

CARING MORE THAN MOST

A profile of UK families caring for disabled children



contact *For families
with disabled children*

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

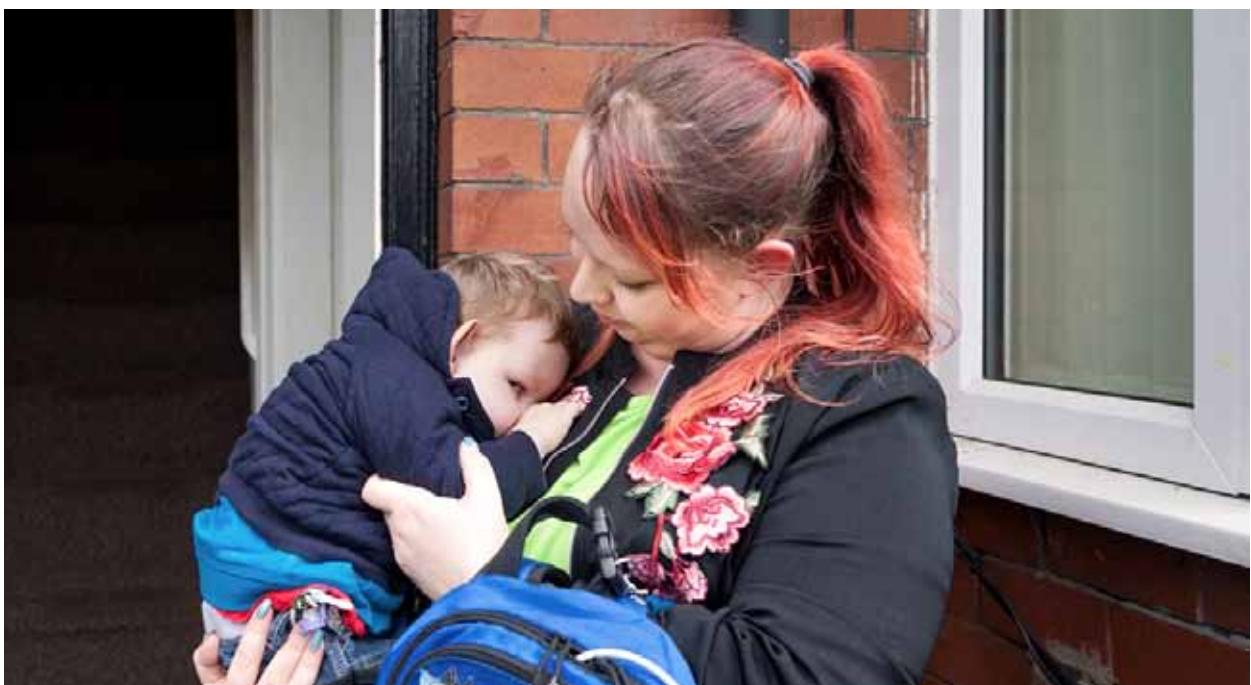
More likely to be managing on a low income

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.

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INTRODUCTION

Contact commissioned the University of Leeds (Dr Lisa Buckner) to conduct this research, in consultation with Dr Sue Yeandle.¹

This report presents information on the characteristics of disabled children and young people under 20 years old in the UK, and their families¹. It shows their numbers, and also:

- *indicates that for many, their health problems or disabilities substantially limit their daily activities*
- *shows how the patterns of their limitations and poor health differ by gender, ethnicity, age, and according to where they live.*

The report shows that disabled children and young people are more likely than others of the same age to live in disadvantaged circumstances in terms of:

- *housing*
- *household economic situation*
- *their parents' employment status.*

The report also shows that parent carers of disabled children are more likely than other carers to:

- *be female*
- *managing on a low income*
- *feel they have a poor quality of life with restricted social and life choices, and*
- *report problems with their own health.*

This worrying situation means everyday life is very difficult for many families, and suggests many of the children and their families urgently need access to better support and opportunities.

The report is based on analysis of data from three major official data sources, and presents a true and reliable picture of the lives of families with disabled children across the country. It begins with a description of the data (Section 1) and includes:

- *the numbers and characteristics of disabled children (Section 2)*
- *a profile of their families (Section 3)*
- *a comparison of parent carers of disabled children (contrasted with carers of adults with illness/disability and people without any such caring responsibilities (Section 4).*
- *policy recommendations, based on the report's findings (Section 5)*

At the end of the report:

Appendix A provides details of the number and percentage of children with limiting long-term illness (LLTI) in each local authority in England, Northern Ireland, Scotland and Wales. This is available online at www.contact.org.uk/la-numbers

Appendix B provides details of the specific questions respondents asked in the data sources used. See page 23.

¹ The main analysis is based on the 2011 Census Sample of Anonymised Records (SAR) (regional) and includes all (usually resident) people aged 0-19 living in households, and their families. Other official data is used as appropriate, with relevant sources indicated.

SECTION 1. DATA SOURCES

The analysis in this report is based on data from three sources:

- 1 The 2011 Census of households and people [Census]. This is based on a count of all people in the UK undertaken every ten years. In 2001 and 2011 (only) it included a question asking respondents 'Do you look after, or give any help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill-health /disability, or problems related to old age? (Do not count anything you do as part of your paid employment)**
- 2 The Carers in Households in England Survey 2009/10 [CiH]. This had a sample size of 2,401 carers who were identified by asking respondents, is there someone who is 'sick, disabled or elderly whom you look after or give special help to'. (This survey was not undertaken in Wales, Scotland or Northern Ireland.)**
- 3 The Health Survey of England (2012, 2013 and 2014) [HSE], which has a sample size of approximately 10,000 people each year. To create a sample large enough for analysis, three years of data were combined, producing a sample of 4,908 carers. (Although the Welsh Health Survey,**

Scottish Health Survey and Health Survey of Northern Ireland included questions on carers, there was no simple method of identifying those caring for children aged under 16 or under 20.)

