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Exploring disability, family formation and break-up: Reviewing the evidence

Harriet Clarke and Stephen McKay

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Abbreviations

BHPS	British Household Panel Survey
CNS	Central nervous system
DDA	Disability Discrimination Act
DWP	Department for Work and Pensions
FACS	Families and Children Study
FRS	Family Resources Survey
HBAI	Households Below Average Income
IS	Income Support
LFS	Labour Force Survey
LLTI	Limiting long-term illness
LSI	Longstanding illness
MCS	Millennium Cohort Study
MS	Multiple Sclerosis
NCDS	National Childhood Development Study
SARS	Samples of Anonymised Records
SCI	Spinal cord injury

Notes on terminology used in the report and statistical significance

Terminology

This report draws on material from a range of literature and analysis of a wide range of datasets. The language used within the report has aimed to achieve consistency across the materials drawn upon, whilst retaining a focus on disability and impairment within the core analysis. It is important, however, to retain reference to the original terms used in the collection of data, in order to be able to analyse them appropriately and to make clear the strengths and limitations of the sources for this kind of analysis.

Wherever possible our own use of terminology reflects the distinction made within disability research and activism within the UK between impairment and disability (Barnes, 1991).

- **Impairment** – the functional limitation caused by physical, sensory or mental impairment (including mental distress).
- **Disability** – restricted access to participation in the normal life of the community as a result of physical, social and attitudinal barriers.

Within the literature review a number of studies have focused on **health status**, for example in relation to cancer and in relation to mental health. These have been included as, when long-standing, these health experiences are widely understood to be related to experiences of disability (for example, within disability legislation and benefit eligibility rules).

Part of the literature review refers to research on **health behaviours**, as work around health status change and marital transitions has predominantly been conducted from health psychology and public health perspectives. This material

has been included as it adds some insights into marriage transitions and well-being, although its individualising focus does not incorporate our interest in (social) disability. Much of our analysis includes measures of people’s experience of **limiting longstanding conditions** as a signifier of experiences of disability. Where possible we have looked at information available on condition or impairment type. The relationship between chronic health difficulties, impairment and experiences of physical, social and interpersonal disability is a complex one. Many disabled people with chronic health difficulties (including mental distress) may experience fluctuations in their functioning (or impairment) whilst experiencing ongoing difficulties in relation to disability.

Statistical significance

The analysis in this report is based on sample surveys, not the complete population. The largest source – the micro-data taken from the 2001 Census – is a three per cent sample of individuals and so still akin to a sample survey with very low non-response.

Any sample survey will interview only a limited number of people and could, by chance, give slightly different results than if everyone was interviewed. We may have more confidence in results where the number of people is larger and for any given sample size it is possible to quantify the level of confidence.

The table below shows the range of population estimates we may make, with a 95 per cent level of confidence, for a result of 50 per cent based on different sizes of survey. Once we have a sample of at least 1,000, then this ‘margin of error’ is as low as three per cent. It takes a sample size of 5,000 to reduce this margin to around one percent (plus or minus).

Sample size		Lower bound	Upper bound
100	40		60
250		44	56
500		46	54
1,000		47	53
5,000		48.6	51.4
100,000		49.7 – 50.3	

Moreover, when two pieces of information are tabulated, such as disability status and family status, there are statistical tools to calculate the probability that the link has arisen by chance, or randomly. Where it is unlikely that such a link will have arisen by chance we say that there is a **statistically significant** relationship between the variables.

It is worth noting two caveats: First, a difference that is statistically significant may be of limited or little practical or substantive significance. With a large enough sample size, almost any difference will be statistically significant. For example,

in Table 3.4, we find that among children aged zero to nine, five per cent of disabled children live with cohabiting parents where only one is the biological parent, compared with four per cent of non-disabled children. This relatively small difference is statistically significant, because of the enormously large sample size (approaching a quarter of a million), but the result seems unlikely to be of practical or policy significance. The second caveat is that a statistically significant association does not prove causation. We can say that a link exists between disability and family status (or, that it is highly unlikely that the observed difference would have arisen by chance if there was no link). This does not prove that one of these **causes** the other – the causation could run in either direction, particularly when looking at snapshots, or some other third factor might be causing both.

The standard tests of significance on cross-tabulations look across the range of categories in the rows and columns. Even if there is a statistically significant association between the two variables, it does not mean that each individual difference may be regarded as statistically significant.

Summary

Introduction

The overall aim of the project is to assess patterns of family formation and change where families include a disabled adult or a disabled child and the primary focus is on family units which include a dependent child. The research involves assessing currently available literature and conducting data analysis to explore the experience of relationship breakdown in families which include a disabled person, and examining whether there are associations that can be highlighted between disability experiences and relationship transitions. There is little British evidence looking at the effect that being a disabled adult, or having a disabled child, has on rates of family break-up or on re-partnering or having children. This study fills this significant gap in our knowledge.

The research seeks to enable Government to build strategies which better support disabled adults and parents of disabled children, particularly in relation to employment roles and additionally, in relation to carer and childcare related needs. The analysis has wider implications for policies concerning flexible leave arrangements in relation to childcare, disability experiences and caring and for support for lone-parents.

We use two main approaches: First, we review the available literature and past research studies. Second, we conduct secondary data analysis, using six datasets comprising:

- for analysis of the current situation:
 - the 2001 Census sample of anonymised records;
 - the 2007 Labour Force Survey (LFS);
- for analysis of changes over time:
 - the Families and Children Study (FACS);
 - the Millennium Cohort Study (MCS);
 - the British Household Panel Survey (BHPS), especially to look at those without children and the transition to having a first child.

Previous research

Whilst there is limited evidence concerning the impact of experiences of impairment and disability on family forms, there is a significant literature concerning disabled children and their families and a growing literature on disabled adults in relation to parenting. The research literature relevant to this topic is particularly diverse, however, two key strands within the literature are clinical and non-clinical approaches. Clinical research is more focused on impairment and 'pathology'. Non-clinical literatures have greater focus on lived-experience and/or welfare experience and service use.

Health psychology research forms a significant proportion of the relevant clinically-minded literature. With a focus on 'health behaviours' and 'health outcomes', the material is **not** easily applicable to experiences of disability and impairment (see Terminology). Indeed, it can be seen to be part of wider public health literature largely focused on prevention of ill-health, and so only relevant to some long-term experiences of chronic ill-health and disability, where, for example, 'life-style' or living in poverty, could be 'implicated' in the impairment or ill-health experience. For example, a number of studies have explored the relationship between marriage, divorce and health behaviours, with findings pointing to increased likelihood of 'unhealthy behaviours' in **post-divorce** individuals (e.g. Lee *et al.*, 2005; Eng *et al.*, 2005). Positive aspects of relationships in the presence of chronic health difficulties or impairment within such studies are only very rarely considered. Findings suggest that appropriate adjustments within a work environment may be important ways of supporting disabled people in the context of their relationships, as job loss seems more often important than disability itself in relationship change.

Families with a disabled child will share many of the same pressures and pleasures of family life as their peers. Any increased risk of separation is most likely during the early stages of parenting a disabled child: this may be linked to questions of parental adaptation **or** to issues of accessing supports. Urbano and Hoddapp (2007) found that whilst divorce rates in families which included children with Downs Syndrome were no different to other families, where divorce did occur, it was more likely to occur during the first two years after birth.

Much research which can help us to examine the impact of the timing of onset of impairment focuses on sudden-onset events, particularly injury. However, it is very challenging to look in surveys at the experience of changeable, unpredictable and/or fluctuating impairments. For example, some forms of mental distress, multiple sclerosis and arthritis may sometimes present as being at the forefront of someone's day-to-day experience; at other times individuals may see disability as less relevant to their own and their families' day-to-day lives.

Disability and family status

Having a long-term limiting illness, impairment or significant health problem (each of which can be understood as related to experiences of social disability) is associated with:

- a higher proportion remaining single;
- a lower proportion being in their first marriage or being married at all:
 - a slightly lower proportion cohabiting;
 - differences in the characteristics of the disabled and non-disabled population account for a large part of the disparity in rates of marriage;
- a higher proportion of disabled people being divorced or separated from marriage;
- a higher proportion experiencing bereavement.

It is unwise to draw conclusions about family status and disability, without first controlling for differences in age and gender. The 'marriage gap' appears to be much larger for men aged 30-44 than for women. If anything, after the age of 50 this marriage gap appears to be larger for women than men.

In general terms, the groups with lower rates of marriage **tended** to have higher rates of divorce. Rates of divorce were higher among those stating they had depression or that they had a mental illness. Conversely, those who said that they had health problems relating to diabetes, to the heart to blood pressure or epilepsy, had rates of divorce within each age band that were similar to those not mentioning any kind of health problem.

Disabled people were slightly less likely than others to have dependent children, for those aged 30-59, but more likely to have children for those aged 20-29. This analysis of the 2001 Census also found that among those aged 30-44, prime years for having children, 73 per cent of non-disabled people had dependent children, compared with 66 per cent of those with a limiting long-term health problem.

There is also a slightly greater chance that disabled children will be living in step-families, as well as in lone parent families.

The dynamics of disability and family change

Taking the main respondent (usually mothers), 70 per cent of those mentioning a disability mentioned it the following year. Conversely, 30 per cent did not. There were similar figures among children. For fathers, 72 per cent of those citing a disability in one survey said the same the following year – with 28 per cent not mentioning this longstanding condition the following year. These figures show a high degree of consistency but one with considerable turnover from one year to the next.

There is a strong level of stability in marital/relationship status overall within the population. Only two per cent of all married people cease to be married a year later and only eight per cent of the singles cease to be single (of whom six per cent have started cohabiting and only one per cent have married). There is also considerable continuity for the divorced and bereaved. Four cohabitants in every five (81 per cent) still cohabit a year later and 13 per cent have become married.

Over a five-year period some 39 per cent of respondents had a longstanding illness in one year or more, though only ten per cent mentioned this every single year. There were similar figures among children.

Only just over half (57 per cent) of families with children managed to stay out of poverty in all five years. Conversely, only four per cent of families were recorded as living in poverty in each and every year out of five.

Disability and family breakdown

In the first years of a child's life rates of lone parenthood climb rapidly for disabled children. The proportion of disabled children living with a lone parent is much higher at age two (33 per cent) than when the child is aged less than one (when 22 per cent live with a lone parent).

Eight per cent of couples separated between the first two waves of the MCS. Rates of breakdown were significantly higher where there were limiting health conditions, including 13 per cent breaking up where the father had a limiting longstanding illness. The impairments that were associated with higher rates of breakdown were depression (16 per cent if the father had been treated for depression, 12 per cent if the mother had been so treated), having fits and diabetes, particularly if requiring insulin – though this did not figure in the cross-sectional results.

In a larger sample of families, drawn from the FACS whilst disability-related questions are associated with a higher risk of breakdown each year, the size of the difference is quite small.

Analysis of the FACS survey data seems to show that those with no experience of disability or who experienced disability in all of the five years observed, were more likely to remain together than those experiencing disability for about three years out of the five. It is possible that more transient reports of disability have less effect – and prolonged disability allows for adaptation in a way more difficult for a less predictable condition.

Disability, partnering and re-partnering

Among those living alone and with a limiting health condition (in BHPS) some 4.7 per cent each year find a partner, compared with 7.6 per cent for those who are not disabled. This is a significant difference that sheds considerable light on the differences we found between disabled and non-disabled people in terms of rates of marriage and cohabitation. For those aged 25 or older, the rate at which single people become couples is rather lower for disabled people. Partnership rates are similar in the early 20s, and disabled people form relationships at a higher rates than average in their teens (though relationships forged at a young age have higher rates of dissolution). A statistical analysis of rates of movement from single to couple found that having a limiting long-term health problem reduced this by 24 per cent – after controlling for differences in age and qualifications and by 28 per cent if we only control for age.

Among those who did not mention any kind of limiting illness in the first five years of BHPS, after five years 27 per cent were part of a couple, and after ten years, half. Where a single person had cited a limiting long-term illness in at least three of the first five years, in only ten per cent of cases had they moved in with a partner after five years, climbing slowly to 18 per cent after ten years.

Rates of re-partnering among lone parents do differ slightly according to disability. However, the rate of movement into all relationships (perhaps especially first relationships) is lower for disabled people than for non-disabled where disabled people fall behind the rest of the population. We do not find much of a link between disability and lone parents forming couples.

Disability and children

Disabled adults aged 20-34 were slightly **more** likely to have dependent children (up to the age of 16) than non-disabled adults. Early parenting is, in fact, often a sign of disadvantage. Once past the mid-30s, disabled people appeared less likely than average to have dependent children. For those aged 35-39 and 40-44 in particular, the gap is quite noticeable.

On average, people have 1.2 children but the average number of children for those with learning difficulties was very low (average 0.3), with a speech impediment (0.5) and for those citing that they had a mental illness, epilepsy or difficulty in seeing (0.8).

There are sizeable differences in the proportions of different groups, defined by disability during 1991-95, having children by either 1995 or 2000. For example, by 2000 some 20 per cent of those not mentioning a disability now had children, compared with only five per cent of those who had mentioned a limiting long-term illness (LLTI) in at least three of the first five years of the study. To some extent this reflects differences in age.

Among existing families there were some effects of disability on the aspiration to have more children but these were relatively small.

Consequences for employment and poverty

There is little relationship between a mother or child having a longstanding illness, and rates of family poverty¹, at least, not when looking at a single year in isolation rather than looking (more informatively) at a succession of years. It is, however, worth noting that there is a higher chance of poverty if a parent is disabled, rather than a child.

¹ Poverty is measured in the standard Households Below Average Income (HBAI) way, as being below 60 per cent of the median equivalised income.

The likelihood that a family had ever been in poverty was greater the more years during which either a child or the mother-respondent said that they had a long-standing illness (LSI). Risks of ever having experienced poverty were greatest where a child had such an impairment during five consecutive years (where it was 52 per cent) and lowest when no such condition was reported.

Where no LSI was reported among children, this conceals an important difference between families where this was reported in the past, and those where a child's illness has never been reported. A poverty comparison between those with and without disabled children runs the risk of misleading. It includes those for whom an LSI is a relatively new feature and where the turnover in reporting such conditions may be high. It excludes the effect of past history, which is important since a greater number of years with an LSI is associated with a higher risk of ever being in poverty.

Where the respondent mentioned an LSI (but not in the previous year) the extent of employment stability reduced. This group were more likely to change employment status and generally speaking were more likely to reduce their working hours than the comparison group (no starting to have an LSI).

A similar analysis looking at the effects of child disability found smaller changes than for changes in the respondent's disability status but these still seemed to be relatively important in reducing rates of paid work.

Conclusions

This study has sought to explore how far disabled people's family status (and trajectories over time) appears to be different from that of non-disabled people.

Our analysis identifies a small effect of the presence of impairment on family breakdown (divorce, separation) in households which include dependent children. In relation to specific impairment experiences, this effect is significantly increased. Moreover, disabled people are rather less likely to enter into relationships than their non-disabled peers.

The presence of child or adult impairment increased the likelihood of a family having experienced living in poverty and this increased in relation to how many years of impairment were reported. The current presence (or not) of disability may not be the most important factor, instead a history of family experiences of disability may have long-lived effects in relation to employment and poverty.

The presence of fluctuating and unpredictable impairments may place families at particular economic risk (in relation to poverty and in access to, and maintenance of employment).

Part 1

Exploring the links between
disability and family formation

1 Introduction

1.1 Background

There is anecdotal evidence – and some relatively limited research evidence – to suggest that there is a higher rate of family dissolution among families containing a disabled person. However, there is little recent British evidence that looks directly at the effect that being a disabled adult, or having a disabled child, has on rates of family break-up or on other important demographic trajectories (particularly re-partnering, having children). This study aims to fill this significant gap in our knowledge in order to contribute towards the development of a range of policies in relation to children, families, employment, ‘care’ and disability.

Much of the policy agenda regarding disabled people has been set by the pivotal report of the PM’s Strategy Unit, *Improving the life chances of disabled people* (2005). This report included a strong statement of the direction of policy. Its main aim is that ‘*By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society*’. Promoting understanding of disabled people’s experiences in the context of their relationships (including as parents, as children, as partners) and understanding the experience of disability over time, in life-span context, will be important for securing this ambition.

There are a range of different policy areas where the results of this study may be relevant – in terms of developing better strategies towards supporting disabled adults (and those with disabled children); the role of childcare; policies towards carers; child support issues for disabled families; employment for disabled people and carers (given the associations between family status and work). In addition, access to and the delivery of children’s services (core to *Every Child Matters*, DfES 2003) has implications for how children and parents experience day-to-day family life. Such strains and stresses may be hypothesised to impact on both partner relationships and decisions about further children. The importance of family support has been recognised in Standard 8 of the National Service Framework for Children (DoH, 2004), which stresses the importance of child and family-centred, coordinated services, which as much as possible support families to have ‘ordinary

lives'. The delivery of services to children and families is currently undergoing change, for example, in relation to disability policy, this includes the rolling out of both direct payments and individualised budgets (HM Treasury/DfES, May 2007). Research examining the implications of these approaches for families and for family relationships, in contrast to traditional forms of delivery and organisation, could be valuable.

We explore existing published research that has looked at the demographic implications of disability. A number of studies have been conducted, of varying degrees of relevance because they are often relatively narrow. We summarise what may be learned from previous research on family change and disability. We then analyse the main relevant datasets to chart the links between disability and family formation, both looking at snapshot information (the situation at a point in time) and following families over time.

In this study we will consider if there are particular effects of disability relating to:

- 1 **Family breakdown** – that is, splitting up among both married and cohabiting couples.
- 2 **Moving into couples from single status** – and whether this entails marriage or cohabitation. Sometimes the term 'partnering' is used as a shorthand for this change.
- 3 Any **effects on family size**, through possible effects on the timing of any subsequent births and whether they happen at all. This represents a more exploratory element of the project.

In the study we also look separately at adult disability and child disability, contrasting their different effects and influences.

1.2 Aims

The main aims of this research project cover:

- the rate of partnership dissolution among families with a disabled adult and/or child – and how this compares with families with no disabled member;
- the timing of family dissolution in relation to the arrival of a disabled child/the onset of impairment or chronic ill-health of a family member;
- the factors associated with family dissolution amongst families experiencing disability;
- the relationship between experiencing disability within the family context and access to employment and family experiences of poverty

The research, therefore, models the likelihood of relationship breakdown, as its main focus and considers how it differs between families with and without disabled members.

In addition to this key aim we extend the analysis to cover two other transitions – first that from single person to couple. It has been well-established that the rate of lone parenthood depends on the rate at which people leave lone parenthood, as well as enter it (Ermisch 1991). The growth of lone parenthood over the 1990s was also partly due to decreases in the rate of leaving lone parenthood (Rowlingson and McKay 1998). Second, we broaden the analysis to also consider if experiencing impairment and disability affects decisions about family size, and we propose an exploratory investigation into the childbearing decisions of families containing a disabled person (whether adult or child).

1.3 Methods and data

We use two main approaches: First, we review the available literature and the different studies that have previously been conducted. Second, we conduct secondary data analysis, using an impressively wide range of data sources.

These datasets comprise:

- for analysis of the current situation:
 - the 2001 Census sample of anonymised records;
 - the 2007 Labour Force Survey (LFS);
- for analysis of changes over time:
 - most important, the Families and Children Study (FACS);
 - the Millennium Cohort Study (MCS), particularly for changes in the early years of a child's life;
 - the British Household Panel Survey (BHPS), especially to look at those without children, and the transition to having a first child.

Secondary analysis of the FACS investigates family change among disabled adults and families with disabled children. It looks, in particular, at any effects on the likelihood of partnership dissolution and of re-partnering. Some exploratory analysis also considers if there are effects on fertility decisions (size of family).

The methods used in this study are relatively descriptive, reflecting the interim nature of this report and the main issues being investigated. This is justified, in part, because the data has not been much exploited in this area, and partly this is to increase the accessibility of the results. However, on occasion we use slightly more complex methods of analysis, such as multivariate methods (regression) to control for differences between families that may not be related to their disability status or caring. If, for example, those with particular family types or those with particular qualifications were more likely to have impairments or limiting long-term illness (LLTI) and if those characteristics were linked to rates of economic activity, then a simpler analysis might overstate (or understate) the effect of impairments/long-term limiting illness. A regression approach, using a range of information, helps to address this particular problem.

1.3.1 Overview of the key datasets

In this section we provide some key notes about each of the datasets used in the report. Later sections provide greater detail.

The 2001 Census microdata is a vast sample (1.8m people, or three per cent of individuals). It asked about the health status of each person in the UK, which formed question 13:

Q13. The main questions about health and disability

- ☐ Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?
- Include problems which are due to old age.
 - Yes No

The Family Resources Survey

The 2004/05 Family Resources Survey (FRS) interviewed about 50,000 adults. The FRS uses a definition of people with a longstanding illness, disability or infirmity, who have a significant difficulty with day-to-day activities. It is funded by the Department for Work and Pensions (DWP) and, the principal source of information about incomes and poverty.

The LFS

The questions used to create a derived Disability Discrimination Act (DDA) measure cover the following:

- Do you have any health problems or disabilities that you expect will last for more than a year?
- Does this health problem affect the kind of paid work that you might do?
- Does this health problem affect the amount of paid work that you might do?
- Do you have...[list of 17 'health conditions'] ; which is main?
- Do these health problems or disabilities, when taken singly or together, substantially limit your ability to carry out normal day-to-day activities? If you are receiving medication or treatment, please consider what the situation would be without the medication or treatment.

The FACS

- Started with low-income families in 1999, continued annually, all families from 2001.
- Original 8,000 families followed up, plus new households introduced as they have children (or move to sampled areas).

- Measures, most years, of disability and impairment status using a range of different approaches.
- Detail on outcomes.
- Lends itself to looking at:
 - longer-term effects of earlier changes;
 - child disability issues.

The BHPS

- Started 1991, continued annually.
- Original 5,500 households followed up, plus new households introduced.
- Measures, most years, of disability status using a range of different approaches.
- Detail on outcomes.
- Lends itself to looking at:
 - annual changes in status;
 - longer-term effects of earlier changes.

The MCS

- Quite ‘medical/clinical-model’ in its outlook.
- Only a short time-frame to consider.
- Large sample size for a followed-up group.
- Controls for range of factors, given the similarity of people’s situations.

1.3.2 The key cross-sectional datasets: Census 2001 and FACS

Sample data from the **2001 Census** has been made available at individual level, on an anonymised basis with various data banded to rule out identification. In early November 2004 access was granted to the 2001 Census Samples of Anonymised Records (SARs). This dataset may be less familiar to many readers, so we present a few more details of this coverage and potential use. It is a three per cent extract (or abstract) of individuals from the April 2001 Census. The information collected is based on a separate record for the overall household, plus information about each individual.

The information includes, most notably:

- Household level – type of accommodation, housing tenure, cars available, number of carers in the households, number of employed adults, number in household with LLTI, number of household members with poor health, number of rooms.

- Individual level – age, sex, ethnic group, general health, LLTI, marital status, whether carer and how many hours, qualifications, economic activity, hours worked.

In most cases the individual-level information extends to all age groups, including young children (questions about work and qualifications are restricted to those aged 16-74). The 2001 Census questions on health comprised:

- Over the last 12 months would you say your health has on the whole been: good, fairly good, not good?
- Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do? [include problems which are due to old age]. Yes/No.

This source of data brings two principal advantages: First, since it is based on a compulsory source the response rate was extremely high (not 100 per cent in 2001 but probably of the order of 98 per cent). Therefore, the problem of non-response, sometimes an issue with surveys of disability benefit recipients or of health, is largely removed. Second, the number of individuals to analyse is immense – over 1.8 million, a three per cent sample of individuals in the UK. This is far larger than any other source, over ten times larger than a single quarter from the LFS, for instance. Therefore, results from this source carry a unique level of authority.

The main disadvantage is that the questions did not go into a lot of detail. This was partly, of course, for reasons of space, and partly because the census is self-completion rather than interviewer-administered. As a result, sample estimates do differ from those from other (survey) sources commonly used, though the size of the difference is relatively small (see Bejekal *et al.* 2004: Table 3.2). Some of the information is also 'banded' after collection (i.e. put into groups) in order to protect respondent confidentiality – for instance, only five ethnic groups are identified even though data was collected about a larger number, ages are banded for those of working age and some age groups remain quite wide (e.g. those aged 30-44 form a single group).

As mentioned previously, the main data source for the analysis would be FACS. FACS is able to provide considerable detail about families with children, both in and out of paid work. The main limitation is that FACS only includes families with children, not those without dependent children. It does, however, contain a full eight-year panel for those families not in paid work and a six-year panel among a representative sample of all families with children, whether or not they are in employment.

The information relating to disability covers:

- **children** (asked of parent) health status, LLTI, type of health problem/disability, likely duration, age of onset, caring required, effect on employment, A&E admissions;

- **parent** (asked of responding partners, in addition) health status, LLTI, type of health problem/disability, depression, age of onset, likely duration, effect on amount/kind of work, benefits received.

FACS also contains a large range of questions that measure incomes, living standards and employment status. The survey is run by the DWP so questions reflect its interests very closely.

2 Previous research

2.1 Background to the literature review

This project identifies patterns in family break-up, partnering and having children, in relation to the presence of a family member (adult or child) who has an impairment. There is very little British evidence concerning the impact of experiences of impairment and disability on family forms, although more broadly there is a significant literature concerning disabled children and their families (e.g. Clarke, 2006) and a relatively recent, but growing, literature on disabled adults in relation to parenting (see Morris and Wates, 2006). Survey research provides us with invaluable evidence concerning individual and family circumstances. Such patterns can be carefully analysed statistically but their meaning can only be explored fully with reference to the meanings which people hold important in their day to day lives, and the social and cultural influences on lived experience. It is important that research which demonstrates current ways of thinking about and current experiences of disability, reproduction and relationships are considered before we present and explore our analysis of the data. This review has sought to identify and explore current qualitative and quantitative evidence, from the UK and abroad, on the impact of disability on partnering, re-partnering and having children.

The research literature relevant to this topic is particularly diverse. Studies have been conducted in different ways and in different settings (including international work), for different purposes. This initial wide-ranging analysis of the literature provides an important reference for the later data analysis. The range of policy areas for which this study has relevance (such as education; employment; income and disability benefits; childcare services; social care and health) reflects the complexity of the issues which are involved in individual and family experiences of disability.

2.1.1 Literature search strategy

The primary aim of this review has been to synthesise evidence from disparate literature concerning disability and family forms, in relation to family members' experiences of impairment. The strategy has been an inclusive one. Research

has not been excluded on the basis of the geographical location, theoretical perspective or academic discipline of authors and researchers. We have sought to include information from wide ranging sources.

Research materials have been identified from searches of academic literature databases. Searches were conducted using a wide range of key words and phrases in relation to disability, marital status, family formation and change over time.

2.1.2 Literature strands in disability and family research

We next identify key features of research literature relevant to understanding disability and family supports.

