

Managing More than Most:

A statistical analysis of families with sick or disabled children



Parents of sick or disabled children face significant challenges in entering or remaining in paid work which are often little understood by employers, service providers and policy makers.

This report explores statistics about caring for a sick or disabled child and its impact on parental employment.



Definitions

The statistics used in this report are from the 2001 Census, the most reliable and comprehensive source of information about people with unpaid caring responsibilities. Data used in the report are for England and Wales. The definitions of the key terms used in this report are:

Limiting Long-term Illness

The 2001 Census asked:

'Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?'

This information was collected about all household members, including children.

Carers

The 2001 Census included, for the first time, a question on the **provision of unpaid care**:

'Do you look after or give any help or support to family members, friends or neighbours or others because of: long-term physical or mental ill-health or disability or problems related to old age?'

This has revealed that across England and Wales 10% of the population – almost 5.2 million people – provide unpaid care.

Families

A 'family' is at least one parent living in the same household as at least one dependent child aged 0-15. Using this definition, very few households contain more than one family.

Sick or disabled children

- There are nearly half a million sick or disabled children in England and Wales¹
- Nearly all of them - 99.1% - live at home with their families
- 34% live in households where there is no adult in paid work, compared with 18% of children who are not sick or disabled

¹ In this document we refer to 'sick or disabled' children as those who have a limiting long-term illness (LLTI).



How many families?

The 2001 Census² shows that about 462,000 families in England and Wales have at least one child (under the age of 16) and a son or daughter with a limiting long-term illness (LLTI).

Only 0.9% of children with a long-term illness or disability – fewer than 4,000 children – live away from their families in residential schools or care homes.³

Of families with a sick or disabled child:

- 158,000 have at least one carer in the household who provides 20 or more hours unpaid care each week
- A further 54,000 have at least one carer in the household who provides up to 19 hours unpaid care each week
- 250,000 are families where no-one describes themselves as 'a carer' (other research shows some parents do not describe looking after a sick or disabled child as 'unpaid care')
- In 44% of families with a sick or disabled child two parents each provide unpaid care

What do we know about these families?

462,000 families have a child (of any age) who is sick or disabled and at least one child under 16. They make up 8% of all families in England and Wales.

Of these:

- 32% are single parent families, although single parent families are only 25% of all families
- 10% have more than one child with a LLTI – there are about 46,000 families in this situation

² 2001 Census Special Licence Household Sample of Anonymised Records. This work is based on the SARs provided through the UK Data Archive at the University of Essex and prepared through support by the Centre for Census and Survey Research at the University of Manchester with the support of ESRC and JISC. These data are Crown Copyright and are reproduced with the permission of the Controller of HMSO.

³ Referred to in the Census as 'Communal establishments'.

- 33% of families with a sick or disabled child have at least one adult who also has a LLTI
- 23% of these families have no access to a car or van. This compares with 17% in families where there is no sick or disabled child
- 16% are living in overcrowded accommodation, compared with just 10% of households without a child with a LLTI
- 34% are living in social housing, compared with 21% of households without a child with a LLTI
- Only 38% contain two working adults, compared with 55% of families without a sick or disabled child

What do we know about children with a LLTI?

In England and Wales 4.3% of all children (448,000 children under 16⁴) have a LLTI.

Of these:

- 21% are aged 0-4 years
- 35% are aged 5-9 years
- 44% are aged 10-15 years
- 17% were described as in poor health, compared with only 1% of children without a LLTI
- 32% live in lone parent families - compared with 23% of children without a LLTI
- 20% live in large households with 4 or more children - compared with only 16% of children without a LLTI
- 6% of Pakistani and Black Caribbean children and children from mixed ethnic groups have a LLTI, compared with just 3% of Indian and 4% of White British children

⁴ These sick or disabled children under 16 live in 397,000 families.