The Census is an invaluable resource that allows analysis at local level, but is limited in the questions it asks on caring. In the CiH and HSE, which both contain a wide range of questions about carers and their caring situation, every effort is made to achieve representative samples, but scope for local level analysis is limited by the sample size. For this reason, analysis of all three sources has been used to produce as full a picture as possible of disabled children and their families.



2 The Census does not ask those replying 'yes' to this question who they support, so we cannot be certain that, (for example) in a household with one person who reports providing such support and one person in poor health or with a LTTI, the adult providing care is referring to care given to that person (although it is very likely that is the case). An official report comparing data produced about unpaid care in 2001 and 2011, using Census data for England and Wales, is available from the Office for National Statistics at www.ons.gov.uk//2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15

SECTION 2. DISABLED CHILDREN: NUMBERS & CHARACTERISTICS

NUMBERS

In the UK, there are 641,500 disabled children and young people under 20 years old, representing approximately 1 in 25 (or 4.2%) of all young people of this age (2011 Census).

40% of disabled children are ‘limited a lot’ in their day to day activities (2 in 5, or 255,500)

14% report that health is ‘bad’ or ‘very bad’ (1 in 7).

Whilst very few (0.1%) of children without a LLTI report such poor health.

This group of disabled children includes:

14% (86,900) aged 0–4 years

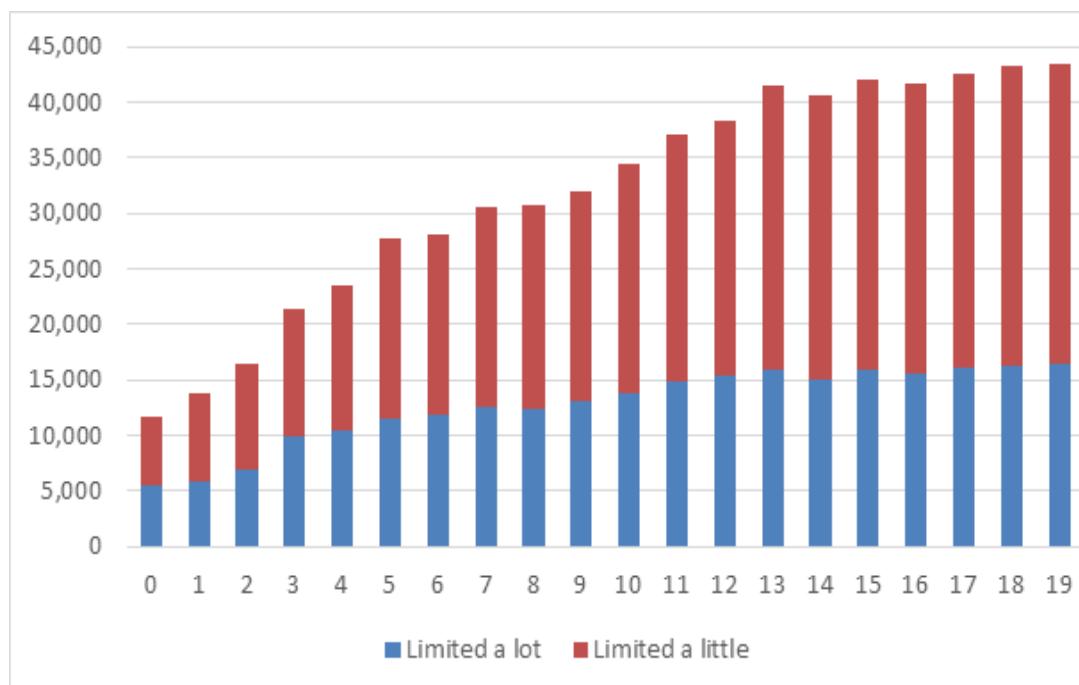
23% (149,100) aged 5–9 years

30% (192,400) aged 10–14 years

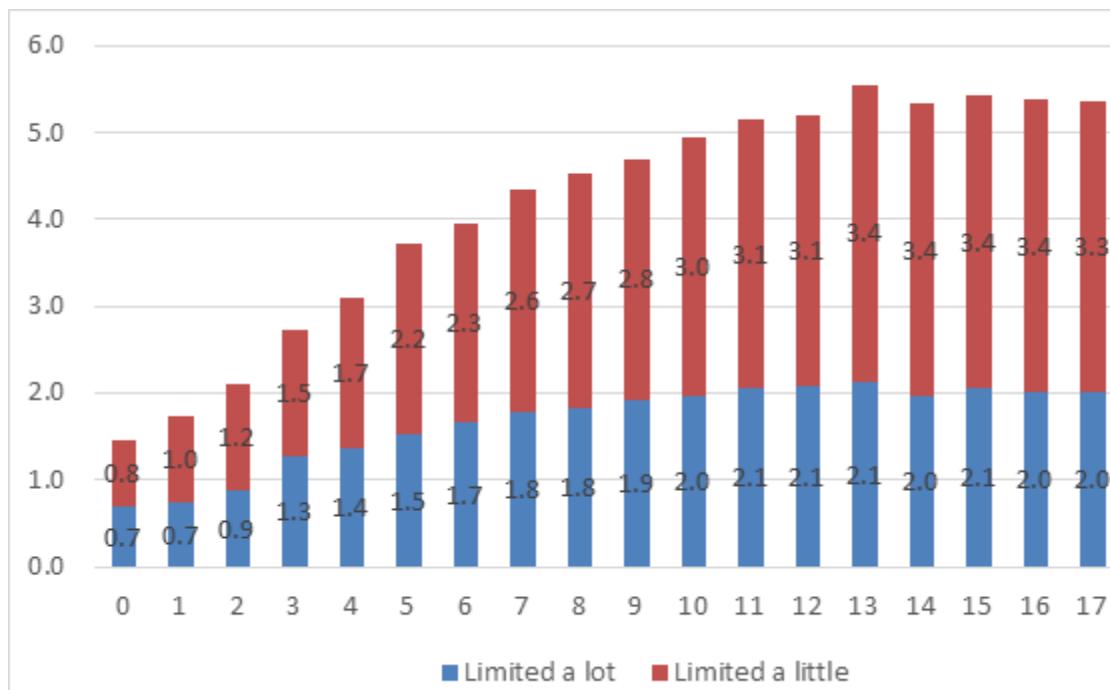
33% (213,600) aged 15–19 years.