Impairment and disability

Whilst there are clearly a range of research perspectives on family and disability, two key strands within the literature are clinical and non-clinical approaches. Both of these broad approaches are relevant to our research needs but they sit within different research traditions and draw on different academic disciplines. Clinical research is more impairment-focused, more concerned with aetiology, risk and/or adjustment and 'pathology'. Non-clinical and social model literatures have greater focus on lived-experience and/or welfare experience and service use. Clinical (and quasi-clinical) studies focus on individuals and their impairment as the primary focus of analysis; more social approaches are concerned with issues of social, material and interpersonal barriers to full participation.

Each 'lens' brings different research questions to the fore. For example, in relation to disabled people as parents, the clinical approach has been characterised as seeking pathological functioning, that is the negative impacts of impairment on individual or family functioning (Olsen and Clarke, 2003). Similarly, the findings of more clinical approaches to understanding disability in childhood are often centred on issues such as individual biological vulnerability and 'developmental delay'. So, in relation to both disabled adults and disabled children, more clinical approaches are particularly likely to be focused on individual functioning, with family experience and policy implications often only of interest in relation to negative outcomes.

This current study recognises that exploring links between impairment and family is about much more than experiences of impairment and their impact on family life. Whilst family forms and experiences may often be examined by researchers in relation to specific impairments, broader issues of care, health, welfare and maintenance of interdependence within family relationships are important parts (indeed, often the most significant parts) of the equation.

Life-stage compared to life-course

A further feature of disability and family literature is that research examining childhood and adulthood experiences of disability often exists within different research and policy 'bunkers'. The literature that is available on family experiences

of disability often focuses on either adulthood or childhood impairment, reflecting divisions in service delivery and also difficulties in developing longitudinal or life-span-informed research projects. Within disability studies there have been some recent developments addressing concerns that a life-course perspective is required to fully understand and respond to disabled people's life choices and life chances (most notably by Priestley, 2003). This is also arguably reflected in some cross-Government policy work that has focused on disabled people's life-chances (PMSU, 2005). Interestingly, within this latter document some (brief) references were made to barriers faced in the context of disability in personal and family roles and relationships. And whilst there may be some methodological limits to large-scale research which could explore this issue in-depth and over time, this current research seeks to maximise the data which is available to begin to draw out relevant accounts.

Dependency compared to interdependency

In the UK there has been significant development in disability activism, politics, and research; alongside this, a carers' 'movement' or policy agenda has also developed. The disability approach has asserted disabled people as individuals in their own right, seeking to have rights to family life (e.g. in relation to childhood and in relation to parenting) acknowledged and protected. The carers approach has involved exploring the experience of disability in family context, yet has been accused of having done so in a way which can support the disempowering of family members (whether or not they are carers and/or disabled people). This is particularly the case when disabled people have been positioned as 'dependent' rather than interdependent in research work, (where, for example, care-giving or other key roles have not been acknowledged). Finally, within some (social care and health) practice contexts there have been some moves to develop 'whole family' thinking, which challenges the traditional policy separation between child and adult services and requires a more holistic (and complex) approach be taken to understand family-level experiences of disability (and related support needs).

Social control compared to emancipatory approaches

Finally, the experiences of disabled people in relation to family life, partnering and parenting cannot be explored without some reference to the extent to which those aspects of life are felt to be denied or controlled or accessible and unquestioned, and so on. In this respect there have been some who claim that the eugenics programs of the 20th century has cast a '21st century shadow' (Sayce and Perkins, 2004), which can affect disabled adults and disabled children alike.

The historical and current control of some disabled adults' sexuality and parenting requires acknowledgement: that is, reduced or disrupted patterns of partnering and parenting might be understood as a specific manifestation of 'sexual oppression' in the context of disability (Fiduccia, 2000: pg 169). High divorce rates and low marriage and remarriage rates, could therefore signal a lack of sexual and reproductive rights.

One of the predominant ways in which the control of disabled people's reproduction can be explored is through examining the roles of health and disability professionals. Kliever and Drake (1998) argue that the disability professions, which developed in the late 19th and early 20th centuries, based their professional status and defended their (segregationist) practices on scientific claims. They maintain that these **claims** to science (i.e. 'scientism') continue to be used to justify segregational policies and practices and challenge inclusionary approaches but in fact these claims can be seen to hide an ideology of control which they argue is traceable to the eugenics movement. Extending their argument, we could hypothesise that the use of the language of 'science' (including from genetics, biology, psychology) in professional discourses about disability and sexuality can exert their influence beyond the one-to-one actions of practitioners in specific circumstances. The process of control of sexuality and reproduction is, for disabled young people, likely to start in childhood, when educational and/or parenting practices have been informed by denials of, or fears about, the development and expression of sexuality (Anderson and Kitchin, 2000).

Whilst Kliever and Drake focused their analysis of professional power on US-based education policy and practice debates, their account reminds us that many disabled adults in middle to late adulthood in the UK in the early 21st century may have experienced a very segregated education, sometimes residential and highly institutionalised, which was expected to see students go through the transition to similarly rigid and controlled (often institutional) circumstances. Whilst this is a more marginal experience today, some groups of disabled people (for example, young people entering adulthood and adults with significant learning difficulties) often continue to experience lives where their relationships (including knowledge about, and access to, sexual relationships) are limited by others.

The sexual and reproductive rights of disabled people are increasingly being vocalised, however, the 'private' experience of disability and social relationships has, overall, had less activist and policy focus than access to public spaces or to public roles and relationships. One of the strongest statements of concern about the relational experiences of disabled people in western societies came from Waxman and Finger (1991), who argued that disabled people are more often denied sexual and reproductive rights than other social groups, including rights to marry, bear and rear children (cited in Anderson and Kitchen, 2000: p 1165). Whilst this may have been particularly evident under conditions of high levels of institutionalisation, and high levels of professional control, there is an ongoing need to revisit this issue, for different generations and under different social and policy circumstances. Further, disabled men and disabled women, and boys and girls, are likely to experience gendered cultural messages about their impairment, their sexuality and anticipated or actual relationship and parenting experiences.

In relation to disabled people as parents, genetic arguments used to restrict disabled people's access to parenting have largely been replaced with concerns about parenting capabilities. This 'updated' approach can still arguably lead to professional dissuasion from child-bearing, counselling towards termination,

or later separation of parent from the child (Sayce and Perkins, 2004). Similar concerns (particularly in relation to mental health) have been raised by Beresford and Wilson (2002), who consider that mental health service users (in the UK setting) are given the message that they '*...have a moral responsibility not to have children in the interests of preventing further unnecessary suffering*' (p 547). Research questions which are more biologically-based (than modern disability policy-focused approaches) might nod towards such a perspective, as might clinically-based approaches (e.g. where medication use is presented implicitly or explicitly as a barrier to reproduction).

Further barriers to reproduction have recently been considered by researchers in the UK context. Restrictive institutional residential structures have been (partially) replaced by attitudinal and structural community-based barriers, including within health services. This theme strongly came through in Anderson and Kitchen's (2000) work examining family planning environments and services in Northern Ireland. Access to sex education, sexual health services, family planning and antenatal care are significant issues for disabled men and women.

Legal, professional and lay responses to disability in childhood are currently strongly influenced by developments in and the perceived potential of genetic and reproductive technologies to exert change (to increase choice or to reduce the diversity of human experience – depending on one's perspective). Whilst most impairments are acquired (Shakespeare, 2005), attitudes and practices towards congenital impairment and its desirability or otherwise have wider relevance for attitudes towards disability and family. This is particularly the case for families which include a disabled child and for families who are aware of an inheritable condition. Disabled people with acquired or non-inherited conditions may also be more aware than non-disabled people of ongoing debates about prenatal testing and termination.

This project, therefore, explores the data with an acknowledgement of the importance of sensitive, aware analysis given the highly problematic nature of approaches which (explicitly or implicitly) result in the control of the reproduction of disabled people.

2.1.3 Conceptual issues: disability definitions and disability experience

The clinical/social lenses identified above themselves lead to different definitions of 'disability', the former focusing on restricted function in relation to impairment, the second with material, interpersonal and organisational barriers to participation. Disability estimates in population surveys differ considerably and Bejekal *et al.* (2004) have highlighted that the ways in which disability is defined is one of the core reasons for this. They report that within the UK, the disability legislation definition has been incorporated into survey research but that the way this has been operationalised has not been consistent. Given the different approaches within different studies, it is important to be aware of how estimate differences are generated and how to make use of the data appropriately in research work.

Within different definitions, different impairment experiences may be included or excluded (e.g. chronic health difficulties; mental health difficulties; learning difficulties). Even where it is clear what the range of included impairment experiences are, there will be significant differences in impacts and this will not only differ by impairment type: time of onset (including whether the impairment was congenital or acquired), whether the impairment is visible or invisible and the current impacts compared to lifetime impacts will vary significantly. The experience of disability itself will also be structured (through gender, ethnicity, and class, for example), therefore these are likely to filter implications for family formation in slightly different ways.

2.2 Disability, family and lived experience

2.2.1 Introduction

Before examining research which directly sheds light on the relationships between the presence of impairment and family forms, a brief review of research on disability and lived experiences of family life highlights some of the issues which may help to explain any patterns found and/or inform future research work in this area.

2.2.2 Childhood disability and family experiences

It is likely that in many cases of childhood impairment there may be a complex inter-relationship between poverty and disability – a theme to which we return in Chapter 8. The financial circumstances of disabled children and their families may influence risk of impairment and/or chronic health difficulties in childhood, as well as childhood impairment having an impact on household finances. For example, Gordon *et al.* (2000), analysing the OCPS Disability Surveys 1986, found that there were significant differences in the prevalence of impairment by social class, with children being three times as likely to have an impairment if their father was an unskilled manual worker, compared to children of professional workers. They further found that parents of disabled children were less likely to be in employment. More recent survey analysis, of the fourth wave of FACS, by Emerson and Hatton (2005) has compared households which include a child reported to have a long-standing illness or disability and/or special educational needs with families with no disabled child. They estimated that there are currently over one million families which included a child 'at risk of disability' and that those families were 1.45 times more likely than others to live in poverty. Their analysis suggests that for around a third of families which include a disabled child, anxiety around financial pressures (as well as the material stressors of poverty) would be a particular burden for parents.

Housing has also been identified as a core issue impacting day-to-day life within disability and childhood research. Emerson and Hatton's (2005) analysis of FACS provided estimates that 85,000 families in Britain with a disabled child were living in overcrowded accommodation and that over 50,000 such families would consider their homes to be in poor repair. Inadequate housing was also reported

from Beresford and Oldman's work (2002), which surveyed over 2,500 parents and over 100 practitioners. Difficulties reported with housing included lack of space, home location, unsafe internal environments, access problems and inadequate bathrooms. Around 90 per cent of families experienced at least one housing difficulty, with those renting and on low-incomes most likely to experience greater numbers of problems: however, even middle/higher income groups reported an average of three housing problems. The authors assert that with inappropriate housing comes increased risk of physical and mental health difficulties for parents. In previous work, Oldman and Beresford (2000) reported that health had emerged as an unprompted theme in interviews with parents of disabled children about housing, with family physical and mental health affected by a lack of suitable adaptations, access problems within the home, and lack of personal space. (Such work also serves to highlight the ways in which some households are more likely to include more than one family member experiencing impairment or long-term health difficulties.)

2.2.3 Adulthood disability and family experiences

Parental disability has been identified as increasing the risk of children living in poverty compared to households which do not include disabled parents. Stickland and Olsen (2006) report, from their analysis of a number of data sources, that this increased risk of family poverty holds true for both dual and single parent families and can most strongly be associated with worklessness; further, disabled parents who do work are more likely than non-disabled parents to be in low-paid, insecure and part-time work. Risks of child poverty have been recognised in a number of documents, including the PMSU (2005) *Improving the Life Chances of Disabled People*. Disabled parents' needs in relation to employment and combating low incomes has, therefore, become increasingly well recognised in recent years. Preston (2006) reports from recent research with disabled parents, that there are several barriers to employment (and maintaining employment), including discrimination, employer recognition of skills, access to training, combining care services and employment, benefit concerns and access to appropriate childcare. She reports that lone disabled parents can face particular difficulties in combining work and parenting.

Some elements of the relationship between presence of impairment and increased risk of socio-economic disadvantage has also been summarised by Morris and Wates (2006) in their knowledge review for the Social Care Institute for Excellence. They report that parents living in the poorest communities are at increased risk of long-term health difficulties, mental ill-health and disability.

The extent to which the housing needs of disabled parents and their families are met is likely to be a particularly powerful determinant of how families experience day-to-day life. Wates (2006) argues in her review of current evidence, that unmet housing needs can put significant levels of strain on all family members. Olsen and Clarke (2003) report from their interviews with disabled parents and their families that a small minority faced extremely trying housing problems: for example, a

lack of private space (e.g. parents sleeping in living room) and lack of access to children's rooms (therefore, creating pressures in terms of child care and concerns about risk) could each exert significant stress upon parents and children alike.

A further important issue in understanding day-to-day experiences of disability in family context, concerns the ways in which services are assessed and delivered, including the specific approaches taken within assessments and care planning to 'involving' family members in the 'care' of a disabled family member. This may have implications for how all involved feel about their own autonomy to negotiate interdependent family relationships.

2.2.4 Health, impairment in family context and marital status

Within both research focusing on childhood impairment and research exploring adulthood impairment, increased risk of ongoing health difficulties has been identified. Health differences (rather than impairment) by marital status is an important area of the research literature, with relevance for our analysis here. In particular, the different explanations put forward for different family forms in relation to adult health can begin to be tested out within UK-based data analysis.

Joung *et al.* (1998) report on different explanations for observed differences in morbidity and mortality between divorced and married individuals. They present both causation theory (marital status impacts upon health) and **selection** theory (health impacts upon marital status) as having a role. For example, their research (using Dutch longitudinal data) suggests that subjective health complaints and reports of two or more chronic conditions increased the likelihood of divorce. Joung *et al.* (1994) also highlight difficulties when relying on marital status alone in examining health differentials, with Dutch analysis suggesting that those living with (but not married to) a partner have lower morbidity rates than those who live alone.

The selection and causation explanations have been assessed in a number of areas, including mental health. Wade and Pevalin (2004) have reported from analysis of the British Household Panel Survey (BHPS) that mental health difficulties are more prevalent in those moving out of marriage, and that the data suggests evidence for both social causation and social selection processes. Willitts *et al.*'s (2004) analysis of the BHPS does, however, suggest that marriage or partnership is generally protective of mental health and that splits worsen mental health, usually with longer-lasting negative impacts on women.

A number of studies have explored the relationship between marriage, divorce and **health behaviours** (i.e. concerning whether people do, or do not, maintain a healthy lifestyle), with findings pointing to increased likelihood of 'unhealthy behaviours' in **post-divorce** individuals (e.g. Lee *et al.*, 2005; Eng *et al.*, 2005). The implications of **health behaviours** for marital status (rather than marital status on health behaviours) should also be considered. Patterns within the research findings may not be as expected.

For example, Cheung (1998) explored longitudinal data from the 1958 UK birth cohort of the National Childhood Development Study (NCDS). Focusing on those who were first married at age 23, and examining marital status at 33, the study found that for women a number of factors increased the likelihood of divorce (including being a council tenant; being a harmful level drinker). Having poorer self-related health **was** related to being **less likely** to divorce and the authors suggest that this might be because those with health problems have more to gain from the maintenance of a relationship than its loss. Again, with a functional analysis of relationship gains and losses, the data suggested that in relation to men, unemployment rather than either health status or health behaviours were more significant. We might hypothesise that this indicates the strong impact of gender-based expectations, alongside income realities in workless or low-work households. Socio-economic status may be an important consideration in terms of who enters marriage early and stays in early marriage despite poor health prospects. Cheung and Sloggett (1998) also report from the NCDS and argue that smokers from lower socio-economic backgrounds are most likely to marry young and have less good health prospects than non-smokers from higher socio-economic groups who tend to marry later.

Positive aspects of relationships in the presence of health difficulties within such studies are only very rarely considered. Where they are addressed, it is often in relation to cost/benefit forms of interpretation which may not help us to fully understand interdependent, care-based relationships and the features which support or serve to undermine them. For example, Charles and Stephens (2004) conducted analysis of US panel data and the research was grounded in economic theory. They found that although disability had long-term impacts on economic well being, it did not increase the likelihood of divorce. Job loss did, however, and this was presented here as supporting the hypothesis that job loss (particularly individual lay-off rather than mass redundancy) presented particular evidence concerning the spouse's 'fitness as a mate' (sic). Put another way, however, access to and appropriate adjustments within a work environment may be important ways of supporting disabled people in the context of their relationships.

2.3 Childhood disability and family forms

Families with a disabled child will share many of the same pressures and pleasures of family life as their peers; relationship pressures, separation, divorce and deciding (or not) to have more children are often complex processes and the purpose of our review is to ensure recognition of this complexity is maintained in our analysis and interpretation. Families will vary in how they experience and respond to the needs of a child living with impairment. As explored earlier, this may often be shaped by a range of factors (and not just the type or severity of impairment), including by the families' resources and access to support.

2.3.1 Marital status and childhood disability

Research has explored the ways in which parents respond to a child's impairment, and much of this has concentrated on families whose child is diagnosed before, at, or shortly after birth. Therefore, whilst most **adulthood** impairment is acquired, in childhood and family research there is a particularly strong focus on parental responses to babies'/infants' impairment and less on the impact of later onset. For example, Kulczycki *et al.* (2006) report from US data that the delivery of a very low birth weight child is significantly related to dissolution of marriage (with ten per cent ending by 18 months post-birth, compared to one per cent of other marriages); after 18 months no differences were found in the probability of marriage dissolution.

Fertig (2004), however, has looked at disability in childhood more broadly, using both US and UK data to look at the relationships between child health status (low birth weight and chronic conditions) and the likelihood that parents divorce. Both low birth weight children and children with chronic conditions in the US was related to increased likelihood of divorce, whilst UK data **did not** demonstrate such a link. It is suggested that the presence of a universal health system may itself protect those families with sick children from the risk of divorce. Other differences between the UK and US might also need to be considered (e.g. in welfare access and in social care support) in order to explain these contrasting findings.

A number of studies are beginning to challenge previous findings, suggesting that research approaches have changed and/or that families' experiences of disability are changing. For example, in the US Urbano and Hoddapp (2007) have found that divorce rates in families which included children with Downs Syndrome were no different to other families which included a child with a 'birth defect' and to families where a child has no identified impairment. However, where divorce did occur in the Downs Syndrome group it was more likely to occur during the first two years after birth. Similarly, a meta-analysis of available research on marital satisfaction and divorce in parents of children with developmental disabilities was presented by Risdal and Singer (2004) who found that negative effects on partner relationships are less strong than older assumptions might assume.

Within the UK-interesting work by Hirst (1991) used survey data collected from disabled young people and compared this to a matched sample of non-disabled young people; there was **no** increased risk of living in a one-parent household for disabled young people or any evidence that the type of impairment either increased probability of dissolution or decreased experience of reconstitution.

Current research would, therefore, suggest that any increased risk of separation is most likely during the early stages of parenting a disabled child: this may be linked through to questions of parental adaptation or to issues of accessing supports (e.g. appropriate information, networks, services and so on). Where increased risk of separation and ongoing lone parenthood are identified for families including a disabled child, it is important to ask both what helps parents stay together and

what features of support are important (within both single parent and dual parent households).

2.3.2 Importance of the availability of support

Research by Shapiro (2004) has explored 2000 couples' experiences of relationships through the 'Contact a Family' organisation. Respondents rated **the types of support that did help them in their relationship**, which in order of importance were:

- 1 Time away from the child to be with their partner.
- 2 Ability to communicate openly.
- 3 Sharing the care of the child between the parents.
- 4 Support of family and friends.
- 5 Local and national support groups.
- 6 Lack of money worries.
- 7 Support from professionals (e.g. GP, therapist).
- 8 Work, either staying in or giving up work.
- 9 Having other, non-disabled children.
- 10 Child going to full time school.

Respondents were also asked to state **features not present which could have helped**. These were (again, in order of importance):

- 1 A break or more breaks, or more flexible breaks.
- 2 Emotional support/counselling.
- 3 Support and information around diagnosis.
- 4 Fewer financial worries.
- 5 Help and support from family and friends.
- 6 Professional support.
- 7 Support for the father.
- 8 Recognition of the needs of the whole family.
- 9 Practical help at home.
- 10 Information about services and entitlements.

This research highlights the importance of the range of formal and informal supports and the mix of practical, emotional, informational and material factors which can help families and parent relationships to work well in the context of childhood disability.

2.4 Adulthood disability and family forms

2.4.1 Temporal factors and the impacts of impairment and disability

There are a range of impairment-related factors which are potentially of relevance to our analysis, including temporal features (such as whether impairment is congenital or acquired, existed pre-marriage or occurred post marriage, existed pre-parenting or occurred post-parenting). This aspect is particularly important as different patterns may be identified in relation to entering partnership relationships and/or becoming a parent, as compared to maintaining family roles and relationships.

2.4.2 Impacts of childhood onset illness and impairment: the example of childhood cancer

A significant amount of research has explored the marital status of adults who had experienced childhood cancer. Research in this area has tended to be grounded in medical and cancer literatures (with cancer as an acute health experience), rather than having an explicit disability focus. However, there are some references to the impairment-related and health-related quality of life outcomes of cancer, and to understanding the impacts of the cancer experience in life-span context. This work has consistently found that people who had experienced childhood cancer were as a whole less likely to marry (e.g. Byrne *et al.*, 1989; Pastore *et al.*, 2001; Rauck *et al.*, 1999; Frobisher *et al.*, 2007). For instance, Byrne *et al.* (1989) looked at the marital status of those who had childhood cancer (n=2,170) with siblings (n=3,138) as controls, within a US larger study examining long-term impacts of childhood and adolescent cancer. Their finding, that there was a marriage 'deficit' or gap between survivors and controls, was largely due to the much reduced marriage rate amongst those who had experienced brain or Central Nervous System (CNS)-based tumours; similarly, CNS survivors were also reported to be least likely of all cancer survivors to marry by Pastore *et al.* (2001) and gender differences were found with male CNS survivors having a higher marriage deficit. This work, conducted in Italy, accessed marital status records for 690 sampled childhood cancer survivors, with further additional data received via questionnaire from 485 of this sample. Interestingly, CNS survivors scored lower on a number of measures compared to other cancer survivors, including educational achievement, employment and health-related quality of life. Variation in outcome amongst the cancer survivor population is also stressed by Green *et al.* (1991), who found that many survivors 'achieve' life goals and rather than seek to identify health or impairment groups whose risk of marriage or child bearing is diminished, research should aim to pinpoint specific risk factors.

Using data from nearly 10,000 self-report questionnaires in the British Childhood Cancer Survivor Study, Frobisher *et al.* (2007) report reduced marriage rates among survivors: this research points to those least likely to enter marriage as male survivors, those who had CNS cancer, those who had radiotherapy, those

diagnosed with mental retardation (sic), those who were registered blind, those assessed as having 'low social functioning' (using SF-36) and those with the highest educational attainment (perhaps signalling later marriage patterns in this educational group generally). Interestingly, within this study there was no link found between having been told that fertility was highly compromised and marriage or age at marriage/cohabitation.

Where gender differences are found in marriage rates, this may be due to the different impacts of cancers and their treatment on men and women and/or on impairment effects and gendered expectations of roles and relationships. A number of studies (e.g. Green *et al.*, 1991; Rauck *et al.*, 1999) report that, overall, women child cancer survivors were least likely to marry; findings also suggest that in specific cancer types there are different patterns, specifically that men who had experienced CNS cancers were less likely than women to marry (Rauck *et al.*, 1999; Frobisher, 2007). Rauck *et al.*'s (1999) study reported on findings from research using self-reported marital status from over 10,000 childhood cancer survivors in the US and Canada; they additionally suggested differences by ethnicity as well as gender in relation to both marriage and divorce.

Some key elements are either missing from, or marginal to, much of this literature: in particular, there is a lack of explicit and in-depth reference to long-term impairment outcomes of childhood cancer; and specifically, there is often only limited reference to infertility impairment. What is needed in the context of understanding family formation is some understanding of the psycho-social, as well as physical, implications of some impairments, health conditions and treatments. These issues are increasingly coming to the fore, as more young people survive childhood cancer into adulthood.

Research concerning the presence or absence of specific impairment effects following childhood cancer, suggest that physical impairment alone is not necessarily a marker for marriage differences. Nagarajan *et al.* (2003) looked specifically at bone cancer survivors whose cancer had been within the pelvis or legs. The researchers compared outcomes for those who had experienced amputation and those who had not – and found no difference in marriage rates. However, all cancer survivors were also compared with siblings and this analysis highlighted that additional supports could be beneficial in relation to education, employment and marriage. Further, Punyko *et al.* (2007) in the US context have explored quality of life outcomes and life 'goal' achievements amongst more than 400 childhood cancer survivors, compared with over 2,500 siblings. Whilst there was a reduced rate of marriage amongst cancer survivors, this did not seem to be related to the presence of medical difficulties or impairment, except in an unanticipated way:

'...our analyses showed the curious result that the likelihood of ever being married was increased among those with moderate to severe levels of cancer pain. We are unable to explain this finding, but can speculate that those with pain are more likely to seek a partner to support them emotionally and physically.'

(Punyko *et al.* (2007): 34)

Clearly, such speculation suggests that individuals have an instrumental approach in 'accessing' personal relationships, and would require further research to explore and/or refute. This functional form of explanation may also be a feature of some analyses of partnership behaviour in relation to fertility. For example, Schover (1999) has addressed the infertility impairment issue directly, reviewing the literature to explore the psycho-social impacts of infertility amongst cancer survivors, and explicitly arguing that '[In]fertility may be a real, or at least perceived, factor decreasing a survivor's ability to find an attractive mate'. Importantly, more qualitative research is now being conducted exploring young people's attitudes towards fertility issues (Crawshaw and Sloper, 2006; see also Balen and Crawshaw, 2006). Understanding the experience of potential or actual fertility impairment as dynamic and lifelong, and developing an approach to explore fertility and identity, may support our understanding of support needs in this area.

2.4.3 Experiencing sudden onset of impairment: the example of spinal cord injury

Much research which can help us to examine the impact of the timing of onset of impairment focuses on sudden-onset events, particularly injury. In some respects a focus on this within our discussion could hide the range of experiences of 'onset', (including unclear and/or gradual onset, experiencing impairments which involve remission or recovery periods and so on). With this important caveat, here research with people who have spinal cord injury (SCI) will be used to consider issues of onset in relation to marriage and parenting.

