

Breaking down barriers:

making work pay for families with disabled children

"I could not afford to go back to work full time as both my children have disabilities and would need separate childcare which is unaffordable also I have no-one to look after them during holidays and the cost would then make working a pointless exercise."

The Every Disabled Child Matters (EDCM) campaign in partnership with the Family Fund conducted a survey of families with disabled children of their experiences of childcare and employment. The Family Fund is a charity that provides grants to low income¹ families caring for severely disabled children. All of the families included in the survey have received support from the Family Fund in the last year. **Only one third of the parents responding to the survey stated they were currently in employment.** The results from the survey therefore act as a snapshot of the main barriers to work that the lowest income families with disabled children face².

Making work pay for everyone is an aim at the heart of the Coalition Government.

Currently work does not pay for many families with disabled children. This report examines the difficulties parents face and makes recommendations on how the Government can break down barriers to employment for families with disabled children.

Responses from parents identify the three main barriers to work for families with disabled children as:

Lack of affordable and accessible childcare

High cost and a lack of inclusive childcare settings prevent families with disabled children from partaking in employment and reduce their earning potential.

Low incomes squeezed by lack of financial support

Families with disabled children experience high unavoidable costs. These costs act as a barrier to many families entering or remaining in employment because families cannot afford work related costs such as childcare.

Lack of family friendly workplaces

Flexible working is vital to enable families with disabled children to juggle their working and caring commitments.

¹ To receive a Family Fund grant you must be the parent or carer of a severely disabled child or young person aged 17 or under who lives at home. Families must also be eligible to receive and can send us evidence of one of the following: Child Tax Credit, Working Tax Credit, Income based Job Seekers Allowance, Income Support, Incapacity Benefit, Employment Support Allowance, Housing Benefit, or Pension Credit.

² The quotes and statistics used throughout this report were all collected in a Family Fund survey of 50 families in May 2011.

Lack of affordable and accessible childcare

“If I could afford the special childcare, particularly in the school holidays, I could go back to work”

Families can struggle to access suitable and affordable childcare for disabled children. Lack of trained staff or inaccessible facilities mean that childcare places for disabled children are scarce. Where they do exist they are in high demand and therefore parents pay a premium cost.

Availability

Only 24% of respondents currently access childcare

One of the main reasons for low uptake of childcare is a lack of suitable childcare providers. Lack of availability of suitable childcare is an issue that is recognised by local authorities (LA); in 2010 almost half of LAs reported insufficient childcare for disabled children (49%) and insufficient childcare for older children (47%), which families with disabled children are disproportionately likely to access³. The Childcare and Early Years Survey of Parents 2008 – 2009 found that 31% of families with disabled children⁴ disagreed or strongly disagreed that there were childcare providers in their local area that cater for their child’s condition.

“In the past when I did have child care, I found it difficult to find carers. When we approached they would only see my son’s problems and not the human being.”

Lack of suitable childcare is particularly problematic during the school holidays due to the additional number of hours of childcare that families need to access. Lack of childcare during the school holidays can lead to parents having to give up work over the summer holidays and then try and find new employment in the autumn, or remain out of employment.



Cost

66% of respondents pay more for childcare for their disabled child than for their non-disabled child

These additional childcare costs for disabled children inevitably makes it more difficult for work to pay for many families. An earlier national survey of 350 families with a disabled child found that 90% of families reported that the costs of childcare were a major deterrent to work⁵. Additional costs are attributed to the perceived and real cost to childcare providers of facilities and equipment, appropriate staffing, and providing transport provision for disabled children and their families to help them access childcare services⁶. This is particularly worrying in light of the duties on service providers to make reasonable adjustments under the Equality Act. Both families and service providers are often unclear as to what represents a legitimate cost for a particular specialist service, and what constitutes a failure to make reasonable adjustments.

As with childcare costs for all families the price that families with disabled children pay varies by location. The national average cost for childcare is approximately £3.50 – 4.50⁷ per hour. Several parents told the Family Fund that they experience costs of between £12 – 14 per hour, and other recent research reported costs of up to £20 per hour⁸. It is therefore clear that childcare costs for disabled children are substantially higher than for non-disabled children.

Accessibility

58% of respondents used different childcare for their disabled child and their non-disabled child

The use of different childcare for disabled and non-disabled siblings indicates that there is a lack of inclusive and accessible childcare settings for parents to place both their disabled and non-disabled children. The complexity of having to access multiple childcare providers' acts as an additional barrier to returning to work. Families with disabled children report having to travel further for suitable childcare settings for their disabled child - The Childcare and Early Years Survey of Parents 2008 – 2009⁹ found that 24% of families with disabled children found it difficult or very difficult to travel to the nearest provider, therefore when accessing different childcare providers for disabled and non-disabled children parents may have to travel some distance between the two.