See Figure 1a and Figure 1b.

Figure 1a: Children and young people with a LLTI, by age in years (numbers)



Source: Census

Figure 1b: Children and young people with a LLTI, by age in years (percentages)

Source: Census



CHARACTERISTICS

Between 2001 and 2011³, the percentage of children with a LLTI fell very slightly (from 4.5% to 4.2%), reflecting a small reduction in reported LLTI at younger ages (Figure 2). Across the UK, the percentage of children and teenagers who are disabled varies by several important characteristics:

Age

Older children and young people are more likely to have a LLTI than those who are younger (Figure 1b).

Gender

Boys are more likely to have a LLTI than girls (at all ages) (Figure 3).

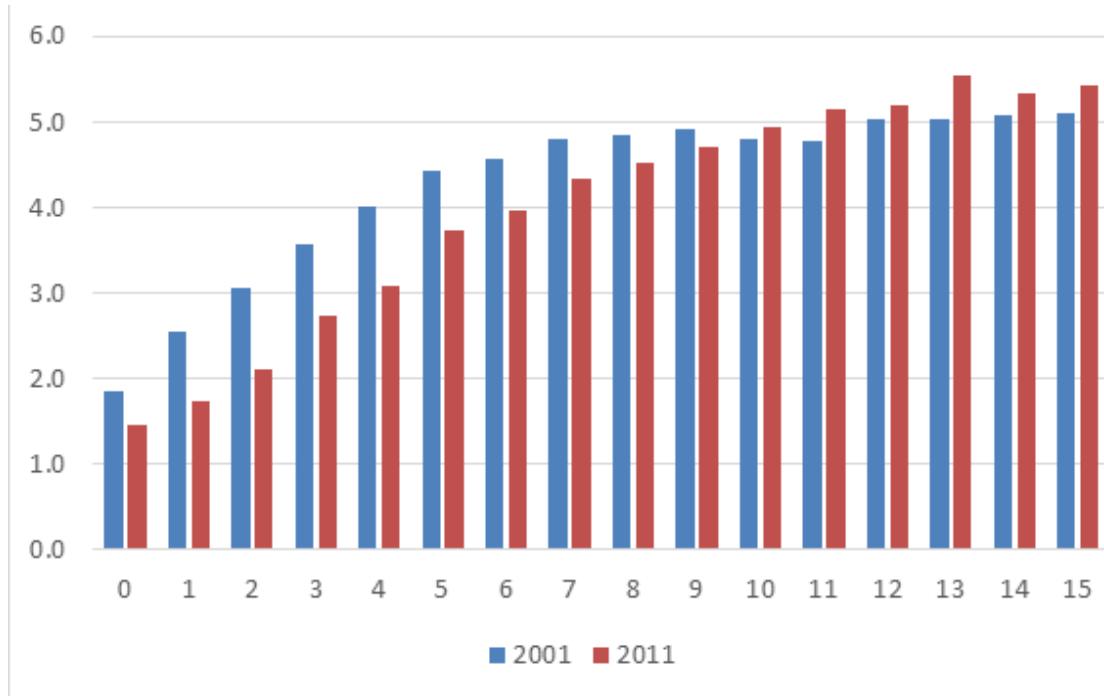
Ethnic group

For example 8.0% of children in the Gypsy and Irish Traveller community, compared with 2.2% of children of Chinese ethnicity (Figure 4). (*Note that some of these groups are very small, for example, 8% of Gypsy and Irish Traveller children represents about 2,000 children, whereas 4.4% of White British children represents about 512,000 children.*)

Region

5.6% of children in Northern Ireland, compared with 3.5% in Outer London, for example (Figure 5).

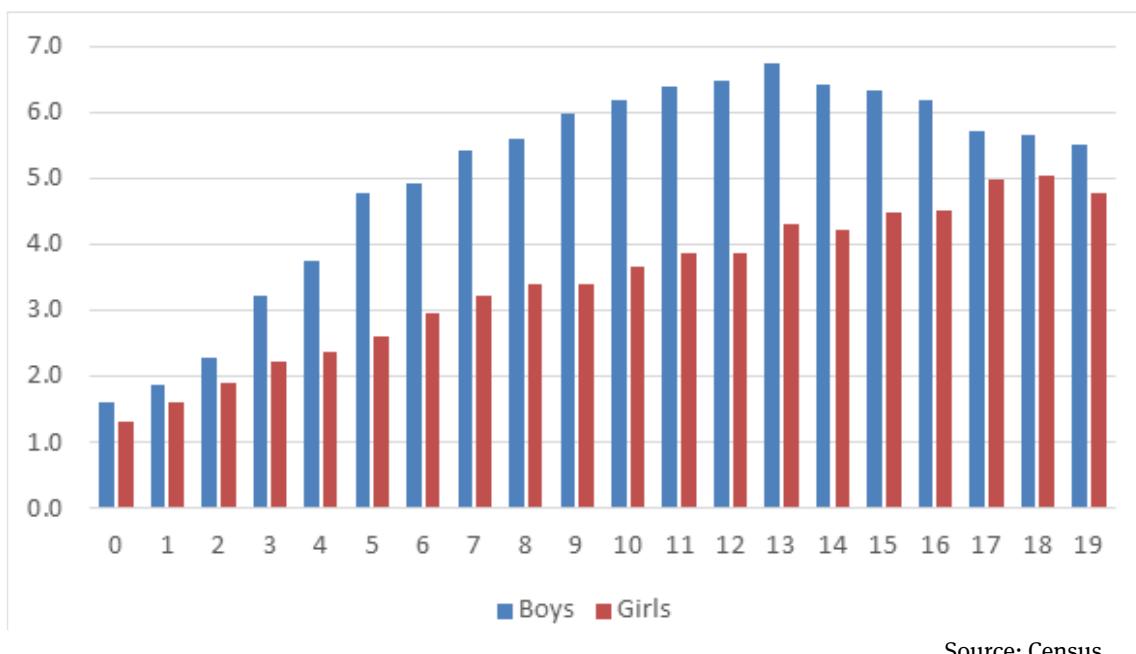
Figure 2: Children with a LLTI, 2001 and 2011 (percentages)⁴