Research conducted in the US by Crewe *et al.* (1979) involved interviews with (and psychological assessments of) 55 people with SCI and their spouses. The findings were that pre-injury marriages were largely less happy than post-injury marriages. Disabled partners who married post-injury were more likely to be in work and were more likely to be assessed as better adjusted and more highly motivated for independence than those whose injury occurred during marriage. The researchers also found that disabled people in pre-injury marriages were most likely to receive support from their spouse: the researchers consider the potential impact of age and health status on marriage, alongside the qualities of those who form relationships post-injury. However, wider factors which might shape how relationships are experienced and conducted, such as the extent to which spouses find caring expectations debilitating for their relationship, and how the experience of this might differ between pre and post injury marriages, are not explored. In later research Crewe and Krause (1992) also suggest that, as a group, those who marry post-injury are likely to differ from those who do not marry.

Overall population and patient sample studies are more descriptive than explanatory and raise questions about the ongoing negotiation of relationships and of disability. From a clinical perspective, one of the approaches to exploring more relational aspects has been to examine patient 'adjustment' and family adjustment to an injury. Whilst such approaches are often considered to identify risk factors and problems within individuals or families, Alexander *et al.* (2002) instead present findings of positive experiences of mothers with SCI and their children. Within this study, the onset of mothers' SCI was before the child was two years old (including before birth) and so does not explore issues of later onset in relation to child age. Whilst the authors acknowledge the sample were perhaps not representative of all mothers with SCI (with higher levels of education, employment and household income), they could conclude that:

'...the presence of maternal SCI does not predict difficulties in children's psychologic adjustment, nor does it lead to problems in areas of parenting satisfaction, parenting stress, marital adjustment, or family functioning. In fact, some evidence suggests that SCI mothers and their partners experience less stress in certain areas of parenting than do their able-bodied counterparts. Partners of SCI mothers, in particular, seem to enjoy more satisfying relationships with their children. Future research might examine the emotional and physical coping techniques used by SCI mothers and their partners that help them succeed in the parenting process.'

(Alexander *et al.* (2002): p 28-29)

Positive experiences of family life in the context of disability are under-represented overall in the literature. However, the research reviewed as part of this study highlights that positive family experiences are often reported by disabled parents and their families.

2.4.4 Experiencing fluctuating and/or unpredictable impairment

As noted earlier, one of the difficulties in exploring the relationship between impairment presence and family forms is the wide range of factors which mitigate experiences of impairment and disability. Perhaps the most challenging one in the context of survey analysis is the experience of changeable, unpredictable and/or fluctuating impairments. For example, some forms of mental distress, multiple sclerosis (MS) and arthritis may sometimes present as being at the forefront of someone's day-to-day experience (because of impairment effects; experience of discrimination or other forms of disability); at other times individuals may see disability as less relevant (or even irrelevant) to their own and their family's day-to-day lives.

It is difficult, from survey data, to unpack the factors involved: for example, Pevalin and Ermisch (2004) have analysed data from the BHPS (1991-2001) to explore the impacts of poor mental health on cohabitations/relationships. They found that mental health difficulties increased the likelihood of relationships ending for men and for women and reduced the likelihood of repartnering. The specific

ways in which mental distress and disability might hinder relationships cannot be read, however, from this analysis and cannot be assumed to be grounded only in difficulties in managing impairment.

Research conducted in the UK with just over 400 people living with MS helps to highlight the range of responses which couples may have to living with impairment and disability: whilst Hakim *et al.* (2000) did not include variability or predictability of MS within their analysis, severity or duration of 'the disease' was not central to the impact of MS on relationships:

The marital status of the majority of patients has not changed following the diagnosis of MS. At the time of the interview 75 per cent of patients were still married, 11 per cent were single, five per cent were widowed and nine per cent were either divorced or separated. This contrasts with an average divorce/separation rate of 13 per cent in the general population in England and Wales in the mid 1980s. Interestingly, some patients and spouses reported that MS was the reason for separation while others believed it was the reason for staying together. There was no association between the severity or duration of the disease and the marital status (Hakim *et al.*, 2000: pg 290).

Within future research work it is likely to be useful to also include variability and predictability of impairment and the implications of these for accessing employment, roles, relationships, services and so on.

2.4.5 Maintaining and changing relationships in the context of impairment

Changing demands of relationships and parenting responsibilities may need to be considered alongside the stability or changeability in impairment-related needs and the availability and appropriateness of supports. Many disabled people and their families will be making decisions and making changes within the same constraints and opportunities which their non-disabled peers face. However, for others, the presence or absence of appropriate support (if required) may play specific roles in the maintenance, or changing shape, of families.

One consideration might be the extent to which couples feel that they are maintaining a partnership role, as contrasted with the development of a carer/cared-for relationship. Resisting 'carer' or 'cared-for' labels may be an important element of maintaining a balanced, inter-dependent relationship, and yet acceptance of or identification with a 'carer' label may be a route to support. This has been explored through interviews with couples (where one partner experiences mental distress) alongside policy and practice analysis by Henderson (2001), who asserts there is often a mis-match between providers and receivers of assessments and services in terms of how relationships are recognised and interpreted.

Finally, there may be a number of routes through which disabled parents feel that they either lose control of, or experience, a reduction in their parenting role. Disabled parents, and particularly parents who have learning difficulties, may be

at particular risk of having their parenting relationship shaped or restricted by the way in which care is delivered or the way in which their parenting is responded to (informally or formally) by professionals. For example, parents with learning difficulties may often experience a range of social difficulties, may find that their parenting is assessed in the absence of appropriate support and may not access advocate support until court proceedings have begun (Tarleton *et al.*, 2006). This highlights the need for support for parents to reduce the risk of crisis situations arising and to reduce the risk of negative assessments occurring where positive parenting can take place. In addition, separation and divorce may place disabled people (and particularly men) at greater risk of losing access to their children; however both these issues (loss of parenting roles; the gendered experience of disabled parents) have been under-researched to date (see Olsen and Clarke, 2003). This study may help to shed light on the significance of different impairments in affecting parental status, and at what point disability affects family status (through separation or reduced probability of forming couples or then having children).

2.5 Conclusions

The research literature relevant to family forms and disability is diverse and includes different understandings of the relationship between impairment, disability, and family experience. This is reflected within the different ways in which disability is operationalised across survey research. Surveys can be used to explore both 'snapshots' and 'stories' of family life, and this needs to be considered in relation to the ways in which different impairment and disability experiences might play a part in shaping family life. The research reviewed here highlights that impairment, health concerns and disability are likely to impact on family experiences of day-to-day life but their relationship to family forms is not a straightforward one.

- There is limited UK evidence available concerning the impact of experiences of impairment and disability on family forms.
- Couples who have a disabled child may experience increased risk of separation during the very early stages of parenting a disabled child.
- A behaviours-orientated health psychology literature has examined the relationships between marriage, divorce and health behaviours: this literature may be relevant to some family experiences but is difficult to transpose to our focus on disability and family forms.
- Social policy research work examining disabled adults as parents and disabled children and their families, provides a contextual base for our analysis, particularly in relation to the dynamics between disability, employment, housing and poverty.
- Impairment-focused research highlights the different issues raised for individuals, families and therefore, policy, in supporting those with stable and those with fluctuating and/or unpredictable impairments.

- Previous research has found a link between families with disabled children and poverty (Emerson and Hatton, 2005).
- Previous literature helps to identify the different types of support parents with disabled children require, to maintain the relationship and through changing forms.

3 Disability and family status

3.1 Introduction

The aim in this chapter is to describe the apparent links between family status and disability. Are disabled people more (or less) likely to be married or divorced or to have dependent children? It is unlikely that there are links between disability and patterns of family formation unless we do uncover links of this kind. To the extent that disabled people have different current levels of marriage, divorce, numbers of children and so on, there is further work to be done investigating the reasons why.

No attempt is made in this background chapter to try to untangle the important conceptual question of cause and effect. If disabled people are more likely to be divorced, then this could be the result of (a) disability leading to a higher risk of divorce or (b) divorce leading to higher rates of disability. Of course, both factors may be acting at the same time – family situation may be both an effect of disability but also a cause.

A further conceptual question concerns the role played by other characteristics – such as income and age. Older people are more likely to be disabled, than younger people. But older people are also more likely than younger people to be married. As a result, there is a danger of concluding that disabled people have high rates of marriage, when in fact the link is due to age. A similar point may be made about incomes. Disabled people have lower incomes than average; lower incomes are known to be associated with divorce. The question we need to understand is how far disability makes an independent difference to family situation, taking such differences into account.

The effect of differences in age is particularly stark if we just consider disabled and non-disabled people in the 2001 Census. It appears that those with a limiting long-term illness (LLTI) are less likely than others to be still single (never-married), only slightly less likely to be married, slightly more likely to be divorced but much more likely to be widowed. Of course these links are mostly the result of differences in age, which is well-known to be associated with disability. Among adults² in the 2001 Census, over half (58 per cent) of those with an LLTI were aged 60 or older. This compares with less than a fifth (19 per cent) among those without an LLTI.

The 2001 Census microdata is a vast sample (1.8m people, or three per cent of individuals). It asked about the health status of each person in the UK, which formed question 13

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

- As may be expected, the likelihood of having an LLTI rises with age and so does the chance of being bereaved. It is unwise to draw conclusions about family status and disability, without first controlling for differences in age. This is perhaps the most important feature of the analysis that follows, in which we look at results **within** age bands where possible, rather than across all ages.

In most of the analysis that follows we look at cohabitation as well as marriage – in other words, at actual living arrangements and not simply formal legal marital status. However, the Census does not ask the questions needed to establish cohabitation, so the emphasis in the next section **is**, unusually, on legal marital status.

² The dataset permits an age cut-off of either 16+ years old or 20+ years old for this definition; we use the latter.

Table 3.1 Disability and marital status, all adults aged 20+ in 2001, and age group

Marital status and age band	Column percentages		
	Has an LLTI	No LLTI	Total
Legal marital status			
Single (never married)	16	29	26
Married (first marriage)	42	48	47
Remarried	8	7	8
Separated (but still legally married)	2	3	3
Divorced	10	8	9
Widowed	22	5	9
Age groups			
20-44	19	55	47
45-59	23	26	25
60-79	41	17	22
80+	17	2	6
<i>Unweighted base</i>	<i>316,209</i>	<i>1,050,898</i>	<i>1,367,107</i>

Source: 2001 Census micro-data. Adults aged 20+.

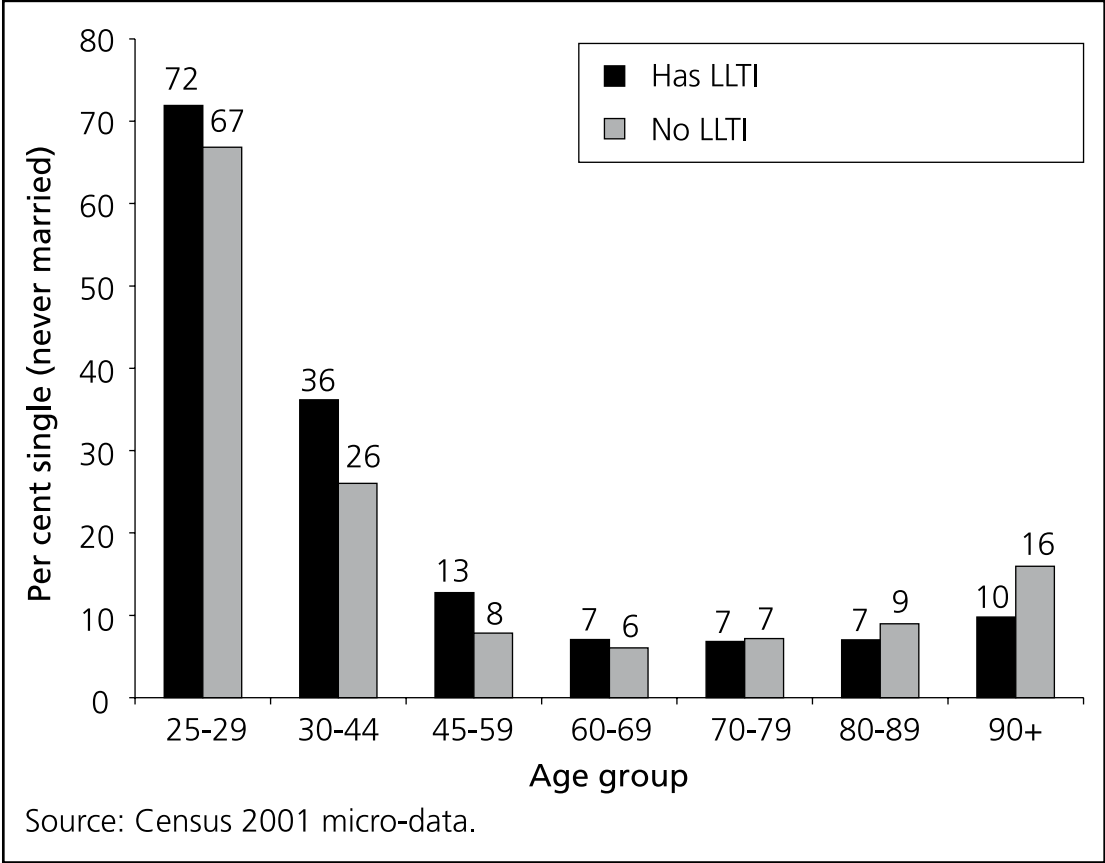
In the following subsections of this chapter, we show that having an LLTI or health problem is associated with:

- a higher proportion remaining single;
- a lower proportion being in their first marriage, or being married at all:
 - a slightly lower proportion are cohabiting;
 differences in the characteristics of the disabled and non-disabled population account for a large part of the disparity in rates of marriage;
- a higher proportion of disabled people being divorced or separated from marriage;
- a higher proportion experiencing bereavement.

3.2.1 Remaining single, never-married

Most people aged under 25 have never been married but in Figure 3.1 we show how many have remained single after this age. For those aged 25-29, and especially those aged 30-44, having an LLTI was linked with remaining single. More disabled people remain single than non-disabled – at least for those aged under 60.

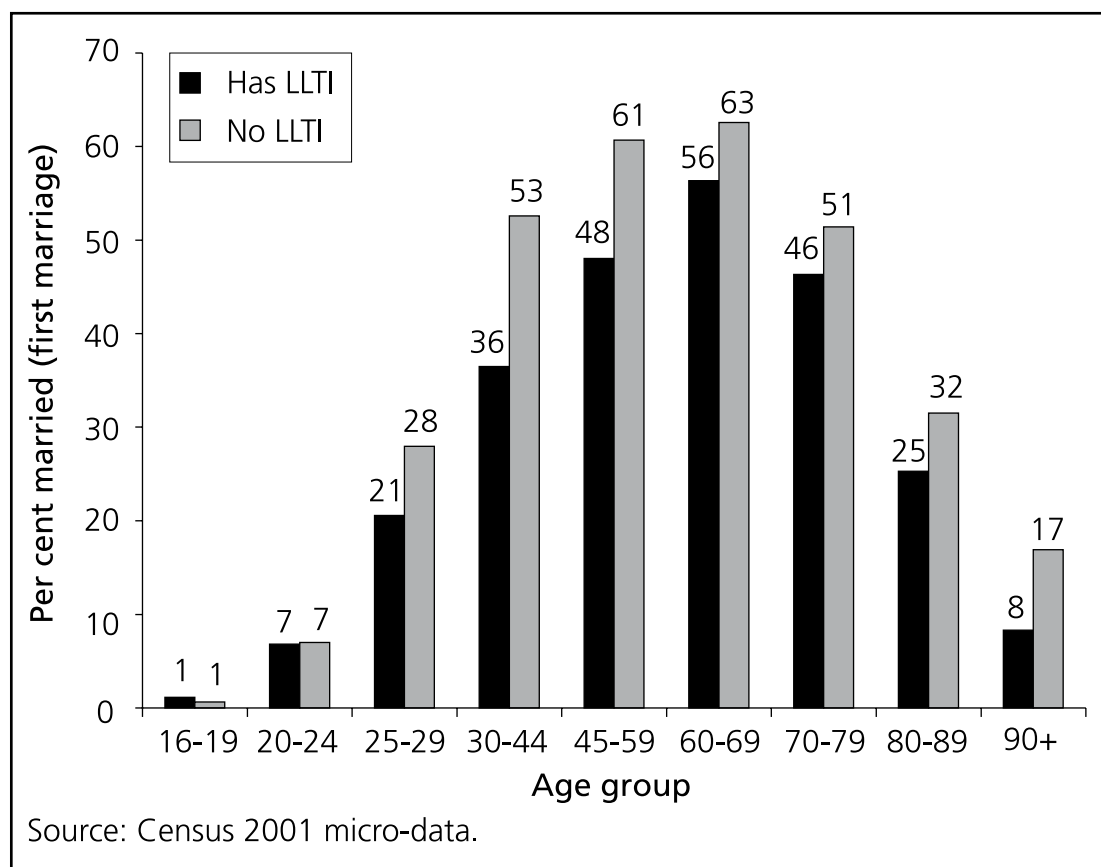
Figure 3.1 Proportion single (never-married) by age group, comparing those with and without an LLTI (aged 25+)



3.2.2 Marriage and cohabitation

As we show in Figure 3.2, for most age bands disabled people are less likely to be in their first marriage than non-disabled. Among those aged 30-44, some 53 per cent of those without a limiting illness were married (and in their first marriage) compared with 36 per cent of those with an LLTI – a gap of 17 percentage points. Among those aged 45-59, some 61 per cent of those without an LLTI were married, compared to 48 per cent of disabled people in the same age bracket. These kinds of differences were also found among both younger and older age groups, though the differences were less pronounced. Among those aged 16-24, where marriage is uncommon, there was no association between disability and being in a first marriage.

Figure 3.2 Proportion married (and in their first marriage) by age group, comparing those with and without an LLTI



It would be useful and interesting to see how disability was associated with rates of cohabitation – living together outside of marriage. In fact this was not recorded as part of the Census data, and for this we must look at an alternative source of data. The Family Resources Survey (FRS) is a suitable source of information, since it asks about disability status and cohabitation for a large sample (about 50,000 adults).

Note: FRS

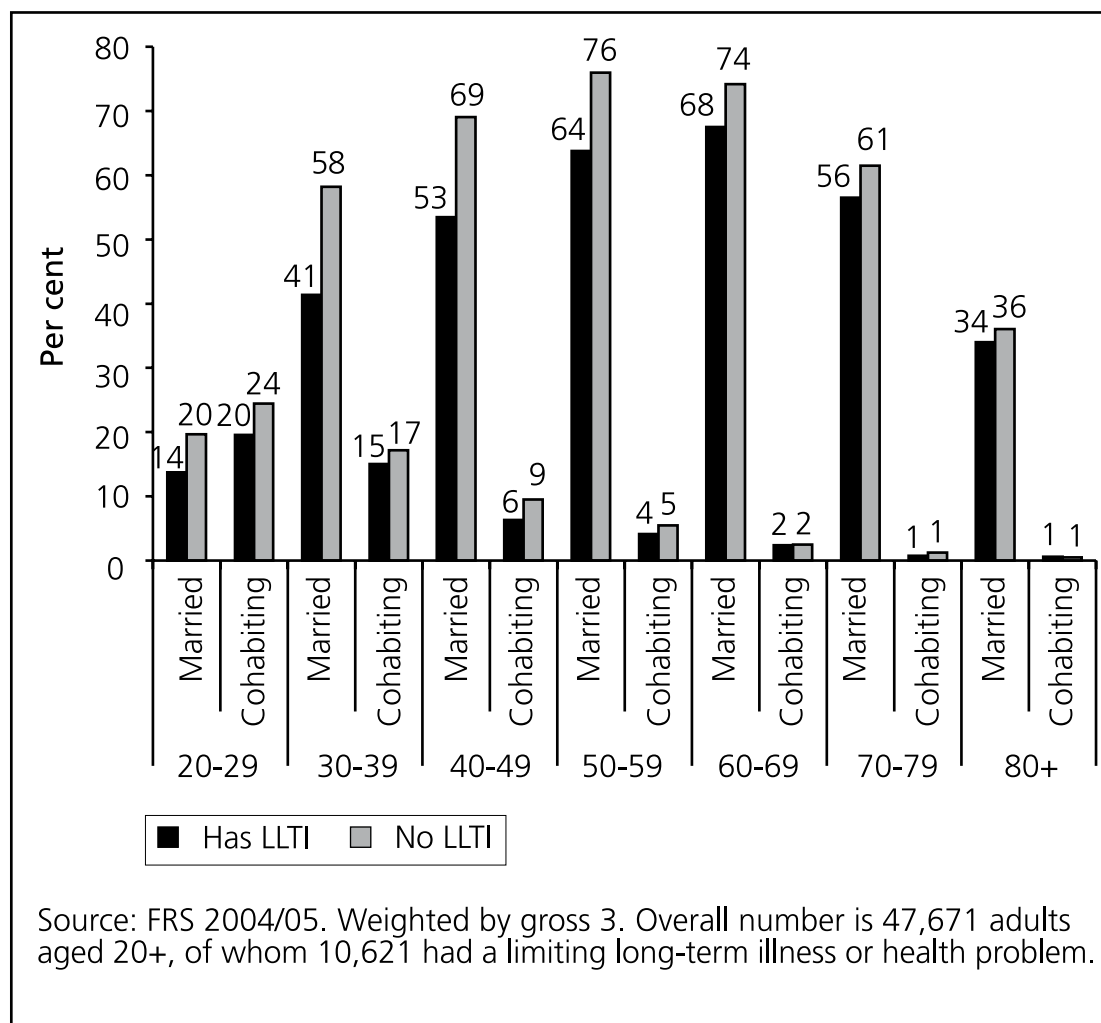
The 2004/05 FRS interviewed about 50,000 adults. The FRS uses a definition of people with a longstanding illness, disability or infirmity and who have a significant difficulty with day-to-day activities. It is funded by the Department for Work and Pensions (DWP) and the principal source of information about incomes and poverty.

Cohabitation is very much an activity associated with younger people. The median age of those married is 51, compared with 32 among those cohabiting and 26 for those remaining single (results from 2004/05 FRS). By comparison divorcees had a median age of 44 and 51 for those separated but not divorced.

In Figure 3.3 we show proportions of people married and cohabiting by age group, looking separately at those with and without an LLTI. These results confirm the earlier picture, of a significant gap in the proportions of disabled people who are married, compared to non-disabled. For example, among those aged 40-49, 69 per cent of the non-disabled were married, compared with 53 per cent of those with an LLTI or health problem. This sizeable gap is consistent with the Census analysis already presented. Are these results repeated for cohabitation or does this offset our findings about being part of a couple rather than living along?

Overall, the effect of disability is **also** to reduce the proportions who are cohabiting. Although the effect looks to be relatively small, this is in the context of a living status that is relatively uncommon, except for those under 40. So, some 20 per cent of those aged 20-29, with a limiting health problem were cohabiting, compared with 24 per cent among other people in this age gap. There was also a two percentage point gap for those aged 30-39 and a three percentage point gap for those aged 40-49 – six per cent of disabled people cohabiting, compared with nine per cent for the non-disabled. These results suggest that any disability disadvantage in rates of marriage is carried over into rates of cohabitation. Controlling for age, disabled people are less likely to cohabit, as well as less likely to be married.

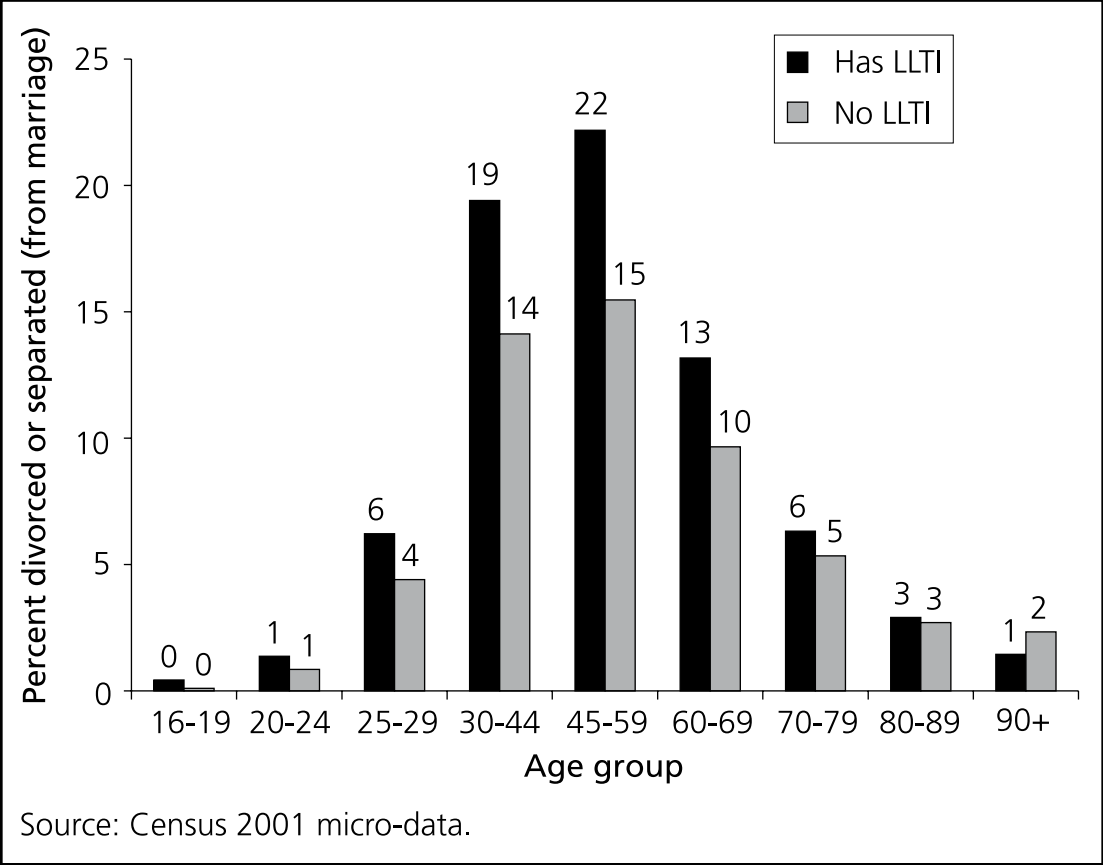
Figure 3.3 Proportion married and cohabiting by age group, comparing those with and without an LLTI



3.2.3 Divorce and separation

Disabled people (those with an LLTI) were more likely than the non-disabled to be divorced, taking account of age. As we show in Figure 3.4, there are sizeable differences. For those aged 30-34, among disabled people 19 per cent were divorced compared with 14 per cent for the non-disabled. For those aged 45-59 there was a gap of seven percentage points, reduced to three percentage points for those in their 60s.

