

CARING MORE THAN MOST

Executive Summary



contact *For families
with disabled children*

ABOUT THIS RESEARCH

Contact commissioned the University of Leeds (Dr Lisa Buckner), in consultation with Dr Sue Yeandle, to analyse data about families with disabled children from three of the largest public population datasets available:

- ***The 2011 Census of households and people [Census]. This is based on a count of all people in the UK***
- ***The Carers in Households in England Survey 2009/10 [CiH]. This had a sample size of 2,401 carers***
- ***The Health Survey of England (2012, 2013 and 2014) [HSE]. This has a sample size of approximately 10,000 people each year.***

Analysis of all three sources has been used to provide the most reliable and comprehensive picture of the lives of UK families with disabled children to date.

Contact's *Caring More than Most* – a profile of UK families with disabled children presents information on:

- ***Numbers and characteristics of disabled children under 20 years old in the UK***
- ***A profile of their families, including a comparison of parent carers to other carers and people without any caring responsibilities***
- ***Contact's response to the analysis and subsequent policy recommendations.***



*“I would like to be a parent to my teenager with complex needs and my other children rather than a doctor, nurse, social worker, teacher, fighter and carer. Getting the balance between being a carer, working, being a mum and having a relationship is almost impossible.” **Parent carer***

KEY FINDINGS

The research shows that there is a marked and **unacceptable difference** between the quality of life and opportunities available to families with disabled children compared to those without disabilities.

Disabled children and their families are at a **significant disadvantage** in many key aspects of life including their **economic situation, health, employment and housing**.

641,500

disabled children and young people in the UK

620,000

adults caring for disabled children under 20 years of age in the UK

When compared with non-disabled children, **disabled children** are:

Twice as likely to live in a home where there is no parent in paid work (34% compared to 17%)

More likely to live in a lone parent household

More likely to live in a household without a car, in a home without central heating, and in overcrowded housing

More likely to live in larger households (containing six or more people)

More likely to live in a household with other disabled people.

When compared with other carers, **parent carers** are:

Twice as likely to care for 100+ hours per week (24% compared with 12%)

Twice as likely to care for 35+ hours a week (56% compared with 28%)

More likely to care for more than one person (20% compared with 15%). This other person included a partner, parent, or another disabled child

More likely to be managing on a low income

More likely to feel they have a poor quality of life, with restricted social and life choices

More likely to report problems with their own health.

IMPACT ON EMPLOYMENT & FINANCES

Parent carers of disabled children under 16 are more likely than other carers to report that their caring role has affected their paid employment.

1 in 5 parent carers have left work due to their caring responsibilities.

Many others have had to reduce their hours or responsibilities, change to flexible working, or arrange to work at home.

Providing 100 hours of care a week is equivalent to three full-time jobs. This makes paid employment unachievable and also has a huge impact on health and social opportunities.

24% parent carers are providing an unimaginable 100+ hours of care a week.

Parent carers of disabled children are also more likely to be in low-paid, low-skilled jobs and less likely to be in managerial or professional occupations, than other carers, or than people without caring roles.

Parent carers are also more likely to live in low-income households.

36% of disabled children had financial difficulties (compared with 21% of other carers)

Disabled children are more likely than other children to live in households with no access to a **car, in a home with no central heating, in overcrowded accommodation,** and in housing rented from the local authority or a housing association.



"I would like to go to work in my chosen profession, which I had to give up because there just weren't the support services available."

Parent carer

IMPACT ON PARENT CARERS' HEALTH

Parent carers of disabled children and young people (aged under 20) are more likely than other carers to report that the help and care they provide has an effect on their own health.

Parent carers say the impact of caring on their health over the last three months is such that:

- 52% suffer from stress
- 49% experience loss of sleep
- 40% are short tempered
- 32% are depressed
- 25% suffer physical strain
- 13% said that caring had made an existing condition worse
- 9% have developed a health condition.

“My son has Tourette syndrome and ADHD. In one year we had 70 appointments, I was trying to come to terms with the diagnosis and also working. It all got too much and I had a breakdown.”

Parent carer

Compared to other adults, parent carers of disabled children are more likely to have poor mental wellbeing.