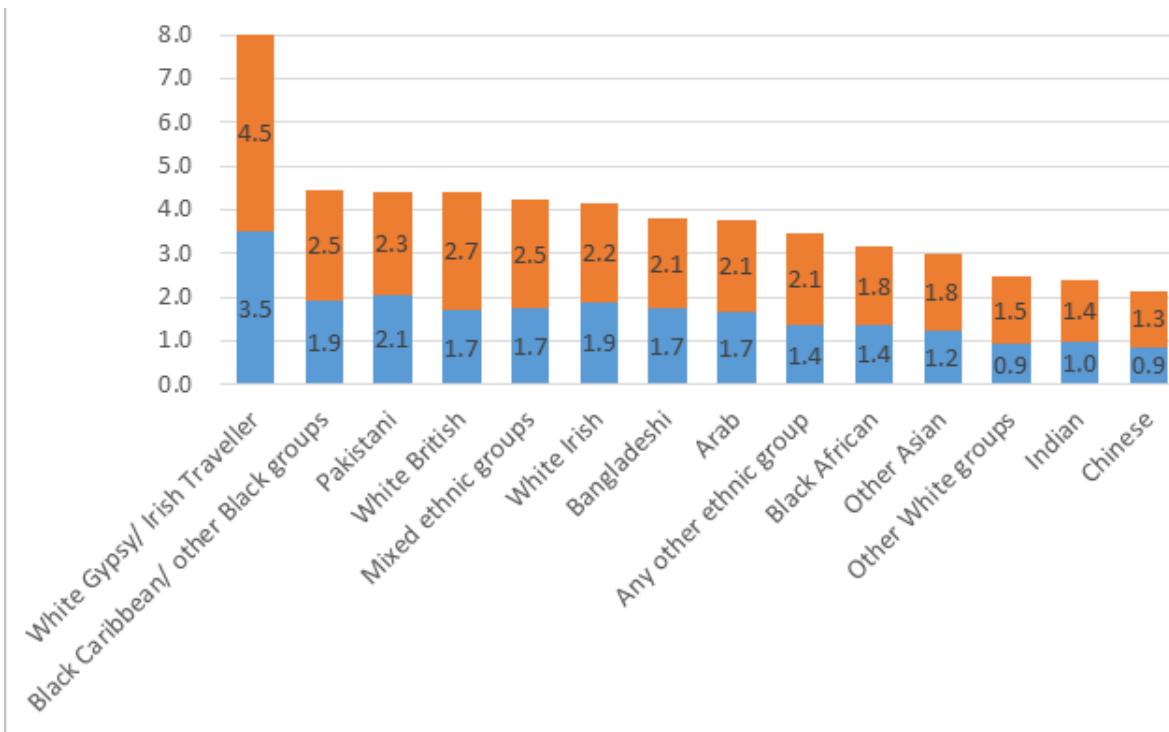
Source: Census

3 The Census question on LLTI changed from a 'yes/no' response in 2001 to 'yes a lot, yes a little, no' in 2011.

4 The data here are for children aged 0-15 due to changes in data available by age between 2001 and 2011

Figure 3: People under 20 with a LLTI, by age and gender (percentages)

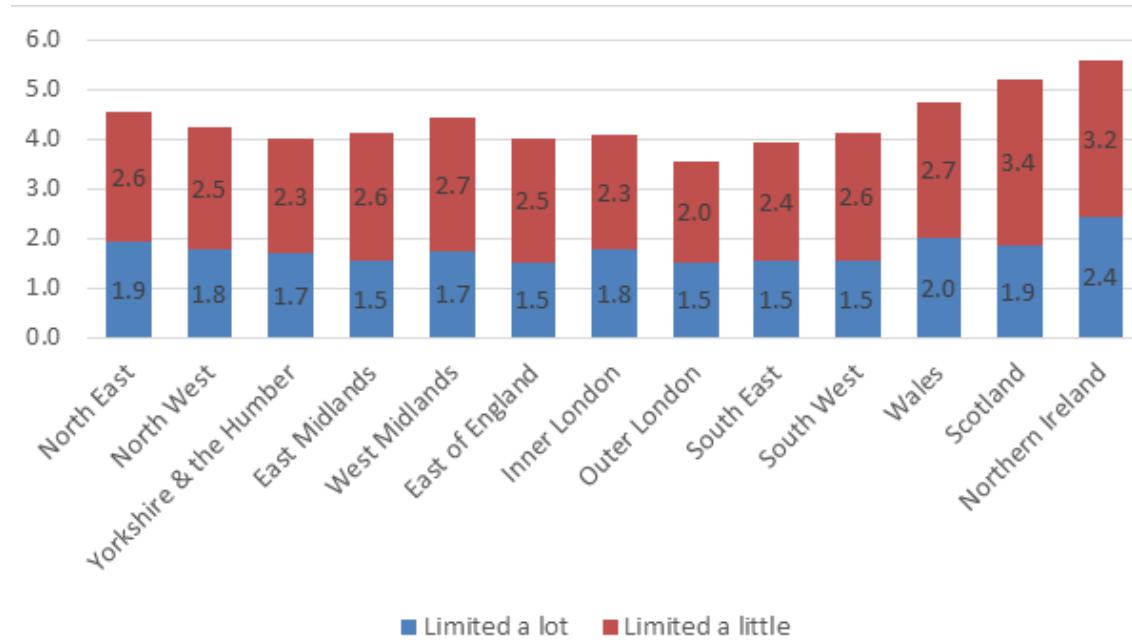
Source: Census

Figure 4: People under 20 with a LLTI, by ethnic group (percentages)^{5, 6}

Source: Census

5 The ethnicity data available in the Northern Ireland Census SAR is not comparable, so this chart is based on data for England, Wales and Scotland only.