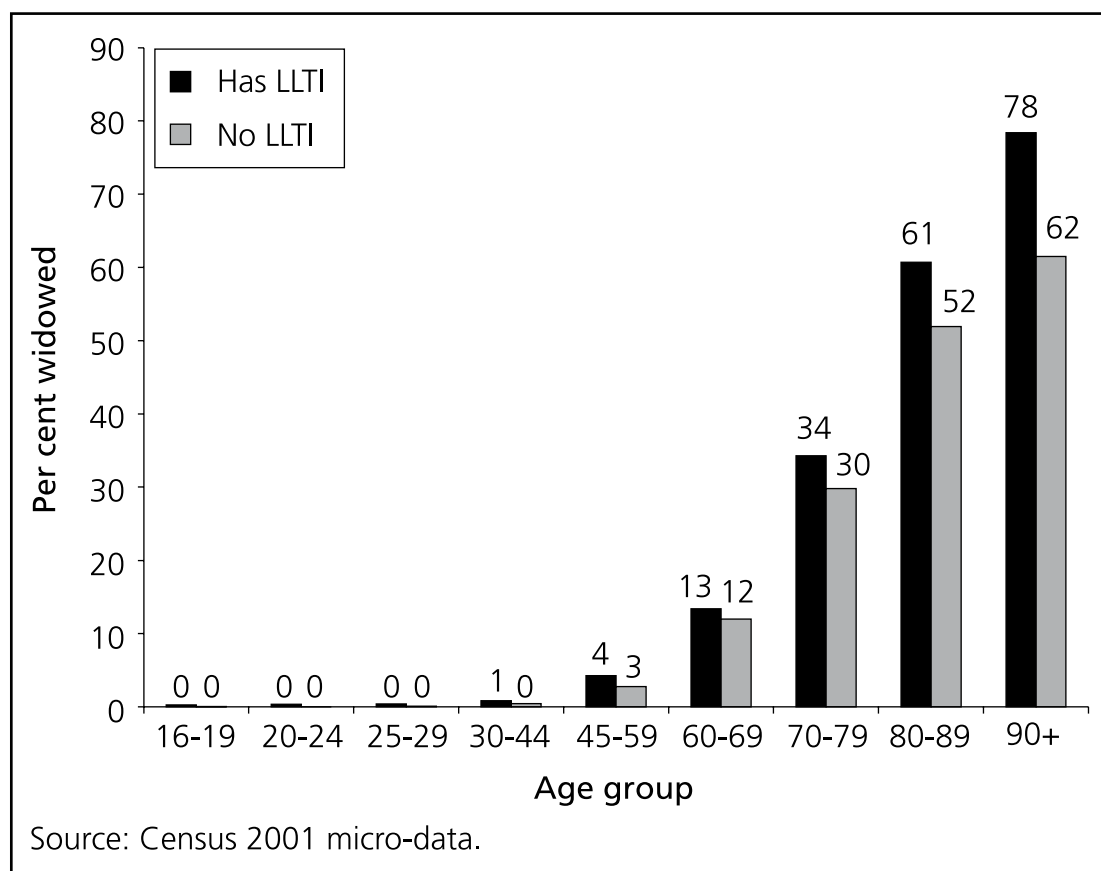
Figure 3.4 LLTI and proportion divorced or separated, by age



In previous sections it has become clear that disabled people are less likely to be married than non-disabled people and more likely to remain single. In this section we saw that rates of divorce and separation **from marriage** are higher for disabled people. Therefore, the large differences in rates of being married appear to be reflecting two distinct patterns: First, a lower propensity to get married among disabled people. Second, a higher propensity for those who do get married to separate and eventually divorce. Of course, disability status is not fixed, but may change over time. It may also respond to changes in marital status. As a result, it is not possible to draw definitive conclusions about the direction of links between family change and disability, at least not from this kind of snapshot analysis.

3.2.4 Bereavement

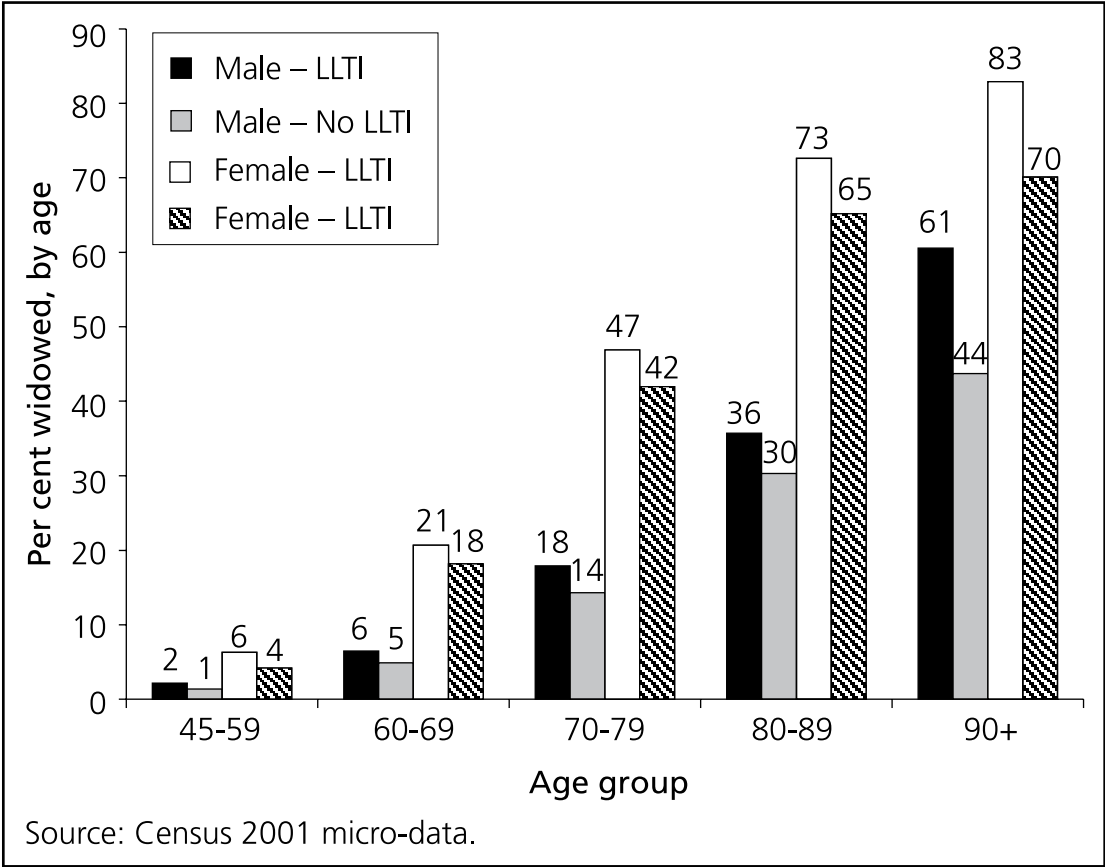
In the interests of showing a complete picture, in Figure 3.5 we show the association between being widowed and having an LLTI. Overall, bereavement is very strongly linked to age (and to gender – women are more likely to lose their partner through death, than men, owing to their longer life expectancies). Controlling for differences in age, those with an LLTI were more likely to face bereavement.

Figure 3.5 LLTI and proportion widowed, by age

Again, it is not clear if this is a cause or effect relationship between bereavement and disability or if some other factor may be driving this association. For instance, reasons relating to those with LLTIs tending to live with others experiencing an LLTI³. To explore this further, in Figure 3.6 we look in detail at those aged 45 or older (bereavement being most uncommon for younger people) by separating men and women. This tends to reduce the differences between those with and without an LLTI, which must be related to the preponderance of women in the older age ranges. Even so, bereavement remains more common for disabled people than non-disabled, controlling for both age group and gender. However, it is only for those older than 90 that this gap exceeds ten percentage points.

³ Married couples share characteristics to a much greater extent than random individuals, including the same housing and environmental conditions.

Figure 3.6 LLTI and proportion widowed, by age



3.3 Exploring the links between marriage and disability

On many measures, married people, on average, do better than those who are cohabiting or living as single. Being married is a sign of a relatively advantaged state – with the possible exception of early marriage. Of course marriage has also been criticised, in terms of the role it may play in enforcing gender-based roles, but it remains the status associated with higher earnings, longer-lived relationships, a lower risk of poverty and so on. It is also likely that this advantage is greater for men than for women.

We have seen that having an LLTI is associated with lower rates of marriage, once we have controlled for important differences in age. The significant link found may be either a cause or effect. Plausibly, disability may be an important cause of changes in family status, as well as a result of such changes – particularly the stressful experience of the ending of a long-term relationship. There may also be important ‘intervening’ variables that account for some of the difference. On average disabled people are poorer than non-disabled people and people living in poverty are generally less likely to be married. So what looks like an effect of disability – or, at least, an association with disability – may be partly or wholly explained by other differences. Such other differences could include lower incomes or being out of the labour market.

3.3.1 Gender and housing tenure

We may label the differences in rates of marriage between disabled and non-disabled people as the 'marriage gap'. This gap appears to be larger for those in middle age, compared with younger and older groups. Early marriage, at younger ages, is less of a marker for advantage. In Figure 3.7 we show that the 'marriage gap' appears to be much larger for men aged 30-44 than for women. However, there are fewer differences among other age groups. If anything, after the age of 50 the marriage gap appears to be larger for women than men.

This is a potentially interesting result. To confirm its importance we replicated the analysis using the 2007 Labour Force Survey (LFS). And the results, shown in the Appendix (Figure A.1), do confirm a larger marriage gap for women than men, above the age of 50.

A second pair of lines on the chart shows the marriage gap among those who own their homes (either outright or buying with a mortgage). Home ownership is a reasonable indicator of relative affluence and the Census has relatively few questions that can be used to measure levels of financial wellbeing. Controlling for tenure in this way (i.e. comparing disabled and non-disabled people living in similar housing tenures), the size of the marriage gaps falls, and indeed the gap is about half as much for many age groups. This strongly suggests that some of the apparent difference in rates of marriage associated with disability may be accounted for by differences in the characteristics of disabled and non-disabled people (such as housing tenure). It is more accurate to say 'accounted for', than explained by, because housing tenure itself may reflect past labour market opportunities and education, which in turn may have been affected by disability status in previous years.

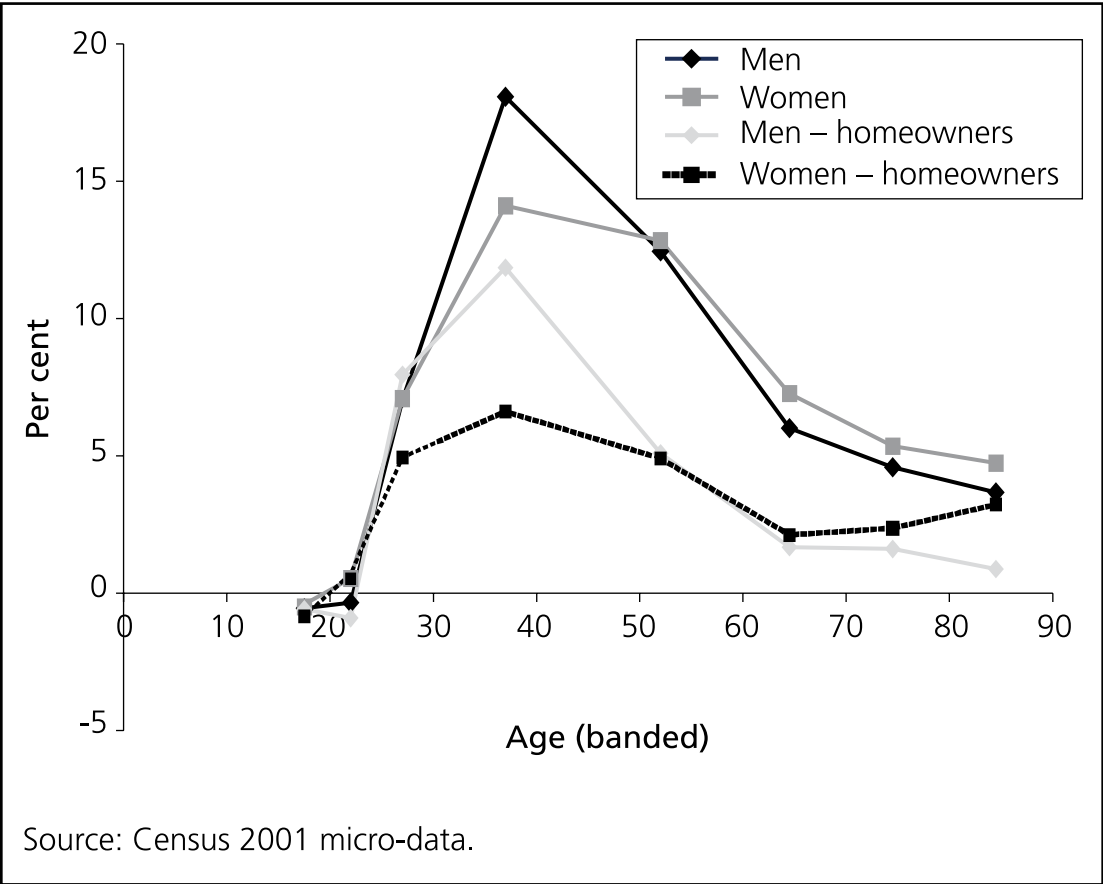
The 'marriage gap' was larger for men than women. It was apparently reduced when looking separately at home-owners, though this may be related to disability through past levels of earnings.

Overall, we may say (on the basis of Figure 3.7) that:

- for those younger than 20, there was no link between disability status and the proportion married;
- for those in their mid-20s, respondents who are not disabled are around five to seven per cent more likely to be married than disabled people of the same age. Controlling for tenure ('affluence') makes little or no difference;
- for those in their mid-30s and 40s, men and women are around 12-15 per cent more likely to be married than disabled people of the same age. The higher proportion of non-disabled married, compared to disabled people, is more marked for men, than for women. However, if we control for housing tenure, then the gap in rates of marriage between disabled and non-disabled people drops by about half. This suggests that the observed differences partly relate to living standards – though of course this may be a reflection of longer-term disability;

- differences in rates of marriage among disabled and non-disabled people persist into later middle age and older age but of a smaller magnitude – about a five percentage point difference for those aged 60+. Again, controlling for housing tenure removes around half of this difference.

Figure 3.7 ‘Marriage gap’ by age and gender, and whether a home-owner (a measure of relative affluence)



3.3.2 Type of impairment (‘health problem’)

Disabled people are, like the rest of the population, a very diverse group. They are drawn from all ages, all regions, all backgrounds. Many analyses of disabled people label them as a separate group but of course there are significant differences between disabled people. That is why we try, where possible, to make comparisons that take account of age group, gender and other different characteristics.

There may also be interest in the links between different impairments and family status. There are a wide variety of different ‘health conditions’ (to use the questionnaire term) – both ‘mental’ and ‘physical’ – that are reported by disabled people to survey interviewers. The Census data mostly used here did not record any information about health, apart from whether a person had an LLTI, and their general health. So, a source like the LFS must be used to consider the effects of a range of ‘health problems’ on marital status.

Note: LFS

The questions used to create a derived Disability Discrimination Act (DDA) measure cover the following:

- Do you have any health problems or disabilities that you expect will last for more than a year?
- Does this health problem affect the kind of paid work that you might do?
- Does this health problem affect the amount of paid work that you might do?
- Do you have...[list of 17 'health conditions'] ; which is main?
- Do these health problems or disabilities, when taken singly or together, substantially limit your ability to carry out normal day-to-day activities? If you are receiving medication or treatment, please consider what the situation would be without the medication or treatment.

We looked at all the health problems that people mentioned, irrespective of whether this was their main health problem. This is the approach recommended by Berthoud (2006: p 36) in his analysis of employment rates. Looking at only the main (first-coded) condition was less effective at explaining differences in employment than taking all the different conditions mentioned.

Results looking at all impairments (health problems) mentioned are shown in Table 3.2. The various health problems are listed in order of proportion of 45-59 year-olds who are married – though the effects are fairly general across all except the youngest age group. Looking specifically at 45-59 year-olds, overall, 72 per cent of those who are not DDA-disabled were married. There are then various groups with much lower rates of marriage:

- a small group of those with learning difficulties (25 per cent married);
- groups where less than half are married, including those with mental illness (41 per cent), depression (46 per cent) and – quite strikingly – those with a speech impediment (43 per cent married);
- a large set of health conditions where 50-60 per cent are married, including epilepsy; difficulty in seeing; skin conditions; chest and breathing problems and those stating they had difficulty in hearing;
- people with a set of mostly physical conditions where over 60 per cent are married, approaching the rate of the non-disabled population. These groups included those listing health problems affecting their limbs, their back, problems with blood pressure and those with diabetes.

Table 3.2 Marriage, disability and health problems, all aged 16+

	<i>Cell percentages</i>					
Rates of marriage	16-29	30-44	45-59	60-69	80+	ALL
DDA-disabled	12	47	63	63	34	53 ¹
Not DDA-disabled	12	60	72	70	38	51
Any health problem of the following kinds (multiple responses)²						
Learning difficulties	3	15	25	[31]	[31]	11
Mental illness, phobia, panics	5	27	41	54	36	34
Speech impediment	2	23	43	55	[45]	34
Depression, bad nerves	11	32	46	54	30	40
Epilepsy	14	41	53	55	[64]	43
Difficulty in seeing	8	45	56	57	27	45
Skin conditions, allergies	9	48	58	60	31	47
Chest, breathing problems	11	50	59	61	34	48
Difficulty in hearing	8	43	59	66	33	51
Stomach, liver, kidney, digestion	13	49	60	62	34	53
Arms, hands	11	46	60	59	29	52
Legs or feet	8	45	61	60	29	52
Back or neck	15	50	62	60	28	54
Other problems, disabilities	9	48	63	64	34	52
Progressive illness not elsewhere classified	19	47	65	71	51	62
Heart, blood pressure, circulation	11	50	66	65	35	59
Diabetes	11	59	68	65	35	61
Total	12	58	69	67	36	52

Source: LFS Q1 2007. Note: numbers in [] are percentages based on fewer than 50 cases and which are, therefore, unreliable. '-' indicates no actual cases in dataset. Overall base size is 95,003 adults with 22,985 having a current DDA disability.

¹ This overall difference – 53 per cent married among the DDA-disabled, compared with 51 per cent among the remainder, is statistically significant at the 0.01 per cent level. It also illustrates how a third variable – age, in this case – can intervene to show a lower rate of marriage within age groups, despite the overall higher rate.

² The rows relate to any health problem or impairment mentioned by the respondent. Therefore, several different impairments could be mentioned by each respondent.

A similar analysis in Table 3.3 looks at rates of divorce, which seems to be more likely among disabled people (see Figure 3.4). These differences are most significant for those aged 30-59. Fewer younger people are divorced (since marriage takes place at older ages) and so are fewer older people (reflecting longer marriage durations). The figures in the table are, again, sorted by the proportion divorced (or separated from marriage) among those aged 45-59, the age group where

the highest proportion are divorced – 16 per cent of those not DDA-disabled and 21 per cent of those who count as disabled under the DDA definition. This high rate of separation in those aged 45-59 is the product of the different life experiences of younger cohorts, as well as the effect of ageing and having been in partnerships.

In general terms, the groups with lower rates of marriage tended to have higher rates of divorce. Rates of divorce were higher among those stating they had depression, or that they had a mental illness. Conversely, those who said that they had health problems relating to diabetes, to the heart to blood pressure or epilepsy – had rates of divorce within each age band that were similar to those without any kind of health problem.

Table 3.3 Divorce, disability and impairments, all aged 16+

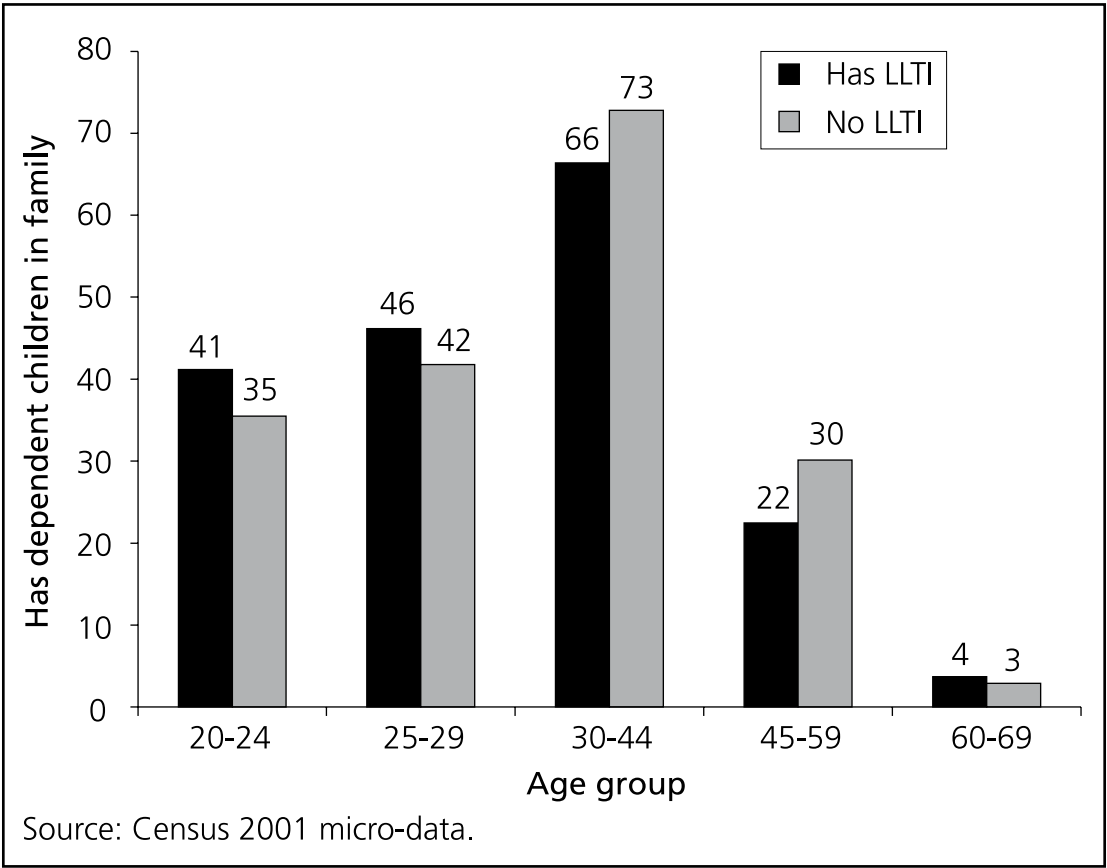
Rates of divorce	Cell percentages					
	16-29	30-44	45-59	60-69	80+	ALL
DDA-disabled	2	17	21	12	4	14
Not DDA-disabled	1	11	16	10	4	9
Any health problem of this kind is mentioned						
Total	1	12	18	11	4	10
Diabetes	1	15	18	10	5	12
Heart, blood pressure, circulation	3	17	19	10	4	12
Progressive illness not elsewhere classified	3	18	20	10	2	12
Other problems, disabilities	2	15	21	12	4	13
Epilepsy	2	13	21	14	[10]	13
Learning difficulties	1	8	22	[19]	[0]	7
Speech impediment	3	5	23	14	[4]	11
Legs or feet	3	18	23	13	5	14
Skin conditions, allergies	3	13	23	14	5	14
Back or neck	3	18	23	13	5	16
Difficulty in seeing	2	12	23	10	4	11
Arms, hands	4	21	24	13	4	15
Difficulty in hearing	1	14	24	9	4	10
Stomach, liver, kidney, digestion	1	18	24	13	4	15
Chest, breathing problems	2	16	25	13	5	14
Mental illness, phobia, panics	1	19	32	19	5	20
Depression, bad nerves	3	22	32	18	5	22

Source: LFS Q1 2007. Note: numbers in [] are percentages based on fewer than 50 cases, and which are, therefore, unreliable. '-' indicates no actual cases in dataset. Overall base size is 95,003 adults with 22,985 having a current DDA disability.

3.4 Disability and having children

Disabled people were slightly less likely than others to have dependent children, for those aged 30-59 but more likely to have children for those aged 20-29. Among those aged 30-44, prime years for having children, where 73 per cent of non-disabled people had dependent children, compared with 66 per cent of disabled people (see Figure 3.8). There was an eight percentage point gap for those aged 45 to 59 years of age, again with disabled people less likely to have dependent children than the remainder of the population.

Figure 3.8 LLTI and proportion with dependent children in family, by age



This lower proportion with children, among disabled people, is perhaps to be expected given the higher proportion who remain single and the lower proportion married (or living as married). These gaps appear to be relatively small and it is possible that further information on circumstances would account for a large part of the gap – indeed the differences in marital status are likely to be strongly associated with the differences in parenthood. However, the gap in rates of marriage is larger than the gaps in the rates of (current) parenthood. This means it is likely that lone parenthood is also playing a role.

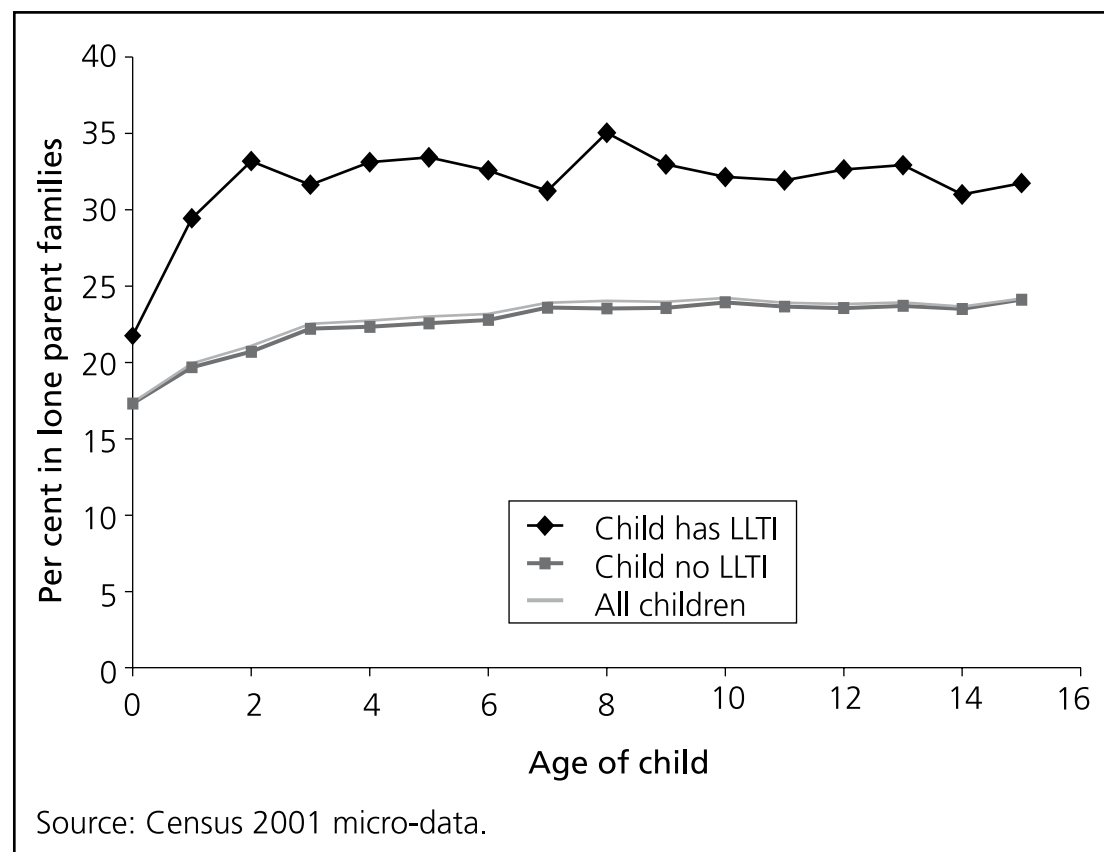
3.4.1 Child disability and lone parenthood

Taken from the perspective of children, those who are disabled are more likely than others to be living as part of a lone parent family. Results are shown in Figure 3.9, splitting children by ages up to the age of 15 years. There is a difference of approximately ten percentage points, meaning that around one-third of disabled children live with a lone parent (overwhelmingly, a lone mother) compared with around one-quarter of other children.

