



# between a rock and a hard place

achieving a work-life balance and finding the right childcare is a challenge for all families.

**For many parents with a disabled child this isn't just a challenge but a distant dream.<sup>1</sup>**

Employment is a key government strategy to end child poverty. Yet for many parents (and in particular mothers) of disabled children 'employment remains a difficult and unreliable route out of poverty'.<sup>2</sup>

The reason that these families experience barriers to employment is that childcare is neither fit for purpose nor affordable. Despite eight years of government childcare strategies there is no evidence that the childcare provision for disabled children is either available or that it meets the needs of parents.<sup>3</sup>

This leaves many families with a disabled child between a rock and a hard place and struggling on a low family income that limits the life chances of all family members.

The Childcare Act 2006 offers the promise of more childcare places and introduces specific duties for disabled children. However this will fail to deliver the promise for these children without additional funding to make childcare places both available and affordable and so help families with a disabled child lift themselves out of poverty.

'Simply getting out of the house can be difficult. I spend all my time organising his different appointments. I used to work as a radiographer in the local hospital. I really enjoyed my job but I can't imagine I'll ever be able to go back, I'd never find the right childcare as he has medical needs.'

'There's all this emphasis on getting people back to work, subsidised nursery places, after school clubs, breakfast clubs. But our children can't access them.'

## why isn't the childcare strategy working for disabled children?

There is a growing body of evidence that the national childcare strategy is not working for disabled children.<sup>4</sup>

There are a number of reasons for this failure:

- a lack of inspection of the supply of childcare places for disabled children
- no funding stream to increase the volume of childcare for disabled children
- a lack of coordination between national and local childcare strategies with other legislation and initiatives aimed at supporting disabled children and their families
- local authorities are not planning childcare based on the increased numbers of disabled children
- families with disabled children are not being consulted about their childcare needs
- current tax credit ceilings and rules do not make childcare affordable for families with a disabled child.<sup>5</sup>

'The growth in childcare provision in recent years has not been matched by a growth in schemes which make childcare available for disabled children.'<sup>6</sup>

## parents need to work

Parents of disabled children share the same aspirations of all parents, most of them need to work and want to work. There are 777,000 disabled children in the UK and an estimated 55% of families with a disabled child are living in or at the margin of poverty.<sup>7</sup>

The low income of families with a disabled child is compounded by high costs, with disabled children costing

three times as much to bring up compared with all children.<sup>8</sup> One in seven families with a disabled child are living in debt and are four times more likely than other families to have debts in excess of £10,000.<sup>9</sup>

'Not working is not an option for me. If I don't work we don't have a roof over our heads or food in the fridge.'

## forced out of the labour market

Although some parents of disabled children actively make the choice to care for their child at home, for the vast majority of parents this is not a choice but a situation forced upon them by the lack of childcare. Sustained periods outside the labour market leads to de-skilling and loss of confidence. In the long run this requires a more intensive and targeted level of back to work support which is currently not available to parents of disabled children.

85% of parents of disabled children want to work either full-time or part-time. Despite this level of aspiration only 16% of mothers of disabled children are in work compared with 61% of all mothers.<sup>10</sup>

'My career has been effectively halted by the fact that I cannot afford childcare for my disabled son.'

## do they really want us to work?

Parents of disabled children report that some professionals act as if it would suit 'the system' better if they remained at home as the main carers of their children. In this way parents attend hospital appointments at times that suit the professionals.

'I was told by the social worker that I should give up my job. That was the solution!'

## parents want to work

As well as needing paid employment in order to lift themselves out of poverty, many parents with disabled children want to work for the social and health gains for the whole family. Going out to work reduces the isolation commonly experienced by these families. In common with other mothers returning to work, mothers of disabled children report increased self-esteem and an identity outside their caring role.

'Employment is not only about money, it's about being part of your community, taking responsibility for your own life, making friends and developing skills.'

## the childcare gap

Despite eight years of government childcare strategies the lack of childcare places for disabled children remains the biggest barrier to work for most families.

Families of disabled children report a lack of childcare in their area.<sup>11</sup> In Suffolk 75% of parents of disabled children said that there were not enough childcare facilities to allow them to work.<sup>12</sup>

Where there are extended school services that could cater for disabled children they do not have transport that would make them a viable form of childcare for working parents. In a survey in Southwark only 9% of the disabled children with the highest needs used extended school services.<sup>13</sup>

'Two years ago I had to resign from my job due to lack of childcare for my severely autistic son. I now receive benefits – I would rather work.'

School holidays are a nightmare 'Last year I found a playscheme for four weeks of the summer holidays, but this year I can only find something for two weeks. I just never know what's going to be available, it's a real problem the inconsistency really affects my son's behaviour. I'm thinking of giving up my job as I can't handle the uncertainty.'

## the tax credit rules are against us

When families do manage to find childcare and claim help through tax credits, if they lose their job help with childcare costs stop immediately. This can mean that a childcare place is lost and the parent cannot then look for other work.

'It's much easier to find a new job than it is to find a new childcare place.'