6 Note: Total population sizes (rounded) for these groups of children & young people under age 20 are: White British 11.6 million; White Irish 48,000; White Gypsy/Irish Traveller 25,000; Other White 504,000; Mixed ethnic group 686,000; Indian 358,000; Pakistani 476,000; Bangladeshi 195,000; Chinese 90,000; Other Asian 248,000; Black African 381,000; Black Caribbean & other Black Grp 269,000; Arab 86,000; any other ethnic group 91,000

Figure 5: People aged under 20 with a LLTI, by UK region (percentages)

Source: Census

LOCAL VARIATIONS

At local authority level, the percentage of children aged 0-15⁷ (0-14 for councils in Northern Ireland) with a LLTI varies considerably (see Figure 6 and Appendix A).

Figures are highest in:

6.9% Belfast

6% Dundee

and lowest in:

2.4% Epping Forest

2.3% Richmond-Upon-Thames.

For children with a LLTI that limits them 'a lot', there is also notable variation by locality:

3.3% Belfast

2.6% Lincoln

Compared with:

0.9% Hampshire

0.3% Isles of Scilly.

In Copeland, half of children with a LLTI are limited 'a lot' in their everyday activities, almost double the figure (26%) in Orkney⁸.

⁷ Due to the age bands available in the Census Standard Tables, the age range here is 0-15 years.

⁸ The figure is lower in the Isles of Scilly (9.1%) but the population size is very small (11 of the population of 337 children reported to have a LLTI).

Table 1: Local Authorities with the highest and lowest percentages of children with a LLTI

LOCAL AUTHORITY/ DISTRICT/COUNCIL	CHILDREN WITH A LLTI: IMPACT ON DAY TO DAY ACTIVITIES			% OF CHILDREN WHO ARE 'LIMITED A LOT'
	LIMITED A LOT	LIMITED A LITTLE	ALL	
Areas with highest levels				
Belfast	3.3%	3.7%	6.9%	47%
Dundee City	2.2%	3.8%	6.0%	37%
Inverclyde	2.0%	4.0%	5.9%	33%
Glasgow City	2.3%	3.6%	5.8%	39%
Lincoln	2.6%	3.0%	5.6%	46%
Areas with lowest levels				
Elmbridge	0.9%	1.5%	2.4%	38%
South Bucks	1.0%	1.4%	2.4%	42%
Windsor & Maidenhead	1.0%	1.4%	2.4%	42%
Epping Forest	1.0%	1.3%	2.4%	43%
Richmond Upon Thames	0.9%	1.4%	2.3%	40%

Source: Census

Nearly all children and young people with a LLTI (98%) live at home with their families. Of these:

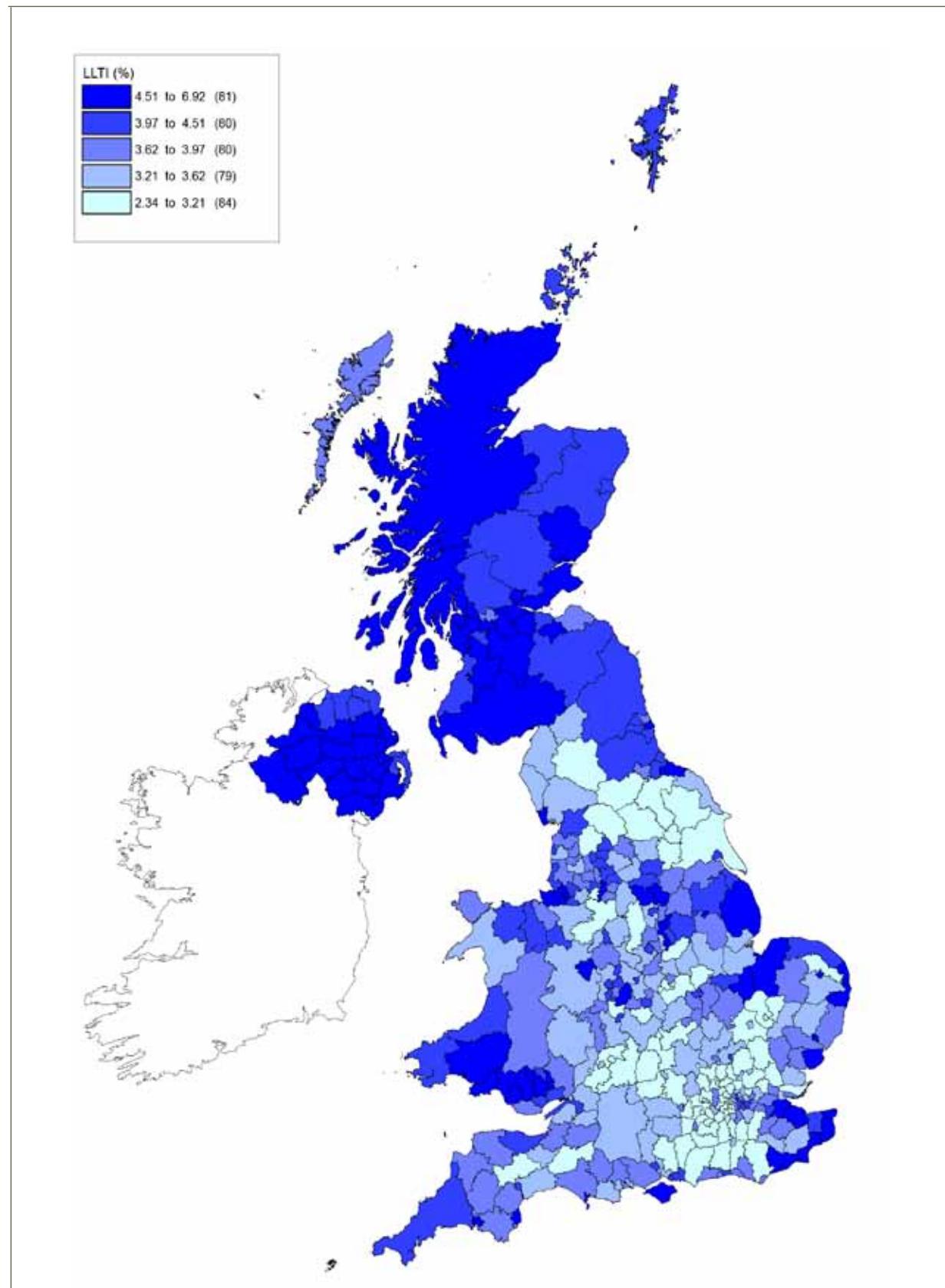
63% (almost two thirds or 395,200) live in a household where someone identified as a carer (i.e. said they looked after, helped or supported a person who was sick, disabled or frail in old age)

37% (233,500) of children and young people with a LLTI) live in households where no-one reported regularly providing such care, help or support

2.5% (under 5,800) of these children and young people were older teenagers living alone.