What stands out, in particular are:

- a slightly rising incidence of lone parenthood as children get older, through flattening off at around the age of eight;
- a sharply rising incidence of lone parenthood among disabled children from the ages of 0-2, after which rates of lone parenthood are fairly constant. It is important to investigate this period in a child's life (which fits the data currently available from the Millennium Cohort Study (MCS) covering birth to age three);
- the difference between children with and without an LLTI seems to be smaller for older children – this may also be reflecting a rising incidence of childhood disability being reported.

Figure 3.9 Children living in lone parent families, according to age and whether they (the children) have an LLTI



There is also a slightly greater chance that disabled children will be living in stepfamilies, as well as in lone parent families. Around 14 per cent of children aged ten to 15, with a limiting disability or 'health problem', live in a family where the children are not all biologically those of the two parents, compared with 12 per cent for non-disabled children of the same age. It is possible that some of these children were previously in a lone parent setting.

Table 3.4 provides further details of the family types of disabled and non-disabled children, looking separately at those aged older and younger than ten.

Owing to the very large sample size, there are strong overall links between the presence of child disability and the family's status (whether married or cohabiting or a lone parent). So, in particular, 31 per cent of disabled children under the age of ten were living with a lone mother, compared with 21 per cent for non-disabled children of the same age. The pattern was similar for children aged ten to 15.

Table 3.4 Child disability and parental family status, children aged zero to 15 in 2001

Age of child	Column percentages			
	Child aged 0-9		Child aged 10-15	
	LLTI	No LLTI	LLTI	No LLTI
Lone parents				
Lone father	2	1	2†	3†
Lone mother	31	21	31	22
'Step' families¹				
Married couple – children do not all belong to both	6	5	8	7
Cohabiting couple – children do not all belong to both	5	4	6†	5†
Married couple – children all belong to both	49	60	50	60
Cohabiting couple – children all belong to both	7	9	3	3
<i>Base (=100 per cent)</i>	<i>8,612</i>	<i>213,340</i>	<i>6,871</i>	<i>133,146</i>

Source: 2001 Census micro-data. People aged 0-15. For ages 0-9; chi-sq(7) = 635; p<0.001. For ages 10-15; chi-sq(7) = 371; p<0.001. All rows are statistically significant at the five per cent level when considered in turn, except those indicated by '†'.

¹ Some cohabiting parents would not, of course, qualify as step-parents which formally means that the parent and partner have married.

3.5 Key findings

It is unwise to draw conclusions about family status and disability, without first controlling for differences in age. Among adults with an LLTI in the 2001 Census,

over half (58 per cent) were aged 60 or older. This compares with 19 per cent among those without an LLTI.

After controlling for age, having an LLTI or health problems is associated with:

- a higher proportion remaining single;
- a lower proportion in their first marriage, or married at all. And a slightly lower proportion cohabiting;
- a higher proportion of disabled people being divorced, or separated from marriage;
- a higher proportion having experienced bereavement.

Rates of divorce were higher among those stating they had depression or that they had a mental illness (LFS analysis). Conversely, those who said that they had health problems relating to diabetes, to the heart, to blood pressure or epilepsy – had rates of divorce within each age band that were similar to those without any kind of health problem.

Disabled people were slightly less likely than others to have dependent children, for those aged 30-59, but more likely to have children for those aged 20-29.

Part 2

The dynamics of disability and family formation

4 The dynamics of disability and family change

4.1 Introduction

In this short chapter we provide an introduction to looking at change over time, and particularly the extent of change in disability and family arrangements over time. This provides a key context to the analysis presented in later chapters. The following chapters track the same people over time, to look at changes in disability and family status and how they are related. This approach (and type of data) is more complex than the 'snapshot' pictures presented in Chapter 3 of this report but in principle is capable of providing a richer account of how people's lives develop.

4.2 Year-on-year changes in disability

We may use the Families and Children Study (FACS) to analyse how year-to-year changes in disability status affect family status, including whether couples separate.

Note: FACS

- Started with low-income families in 1999, continued annually, all families from 2001.
- Original 8,000 families followed up, plus new households introduced as they have children (or move to sampled areas).
- Measures, most years, of disability and impairment status using a range of different approaches.
- Detail on outcomes.
- Lends itself to looking at:
 - longer-term effects of earlier changes;
 - child disability issues.

In FACS, the same people are interviewed for several years. The aim is to interview the mother of any children selected from the Child Benefit database – the source for the study. That person is then re-approached in later years and a number of the questions repeated to identify change over time. Questions are also asked of the main respondent's partner – typically, but not always, the father – and the children residing in the family.

Each year respondents are asked if they have a 'longstanding illness, disability or infirmity'. Further questions then identify the effects this may have on daily activities, work and caring. The same questions are asked of partners, and asked about children, with appropriate changes in wording.

In Table 4.1, which combines three tables relating to mothers, fathers and children, we examine the continuity in reports of longstanding illnesses (LSIs) over time, comparing each year of the survey with each subsequent year. In other words, each pair of years is added to give an overall picture of annual change. Taking the main respondent (usually mothers), 70 per cent of those mentioning a disability mentioned it the following year. Conversely, 30 per cent did not. There were similar figures among the children. For fathers, 72 per cent of those citing a disability in one survey said the same the following year – with 28 per cent not mentioning this longstanding condition the following year. These figures show a high degree of consistency but one with considerable turnover from one year to the next. On the basis of this evidence, it is not possible to infer whether the measurement of disability status is a problem, if people genuinely do not regard themselves as disabled in the following year or if a condition is being described that is characterised by considerable fluctuation. All we can say is that a large proportion (approaching one-third) of people who describe themselves as having a longstanding disability will not say the same the following year in response to an identical question.

Table 4.1 Annual transitions into and out of disability – mother, father and children

	<i>Column percentages</i>		
	Status in previous year (of relevant person)		
	LSI, disability or infirmity	No LSI	All
Status in current year – mother			
LSI, disability or infirmity	70	8	21
No LSI	30	92	79
<i>Unweighted base</i>	5,280	19,930	25,210
Status in current year – father			
LSI, disability or infirmity	72	8	23
No LSI	28	92	77
<i>Unweighted base</i>	1,865	6143	8,008
Status in current year – children¹			
LSI, disability or infirmity	70	9	23
No LSI	30	91	77
<i>Unweighted base</i>	59,59	18,791	24,750

Source: FACS waves 3-7, respondents appearing in consecutive surveys.

¹ This table is based on whether any dependent children in a given family have an LSI.

4.3 Year-on-year changes in family status

In this section we consider the speed of change in a person's marital and family status. This is the main 'outcome' that is being investigated in this study, so it is important to consider the dynamics of family change in addition to the dynamics of disability. Table 4.2 shows how quickly couples with children may split and become lone parents – three per cent each year. It also shows the rate at which lone parents form with a new partner (or previous partner) to become couples with children – which is about nine per cent each year. Since there about three times as many couples with children as lone parents, these figures suggest a roughly even balance of family types. Similar numbers of lone parents become couples, as couples become lone parents – among those with dependent children.

Table 4.2 Annual transitions into and out of lone parenthood and being a couple with dependent children

<i>Column percentages</i>			
	Status in previous year		
	Lone parent	Couple with children	All
Status in current year			
Lone parent	91	3	25
Couple with children	9	97	75
<i>Unweighted base</i>	7,147	18,076	25,223

Source: FACS waves 3-7, respondents appearing in all five surveys.

This is a reasonable degree of turnover each year but it may be difficult to find factors that make a large difference to the break-up rates of couples. Previous research has, however, highlighted such key factors as unemployment, financial shocks and cohabitation rather than marriage.

We are also interested in the rate at which people have children and whether disability affects fertility and family size. In Table 4.3 we consider the annual changes experienced in family size. Most families with one dependent child will continue to have one child the following year (82 per cent), but with nine per cent going on to have an additional child, and a similar number will no longer have a dependent child the following year. There was even greater stability of family size among those with three children or three or more.

Table 4.3 Annual changes in family size (number of dependent children)

Column percentages				
	Status in previous year			All
	1	2	3+	
Status in current year				
None	9	1	*	4
1	82	8	1	39
2	9	88	10	41
3+	*	4	89	16
Unweighted base	10,517	10,336	4,370	25,223

Source: FACS waves 3-7, respondents appearing in all five surveys.

We may also look wider at family change, to include those without dependent children. This requires a data source like the British Household Panel Survey (BHPS) which covers all individuals and not only those with dependent children.

Note: BHPS

- Started 1991, continued annually.
- Original 5,500 households followed up, plus new households introduced.
- Measures, most years, of disability status using a range of different approaches.
- Detail on outcomes.
- Lends itself to looking at:
 - annual changes in status;
 - longer-term effects of earlier changes.

Analysis of BHPS serves to confirm the overall picture of marital stability already shown. As we show in Table 4.4, only two per cent of married people cease to be married a year later and only eight per cent of the singles cease to be single (of whom six per cent have started cohabiting and only one per cent have married). There is also considerable continuity for the divorced and bereaved. Four cohabitants in every five (81 per cent) still cohabit a year later and 13 per cent have become married.

Again, this is a picture of continuity over time, particularly in comparing one year against another.

Table 4.4 Annual changes in family/marital status of individuals of all ages

	<i>Column percentages</i>					
	Married	Cohabiting	Widow	Divorce	Separate	Single, never married
Married	98	12.8	.5	2.0	6.8	1.3
Cohabiting	.3	81	.6	5.0	6.7	5.9
Widow	.8	.3	97	2.8	1.2	.1
Divorce	.2	1.3	1.7	89	22.8	.2
Separate	.9	.3	.1	1.3	61	.2
Single, never married	-	4.7	.1	-	1.7	92
<i>Unweighted base</i>	<i>84,982</i>	<i>15,195</i>	<i>11,754</i>	<i>8,139</i>	<i>2,623</i>	<i>29,418</i>

Source: BHPS waves 1-15, respondents appearing in consecutive surveys.

4.4 Longer-term changes

The year-by-year approach provides considerable detail and gives an idea of the extent of turnover. However, it can seem quite piecemeal and miss the bigger picture. An alternative is to, instead, take a series of years and look at respondents in a more ‘holistic’ manner. In Table 4.5 we look at those respondents who appeared in each of waves 2001/05 (waves 3 to 7 of the full survey or waves 1-5 of the FACS survey extended to all families). This provides an alternative perspective on the rate of change over time. So, 64 per cent of families were never lone parents, some 21 per cent were lone parents in all five years and the remaining group were very evenly distributed across different experiences of lone parenthood – from one to four years. Among the main respondents, some 39 per cent had a longstanding illness in one year or more, though only ten per cent mentioned this every single year. There were similar figures among children.

The final column of Table 4.5 shows how often families were in poverty. Only just over half (57 per cent) managed to stay out of poverty in all five years. Conversely, only four per cent of families were recorded as living in poverty in each and every year out of five.

Table 4.5 Changes over five years in family type, LSI and poverty

Column percentages				
Number of years, from the five observed	Years as a lone parent	Years main respondent has LSI	Years when any children had a health problem	Years below 60 per cent median income ('poor')
0	64	61	56	57
1	4	12	14	18
2	4	7	8	9
3	4	5	7	6
4	4	5	6	6
5	21	10	9	4
Unweighted base	4,398	4,398	4,398	2,932

Source: FACS waves 3-7, respondents appearing in all five surveys.

In the chapters that follow, we will draw on approaches that use the year-to-year (or ‘annual transition’) approach to analysing change. We will also look at changes that take place and are analysed over a longer period, such as the five year time elapsed shown above. The Millennium Cohort Study (MCS) is based on having two time points, between two and three years apart, but otherwise is closer to the longer time period style of analysis, rather than an approach based on looking at annual transitions.

4.5 Key findings

Some 70 per cent of mothers citing a disability also mentioned it the following year. There were similar figures among the children and fathers. Each year:

- around three per cent of couples with children split and become lone parents;
- about nine per cent of lone parents form with a new partner (or previous partner) to become couples with children.

Four cohabitants in every five (81 per cent) still cohabit a year later and 13 per cent have become married.

Across five years of interviews with families with children, 64 per cent were never lone parents, 21 per cent were lone parents in all five years, and the remaining group were very evenly distributed across different experiences of lone parenthood. Similarly, only just over half (57 per cent) managed to stay out of poverty in all five years. Conversely, only four per cent of families were recorded as living in poverty in each and every year out of five.

These findings give an overall indication of the rate of change over time in reported disability status and in family type. The following chapters attempt to look at a number of different transitions in detail, with a focus on the implications of disability on family formation and, towards the end of the report, on employment and poverty.

5 Disability and family breakdown

5.1 Introduction

In this chapter we look at rates of family breakdown over time. We start with couples with children, and consider how many split up (becoming lone parents) and how quickly. Differences in rates of family breakdown are then analysed against a range of factors, particularly including disability. The key research question is how far rates of family breakdown appear to be associated with changes in disability and health. We know from Chapter 3 that disabled people are less likely than others to be married; and that disabled children are more likely than average to be living in lone parent families. These bold facts suggest there may be something of a link between disability and family breakdown. But it remains to be seen if **changes** in disability status are the key causal factor, or if there are other key characteristics that operate, or if disability status is itself a response to changes in family status rather than the reverse.

We start with analysis of the Millennium Cohort Study (MCS), which provides analysis of a key time for family change – the first years of a child's life. This seems to be a time when rates of lone parenthood climb rapidly for disabled children, and is therefore an important time on which to place our analytical lens.

5.2 Family breakdown from birth to three years

The MCS provides an excellent opportunity to explore family breakdown from the birth of a child, as that child ages. We saw in Chapter 3 that the proportion of disabled children living with a lone parent is much higher at age two (33 per cent) than when the child is aged less than one (when 22 per cent live with a lone parent).

Note: MCS

- Quite 'medical/clinical-model' in its outlook.
- Only a short time-frame to consider.
- Large sample size for a followed-up group.
- Controls for range of factors, given the similarity of people's situations.

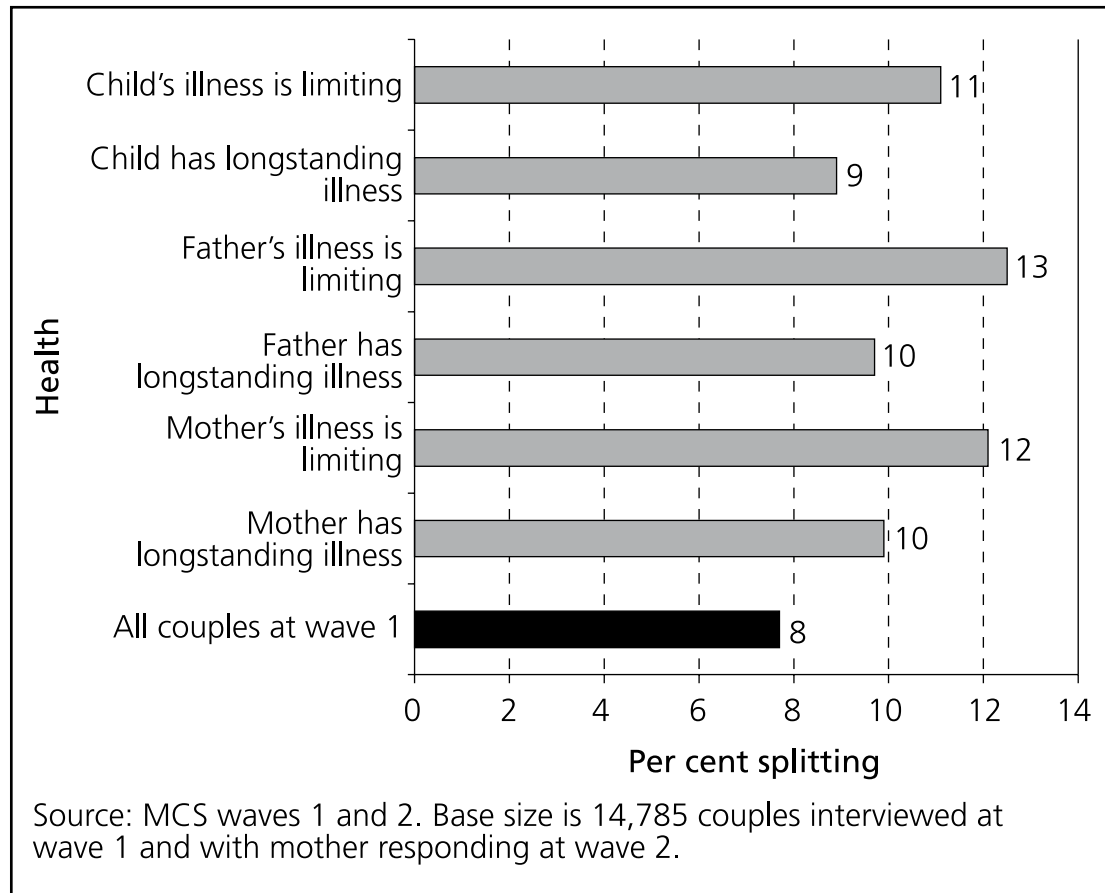
There are different possible explanations for this difference. It could be that lone parents are more likely to report that their child had a disability as that child ages. It could alternatively be a reflection of childhood disability affecting rates of family breakdown.

In Figure 5.1 we show that eight per cent of couples separated between the first two waves of the MCS. Rates of breakdown were significantly higher where there were limiting health conditions, including:

- a 13 per cent rate of break-up where the father had a limiting long- term illness (LLTI);
- a 12 per cent rate of break-up where the mother had an LLTI;
- an 11 per cent rate of break-up where the cohort child had an LLTI.

These all exceed the rate of the general population and clearly would, therefore, exceed that of the non-disabled population – though it would be wrong to read too much into the different rates between mothers, fathers and children. What is also apparent is that the questions that relate to simply having an illness, without further investigation of its effects on life, do not provide much useful information. They appear to increase the rate of break-up compared to the rest of the population, but only marginally. In this instance, by one or two percentage points.

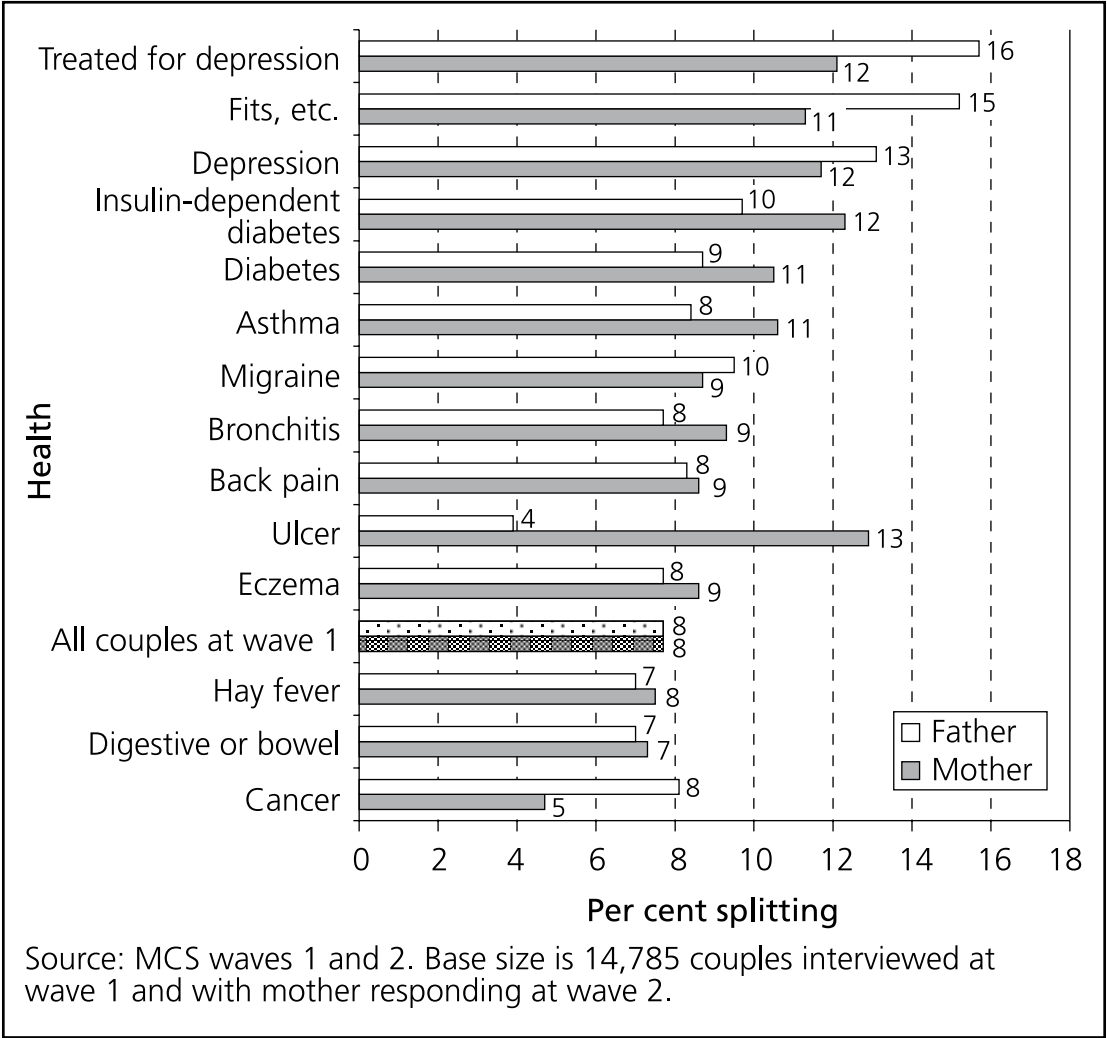
Figure 5.1 Proportion of couples separating, by disability status of mother, father and child



The rate of break-up is also affected by the type of 'health problems' that people mentioned they had and this is illustrated in Figure 5.2. Again, the rate of break-up between the two interviews was eight per cent. This was actually lower or very similar among those who had a diagnosis of cancer (five per cent break-up rates if it was the mother with cancer, still at eight per cent if it was the father); or for digestive or bowel conditions. These did not increase the risk of family breakdown.

The 'health problems' that were associated with higher rates of breakdown were depression (16 per cent if the father had been treated for depression, 12 per cent if the mother had been so treated), having fits and diabetes, particularly if requiring insulin. For many other 'health problems' the risk was higher than for those without but not by a large magnitude.

Figure 5.2 Proportion of couples separating, by disability status of mother and father⁴



To put these figures into some kind of context, the break-up rate between interviews was four per cent among those who were married (at the time of birth) and 14 per cent among those who were cohabiting. These differences in legal status, marriage or cohabitation, have larger effects on the rate at which couples break-up than do differences in health and disability status. At least, they did over the course of the few years between the first two waves of the MCS.

We elaborate on these results in Table 5.1. Results are shown separately for those married and cohabiting at the birth of the cohort child. In all cases the rate of break-up was higher for cohabitants than for married couples, and generally by a substantial margin. The presence of disability among parents or children

⁴ For the mothers in the study all the sample sizes exceed 500 except for fits (n=262); diabetes (224); cancer (106); and for the father, fits (183); diabetes (141); cancer (60); treated for depression (276).

contributed to higher rates of break-up, irrespective of formal legal status. The increase was greatest in terms of percentage points among cohabitants, but from a much higher base.

Table 5.1 Transitions from couple to lone parent (first two waves, MCS)

Group	Cell percentages			
	All couples at time of birth %	Parents married at birth %	Parents cohabiting at birth %	Unweighted base
All couples with children	7	4	14	11,941
Mother with longstanding illness (LSI)	9	5	17	2,507
Mother with limiting LSI	11	7	20	1,104
Father with LSI	8	5	16	2,144
Father with limiting LSI	10	6	19	921
Child with LSI	8	4	16	1,781
Child with limiting LSI	10	5	21	335

Source: MCS waves 1-2. Base size is 14,785 couples interviewed at wave 1 and with mother responding at wave 2.

5.3 Year-on-year changes

As we showed in Chapter 4, there is only a relatively low annual risk that a member of a couple with children will become a lone parent – in fact about three per cent make this change each year. It may, therefore, be difficult to find variables that significantly increase this rather low risk, at least taking each year in turn. In Table 5.2 we show how this annual transition is affected by disability status considered in a static way (i.e. actual disability status) at the preceding wave/year. Then we consider the disability characteristics in a more **dynamic** way, looking at mothers and children who start a spell of disability. We also compare these rates against a range of standard socio-demographic characteristics (being in poverty, being a social tenant, receiving Income Support (IS)) that are associated with a faster rate of break-up. The group receiving IS is a fairly good proxy for worklessness or only having a 'mini-job'.

It seems clear that whilst the disability-related questions are associated with a higher risk of breakdown each year, the size of the difference is quite small. Of course, a sustained higher rate of breakdown may cumulatively become quite a large change over a number of years. But for annual transitions, we are looking at small uplifts in the probability of a couple with children becoming a lone parent family. Perhaps the strongest effect is where children have a disability that affects their ability to attend school (or that it will in future) – with an associated annual break-up rate of 5.3 per cent. The use of the 'dynamic' limiting long-term illness (LLTI) variables did not really add much to the analysis.

The socio-demographic information showed a much greater effect, with a break-up rate twice the average for those in poverty (6.6 per cent) and even higher for social tenants (8.6 per cent) or those receiving Income Support (IS) (a high rate of break-up of 11 per cent).

Table 5.2 Average annual transition rate from couple to lone parent (2001-2005)

<i>Column percentages</i>		
Group	Average annual transition rate %	<i>Unweighted base</i>
All couples with children	3.1	18,863
Static variables		
Mother has longstanding health problem	4.3	3,570
This problem affects work	4.7	1,861
Father has longstanding health problem	3.8	2,515
This problem affects work	4.8	1,443
†Any children with a longstanding health problem	3.8	4,256
This problem affects school (or, will later)	5.3	771
Means extra care needed	4.4	1,693
By way of comparison		
In poverty	6.6	1,723
Social tenant	8.6	2,382
Receiving IS	11.0	692
Dynamic variables		
Mother starts a health problem	4.7	1,137
†Child starts a health problem	3.8	1,211

Source: FACS waves 3-7, respondents appearing in all five surveys.

‘†’ meaning **not** statistically different from the overall average with 95 per cent confidence.