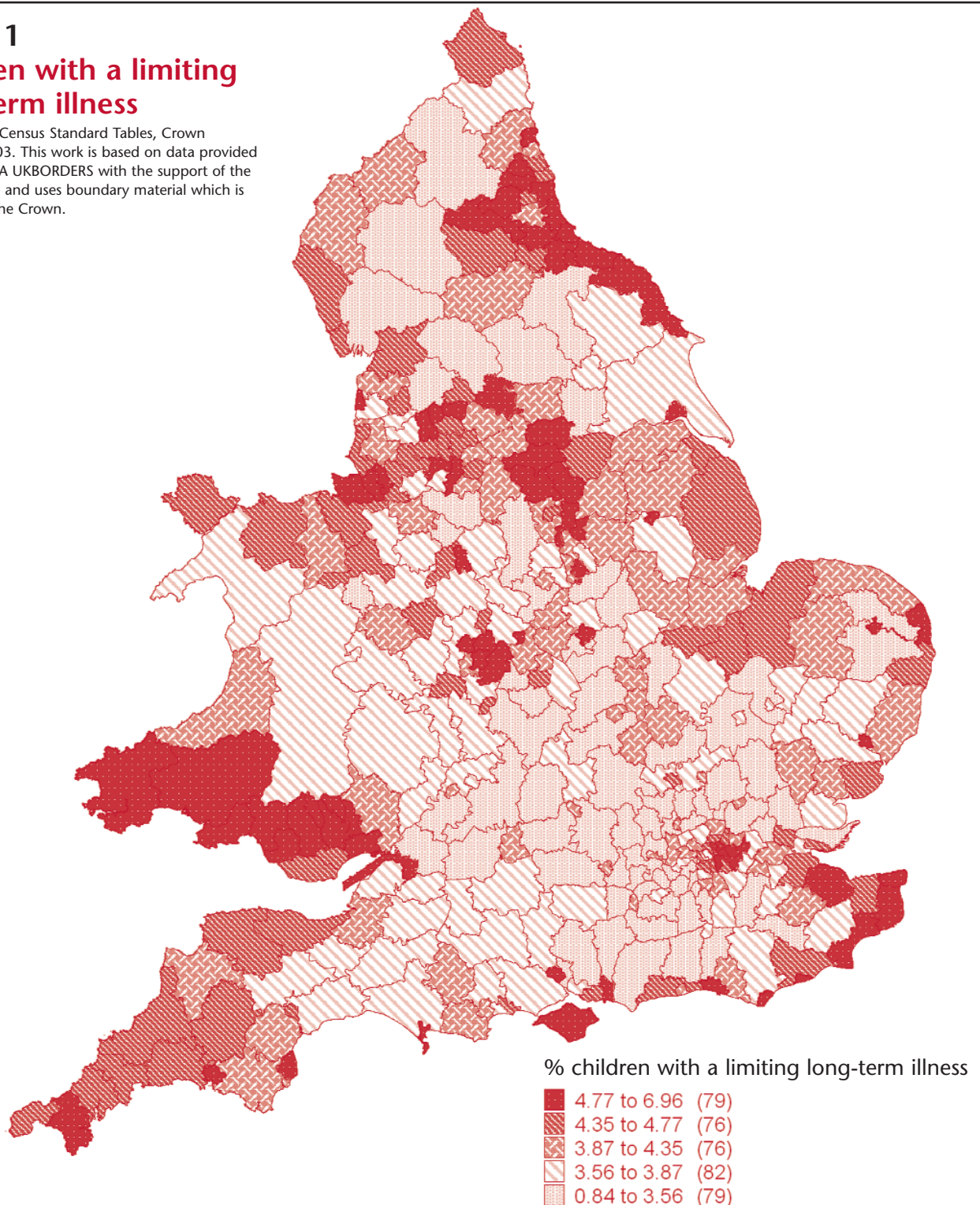


The geographical distribution of children with a limiting long-term illness

The 2001 Census reveals the detailed geographical distribution of children with a limiting long-term illness. The geographical pattern of where these children live closely resembles general patterns of poor health and of socio-economic deprivation.

Figure 1 Children with a limiting long-term illness

Source: 2001 Census Standard Tables, Crown Copyright 2003. This work is based on data provided through EDINA UKBORDERS with the support of the ESRC and JISC and uses boundary material which is copyright of the Crown.





What do we know about carers of sick or disabled children?

In England and Wales, 212,000 families have a child with a LLTI and a co-resident adult who sees him/herself as a carer.

With more than one 'parent carer' in some families, these households contain a total of 305,000 carers, of whom:

- 64% are women; 36% are men
- 20% have a LLTI themselves
- 69% provide 20 or more hours of unpaid care each week
- Of the 195,000 women who care for a disabled child, a quarter are lone parents
- One in seven mothers who juggles a paid job and caring for 20 or more hours each week is in low paid, low skilled employment

Compared with parents whose children are not sick or disabled, parent carers in homes where 20 or more hours of unpaid care is given each week are (as shown in Table 1):

- Older - almost 60% of women and over 70% of men are aged 35-65
- Much more likely to be in poor health – some probably too ill to be the carer in their family