Figure 5: People aged under 20 with a LLTI, by UK region (percentages)



Source: Census

Note: Data represented in this map are presented in Appendix A

SECTION 3. A PROFILE OF FAMILIES WITH DISABLED CHILDREN

Compared with children and young people aged under 20 without a LLTI, disabled children and young people of this age (Table 2) were:

more likely to live in lone parent households (and less likely to live in couple households – that is, households containing two parents and one or more children)

more likely to live in larger households (containing 6 or more people)

more likely to live in a household where other people have a LLTI.

Table 2: Children and young people aged under 20: household characteristics by LLTI status and reported carer in the household¹⁰

CHILD/YOUNG PERSON'S LIVING ARRANGEMENT	CHILD WITH NO LLTI	CHILD WITH LLTI	CHILD WITH LLTI – no carer in household	CHILD WITH LLTI Carer(s) in household
Lives with others and is:				
A child living with two parents	71%	61%	54%	65%
A child living with one parent	25%	35%	39%	32%
A young person living with a partner	0.5%	0.7%	1.4%	0.4%
A parent living with a child	0.3%	0.3%	0.7%	0.1%
Living with unrelated persons	2.5%	3.3%	4.7%	2.5%
All above*	100%	100%	100%	100%
Lives in a household of six or more people	13%	15%	13%	16%
Lives in a household with others with a LLTI	19%	47%	40%	51.0%

Source: Census

*Figures are rounded, so may not add to exactly 100.0%

10 Excludes young people aged under 20 who live on their own.

INDICATORS OF ECONOMIC DISADVANTAGE

Disabled children and young people are:

Twice as likely as other children or young people (34% compared to 17%) to live in families where there is no parent in paid work (Table 3)

less likely to live in families with two working adults

more likely to live in families where the 'Household Reference Person' (HRP)⁹ has never worked, is working in a low paid, low skilled routine job or is unemployed

less likely to live in a household where the HRP has a managerial or professional job.

Table 3: Living circumstances of children and young people aged under 20: economic indicators, by households with/without a child with a LLTI or reporting a carer in the household¹⁰

HOUSEHOLD ECONOMIC CIRCUMSTANCE	CHILD WITH NO LLTI	CHILD WITH LLTI	CHILD WITH LLTI – no carer in household	CHILD WITH LLTI Carer(s) in household
No working adult	17%	34%	30%	35%
One working adult	36%	37%	37%	37%
Two working adults	47%	29%	32%	27%
Total	100%	100%	100%	100%
Of the above:				
HRP never worked	3.5%	6.6%	7.7%	32%
HRP in routine/semi routine job	24%	31%	30%	32%
HRP in professional/managerial job	32%	24%	23%	24%
Social grade of HRP DE ¹¹	28%	39%	39%	38%
Household amenities				
No access to a car	17%	24%	31%	19%
Rents from LA or HA	21%	34%	34%	35%
Overcrowded*	9.1%	10%	10%	10%
No central heating	1.1%	1.3%	1.7%	1.1%

Source: Census

*Note: Defined as more than one person per room

9 The Census uses the concept of a 'Household Reference Person' (HRP). This replaced the previous 'head of household' concept. It identifies an individual person in a household who is treated as a reference person 'for producing further derived statistics and for characterising a whole household according to characteristics of the chosen reference person' (ONS – 2011 Census Glossary).

10 Excludes young people aged under 20 who live on their own.

11 Social Grade DE (the lowest) includes people in semi-skilled & unskilled manual occupations or unemployed.

Disabled children and young people are also:

more likely than other children and young people to live in households with no access to a car

more likely to live in a home with no central heating, in overcrowded accommodation

more likely to live in housing rented from the local authority or from a housing association.

When questioned in the CiH survey:

11% of parent carers of a disabled child under 16 said they had severe financial difficulties (compared with 5.4% of other carers)

25% said they had some financial difficulties (compared with 16% of other carers)

36% of parent carers are more likely to have financial difficulties (compared with 21% of other carers).



SECTION 4. A COMPARISON OF PARENT CARERS WITH OTHERS

In the UK in 2011 there were 620,000 adults¹² caring for disabled children and young people aged under 20. Compared with other carers and people who do not provide care, parent carers:

More likely to be women (65% compared to 58% and 51% respectively¹³)

68% are under age 45 (compared with 30% and 49% respectively)

Most (82%) said their caring role related only to a child (or children) under 16. However parent carers of a disabled child under 16 were¹⁴:

More likely to care for more than one person (20% compared with 15%) [CiH].

Of these:

7.3% also care for a partner

6.4% also care for a parent (in-law) or grandparent

7% cared for more than one disabled child under 16.

Compared with other carers, parent carers are twice as likely to care for longer hours:

56% provide 35+ hours of care per week (compared with 28% of other carers)

24% provide 100+ hours of care per week (compared with 12% of other carers).

Parent carers of disabled children are more likely to have an irregular pattern of care:

70% said their care followed a regular pattern (compared to 74% of other carers)

21% said the pattern was irregular, changing from day to day – a substantial minority (compared with 10% of other carers) [CiH].



12 This estimate is calculated by applying the age-sex caring rates from the HSE 2012, 2013, 2014 to the 2011 Census population estimates for the UK for people aged 16 and over.

13 Health Survey of England 2012, 2013, 2014.

14 Survey of Carers in Households 2009/10.

IMPACT ON EMPLOYMENT

Women caring for a disabled child or young person were:

less likely to be in paid employment¹⁵ than other carers or than women without such caring roles (Table 4).