One way of looking at a range of variables all at the same time is to use a statistical technique called ‘regression’. Where the outcome being explained is a simple yes/no (did the couple break-up or not) the most appropriate variant is known as logistic regression. We present some results from such a statistical approach in Table 5.3. This shows, in the upper panel, information relating to having a longstanding health problem. When information about the ‘health problems’ of the mother, father and children are all included, only that of the father is statistically significant. The effects associated with the mother’s health problem, or that of the children, are small and could be due to chance – once the information on fathers is also included. The right-hand column shows, however, that the effect of being in poverty is much stronger. Where a family is in poverty, there was no additional effect of break-up from having a disabled mother, father or child. A

caveat is that this assumes that poverty is itself unrelated to disability, which may be false. Even so, the model suggests that being in poverty is what matters for the risk of break-up, and additional information on the disability status of the family, as measured by a question about longstanding health problems, does not add further information.

It is still an important finding, however, that having a mother with a 'health problem' is significantly linked to the risk of break-up, regardless of poverty.

Disability is, however, usually taken to mean having a health condition that has particular consequences, not merely the presence of an illness or an impairment. So, in the lower panel of Table 5.3 we use data on whether any longstanding health problem affects work. The earlier analysis suggested this would be likely to have a strong effect. And this seems to be true. In a simple model containing only information about limiting health problems, having a disabled mother, father or child was each associated with a higher rate of breakdown, and in a statistically significant manner. After controlling for differences in the risk of poverty, only the disability status of the mother remained statistically significant – and meant that the odds of separation were 1.4 times greater for this group than for those without a disabled mother.

Table 5.3 Logistic regression model of the annual transition from couple to lone parent (2001/05)

Variables in equations	Effects on odds of separating	
	Column percentages	
	Model – disability variables only	Model – with poverty added
Mother has longstanding health problem	1.2	1.2
Father has longstanding health problem	1.3*	1.2
Any children with a longstanding health problem	1.1	1.0
In poverty (below 60 per cent median income)		2.0 **
Mother has longstanding health problem that affects work	1.3*	1.4*
Father has longstanding health problem that affects work	1.4**	1.2
Any children with a longstanding health problem that affects school	1.5*	1.4
In poverty (below 60 per cent median income)		2.0**

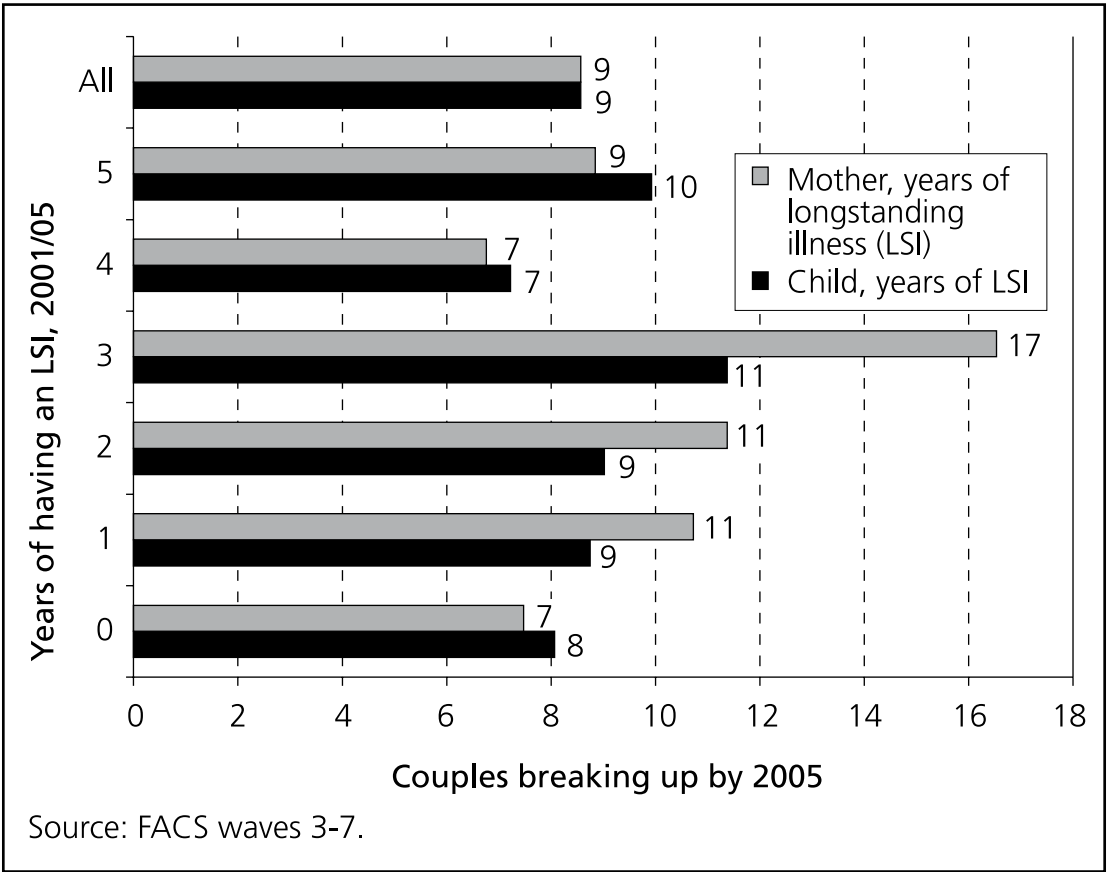
Note: '**' denote significant at five per cent level; '***' denotes significant at one per cent level.

Source: Families and Children Study (FACS) waves 3-7, respondents appearing in consecutive surveys.

5.4 Longer-term effects

Analysis of the FACS survey data seems to show that those with no experience of disability, or who experienced disability in all of the five years observed, were more likely to remain together than those experiencing disability for about three years out of the five. Some results appear in Figure 5.3. It is possible that more transient reports of disability have less effect – and prolonged disability allows for adaptation in a way more difficult for a less predictable condition.

Figure 5.3 Proportion of couples separating, by disability status of mother and child, during 2001-05



5.5 Key findings

Eight per cent of couples separated between the first two waves of the MCS (about 26 months apart). Rates of breakdown were significantly higher where there were limiting health conditions, including:

- a 13 per cent rate of break-up where the father had an LSI;
- a 12 per cent rate of break-up where the mother had an LSI;
- a 11 per cent rate of break-up where the cohort child had an LSI.

The health problem most associated with higher rates of breakdown was depression (16 per cent if the father had been treated for depression, 12 per cent if the mother had been so treated).

The presence of disability among parents or children contributed to higher rates of break-up, irrespective of formal legal status. The increase was greatest in terms of percentage points among cohabitants (from a higher base).

Being in poverty is what matters for the risk of break-up and additional information on the disability status of the family, as measured by a question about longstanding health problems, does not add further information.

After controlling for differences in the risk of poverty, only the disability status of the mother remained statistically significant – and meant that the odds of separation were 1.4 times greater for this group than for those without a disabled mother.

6 Disability, partnering and re-partnering

6.1 Introduction

In this chapter we look at the rate at which single people become couples (using British Household Panel Survey (BHPS)) and lone parents become couples with children (using the Millennium Cohort Study (MCS) and the Families and Children Study (FACS)). As we mentioned, the lower overall rates of partnership (marriage and cohabitation) among disabled people could be reflecting a lower rate of movement into couples ('inflow') or a faster rate of separating from couples ('outflow'), or some combination of both.

In this chapter the BHPS analysis finds an important slower rate of inflow for disabled people moving from being single to forming couples. The rates at which lone parents re-partner, however, are not so much affected by disability considerations, either for them or their children.

6.2 Partnerships for those with and without children

In much of this report we have been concerned with families with children. This section broadens the perspective to look at all individuals and provides analysis from BHPS. As well as a focus on all individuals, not just those who have already had children, the BHPS provides a longer run of data, covering 15 years in all. Data collection began in 1991, and the 15th wave was mostly conducted in 2005, with a few interviews conducted in early 2006.

In any given year, around seven per cent of those on their own will find a partner and become a couple (whether through marriage or cohabitation). This is quite dependent on age group, ranging from about 11 per cent among those aged 20-39, to just over two per cent for those aged 40-59 and under 0.5 per cent for those over 60. These results are shown in Table 6.1. We also find a large difference between those with and without a limiting long-term illness (LLTI). For

those with such a disability, some 4.7 per cent each year find a partner, compared with 7.6 per cent for those who are not disabled. This is a significant difference that sheds considerable light on the differences we found between disabled and non-disabled people in terms of rates of marriage and cohabitation.

Table 6.1 Average annual transition rate from single person to couple (1991-2005/06)

<i>Column percentages</i>		
Group	Average annual transition rate %	<i>Unweighted base</i>
All single persons	7.2	29,301
Has an LLTI	4.7	2,794
No LLTI	7.6	22,057
Aged 20-39	11.0	16,504
Aged 40-59	2.4	3,202
Aged 60+	.4	2,567

Source: BHPS waves 1-15.

Age was also clearly very important to rates of transition from single person to couple. Hence, we analysed results by disability status separately for the younger and middle-aged groups, with results in Table 6.2. For those aged 25 or older, the rate at which single people become couples is rather lower for disabled people. Partnership rates are similar in the early 20s, and disabled people form relationships at a higher rate than average in their teens (though such relationships forged at a young age have higher rates of dissolution).

Table 6.2 Average annual transition rate from single person to couple (1991-2005/06), those aged 16 to 44

<i>Column percentages</i>				
Average annual transition rate (per cent)				
Group, by age	Has an LLTI	No LLTI	All single persons	<i>Unweighted base</i>
All single persons	4.7	7.6	7.2	29,301
16-19	6	3	3	7,028
20-24	10	10	10	8,142
25-29	11	15	15	4,369
30-34	9	12	12	2,410
35-39	4	8	7	1,583
40-44	2	3	3	2,012

Source: BHPS waves 1-15.

A statistical analysis of rates of movement from single to couple found that having a limiting long-term health problem reduced the odds of this happening by 24 per cent, after controlling for differences in age and qualifications or by 28 per cent if we don't control for qualifications.

We may also use the BHPS to consider the longer-term effects of disability. There are a number of ways of approaching this question. We take the following simple route:

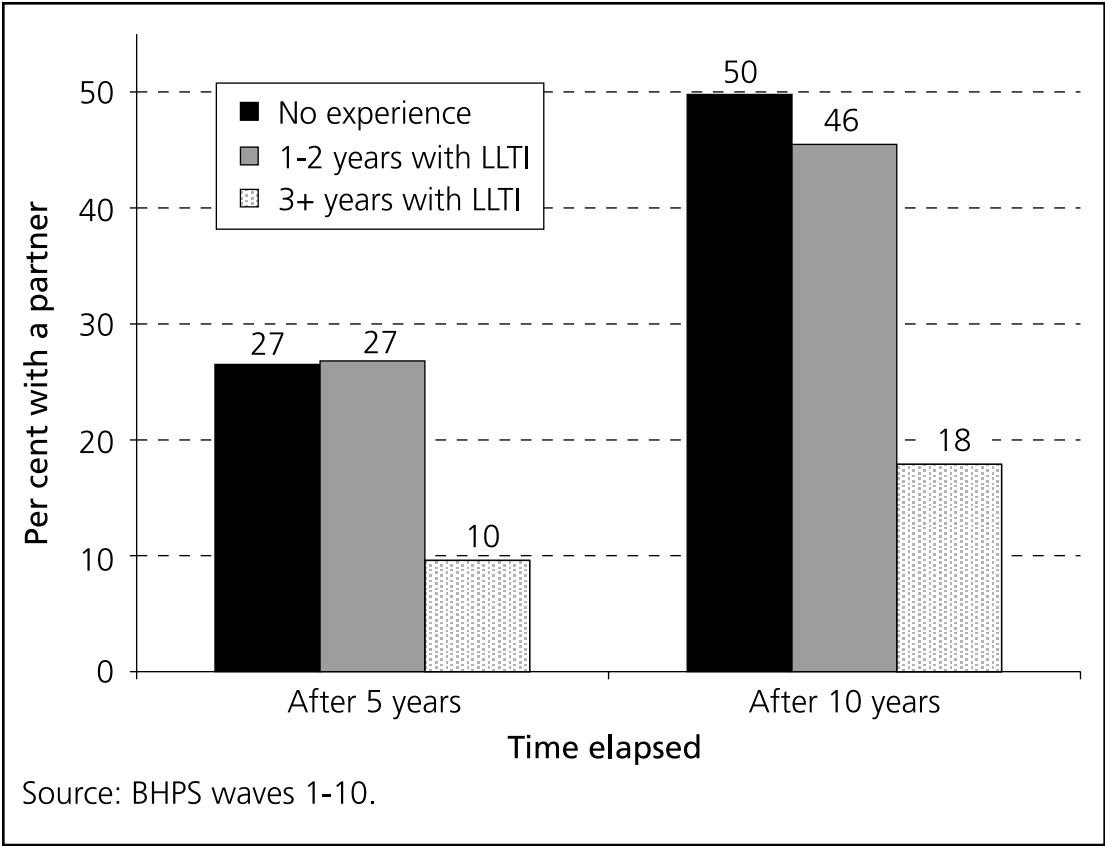
- 1 we identify those single in the first year of the study;
- 2 we explore reports of disability in years 1-5;
- 3 we report the proportions who have formed with new partners after five years, and then after ten years.

Other approaches have the virtue of greater statistical finesse, and may use more of the available data, but this approach provides an accessible way of looking at the effect of disability on later family status.

Taking this approach there are quite stark differences (shown in Figure 6.1). Among those who did not mention any kind of limiting illness in the first five years, after five years 27 per cent were part of a couple and after ten years, half. Where a single person had cited an LLTI in each at least three of the first five years, in only ten per cent of cases had they moved in with a partner after five years, climbing slowly to 18 per cent after ten years.

What is also interesting is that there were few negative effects on the rate of forming couples for those mentioning an LLTI in only one or two of the first five years. As with other evidence presented in this report, where a disability is mentioned in a somewhat sporadic manner, often it appears to have much less of an effect. Conversely, a person does not have to mention such a condition in every single year for it to become significant. Indeed, in some analyses a condition that is mentioned each year may have less of an effect than one that is mentioned in **most** years. And we have speculated about the reasons why this may happen, related to stability and expectations.

Figure 6.1 Proportions of single people becoming couples, by reports of LLTI in first five years



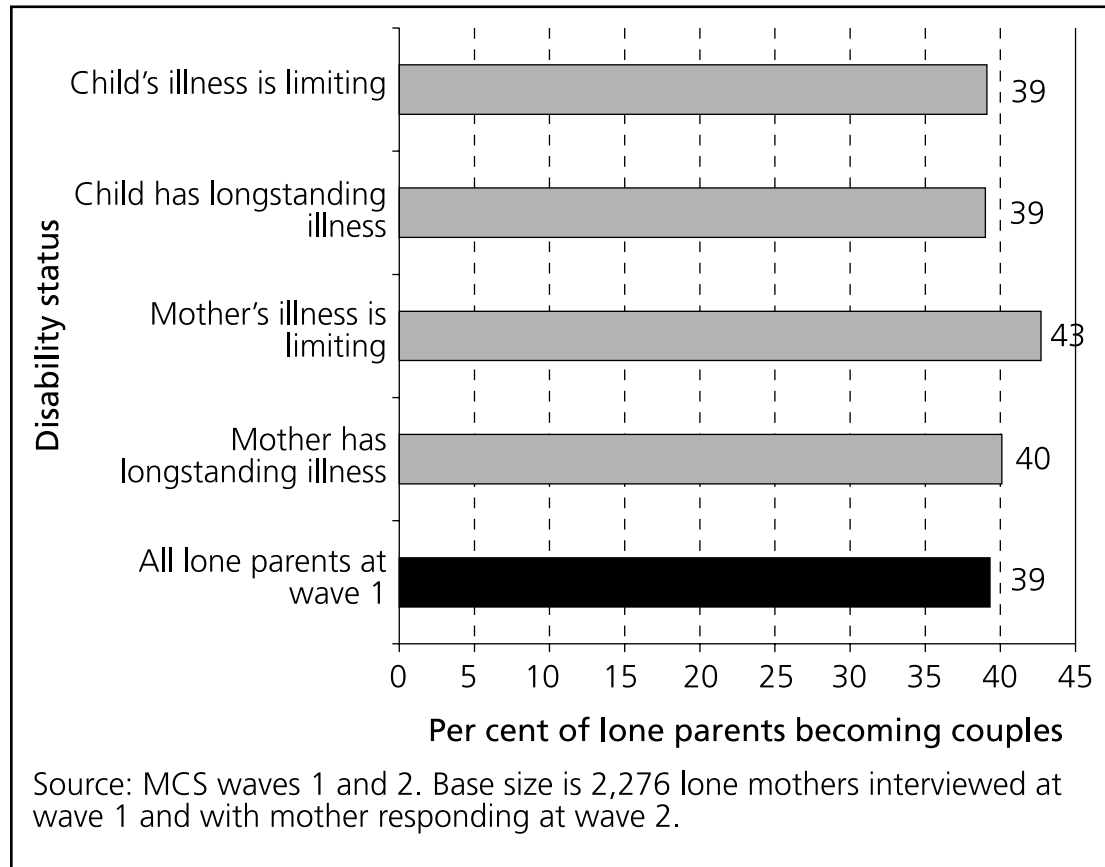
In the remainder of this section we look at lone parents and how quickly they become couples. Some small results are found, but the findings from the BHPS provide good evidence that it is in the rate of movement into all relationships where disabled people fall behind the rest of the population. With the BHPS we are often discussing first and early partners, rather than later partners that will generally be the subject of analysis for lone parents.

6.3 Lone parents becoming couples: birth to three years

The MCS provides an excellent opportunity to explore the rate at which lone parents become couples in the early years of a child’s life. Between the two MCS interviews, a gap of two and a third years on average⁵, close to four in ten of the lone parents formed a new couple unit with a new partner (often, in fact, the father of the cohort child). However, as we show in Figure 6.2, there were only limited links between the disability status of mother or baby and the proportion of lone parents undergoing this significant transition.

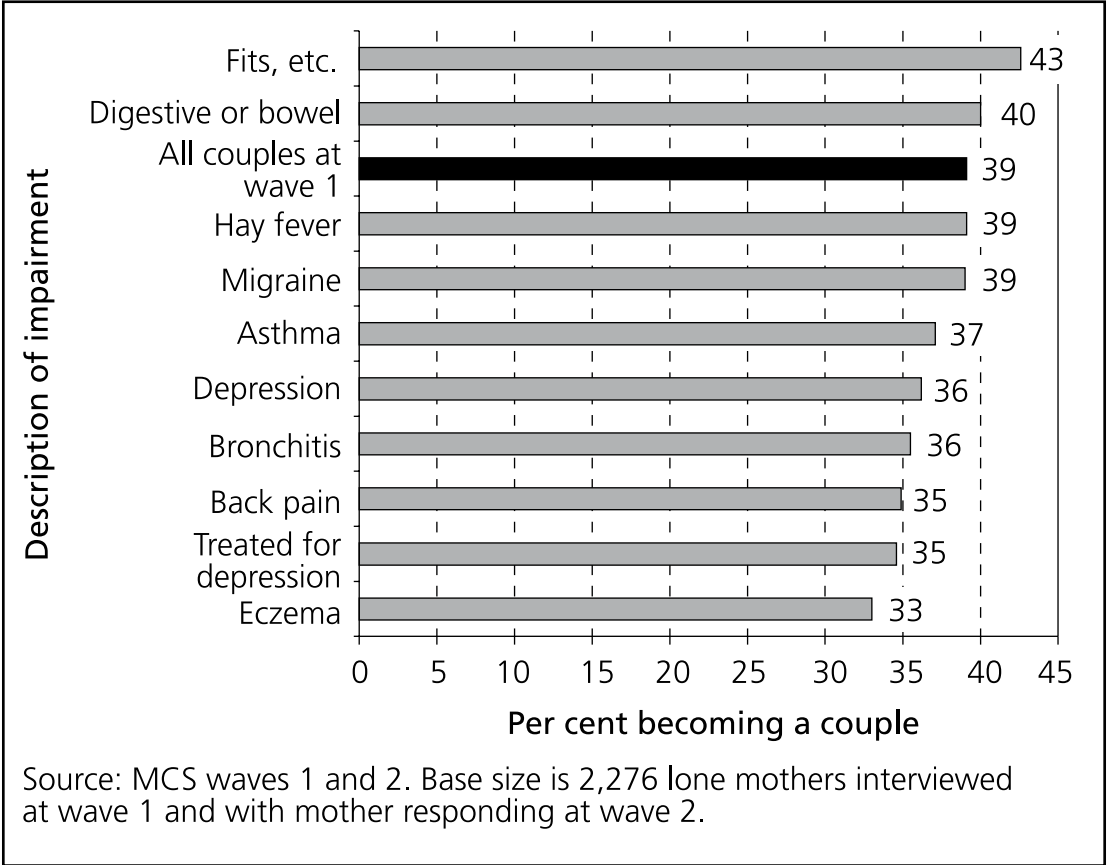
⁵ In fact, 85 per cent of respondents had a gap of between 26 and 29 months between the first two waves of interviews.

Figure 6.2 Proportion of lone parents becoming couples, by disability status of mother and child



We may shed greater light on the effect of disability status on such transitions by looking instead at the kinds of 'health condition' mentioned. Again, we find some differences but a greater range of differences might have been anticipated. As with the broader-brush classification of health status, few differences are worth remarking upon.

Figure 6.3 Proportion of lone parents becoming couples, by mother’s description of ‘health problem’



6.4 Year-on-year changes and longer-term effects

In this section we consider year-on-year changes and longer-term effects but with little progress on the kinds of conclusions reached above. As we showed in Chapter 4 with FACS, there is only a relatively low annual risk that a lone parent will become a couple with children. Fewer than one in ten (nine per cent) make this change in any given year. It may, therefore, be difficult to find variables that significantly increase this rather low risk, at least taking each year in turn. This turns out to be the case (Table 6.3). Of the variables lists, only receiving Income Support (IS) had a statistically significant effect on the average annual transition rate from lone parent to couple.

Table 6.3 Average annual transition rate from lone parent to couple (2001/05)

<i>Column percentages</i>		
Group	Average annual transition rate %	<i>Unweighted base</i>
All lone parents	8.9	6,281
All lone parents with no longstanding health problem for mother	9.1	4,619
Static variables		
†Mother has longstanding health problem	8.3	1,662
†This problem affects work	8.0	1,027
†Any children with a longstanding health problem	8.4	1,657
†This problem affects school (or, will later)	7.6	432
†This problem affects paid work	5.9	382
†Means extra care needed	8.4	824
By way of comparison		
†In poverty	8.6	2,425
†Social tenant	8.6	3,113
Receiving IS	7.6	2,845
Dynamic variables		
†Mother starts a health problem	8.6	488
†Child starts a health problem	10.0	480

Source: FACS waves 3-7, respondents appearing in all five surveys.

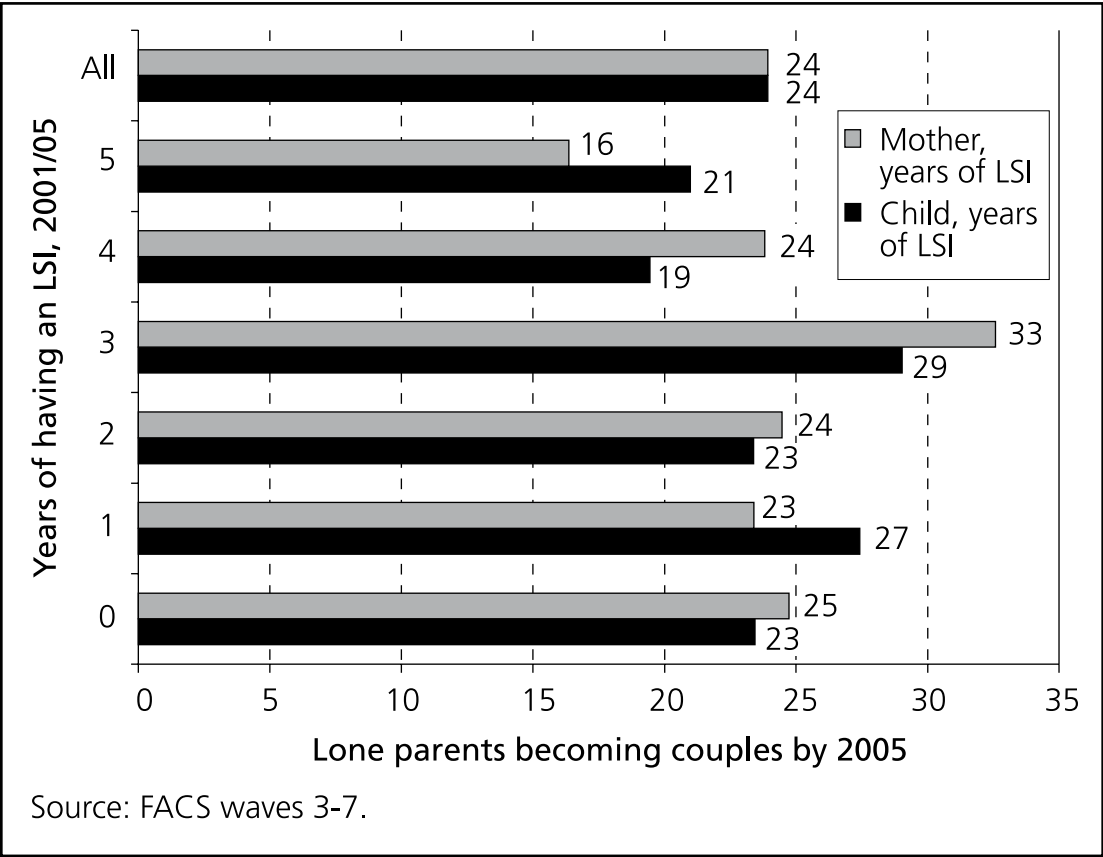
‘†’ meaning **not** statistically different from the overall average with 95 per cent confidence.

A further logistic regression model analysis did not find significant effects of child or mother disability status on the rate of movement from lone parent to couple. This has not been written up in any detail given the lack of success.

We do not find much more of a link between disability and lone parents forming couples if we look over a longer period of time. In Figure 6.4 we plot the percentage of lone parents who became couples during 2001/05. As we saw in the analysis of family breakdown, it is often difficult to discern effects and those with the least change in disability (whether a long period of disability or a long period without disability) appear to display similar traits.

Nevertheless, there are some important differences, where we find an effect of disability on transitions. If a lone mother had five years of longstanding illness (LSI), only 16 per cent become couples during this five-year period, compared to 25 per cent of those with no LSI. However, there was no uniform pattern by years of being disabled.

Figure 6.4 Proportion of lone parents becoming couples, by disability status of mother and child, during 2001-05



6.5 Key findings

Among single disabled people, some 4.7 per cent each year find a partner, compared with 7.6 per cent for those who are not disabled. For those aged 25 or older, the rate at which single people become couples is rather lower for disabled people than for others.