- Very much more likely to have a long-term illness or disability themselves
- More likely to be lone parents (especially men)
- More likely to lack formal qualifications
- Less likely to be educated to degree level
- Considerably less likely to be in employment – especially if they are women

Parent carers who care for 20 or more hours each week and who are also in paid work

As shown in Table 2, compared with employed parents who do not have a sick or disabled child, these parent carers are:

- A little more likely to work part-time
- Just as likely to be working long hours
- More likely to work in low-skilled, low-paid 'elementary' jobs
- Considerably less likely to be in managerial or senior positions
- Also found in a wide range of industries
- More likely to be in jobs very close to where they live



Table 1 Characteristics of parents, families with one or more parent carers and at least one child under 16 with a LLTI

%

Parent characteristics	Families with at least one child with a LLTI: parent carers providing 20 or more hours of care each week	Families which do not have a child with a LLTI: all parents
Age – Men		
<36	27	33
36-65	72	66
66+	1	1
Age - Women		
<36	41	46
36-65	59	53
66+	0	1
Poor health		
Men	11	5
Women	12	5
LLTI		
Men	20	9
Women	19	9
Lone parent families		
Men	15	3
Women	27	23
No qualifications		
Men	24	18
Women	28	19
Qualified to degree level or above		
Men	17	23
Women	14	20
In employment		
Men	72	89
Women	35	63

Source: 2001 Census Special Licence Household Sample of Anonymised Records. This work is based on the SARs provided through the UK Data Archive at the University of Essex and prepared through support by Centre for Census and Survey Research at the University of Manchester with the support of ESRC and JISC. These data are Crown Copyright and are reproduced with the permission of the Controller of HMSO.



Table 2 Parent carers in employment who live in families with at least one child under the age of 16 with a LLTI

%

Parent characteristics	Families with at least one child with a LLTI: parent carers providing 20 or more hours of care each week	Families which do not have a child with a LLTI: all parents
Proportion who work part-time		
Men	8	5
Women	67	61
Proportion who work long hours (48 hours or more per week)		
Men	30	30
Women	6	5
Elementary occupations		
Men	12	9
Women	15	13
Managers or senior officials		
Men	30	35
Women	17	19
Industrial distribution		
Men		
Manufacturing	22	22
Construction	12	13
Wholesale and retail	16	15
Transport and storage	13	10
Real Estate	10	13
Women		
Wholesale and retail	17	18
Education	19	15
Health	25	21
Work 2km or less from home		
Men	34	29
Women	55	51
Work 20km or more from home		
Men	16	18
Women	5	7

Source: 2001 Census Special Licence Household Sample of Anonymised Records. This work is based on the SARs provided through the UK Data Archive at the University of Essex and prepared through support by Centre for Census and Survey Research at the University of Manchester with the support of ESRC and JISC. These data are Crown Copyright and are reproduced with the permission of the Controller of HMSO.



Caring for sick or disabled children

Our new companion study, exploring in detail the situation of a group of parents of sick or disabled children, shows:

- Most value the opportunity to have a part of their life away from caring
- For most, their income from employment is very important
- Many find caring has an adverse impact on their own employment or career
- Flexible working and supportive managers are crucial
- Some manage to change their working patterns, but many feel forced to look for another job
- Tiredness and stress are especially difficult problems
- At work some have been met with ignorance, disrespect or hostility because of their need to work flexibly

The new report:

Caring for Sick or Disabled Children: parents' experiences of combining work and care

by Bernadette Stiell, Lucy Shipton and Sue Yeandle is published by Carers UK and Contact a Family, and available from November 2006 from

www.carersuk.org
www.acecarers.org.uk
www.cafamily.org.uk

CARERS UK
the voice of carers

Parent carers' comments

"I get a lot of satisfaction from working – it does mean a lot to me. It keeps me sane – it's nice to be in contact with other adults."

"Work is tiring, but we will need to continue to work, probably well past our retirement age, to pay for the work we've needed on our house for our son."

"They tell you when your child is born that things are different today – and then they get to 18 and you are expected to give (work) up and be a carer around the clock until you die."

Finding out more

Carers UK improves carers' lives through information provision, research and campaigning. This research was commissioned by Carers UK on behalf of the ACE National partnership, and part-funded under the European Social Fund's EQUAL Community Initiative Programme.

Authors: Lisa Buckner and Sue Yeandle, University of Leeds, November 2006

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Carers UK
20/25 Glasshouse Yard
London EC1A 4JT
T: 0207 490 8818
E: info@carersuk.org

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