Parent carers of disabled young people of both sexes were also

more likely to be in low paid, low-skilled jobs

less likely to be in managerial or professional occupations) than other carers, or than people without caring roles

more likely to live in low income households.

Table 4: People aged 16-64: employment and household income, by whether caring for a disabled child of specified age

EMPLOYMENT STATUS	CARERS OF PEOPLE AGED:				NOT A CARER
	< 16	16-19	20+	< 20	
% of people in paid employment					
Men	72%	70%	69%	72%	74%
Women	47%	53%	64%	49%	64%
Household income in bottom third of household incomes ¹⁶	47%	37%	31%	44%	28%
Type of employment (for carers in paid work)					
Managerial and professional occupations	30%	31%	37%	31%	38%
Intermediate occupations	24%	21%	26%	23%	24%
Routine and manual occupations	46%	48%	37%	46%	39%
All occupations	100%	100%	100%	100%	100%

Source: Census

Note: Columns may not add to exactly 100% due to rounding.

15 Includes carers aged 16-64 only.

16 Statistics in this row refer to income adjusted to take account of household size.

Parents of disabled children under 16 were also more likely than other carers to report that their caring role had affected their paid employment (Table 5)¹⁷:

46% report their caring role affected their paid employment

They were also more likely to have left employment, taken up a new job, reduced their hours (or responsibilities), changed to flexible working, or to have arranged to work at home.

Compared with:

33% of carers of young people aged 16-19

17% of carers of people aged 20 or over
(Table 5).

Table 5: Parent carers of children and young people: effect on employment of assistance given, carers aged 16-64

HAS YOUR ABILITY TO TAKE UP, OR STAY IN, EMPLOYMENT BEEN AFFECTED BY THE ASSISTANCE YOU GIVE?	CARERS OF PEOPLE AGED:			
	< 16	16-19	20+	< 20
Left employment - (p<0.001***)	20.0%	14.0%	4.5%	19.0%
Took a new job - (p=0.022*)	2.7%	1.2%	0.8%	2.3%
Worked fewer hours - (p<0.001***)	16.0%	13.0%	6.4%	15.0%
Reduced responsibility at work - (p<0.001***)	6.8%	2.4%	1.5%	5.6%
Had flexible employment agreed - (p=0.004**)	8.1%	4.8%	3.6%	7.2%
Changed to work at home - (p<0.001***)	3.6%	2.4%	0.8%	3.3%
Employment not affected - (p<0.001***)	54.0%	67.0%	83.0%	57.0%

Source: Health Survey for England 2012, 2013, 2014

17 'p' values shown in Tables 5 to 7 refer to tests of statistical significance. The number of asterisks (*) indicates the level of probability with * P ≤ 0.05, ** P ≤ 0.01 and *** P ≤ 0.001.

IMPACT ON HEALTH & WELLBEING

Parent carers of disabled children and young people (aged under 20) were more likely than other carers to report that the help and care they provided had an effect on their own health (Table 6).

Table 6: Effect on carer's health of help or support given to a child or young person with disability

HAS YOUR ABILITY TO TAKE UP, OR STAY IN, EMPLOYMENT BEEN AFFECTED BY THE ASSISTANCE YOU GIVE? ¹⁸	CARERS OF PEOPLE AGED:			
	< 16	16 - 19	20 +	< 20
Tired - (p<0.001***)	59%	45%	28%	55%
Depressed - (p<0.001***)	32%	26%	14%	31%
Loss of appetite - (p<0.001***)	14%	5%	4%	12%
Disturbed sleep - (p<0.001***)	49%	32%	20%	45%
General stress - (p<0.001***)	52%	32%	26%	47%
Physical strain - (p<0.001***)	25%	20%	9.5%	24%
Short tempered - (p<0.001***)	40%	29%	18%	37%
Developed health condition - (p<0.001***)	8.7%	3.5%	2.5%	7.3%
Made existing condition worse - (p<0.001***)	13%	5.9%	6.1%	11%

Source: Health Survey for England 2012, 2013, 2014

The HSE included a question using the Warwick-Edinburgh Mental Well-being scale (WEMWBS), a validated, 14-item, scale used to measure mental well-being¹⁹. Responses to this (HSE 2012-14) showed that parent carers of children and young people aged under 20 were statistically more likely (p<0.001***) to have poor mental wellbeing than either carers of other people (disabled adults or older people) or than people who were not carers:

- **Carers of children aged under 16 had an average score of 49**
- **Carers of young people aged 16-19 had an average score of 48**
- **Carers of people aged 20 or older had an average score of 52**
- **People who were not carers had an average score of 53**

In 2011, the average WEMWBS score for the entire population of England was 53²⁰.

18 Health Survey for England 2012 Program Documentation Household Questionnaire.

19 www2.warwick.ac.uk/fac/med/research/platform/wemwbs

20 www2.warwick.ac.uk/fac/med/research/platform/wemwbs/researchers/interpretations/wemwbs_population_norms_in_health_survey_for_england_data_2011.pdf

Parent carers of disabled children (aged under 16) were also more likely than other carers to report that their quality of life was ‘fairly bad’ or ‘very bad’ (Table 7). These carers were also more likely to report that caring had affected their personal relationships and leisure activities.

Table 7: Effect of caring role on carer’s quality of life, leisure and relationships

	CARER OF DISABLED CHILD UNDER 16	OTHER CARERS UNDER 16
How would you rate your quality of life?		
Very good	27%	34%
Fairly good	50%	44%
Neither good nor bad	14%	13%
Fairly bad	6%	5%
Very bad	3%	2%
All	100%	100%
Carers saying specific items were affected by their caring role*:	68%	43%
Ability to spend time on leisure or social activities ($p<0.001^{***}$)		
Unable to socialise ($p<0.001^{***}$)	33%	15%
Reduced time with spouse/partner ($p<0.001^{***}$)	28%	13%
Reduced time with other family members ($p<0.001^{***}$)	34%	14%
Reduced time with friends ($p<0.001^{***}$)	45%	23%
Difficulties making new friends ($p<0.001^{***}$)	19%	6%
Reduced time to do sport or physical activity ($p<0.001^{***}$)	27%	12%
Reduced time for hobby or pastime ($p<0.001^{***}$)	33%	19%
All with personal relationships, social life or leisure affected ($p<0.001^{***}$)	71%	39%
In what way have you been affected? ²¹		
Too tired to go out ($p<0.001^{***}$)	46%	39%
Restricted life/choices/family activities/social life/everything has to be planned/nothing spontaneous ($p=0.01^{**}$)	11%	5%

Source: Survey of Carers in Households 2009/10
 *%s for this question do not add to 100 as respondents were asked to indicate all which apply.