A statistical analysis of rates of movement from single to couple found that having a limiting long-term health problem reduced the odds of this happening by 24 per cent, after controlling for differences in age and qualifications or by 28 per cent if the effect of qualifications is not controlled for.

7 Disability and children

7.1 Introduction

In this chapter we consider links between disability and fertility. How does disability affect decisions about wanting more children and going on to have children?

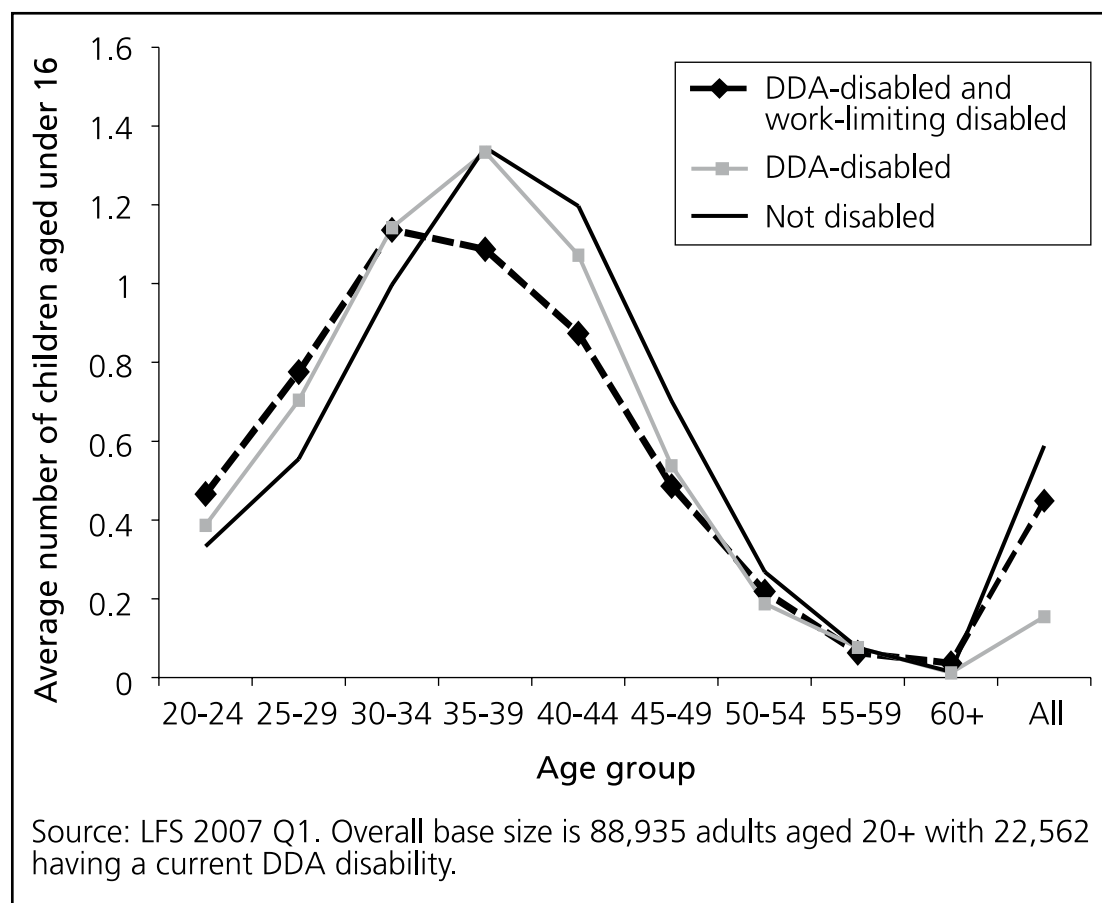
7.2 Background

We saw in Chapter 3 that there was only a limited link between disability and the presence of dependent children. We first review some of the differences in family size between those who are disabled and non-disabled, using evidence from the Labour Force Survey (LFS). This confirms that there are only limited differences in the average number of dependent children according to disability status, after controlling for age. Some results are shown below, including those who are disabled according to the Disability Discrimination Act (DDA) definition, and limiting in the work they can do, those meeting the DDA definition only and those not disabled (against the DDA definition).

Disabled adults aged 20-34 were slightly **more** likely to have dependent children (up to the age of 16) than non-disabled adults. Early parenting is, in fact, often a sign of disadvantage. Once past the mid-30s, disabled people appeared less likely than average to have dependent children. For those aged 35-39 and 40-44 in particular, the gap is quite noticeable – although most of the difference is among those with a work-limiting disability as well as meeting the DDA definition of disabled.

This analysis shows **some** differences between the disabled and non-disabled populations. Slightly lower rates of parenthood overall; slightly higher rates of having children at younger ages. These differences may be related to disadvantage in general. The gap, whilst clear, is of the order of 0.2 fewer children on average, among those age groups most likely to have children.

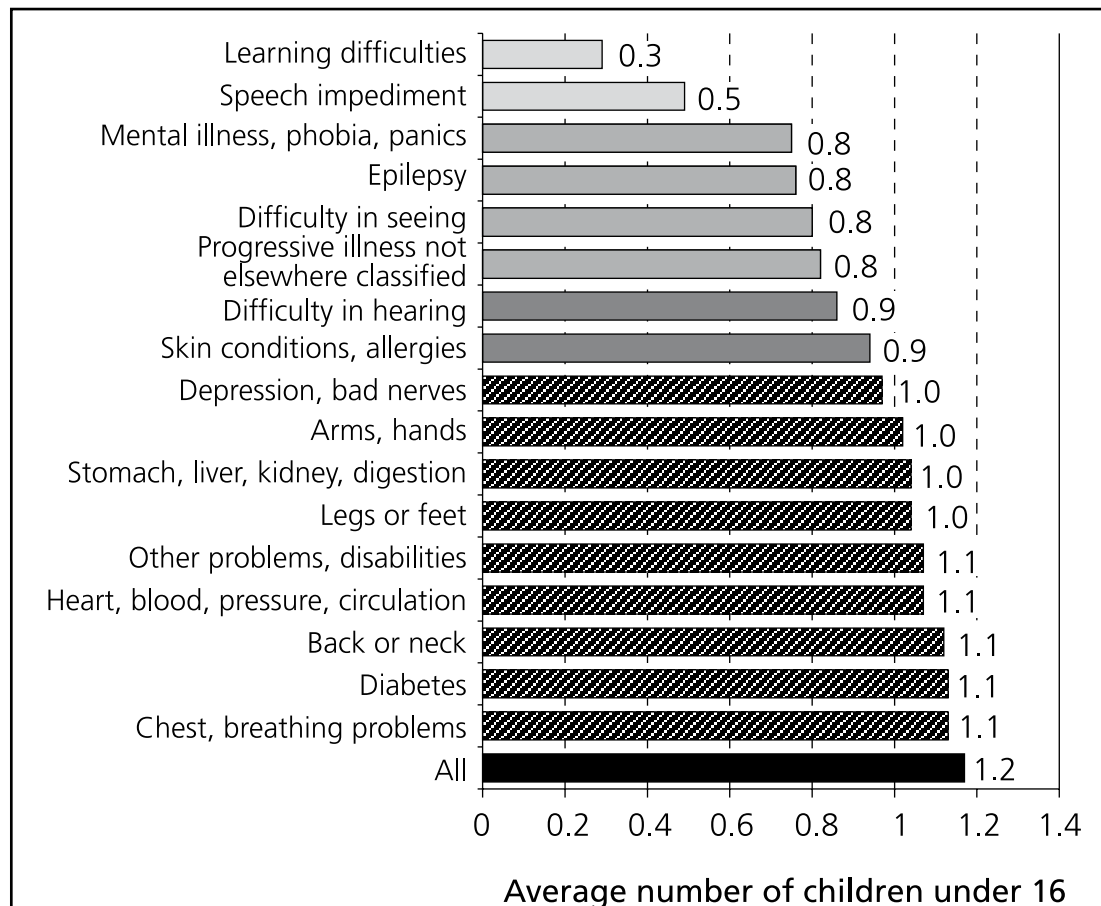
Figure 7.1 Average number of dependent children (aged under 16) by disability and age group



We may also analyse the types of 'health problem' that appear to be most associated with this lower overall rate of having dependent children. In Figure 7.2 we consider those aged 30-44, which are the age ranges where it is most common to have dependent children to look after. We show the average number of dependent children according to different 'health problems' mentioned by respondents.

Overall, people aged 30-44 had, on average, 1.2 dependent children in their families. Among those respondents with a variety of disabilities and illnesses, the number of children was very similar – averaging 1.1 for those with diabetes or with 'health problems' associated with the back or neck, breathing problems or those relating to the heart or circulation. Quite similar to the overall average. However, the average number of children for those with learning difficulties was very low (average 0.3), with a speech impediment (0.5) and for those citing that they had a mental illness, epilepsy or difficulty in seeing (0.8).

Figure 7.2 Average number of dependent children (aged under 16) by type of impairment described in peak childrearing age group (30-44 years)



Source: LFS 2007 Q1. Note: the different shading of bars is to separate different sizes of effects.

Note The unweighted sample sizes reflected in this chart are as follows, with '†' meaning not statistically different from the overall average with 95% confidence:

†Chest, breathing problems [1373];

†Back or neck [1382];

Other problems, disabilities [844];

Stomach, liver, kidney, digestion [694];

Depression, bad nerves [848];

Difficulty in hearing [261];

Progressive illness n.e.c. [237]

Difficulty in seeing [189];

Mental illness, phobia, panics [455];

Learning difficulties [162]

†Diabetes [382]

Heart, blood, pressure, circulation [853]

Legs or feet [1041]

Arms, hands [764]

Skin conditions, allergies [478]

Epilepsy [173]

Speech impediment [63]

7.3 First births – analysis of the British Households Panel Survey

In this section we repeat some of the simple analytical approaches that we used in Chapter 6. We take those without children in their families in 1991, and see how many have children in both 1996 and in 2001 – contrasting the experience of disability in the first five years. This is a simple but powerful application of tracking families over time.

There are sizeable differences in the proportions of different groups, defined by disability status during 1991/95, having children by either 1995 or 2000. For example, by 2000 some 20 per cent of those not mentioning a disability now had children, compared with only five per cent of those who had mentioned a limiting long-term illness (LLTI) in at least three of the first five years of the study.

To some extent these differences reflect differences in age. Older groups are both more likely to have ‘health problems’ and not to have any children. The lower half of Table 7.1, therefore, restricts attention only to those aged 45 or younger in 1991. This helps to remove the concern about age differences affecting the results. The results are again striking. There is now a big divide between those describing a disability in at least three of the first five years and all other respondents. By the year 2000, about four in ten of those without a history of disability now had children – about double the proportion of those who had consistently mentioned a disability. Just to confirm this is after controlling for age (to some extent) by an age restriction; and none of these respondents had dependent children in their families in 1991.

Table 7.1 Those without children in 1991: presence of children in 1995 and 2000 by reported disability in 1991/95

	Disability status during 1991-95			Cell percentages
	LLTI not mentioned years 1-5	LLTI mentioned 1-2 times	LLTI mentioned 3+ times	Base (all)
All respondents: 1995	11	7	2	4,613
All respondents: 2000	20	14	5	3,848
Aged up to 45 in 1991				
All respondents: 1995	22	22	10	1,878
All respondents: 2000	39	37	20	1,659

Source: BHPS waves 1-5 and 10.

7.4 Second and later births – analysis of the Millennium Cohort Study

From the earlier snapshot pictures we may conclude that there seem to be differences in the number of children of disabled people, compared with the wider population. However, this difference is relatively small, apart from those whose 'health problem' is quite rare and specific. In this section we analyse the process of having a second (or later) child, drawing on the Millennium Cohort Study (MCS). We already have good evidence on first births from the British Household Panel Survey (BHPS), where disability (consistently mentioned) does seem to lower the propensity to have children.

Everyone present in the MCS gave birth to a child during 2000/02. Sometimes this was a first child, at other times a second or later child. The common link between respondents means that this is a good source for making comparisons. Their age range is relatively similar and there are fewer issues around timing, since all gave birth at about the same time. There are strong methodological grounds for using a birth cohort study to explore issues of later births and plans for having a larger family.

Nevertheless, there are also problems with using the MCS, which we included in the box in Section 5.2. The perspective was relatively medical, both for the adult and the relevant child. So far, we only have a roughly three-year gap between the two interviews that have taken place. We may see what happens between birth and three years later but not further – with existing information.

7.4.1 Plans to have more children

First we consider how far disability status appears to affect people's **plans** to have more children. When the cohort child was about nine months' old, the parents were asked a number of questions about the development of the child, their own circumstances and future plans. One question asked whether they were planning to have more children in the future. There is a strong connection between plans to have more children and going on to have more children two to three years later. Of those who planned to have more children when interviewed, 47 per cent had an additional child by the second wave some two to three years later, compared with only nine per cent among those not planning to have any more children – and 22 per cent among those who were unsure.

In Table 7.2 we analyse plans to have children by the disability status of the mother, the father (where these details are known) and the cohort child.

There were some effects of disability on the aspiration to have more children but they were relatively small. Where the mother had a longstanding health problem that limited her activities, only 31 per cent were planning to have more children. This is a bit lower than the overall average, of 34 per cent, and this is statistically significant with a 95 per cent level of confidence). The father having a limiting

health problem had a still larger effect – for only 28 per cent of this group was the main respondent expecting to have more children. This compared to 38 per cent where the father was not disabled. In both cases, it is possible that the health of the parent, and the lowered aspiration for more children, is at least partly a result of being slightly older than those without health problems.

The disability status of the child did not really affect the likelihood that more children were planned.

Table 7.2 Plans to have more children and disability status of parents and child (when child aged nine months)

	Whether planning to have more children			Row percentages
	Yes	No	Don't know	Base (=100%)
Child has any longstanding health conditions?				
Yes	33	51	15	2,193
No	35	49	16	11,787
That limit child's daily activities?				
Yes	34	51	15	421
No	33	51	15	1,772
Mother has longstanding health condition?				
Yes	33	53	14	3,064
No	36	48	16	11,025
Mother's health condition is limiting				
Yes	31	54	15	1,404
No	35	51	13	1,660
Father has longstanding health condition?				
Yes	33	52	15	2,109
No	38	46	15	8,431
Father's health condition is limiting				
Yes	28	55	16	921
No	36	50	15	1,186

7.4.2 Having more children

The previous section was about plans for more children. This is important in its own right, as sign of whether people are able to plan and to what extent 'health problems' make a difference. We found that disabled people – particularly in the case of fathers with a limiting health condition – were less likely to be planning more children, although often the differences were not particularly great.

We now turn to the actual outcomes. How far did disability status at the first interview (when a new child was about nine months old) affect whether they had borne further children by the time of the second interview (two to three years later)? Overall, around three families in ten (29 per cent) had a further child before the second interview (see Table 7.3). Lone parents were rather less likely to have had a further child than couples. There were, however, relatively few differences that appear to be associated with disability, at least not in any readily explicable or reliable way. For instance, where a child had a limiting condition, some 31 per cent had gone on to have a subsequent child, compared with 28 per cent overall – statistically significant, though only a difference of three percentage points. This higher rate of subsequent fertility was found only for couples, not lone parents. There is no clear explanation for this difference.

Table 7.3 Disability status (when child aged nine months) and whether had more children three years later

	More children by wave 2			Cell percentages
	All wave 1 and wave 2 %	Lone parents (wave 1) %	Couples (wave 1) %	Base (all)
All respondents	28	21	29	14,416
Child has any longstanding health conditions?	25	21	26	14,414
That limit child's daily activities?	31	19	34	2,238
Mother has longstanding health condition?	25	20	26	14,411
Mother's health condition is limiting	24	18	25	3,091
Father has longstanding health condition?	27	...	27	10,843
Father's health condition is limiting	27	...	27	2,173

Source: MCS waves 1 and 2.

7.5 Key findings

Older groups are both more likely to be disabled and not to have any children.

Disabled adults aged 20-34 were slightly **more** likely to have dependent children (up to the age of 16) than non-disabled adults. Early parenting is, in fact, often a sign of disadvantage. Once past the mid-30s, disabled people appeared less likely than average to have dependent children. For those aged 35-39 and 40-44 in particular, the gap is quite noticeable.

8 Consequences for employment and poverty

8.1 Introduction

In this chapter we consider the different effects of changes in disability and family status on some key outcomes, including consequences for poverty and employment.

8.2 Current rates of family poverty

Perhaps surprisingly, there is little relationship between a mother or child having a longstanding illness and rates of family poverty. Here we measure poverty in the same manner as the Households Below Average Income (HBAI) statistics, as having an income below 60 per cent of median equivalised family income⁶. In Figure 8.1 we show results based on mothers' disability situation and do the same for children in Figure 8.2. In each case results are contrasted by family type and working arrangements, which are among the main correlates of being in poverty.

Workers are much less likely to be in poverty than non-workers and dual earners least likely. Even so, there are still lots of families living in poverty who do have someone in paid work.

Overall about one in six families (17 per cent) were measured as being in poverty in 2005 where the mother didn't have a longstanding illness – see Figure 8.1. This approached one in four (23 per cent) where the mother had a longstanding

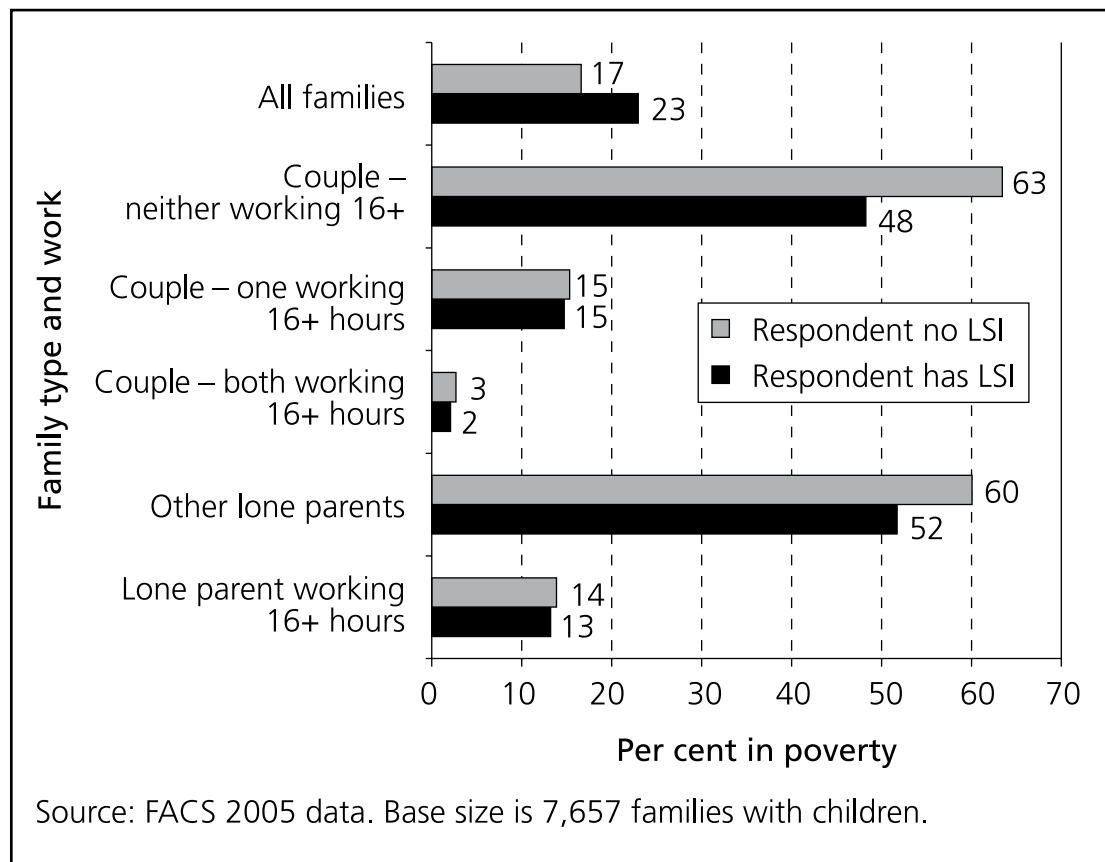
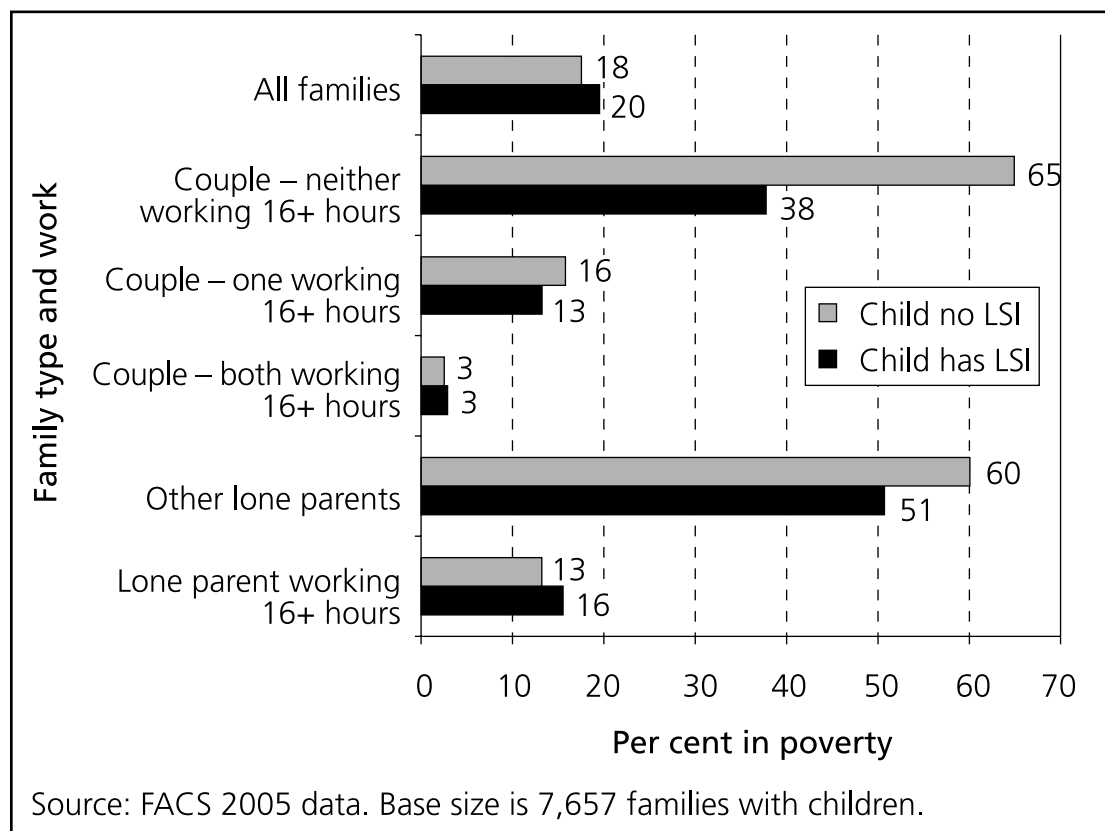
⁶ In fact the measure used to identify poverty in Families and Children Study (FACS) is adjusted so that it gives the same number of families with children in poverty as do calculations based on the Family Resources Survey (FRS). In practice this means a slightly different income cut-off, which reflects sampling error, differences in survey timing and differences in the way the information is collected.

illness (LSI). This difference arises because (as we later show) where the mother had an LSI the family tended to have fewer people in work. Controlling for work status, having an LSI made no difference to rates of poverty. In fact, for those out of work having an LSI was associated with a lower risk of poverty, both among couples and lone parents. However, this difference is mostly explained by the additional cash benefits available for disabled people and for disabled children. In the calculation of income for measuring poverty, disability benefits count as higher incomes, with no adjustment for higher needs or costs that the receipt of such benefits implies. However, overall the additional cash benefits may not cover the extra costs of disability.

The results considering child disability status had certain similarities to these patterns. There was little difference in rates of poverty where any child had a longstanding illness (20 per cent) compared to where they did not (18 per cent). If we take into account differences in working status, this difference in rates of poverty generally vanished, and in many cases having a child with an LSI meant a lower rate of poverty. To take the clearest example, where couples had no-one working 16+ hours the rate of poverty was 65 per cent where all children were free of any LSI but 38 per cent among those where a child had an LSI. However, since disability is strongly related to employment status the 'raw' results, not controlling for work status, may be more valid.

These results suggest that it is the effect of disability on rates of employment that is most worthy of study. **Overall** rates of poverty reflect any differences in numbers in work and in the balance between lone parents and couples given the higher poverty rates of the former group. After allowing for these differences in family size and employment, having a disabled mother or child did not mean any increased risk of poverty. Much of this report has looked at the effects on family size and type, so later in this chapter we consider differences in employment.

Some of these results do suggest a considerable difference in numbers in poverty for whether mother has an LSI or not.

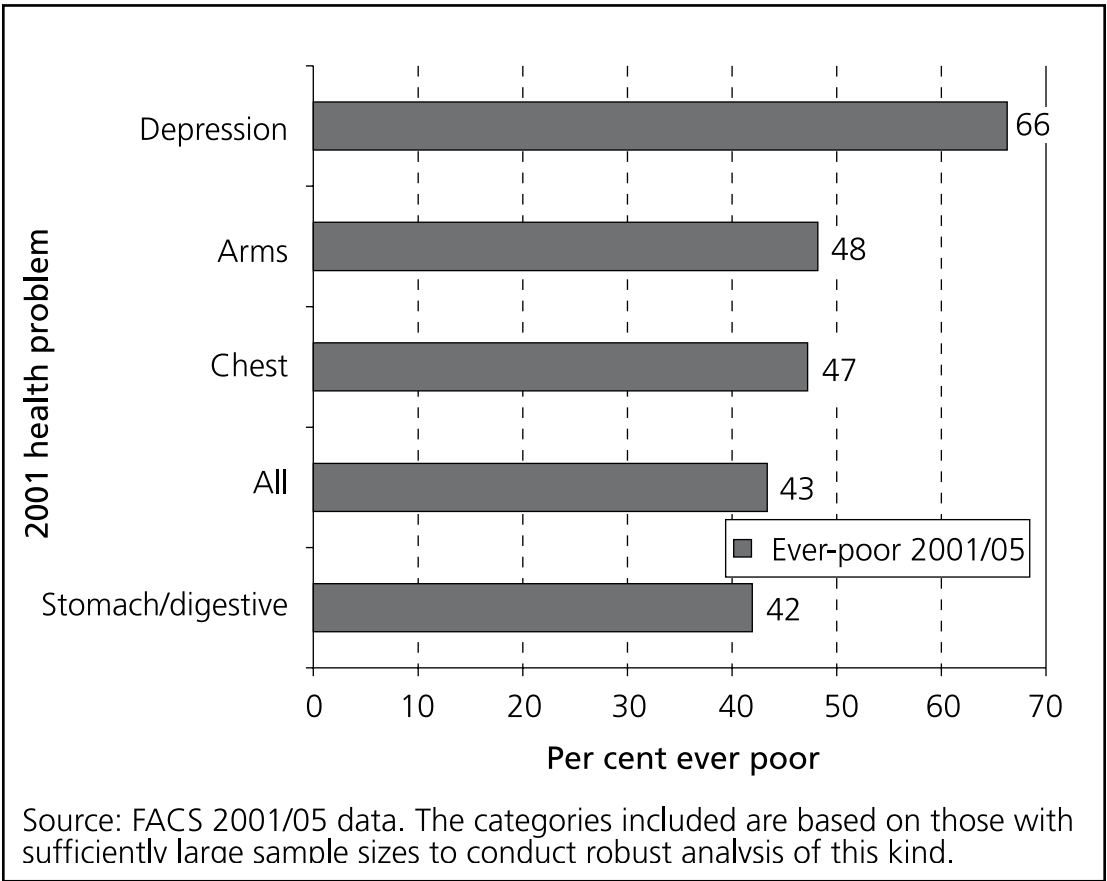
Figure 8.1 Poverty rate, by mother disability and family type**Figure 8.2 Poverty rate, by child disability and family type**

8.3 Poverty dynamics

The previous section looked at poverty at a particular point in time. In this section we broaden the perspective to consider poverty across a five-year period. This is something we mentioned in Chapter 4 of this report. Overall 43 per cent of FACS families were in poverty at least once during 2001/05. The only type of ‘health problem’ to significantly increase this proportion was for those citing ‘depression’, among whom, two-thirds (66 per cent) had at least some experience of poverty during this period (Figure 8.3). Other more ‘physical’ types of impairment did not change the extent to which people were income poor during this period or increased it only by a small proportion.