IMPACT ON ISOLATION

Parent carers are more likely to report that caring has affected their personal relationships and leisure activities. Parent carers of disabled children (aged under 16) are also more likely than other carers to report that their quality of life is ‘fairly bad’ or ‘very bad’.

“It is difficult finding time to be with family and friends because we are often tired and stressed due to having so many disturbed nights of sleep.” **Parent carer**

“With a non-disabled child, you feel isolated, but with a disabled child that feeling is exacerbated. For the first two years of Nicky’s life, I had a lot to come to terms with, and at the same time I had to put an enormous amount of things into place like facilities and the professionals involved in Nicky’s care.”

Parent carer

POLICY RECOMMENDATIONS

Health and social care services provide a vital lifeline to families with disabled children, helping them stay together and stay healthy. These services include short breaks, a range of therapies, personal care, home help, and the provision of equipment and adaptations. For disabled children they are crucial in:

- *ensuring their development*
- *helping them to go to school*
- *helping them to have friends*
- *helping them to stay well.*

For parent carers, these services enable them to:

- *work*
- *spend time with other children or their partner*
- *live their life in a way which helps them maintain their mental and physical health.*

Sadly, health and social care services have experienced reductions in funding and cuts, meaning that parents of disabled children are caring more than most.

That's why we have come together as the Disabled Children's Partnership, a growing coalition of more than 50 charities and families, to launch *The Secret Life of Us* campaign.

The *Secret Life of Us* campaign wants the Government to follow a 5-step plan to address the growing crisis in health and social care for families with disabled children.

- 1 MAKE DISABLED CHILDREN A PRIORITY**
Provide ministerial leadership to ensure a cross-departmental approach to improving outcomes for disabled children and their families.
- 2 REVIEW CURRENT FUNDING**
Review funding of short breaks provision for disabled children and their families.
- 3 CLARIFY EXISTING RIGHTS**
Clarify current rights and entitlements by co-producing guidance for local agencies on their existing statutory obligations, together with families of disabled children.
- 4 CREATE A FUND**
Improve health and social care services for disabled children by providing an early intervention and family resilience fund.
- 5 CHANGE THE SYSTEM**
Commission a review of health and social care law, to strengthen and clarify rights and entitlements for disabled children and their families.

"The whole social care and health system for families like ours works on a system of crisis management. There's no forward thinking. We live with the constant feeling that at any given moment our situation could implode."

Parent carer

"I was working full time but it was way too much. My employer was brilliant and allowed me to change my contract to term time only."

Parent carer

"It's hard to quantify but some weeks I provide 50+ hours of care just to my son. He needs lots of physical and personal care including, feeding, dressing, changing nappies as well as attending frequent appointments with professionals like neurologists, eye specialists, social workers and school, which are all intense 1-2 hour-long meetings."

Parent carer



"I'm constantly writing letters, filling out forms, attending hospital appointments as well as all the day-to-day medical care she needs. It's definitely a full time job."

Parent carer



We are Contact,
the charity for
families with
disabled children.

We support
families, bring
families together
and help families
take action
for others.



GET IN CONTACT

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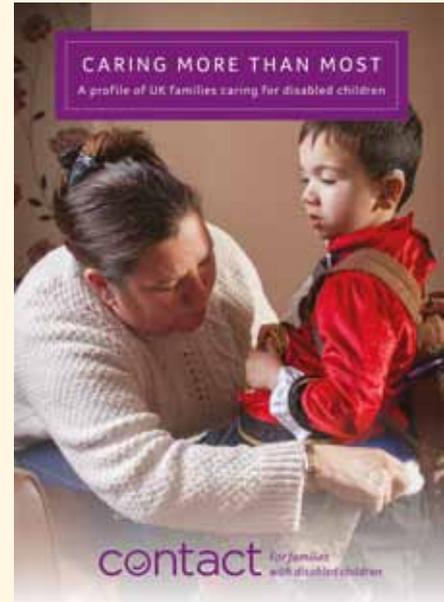
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READ THE FULL REPORT

Caring more than most – a
profile of UK families caring for
disabled children is available
to download from:

 www.contact.org.uk

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