter fuel grants to parents of disabled children on benefits, particularly those with disabled children under 5 who are at home all day.** This is particularly an issue for parents of young disabled children who are currently unable to find high quality, accessible childcare.

The final benefits issue considered by the Parliamentary Hearings was Carer's Allowance, which is currently paid at a rate described by parents as 'unbelievable' and 'an insult'. We recommend **a review of Carer's Allowance, with a particular focus on the bar to full-time study, the need to taper the reduction as carers take on work and the need to increase payments for those caring for two or more dependants.**

💧 If my daughter went into residential care it would cost the local authority £135k per year minimum. We shouldn't have to live like this. 💧

Family Fund grants

The Family Fund should be viewed by the government as a key agent in the battle to end child poverty for families with disabled children.⁴³ The Fund already distributes £28.2 million to 50,000 of the poorest families of severely disabled children. It has 176,000 families on its database.

The Fund is an efficient delivery mechanism for financial support to families with disabled children, distributing over 90p of every £1 it receives. In spring 2006, the Fund distributed £200,000 in only three months to more than 320 families of disabled 16-year-olds in one-off projects funded by the Scottish and Welsh administrations. However, the Fund's government income in England has not been increased since April 2003, despite increases from devolved administrations in the other UK nations.

To maximise the potential of the Fund to help end child poverty for families with disabled children, **English government departments should collaborate to increase the Family Fund's income by £34 million in 2008–2011**. The Fund could then afford to help young people up to age 18 (current cut-off is 16) and families earning up to £25,500 (current cut-off in England is £23,000).

Services and Family Support

Services that help keep families together implicitly support parents to find and sustain work. **DCSF should ensure that the £280 million allocated to short break services in *Aiming High for Disabled Children*, along with further funding due to be allocated from the Department of Health budget, is targeted on families with the highest level of need.**

In addition, to tackle the poverty impact of unco-ordinated support and duplicated assessments, as described in Amy's story above, **the government should continue to promote models of key working and co-ordinated support for families such as Early Support and the new Transition Support Programme, ensuring that school-aged children aged 5–14 do not miss out.**

Housing

Despite the recent improvements to the Disabled Facilities Grant (DFG), the maximum grant of £25,000 still does not meet the actual cost of significant adaptations to a family home. **Where a family is assessed as requiring significant adaptations to its home, local authorities should have the discretion to award DFG payments of up to £50,000.**

Conclusion

The briefing on disabled children and child poverty produced by the Council for Disabled Children and End Child Poverty in 2003 stated that, 'Disabled children and their families are a clearly defined population for whom it should be possible to eradicate poverty and improve life chances with a modest investment of public funds.'⁴⁴ Nothing has happened in the past four years to contradict this analysis.

Although many of the solutions outlined above carry front-loaded costs, there will be a range of costs to the government in not acting to tackle child poverty in families with disabled children in addition to the costs to children and families. The first of these will be political – it will be difficult for the government to reach the 2010 target and impossible for it to reach the 2020 target unless specific measures are put in place to address poverty in families with disabled children.

The second set of costs will be financial – families will continue to struggle to cope unsupported. Many will continue to be excluded from seeking paid

employment, there will be a financial impact on carers health and well-being, and there will be a continuing rise in costly residential placements for disabled children whose parents are ultimately unable to carry on caring. As one parent told the Parliamentary Hearings on Services for Disabled Children:⁴⁵

'I have given up a £25k a year job and now find myself in serious poverty. If my daughter went into residential care it would cost the local authority £135k per year minimum. We shouldn't have to live like this.'

The new Secretary of State for Children, Schools and Families, Rt Hon Ed Balls MP, has shown his commitment to families with disabled children through championing the government review that led to *Aiming High for Disabled Children*. As a result of his efforts and those of his Ministerial colleagues Lord Adonis at DCSF and Ivan Lewis MP at the Department of Health, new investment and a new performance framework will start to transform the services that families with disabled children receive.

DCSF now has lead responsibility for the government's child poverty targets. The Secretary of State and his Ministerial team have the opportunity put disabled children at the centre of the government's plans to meet the targets. The Secretary of State has recognised the challenge. Giving evidence to the Parliamentary Hearings, he stated:

'Working in a family with disabled children is much harder for mothers and this is why families are much more likely to live in poverty.'

As supporters of End Child Poverty, EDCM is calling on the government to spend the £4 billion needed on benefits and child tax credits to reach the 2010 target of halving child poverty to improve the life chances of millions of children across the UK.

Looking in particular at families with disabled children **EDCM's three key proposals** to the government, as set out in this briefing, are:

- 1 DWP should invest in a major advertising campaign, based on the model used for tax credits, to promote take-up of DLA.**
- 2 HM Revenue and Customs should increase the upper limit of eligible childcare costs under Working Tax Credits for families with a disabled child to £300 per week.**
- 3 DWP should consider again whether to uplift DLA significantly to come closer to meeting the real additional costs of bringing up a disabled child.**

Action on at least one and ideally all of these recommendations would significantly increase the chances of the government meeting its 2010 target and, far more importantly, would help improve the life chances of families with disabled children, who remain one of the most marginalised groups in society.

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