It remains true, of course, that there is also a reverse link between depression and poverty, i.e. not only might the experience of depression have long-term effects on economic activity and access to sustained employment, also living long-term on low incomes can increase risks of experiencing depressive symptoms and mental distress. It is not easy to work out what is ‘cause’ and what is ‘effect’ – whether poverty causes depression or depression causes poverty. Even if we could identify which was reported first, it is also possible that the **anticipation** of either poverty or depression might be driving the other, despite the apparent timing of when each occurred.

Figure 8.3 Poverty rate over time (‘ever-poor’) by type of adult impairment

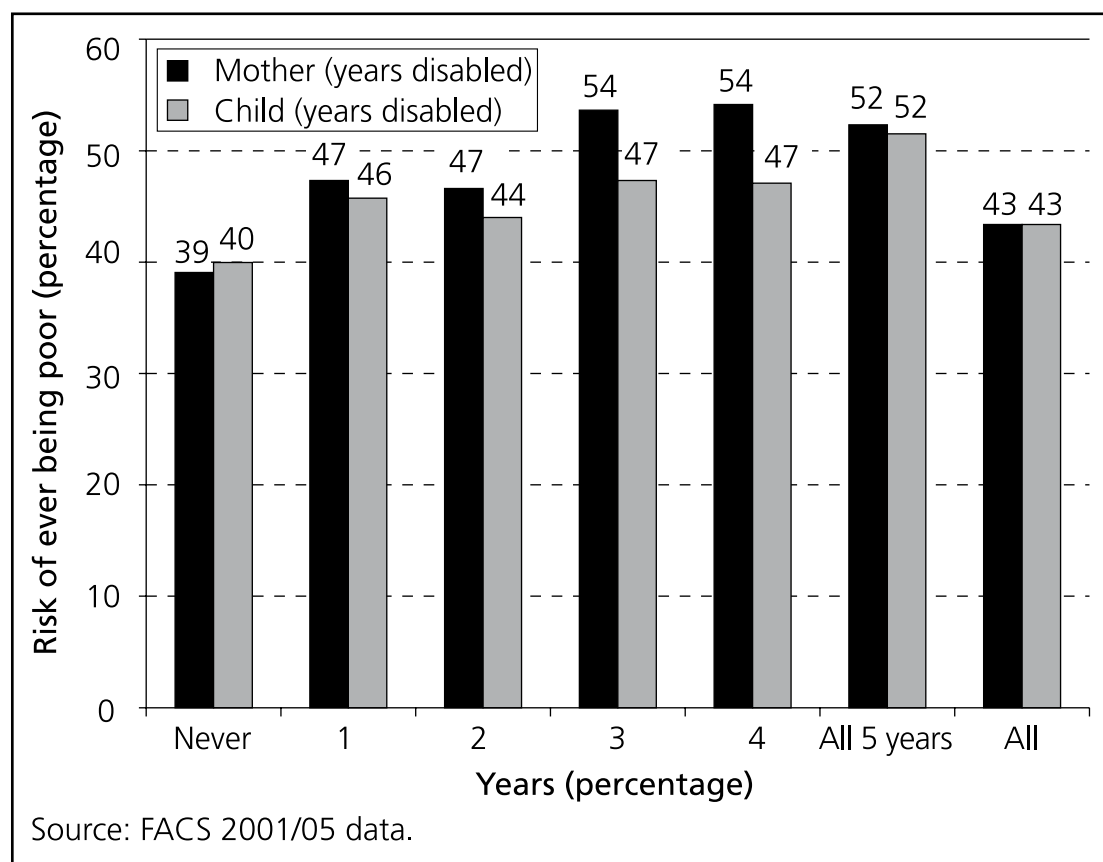


8.4 Child poverty dynamics

We saw previously that having a child with an LSI made relatively little difference to overall poverty rates and probably none at all after controlling for differences in family status and work profile. In this section we broaden the perspective to consider having ever been in poverty over the period observed within FACS.

The likelihood that a family had ever been in poverty was greater, the more years during which either a child or the mother-respondent said that they had an LSI. Risks of ever having experienced poverty were greatest where a child had such an impairment during five consecutive years (where it was 52 per cent) and lowest when no such condition was reported (where 'only' 40 per cent experienced poverty at least once, see Figure 8.4). The effect of mothers having an LSI was at its highest if such a condition was reported in at least three years out of five, and no higher if the LSI was reported more often than this.

Figure 8.4 Poverty rate over time, by duration of mother, child disability



Another reason for the lack of a strong link between current child illness and current poverty rates concerns the effects of children having an LSI in the past and the rate of transitions either into or out of such conditions. Where no LSI was reported among children, this conceals an important difference between families

where this was reported in the past and those where a child illness has never been reported.

So, among families where no child is reported to have an LSI the poverty rates are:

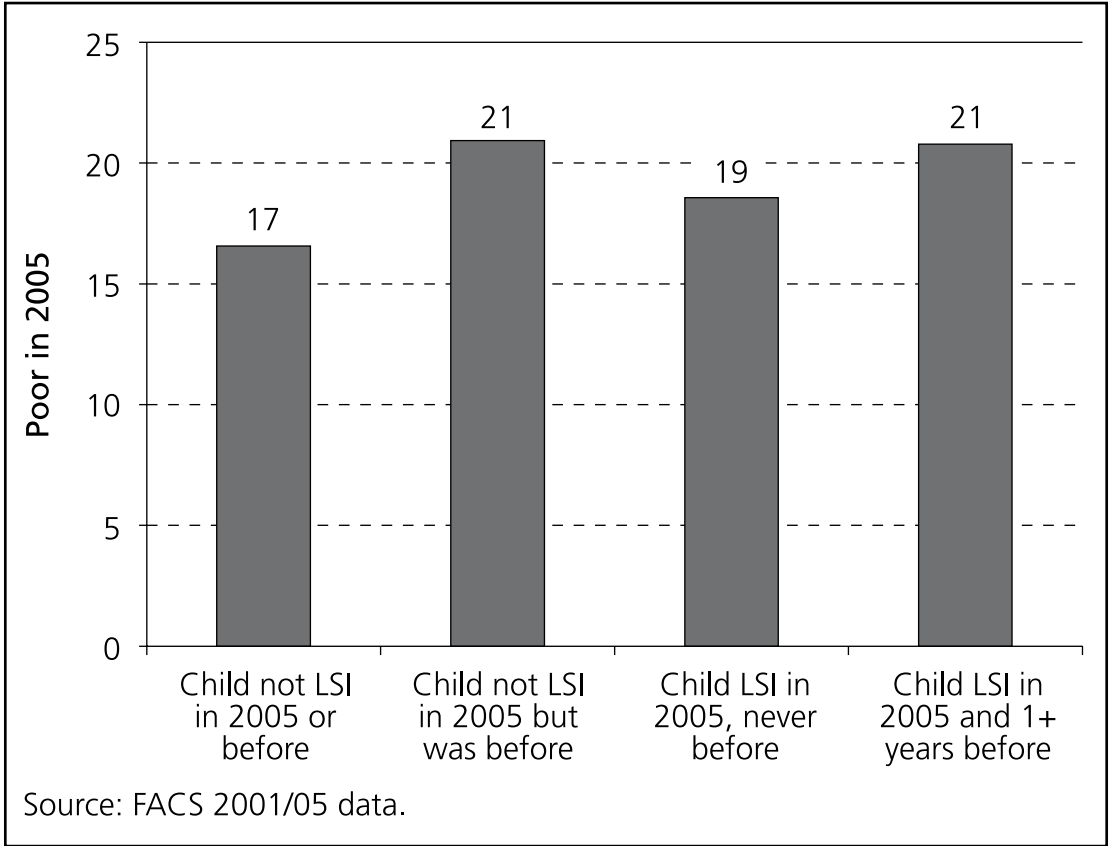
- 17 per cent if such a condition has never been reported; but
- 21 per cent if such a condition has been reported at least once before (during 2001/05).

Conversely, if a child is reported to have an LSI, the risk of poverty varies from:

- 19 per cent where this is the first time it has been reported, compared with;
- 21 per cent if such a condition has been reported at least once before (during 2001/05).

Overall, a poverty comparison between those with and those without ill or disabled children present within the family, runs the risk of being slightly misleading. It includes those for whom an LSI or impairment is a relatively new feature and where changes in reporting health or disability experiences may be high. It excludes the effect of past history, which is important since a greater number of years with an LSI is associated with a higher risk of ever being in poverty.

Figure 8.5 Poverty rate in 2005, by current child disability and its history



8.5 Employment transitions and disability

There is considerable stability of employment situation over time. Those in full-time work continue in that status, as do those in part-time work. Those out of work often remain there for long periods of time, despite the incentives provided by tax credits and other policy tools.

In Table 8.1 we contrast the extent of stability in employment status between those who do not have any LSI in two consecutive waves of FACS and those who mention an LSI in any given year but not in the previous year. Those first mentioning an LSI are shown in the lower half of the table. The bold diagonal cells of the table indicate those continuing in the same work status (working 30+ hours, 16-29 hours, less than 16 hours or not working at all). The shaded areas indicate those who have effectively reduced their working hours so as to change category, including stopping work altogether.

Where the respondent mentioned an LSI (but not the previous year) the extent of employment stability reduced. This group were more likely to change employment status and generally speaking they were more likely to reduce their working hours than the comparison group. For both groups, however, some increased their working hours compared to the previous year, even those newly reporting a longstanding illness. But⁷:

- among those working 30+ hours, 19 per cent of those starting an LSI reduced their hours, compared with 14 per cent of those continuing not to quote an LSI (the 'comparison group');
- among those working 16-29 hours, 20 per cent reduced their working hours category, compared to 13 per cent;
- 23 per cent of those working 1-16 hours stopped work altogether, against 15 per cent of those who did not report an LSI in two paired years;
- only 18 per cent of the non-workers now did some work, compared with 23 per cent among the comparison group.

These are gaps of between five and seven percentage points in employment transitions. These count as relatively large effects, particularly given our reservations about the use of one-off data on disability status.

⁷ Figures in text are calculated from the original data, and so may not be equal to summing the figures in the table owing to rounding.

Table 8.1 Respondent disability and employment transitions (2001/05, paired years)

Column percentages					
Respondent status in this year	Respondent status in previous year				All
	Working 30+ hours	Working 16-29 hours	Working <16 hours	Not working at all	
Continues, no LSI					
Working 30+ hours	86	14	5	4	33
Working 16-29 hours	10	73	23	8	30
Working <16 hours	1	6	57	10	11
Not working at all	3	7	15	77	26
Starts an LSI					
Working 30+ hours	81	14	4	5	29
Working 16-29 hours	9	66	21	6	23
Working <16 hours	2	6	52	6	9
Not working at all	8	14	23	82	38

Notes: FACS 2001/05. Chi-square results show statistically significant associations between starting and ending states.

In Table 8.2 we report a similar analysis but based on transitions in the reporting of child disability status. The extent of changes in employment situation is quite similar – with the exception that those working 16-29 hours reported few differences in employment:

- among those working 30+ hours, 22 per cent of those whose child started to be reported as having an LSI reduced their hours, compared with 14 per cent of the 'comparison group';
- among those working 16-29 hours, 15 percent of those reporting an LSI reduced their working hours category, compared to 13 per cent where no LSI was reported;
- 19 per cent of those working 1-16 hours stopped work altogether, against 16 per cent of those who did not report an LSI in two paired years;
- 19 per cent of the non-workers now did some work, compared with 22 per cent among the comparison group.

These represent smaller changes than for changes in the respondent's disability status but still seem to be relatively important.

Table 8.2 Child disability and respondent employment transitions (2001/05, paired years)

Column percentages					
Respondent status in this year	Respondent status in previous year				All
	Working 30+ hours	Working 16-29 hours	Working <16 hours	Not working at all	
Continues, no child LSI					
Working 30+ hours	86	14	5	5	33
Working 16-29 hours	9	74	23	8	29
Working <16 hours	1	5	56	9	10
Not working at all	4	7	16	78	28
Starts an LSI, reported for child					
Working 30+ hours	78	13	6	3	25
Working 16-29 hours	15	72	25	8	28
Working <16 hours	1	8	50	8	11
Not working at all	6	7	19	81	37

8.6 Resilience – how disability mediates family breakdown

In this section we consider if disability affects outcomes for a family experiencing breakdown. Are those with disabled family members more or less likely to move into poverty, to reduce levels of economic activity and so on?

It should be remembered that many of these transitions are likely to be inter-linked. An unreliable link to the labour market may be associated with family breakdown but likewise, family breakdown may necessitate a change in the degree of engagement with the labour market. Changes in employment may also, like family change, be both a result of changes in disability status and a cause of those changes.

In Table 8.3 we show the links between disability among different family members and the kinds of transitions made into, and out of, poverty following a family breakdown. However, partly owing to small sample sizes, these apparent relationships are not statistically significant.

Table 8.3 Movement into (and out of) poverty by family change and disability

		<i>Row percentages</i>			
Couple broke up	<i>Base</i>	Stayed non-poor	Left poverty	Became poor	Stayed poor
Mother has LSI	132	52	12	26	11
Mother, no LSI	404	58	7	22	13
Child has LSI	136	56	8	20	16
Child, no LSI	400	57	6	24	11
Father has LSI	86	50	12	25	13
Father, no LSI	201	62	7	21	10

Source: FACS 2001/05 data.

Note – none of these differences is statistically significant.

In this report, the analysis has generally shown that the presence and onset of disability of a family member has a greater effect on employment status than poverty. We, therefore, include a similar table Table 8.3 for movement into (and out of) employment by family change and disability – Table 8.4. We consider couples (with children) with a breakdown within the course of a year. We then consider whether there are any changes of employment status, for the mother, depending on whether either she or one of the children has an LSI or other health condition.

In each case, having a child or respondent with disability-related responses led to a higher proportion stopping work (among workers) and a lower proportion starting work (among non-workers). Sample sizes for this analysis are relatively small. We may say that there was a statistically significant difference in rates of starting work, among those not working when a couple, by the disability-related answers of the mother. Put more simply, following a family breakdown non-working mothers are less likely to take a job if they are disabled, compared to non-disabled mothers.

Table 8.4 Movement into (and out of) employment by family change and disability

Couple broke up during the course of the year	Row percentages (in each of two panels)			
	Working 16+ hours in previous year		Not working (or <16 hours) in previous year	
	Still working	Stopped	Started working	Still not working
Mother has LSI	81	19	15	85
Base	61		91	
Mother, no LSI	87	13	27	73
Base	271		212	
Child has LSI	83	17	18	82
Base	66		96	
Child, no LSI	86	14	27	73
Base	266		205	

Source: FACS 2001/05 data.

Note: The table implied by the shaded section is statistically significant at the five per cent level. The other results are not statistically significant at the five per cent level ($p=0.076$ for the comparison among workers by mother's status).

8.7 Key findings

Perhaps surprisingly, there is little relationship between a mother or child having an LSI, and rates of family poverty – when using a snapshot survey, without considering previous relationship between disability and ever being in poverty. This reflects how disability benefits are treated as additional income, without any additional 'need' for income. The additional benefit income may take disabled people beyond the measured poverty threshold (60 per cent of median income), whilst still being insufficient to meet the additional costs of disability. Or, more crudely, families with a disabled member may be worse off than other families, whilst appearing to be better off in the statistics.

Overall, 43 per cent of FACS families were in poverty at least once during 2001/05. The only type of health problem to significantly increase this proportion was for those citing 'depression', among whom two-thirds (66 per cent) had at least some experience of poverty.

The likelihood that a family had ever been in poverty was greater, the more years during which either a child or the mother-respondent said they had an LSI. Risks of ever having experienced poverty were greatest where a child had such an impairment during five consecutive years (where it was 52 per cent) and lowest when no such condition was reported (where 'only' 40 per cent experienced poverty at least once).

Among those working 30+ hours, 19 per cent of those starting an LSI reduced their hours, compared with 14 per cent of those continuing not to quote an LSI (the 'comparison group').

Moreover, 23 per cent of those working 1-16 hours stopped work altogether, against 15 per cent of those who did not report an LSI in two paired years.

There were no clear links between disability among different family members and the kinds of transitions made into and out of poverty following a family breakdown. However, there were some tentative links between disability status and subsequent employment following breakdown, particularly in rates of starting work in response.

9 Conclusion

9.1 Introduction

Previous research has highlighted specific pressures faced by those experiencing disability in a family context (e.g. disabled parents and their families; disabled children and their families). However, there has been a lack of analysis of large-scale data sets on family formation and family change in relation to impairment and disability. This study has, therefore, sought to explore the extent to which disabled people's family status (and trajectories over time) appears to be different to that of non-disabled people. The research has relevance to a wide range of policy areas, focusing our interest and understanding on experiences of disability across the lifespan.

In this chapter we present and discuss some the main findings from our analyses; reflect on the contribution of the project to understanding disability in the family context; and identify some policy implications of the research as a whole.

9.2 Key findings

This research work has presented both data 'snapshots' and explored changes over time. The snapshots, examining family shape as described and a particular point in time, show that:

- Experiencing a limiting long-term illness (LLTI), impairment or significant health problem is associated with an increased likelihood for disabled adults of being single/unmarried and an increased likelihood of being divorced or separated: the potential implications of impairment for relationship status have additionally been shown to be different for men and women at different points in the life span.
- Disabled adults are a little less likely than non-disabled people to have dependent children, although younger disabled people (20-29) are more likely to have dependent children than their peers.
- Disabled children have a marginally greater likelihood of living within step-families or within single parent households.

Available data suggests that these basic differences can vary by impairment type or condition but do not tell us why this might be the case. A number of different types of transition have featured within our analysis of change over time:

- changes in relationship status, which occur for only a small minority (of both attached and single people);
- changes in experiencing impairment and/or reporting disability, which might represent the presence of fluctuating conditions, recovery from chronic illness or changes in the extent to which impairment and disability are perceived to be a defining part of everyday life;
- changes in socio-economic context, specifically in family experience of poverty.

Overall, our analysis has pointed towards a small effect of the presence of impairment on family breakdown in households which include dependent children. However, it is likely that under certain conditions and in relation to specific impairment experiences, this effect is significantly increased. Moreover, disabled people may sometimes be less likely to enter into a relationship than their non-disabled peers:

- Those households most likely to remain together appear to be those where no adult experiences impairment or where an experience of impairment is stable: a range of difficulties in managing fluctuating or unpredictable changes in impairment is likely to be at play here.
- In households which include young children, some specific adulthood impairments (e.g. depression; epilepsy) appear to be more related to breakdown than others, although the reasons why cannot be pinned down at this stage.
- In households which include disabled children, the likelihood of becoming a lone parent household appears to climb substantially when the disabled child is aged 12 months to two years.
- For single adults, those living with a 'limiting health condition' are less likely to enter into a relationship than those without an ongoing health difficulty. This includes movement into first and any subsequent relationships.

It is possible to identify some differences between non-disabled and disabled adults in experiences of having and raising children; there are also some differences between disabled adults:

- Younger disabled adults were more likely than their peers to have dependent children, which may be related to either greater experience of socio-economic disadvantage (where early parenting is more likely) and/or to differential access to employment, education and parenting roles (by choice or the presence of barriers).
- Younger adults with learning disabilities were least likely to have dependent children: it is not clear the extent to which this reflects having no children or not maintaining the parenting role (for whatever reason).

Understanding the dynamics of family experiences of impairment, 'caring' roles, access to employment and training and so on, are of central importance to understanding family formation. The presence of child or adult impairment increased the likelihood of a family having experienced living in poverty and this increased in relation to how many years of impairment were reported. The current presence, or not, of disability may not be the most important factor, and it is important to recognise that a history of family experiences of disability may have long-lived effects in relation to employment and poverty.

9.3 Disability in family context

Existing research evidence and our own analyses point to the complexities involved in assessing the impact of disability on experiences of, and changes in, family life. Gaps in current knowledge also continue to exist, most notably in relation to lived experience of disability in family context. Such gaps need to be recognised in order to assess the implications of the currently available data. On this basis, the principal factors underpinning the complex picture which we have highlighted within the report are:

- the different economic contexts of family life;
- stability (or not) of impairment/chronic health difficulty;
- centrality (or not) of impairment on lived experience of disability within families;
- impact of availability of appropriate support on lived experience of disability and impairment within families;
- impact of disability on access to, and maintenance of, private and public roles (e.g. parenting; employment);
- lack of evidence on positive aspects of relationships in the context of impairment.

In particular, the likelihood that a family had **ever** been in poverty was greater, the more years during which either a child or the mother-respondent said that they had a longstanding illness (LSI). The effect of mothers having an LSI was at its highest if such a condition was reported in at least three years out of five but no higher if the LSI was reported more often than this.

9.4 Main policy implications

The research presented here contributes towards a fuller understanding of the experience of disability in a relationship context. Current policy across departments aims to ensure that full opportunities exist for disabled people to have equality with non-disabled people; not only is this crucial in relation to public roles and opportunities but also in private choices concerning choice and opportunity within private lives.

The available literature in combination with our data analysis suggests that for some disabled adults, and those with disabled children, there is an increased risk of family dissolution: a principal implication for family welfare and child poverty policy is that emotional, physical and material costs to individuals and families of disability and 'care' need to be addressed in order to support families; this may not necessarily mean supporting families to 'stay together' but is instead concerned with reducing the likelihood that families break under significant pressure.

Dynamic aspects of the experiences of disability and family life are increasingly being integrated into policy debates, including concerns about ensuring inclusion over the life-span. This research further stresses the dynamics of disability, highlighting that whilst impairment and disability may be a constant feature of some people's lives, for others it is less clear-cut and less often a central shaper of day-to-day lived experience.

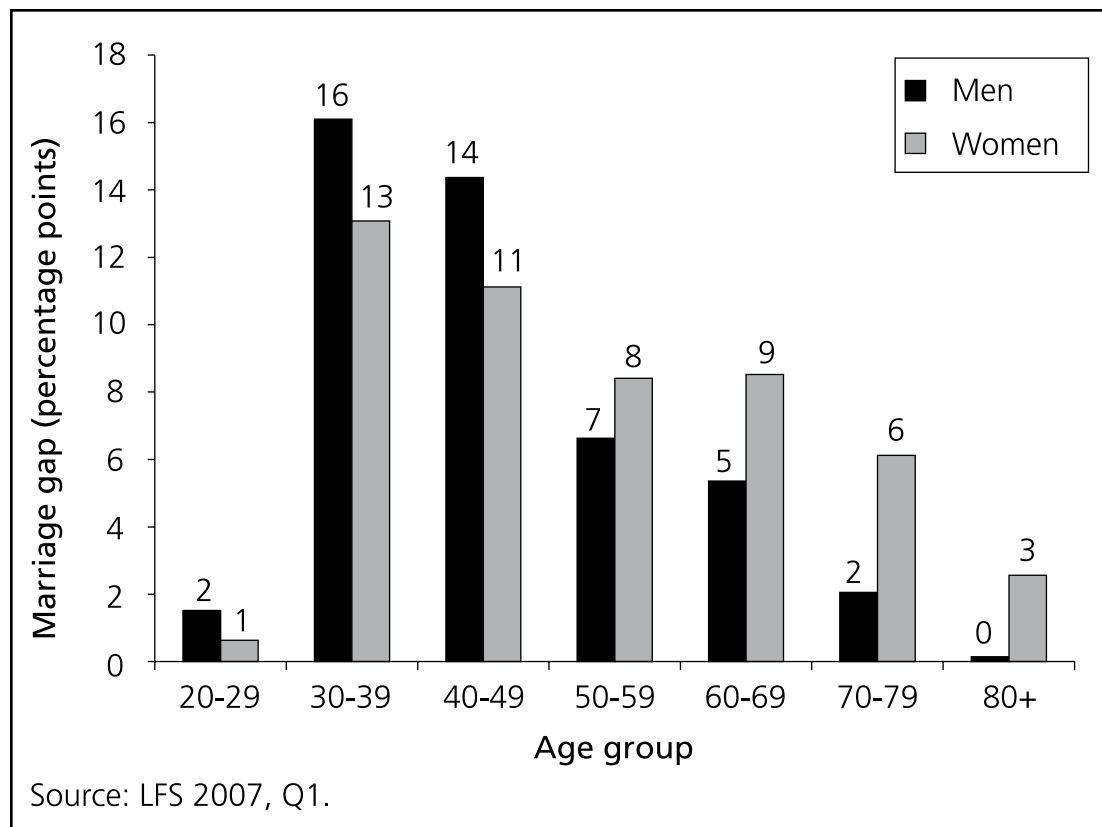
The analysis presented suggests that target areas requiring specific policy focus include families which include younger disabled children and families which include adults with fluctuating and unpredictable impairments who may be most at risk of not receiving responsive services or supports. The impact of individualised budgets and direct payments in supporting or additionally straining family life is of particular importance here. Additionally, the presence of fluctuating and unpredictable impairments may place families at particular economic risk (e.g. in relation to disability benefits; in relation to access to and maintenance of employment and/or training).

Appendix

Extra confirmatory analysis

Results for the marriage gap by age and gender appear to be robust to changes in the dataset. For younger men, the marriage deficit associated with being disabled is greater than for women. Beyond the age of 50 the gap is larger for women, than for men.

Figure A.1 'Marriage gap', by Disability Discrimination Act (DDA) status: Difference between DDA disabled and non-disabled, current status



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