## not fit for purpose

Many parents of disabled children find that childcare services are not fit for purpose, they simply cannot meet their child's needs. The first barrier is the attitude of childcare providers

who make parents feel that the service is 'not for me'.

For most disabled children it is not an issue about physical access to childcare premises. It is about the lack of skills of childcare staff to care for disabled children.<sup>17</sup> Due to the shortage of specialist training courses, a lack of experience and confidence on the part of childcare providers mean that families cannot find a service that they can trust.

'The nursery said they could look after my disabled son but after two hours they called and said they couldn't cope.'

## finding out about childcare

Parents of disabled children report in all surveys that there are real difficulties in finding out about local childcare. Parents cite instances of 'help' consisting solely of being given a list of local childminders with no indication of whether or not they were able to care for a disabled child.<sup>18</sup>

This is supported by Mencap's 2006 mystery shopping research in which it was found that although 6 out of 20 local authorities sent information about childcare providers,

# the affordability trap

A survey of 350 families with a disabled child found that 90% of families reported that the costs of childcare were a major deterrent to work. In this survey 60% of families had been asked to pay a premium to cover additional support in childcare services.<sup>14</sup>

The costs of childcare for a disabled child are often substantially higher due to the need for higher staff ratios or more specialised care.

'The costs when requiring childcare for a disabled child are astronomical.'

### How the affordability trap works

A family with a disabled child employs a home childcare worker with experience of disabilities which costs £8 per hour.<sup>15</sup>

Childcare costs for a 35 hour working week are £280.

Under current Working Tax Credit rules 80% of £175 is the maximum claim.

Only £140 per week can be claimed for childcare costs.

The shortfall of £140 per week makes work uneconomical.

### Childcare can be affordable.

A family with a non-disabled child pays a childminder around £4 per hour.

Childcare costs for a 35 hour working are on average £132 a week.<sup>16</sup>

Under current Working Tax Credit rules £105.60 per week can be claimed for childcare costs.

The shortfall for this family is only £26.40 per week which makes work and childcare viable.

Families with a disabled child pay *five times* more towards childcare costs.

in only one instance was the provider able to care for a disabled teenager. In this same survey none of the 20 agencies offered information or advice about childcare costs.

For families from black and minority ethnic communities a lack of information about childcare is a particular barrier to work. Assumptions based on stereotypical views 'they look after their own don't they' means that information and services are often not targeted at families from BME communities.<sup>19</sup>

**'Parents with disabled children are often isolated and struggling to function day to day, the effort of finding childcare is too much.'**

## we're off the radar

Although finding childcare is a problem for most families with a disabled child, for some families this is just an impossibility. National and local childcare strategies haven't even begun to address their needs. There are several groups who face additional challenges in finding suitable childcare:

- families from black and minority ethnic communities
- families living in rural areas
- families with a child with additional health needs.

**'Her medical needs are regarded as just too complex for childcare services to contemplate. They talk about risk assessments and health and safety and are unsure about administering medication.'**

## the older they get the worse it gets

For all parents juggling work and childcare becomes more complex as children become older, often involving a 'patchwork' of flexible working, the use of friends and relatives as well as unsupervised facilities.

For parents of older disabled children this patchwork is just not there. Disabled children are less likely to be looked after by grandparents than other children and are more reliant on formal childcare.<sup>20</sup> There is a greater need for staffed childcare facilities throughout their child's life.

Not only are the childcare services just not there for disabled young people but they are not affordable either. The current tax credit rules mean that these cannot be

used to fund childcare for children over the age of 16. This funding gap for older disabled young people has not been closed by the Childcare Act 2006 even though this covers disabled children up to the age of 18.

**'We have a 17 year old with a rare disorder. She is physically too old for "childcare" and not mature enough to be by herself in the summer holidays.'**

## is the Childcare Act the answer?

Reducing inequalities is a central theme of the Childcare Act 2006. We know that disabled children and their families have not benefited from successive childcare strategies so there is a real risk that this legislation will also fail this group.

Without significant demand and supply side funding and performance targets local authorities will continue to struggle to deliver any real improvements for disabled children. We will continue to see only a handful of families with disabled children using children's centres and being offered extended services through schools. Patchy childcare provision hampered by inflexible transport arrangements along with gaps in tax credits rules will not give parents with disabled children a realistic route back to work.

**'The local authority never asks us what sort of services we need or want so how will they make childcare right for us parents with disabled children?'**

## it's just not joined up

Local authorities have a legal duty to offer parents with disabled children an assessment of their own needs as part of any Children Act assessment for a disabled child. As a result of the Carers (Equal Opportunities) Act 2004

there is also a duty to consider the parents needs in relation to caring and work. There is little evidence as yet of this leading to improvements in support for parent carers and far less progress has been made in implementing the Carers (Equal Opportunities) Act 2004 so far as parents of disabled children are concerned.

**'There is a need to consider how the national childcare and carers strategies are linked together and how these work streams are coordinated at local level.'**



# what action is needed?

In order to remove the barriers to employment for parents of disabled children specific actions are needed at national and local levels. These actions need to be underpinned by performance indicators and additional funding to make childcare available and affordable for families with a disabled child.