“Because of my child’s difficulties school clubs and other special needs organisations turn him away after the first session”

Families with disabled children are stuck in a Catch-22 scenario. There is a lack of suitable provision in local areas to cater for disabled children’s needs and where there is suitable provision families pay a premium for it. However, making childcare more affordable for families with disabled children is likely to stimulate the market and ensure childcare providers see the business case for providing childcare for disabled children.

“I cannot work because I am a single mum with a profoundly disabled son. I would love to be able to go to work but cannot afford the £12-£14 per hour care for my son - especially in school holidays”

Low incomes squeezed by lack of financial support

“My son has duchenne muscular dystrophy and gets cold really easy and often have heating on for his bedroom. My son is a large 12 year old and I have to buy large men’s clothing and struggle with bottoms that fit due to his leg contractors. He is also on a special low calorie and low fat diet needs lots of fresh food.”

Families with disabled children have higher unavoidable costs. This financial strain is one of the main reasons that they are disproportionately likely to live in poverty. Costs relating to raising a disabled child are in many cases a large proportion of disposable income for low income and out of work families. This leaves very little extra money to enable families to become work ready because they may not be able to afford work preparation or in-work costs such as childcare, training and transport.

Disability Additions

Respondents to the Family Fund survey outlined some of the additional outgoing costs they have. Household’s reported extra costs of up to £400 per month relating to their child’s disability, with many households having extra costs for laundry, heating, hot water, clothing, food and household adaptations. A recent Contact a Family survey of families with disabled children found that more than a third (34%) of respondents have fallen behind with repayments, most for credit cards and loans as well as utility bills¹⁰. When families are living in debt and have high costs to meet their child’s needs this is an additional barrier to work, as there will be no spare money to enable families to meet work related costs. EDCM is therefore concerned about the impact of the Government’s proposal to reduce disability additions for low income and out of work families with disabled children, on making work pay for disabled children.

Currently, low income and out of work families who receive Disability Living Allowance (DLA) are entitled to a 'disability addition' worth £52.08 per week in 2010/11¹¹. Families with a child in receipt of the high rate care component of DLA also receive a 'top up addition' worth an additional £21 per week. However proposals under the Universal Credit will see lower benefit 'additions' drop by over 50%. Although existing claimants will be transitionally protected, in the future up to 63% of those children qualifying for DLA will potentially be affected by this reduction.

The financial impact of the proposed policy can be seen in the below table:

	Benefit per week 2010/11	Proposed benefit per week	Monetary difference per week	Monetary difference per year
Lower disability addition	£52.08	£25.95	-£26.13	-£1358.76
Higher disability addition	£73.08	£74.50	+£1.42	+£73.84

EDCM has concerns that the higher disability addition rate may either be introduced at a lower rate or will not increase with inflation between now and 2013 – this would mean a drop in support for all disabled children who are not transitionally protected. It is vital that the Government carefully considers the implications of this.

A recent EDCM poll showed that 98% of respondents were either 'worried' or 'very worried' about this proposal.¹² Comments from the Family Fund survey on the proposal from families that currently receive this benefit¹³ say:

"This would be devastating for us as I can barely afford to pay the bills etc on what we get now. If it is reduced, I don't know what I would be able to do. It is extremely worrying and my son, like many other disabled children, would be the one to suffer"



"(This) would restrict the quality of life for the whole family"

Reducing disability additions will make it much more difficult for these families to afford work related costs that they pay a premium for such as childcare. For those families who are unable to work because of their caring responsibilities this will make the move to employment much harder as they will be unable to afford costs associated with becoming work ready. This policy is therefore likely to result in many more families with disabled children living in poverty.

Family Fund Grants

The Family Fund provides grants of £26m a year in England to more than 44,000 low-income families with severely disabled children for things that make life easier and more enjoyable. The grants are to cover costs of items such as a washing machine, clothing, bedding, driving lessons, a computer or a much-needed family break together. For many families the grants are a lifeline providing essential help when families need it most. It is imperative that the Family Fund is able to continue to provide this vital financial support to low income families with disabled children to help them meet the high unavoidable costs they face and live ordinary lives.