21 %s of people who said their ability to spend time doing leisure or social activities had been affected.

SECTION 5. POLICY RECOMMENDATIONS

Health and social care services provide a vital lifeline to families, 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, well planned and funded 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, already inadequate health and social care services which in recent years have experienced reductions in funding and cuts means that:

- ***There are not enough health and social care services for disabled children and their families.***
- ***Many existing health and social care services aren't good enough and don't meet their needs.***
- ***Families find health and social care services difficult to access and have to wait too long for support.***

The failure to provide adequate health and social care services risks families reaching crisis point. It is well evidenced that when families reach crisis point, the services they need have a higher cost to the state. Research found that using short break services had potential cost savings of £1,851,550 for just 22 children at risk of being looked after.²²

We believe that disabled children and their families should have the same opportunities and quality of life as those without disabilities. To ensure this, they need access to good quality health and social care services when they need them. This is not asking for disabled children to be treated favourably; this is asking for fairness. Not only would this improve outcomes for disabled children – it would also deliver important cost-savings for the state.

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



²² Impact of the short break programme on the prevention of disabled children entering the 'looked after' system, 2011 [PDF]

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

END NOTES

The data sets used in this report are:

Health Survey for England

NatCen Social Research, University College London. Department of Epidemiology and Public Health. (2015). Health Survey for England, 2013. [data collection]. UK Data Service. SN: 7649, <http://doi.org/10.5255/UKDA-SN-7649-1>

NatCen Social Research, University College London. Department of Epidemiology and Public Health. (2016). Health Survey for England, 2014. [data collection]. 2nd Edition. UK Data Service. SN: 7919, <http://doi.org/10.5255/UKDA-SN-7919-2>

NatCen Social Research, University College London. Department of Epidemiology and Public Health. (2017). Health Survey for England, 2015. [data collection]. UK Data Service. SN: 8280, <http://doi.org/10.5255/UKDA-SN-8280-1>

Carers in Households

GfK NOP, Information Centre for Health and Social Care. (2011). Survey of Carers in Households, 2009-2010. [data collection]. UK Data Service. SN: 6768, <http://doi.org/10.5255/UKDA-SN-6768-1>

Census data

Office for National Statistics (2015). 2011 Census Microdata Individual Safeguarded Sample (Local Authority): England and Wales. [data collection]. UK Data Service. SN: 7682, <http://doi.org/10.5255/UKDA-SN-7682-1>

ACKNOWLEDGEMENTS

Data from the Health Survey for England, 2011 Census microdata, the Survey of Carer in Households 2009-10 and local authority boundaries for mapping were accessed via the UK Data Service and the Ordnance Survey Ireland. The 2001 Census and 2011 Census standard tables data are ONS Crown Copyright Reserved and were accessed via NOMIS.

APPENDIX A

Local authority data for children aged 0-15.
This is available online at
www.contact.org.uk/la-numbers.

APPENDIX B: Survey questions on caring and health

2011 CENSUS: ENGLAND & WALES

This is a respondent completion questionnaire.

Carers

The carer question was developed for inclusion in the 2001 Census and was unchanged.

Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill-health / disability?
- problems related to old age?

Do not count anything you do as part of your paid employment

No,

Yes, 1 - 19 hours a week,

Yes, 20 - 49 hours a week,

Yes, 50 or more hours a week

LIMITING LONG-TERM ILLNESS (LLTI)

This question was changed from the 2001 question which only had the option of yes/no:

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

Include problems related to old age

Yes, limited a lot

Yes, limited a little

No

GENERAL HEALTH

This question was changed from the 2001 question which was 'Over the last 12 months would you say your health has been on the whole: Good?, Fairly Good?, Not Good?'

How is your health in general?

Very good

Good

Fair

Bad

Very bad

SURVEY OF CARERS IN HOUSEHOLDS 2009/10

This asks two questions to identify carers.

Q14 Is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to?

Q15 Is there anyone, not living with you who is sick, disabled or elderly whom you look after or give special help to?

HEALTH SURVEY OF ENGLAND 2012, 2013, 2014

An interviewer-led survey which ask the following question:

Have you personally provided help or support to anyone in the last month because they have long-term physical or mental ill-health, a disability or problems relating to old age?
Do not include help given in a professional capacity or as part of a job, but include help or support given to your family, friends or neighbours.

Include help for wife/husband/partner

1 Yes

2 No



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

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



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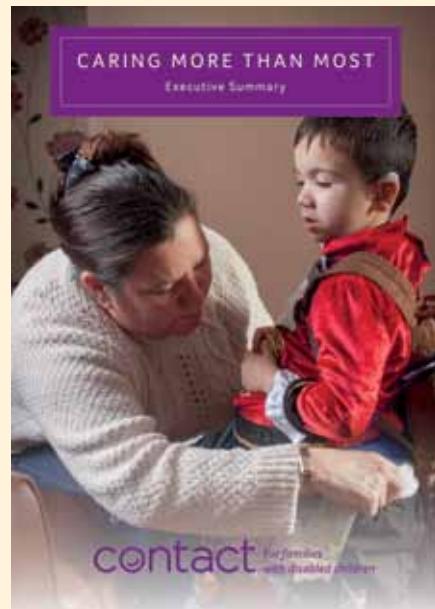
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READ THE EXECUTIVE SUMMARY

Caring More Than Most –
Executive Summary is available
to download from:

www.contact.org.uk

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