'It is difficult to see how the government can ensure equal access to affordable, appropriate and high quality childcare and early years services without significant investment'.<sup>21</sup>

## action by government

### performance

- A new target for Local Area Agreements to increase the stock and take up of childcare by families with a disabled child.
- A stronger standard for local authority Children's Information Services to deliver childcare information for the parents of disabled children aged 0–18.

### demand

- Increase the upper limit of eligible childcare costs under Working Tax Credits for families with a disabled child to £300 per week.
- Close the tax credit gap so that parents of disabled young people aged 16–18 can claim for the childcare element of Working Tax Credit.
- A change in the Working Tax Credit rules that ensures the childcare element is not lost immediately if a parent of a disabled child loses paid employment.
- A Pathways to Work scheme for parents of disabled children.

### supply

- A national disability childcare fund to develop a skilled workforce and increase the supply of childcare places.
- A disability childcare adviser covering the 0–19 age range in every local authority to broker childcare arrangements that support parents and providers.

## action by local authorities

- To develop and implement a local disability childcare strategy that:
  - is advised by parents of disabled children, disabled children and young people and voluntary organisations
  - is based on an audit of demand and unmet need for all families with a disabled child, including BME families and children with additional health needs
  - sets local targets to meet the Local Area Agreement indicator for childcare for disabled children
  - commissions services to stimulate the childcare market for disabled children
  - is delivered by childcare staff with core and specialist skills
  - is agreed by the local Primary Care Trust.
- Monitor the take up of places in children's centres and extended schools to ensure that the Local Area Agreement target is achieved.
- Ensure that the Children's Information Services offer information and advice across the full range of childcare services for disabled children aged 0–18 in the locality.
- Work in conjunction with health authorities to meet the childcare needs of children with additional health needs.
- Access to specialist training courses for all childcare providers.
- Ensure that links are made between local carers and childcare strategies.

## notes

- 1 Paul Ennals, Chief Executive, National Children's Bureau
- 2 Preston, G, 2005, *Helter skelter: families, disabled children and the benefit system*
- 3 National Centre for Social Research, 2005, *Local childcare markets: a longitudinal study*
- 4 National Centre for Social Research, 2005, *Local childcare markets: a longitudinal study*
- 5 Harrison, J and Sinclair, D, 2006, *Poverty and reform of Tax Credits briefing*
- 6 DfES, 2002, *Together from the start*
- 7 Gordon, D et al, 2000, *Disabled children in Britain: a re-analysis of the OPCS disability survey*
- 8 Dobson, B and Middleton, S, 1998, *Paying to care: the costs of childhood disability*
- 9 Harrison, J and Wolley, M, 2004, *Debt and disability: the impact of debt on families with disabled children*
- 10 Russell, P, 2002, *Bridging the gap*
- 11 Bryson, C et al, 2005, *Use of childcare among families with children who have special educational needs*
- 12 Suffolk Action for Communities, 2001, *Challenging inclusion*
- 13 Contact a Family, 2000, *Early education and childcare for children aged 0-14 with disabilities and special needs in Southwark*
- 14 Beresford, B, 1995, *Expert opinions: a national survey of parents caring for a disabled child*
- 15 Unpublished research by Contact a Family, 2002
- 16 Daycare Trust, *Childcare Costs Survey 2006*
- 17 DfES, 2006, *Childcare and early years providers survey*
- 18 Boyd, M, 2002, *Is it child's play? meeting the childcare challenge for children with special needs*
- 19 Chamba et al, 1999, *On the edge: minority ethnic families caring for a severely disabled child*
- 20 Bryson, C et al, 2005, *Use of childcare among families with children who have special educational needs*
- 21 Stanley, K et al, 2006, *Equal access? appropriate and affordable childcare for every child*

The **ACE National** partnership, led by Carers UK, is working to support the inclusion of carers in training and work. It is focused on improving alternative care services such as childcare which will help those juggling work and care. The aim of the partnership is to raise awareness about the Carers (Equal Opportunities) Act 2004 which seeks to give those with caring responsibilities the same opportunities that others take for granted.

For more information

website [www.acecarers.org.uk](http://www.acecarers.org.uk)

tel 020 7608 8742

email [una.summerson@cafamilly.org.uk](mailto:una.summerson@cafamilly.org.uk)

**Every Disabled Child Matters** is a campaign by four organisations working with disabled children and their families: Contact a Family, Council for Disabled Children, Mencap and the Special Educational Consortium. The Every Disabled Child Matters campaign wants all disabled children and their families to have the right to the services and support they need to live ordinary lives.

For more information

website [www.edcm.org.uk](http://www.edcm.org.uk)

tel 020 7843 6448

email [info@edcm.org.uk](mailto:info@edcm.org.uk)

The ACE National Development Partnership and this briefing is part funded by the European Social Fund under the Equal Community Initiative Programme.

**ACE National**  
action for carers and employment  
led by **CARERS UK**



**Equal**