"You have been a lifeline, providing a grant when I needed it the most. As a mum looking after two disabled children I just could not afford items that are essential for me to care for my little ones"

Family friendly working

“I was working and although they said they would be supportive of my care responsibilities, they soon got fed up with me having time off and refused to give it in the end, therefore I had no choice but to resign. I would like to get back to work and am currently looking into doing some training to help me but this costs money and although you can get some help with certain courses, it’s not enough.”

Flexible workplaces are important to families with disabled children to allow them to juggle the responsibilities of caring and working. Parents of disabled children may be more likely to require flexible working hours or to need to arrange time off at short notice, to ensure they are meeting the caring needs of their disabled children. Some parents are therefore hesitant to return to work after having a disabled child because they are concerned that they need to work flexibly from the first day of their job and therefore require employers to make reasonable adjustments.

Routine appointments

“My wife works flexible hours and she’s the parent that takes more care of my son. My work is not flexible and is not supportive at all in my caring responsibilities.”

Parents of disabled children in their responses to the survey reported that one of the main areas of flexible working that they struggle to manage is when they are required to take their child to routine appointments, for example to speech therapy or for hospital check ups. As a result, they may need to be away from work at specific times. These absences do not fit into the category of emergency leave. Families report that whilst employers and colleagues can be supportive of flexible working arrangements to begin with, they can become less supportive as families need to continue to take time off work to meet their child’s needs.



Parental Leave

“I am worried about working because I would need flexible hours as I am a single parent with a disabled son and a daughter with special needs.”

There are times of emergency when parents may be required to take longer periods of time off work. For families with disabled children, particularly for children with fluctuating health conditions or a life limiting illness this requirement to take time off work can happen much more frequently. Parents may be required to support their child whilst they are in hospital or to care for their child if they are too unwell to attend school. Parents of disabled children have a legal right to request parental leave. For many families parental leave is crucial for balancing their working and caring responsibilities. It is vital that parents of disabled children applying for parental leave feel supported both from their employer and colleagues, during these difficult times of their life.

3 Daycare Trust (2009)

4 who had an illness/disability that disrupted their daily life

5 Beresford, B (1995) Expert opinions: a national survey of parents caring for a disabled child

6 HM Treasury/Department for Education and Skills (2007) Aiming High for Disabled Children: better support for families

7 Daycare Trust (2011) Childcare Costs Survey 2010

8 Department for Education (2011) Qualitative research into families’ experiences and behaviours in the Childcare Affordability Pilots (CAP09): Disabled Children’s Pilot

9 EDCM (2011) Unpublished data

10 Contact a Family (2010) Counting the Costs: The financial reality for families with disabled children

11 Families who receive DLA and qualify for the Child Tax Credit are able to access the Disability Element of Child Tax Credit (mirrored for those in receipt of Income support, income based job seekers allowance, housing benefit and council tax benefit as the Disabled Child Premium) for each child in the family who is getting DLA or registered blind.

12 EDCM Facebook poll of 499 people in April 2011

13 These families will be protected from this cut by transitional protection from the Government. These families were aware of transitional protection.

Breaking down barriers:

making work pay for families with disabled children

EDCM welcomes the Government's commitment to make work pay for everyone. In order to ensure that work can pay for families with disabled children regardless of the extra costs they face, EDCM recommends the Government:

Help families afford high quality accessible childcare

- ◆ Commits to improving the quality and availability of childcare for disabled children
- ◆ Commits to recognising the higher costs of childcare for disabled children within the Universal Credit, for example through meeting a higher percentage of childcare costs for disabled children.

Provide financial assistance to families with disabled children

- ◆ Commits to provide at least current levels of direct financial support through disability additions within the Universal Credit, to make work pay for families with disabled children who are out of work or on low incomes.
- ◆ Commits to continuing to fund grant giving organisations, such as the Family Fund, to provide financial support to families with disabled children to help them live ordinary lives.

Family friendly working

- ◆ Extends the right to request flexible working from the first day of employment
- ◆ Work with employers to encourage them to advertise posts as flexible working, where appropriate, and to discuss flexible working options at interview stage.
- ◆ Creates a flexible working kitemark scheme to demonstrate where workplaces are flexible working friendly
- ◆ Extend the right to request flexible working to all employees to reduce stigma and improve attitudes towards parents with caring responsibilities.

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Every Disabled Child Matters (EDCM) is the national campaign to get rights and justice for every disabled child. It is run by four leading organisations working with disabled children and their families – Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium. [Find out more about the campaign at www.edcm.org.uk](http://www.edcm.org.uk)