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Being and becoming:
Social exclusion and the onset of disability

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Contents

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1. Introduction

1.1 Aims of the report

The majority of disabled people experience the onset of their health problem or impairment in adulthood. According to a survey carried out in the mid-1990s, 11 per cent of disabled adults of working age were born with a health problem or impairment, 12 per cent became disabled during childhood, and the remaining three-quarters became disabled during working life. The onset of a serious health problem or impairment may be sudden (for example, as the result of an accident), or gradual (for example, a worsening of a chronic condition), but in either case the adjustments required to everyday life can be considerable. Aside from managing the pain, discomfort and inconvenience which may be caused directly by the condition, changes may be imposed by new needs for financial and practical support, having to negotiate inaccessible buildings, transport or information, and dealing with discriminatory attitudes on the part of employers, service providers and the general public. The impact is likely to vary considerably according to the individual's circumstances – whether they live alone or with a partner, for example, their previous income and employment – and also by the type and severity of their newly-acquired impairment or condition.

The onset of disability has an impact not only on the person directly affected, but also on other family members. A spouse may find he or she wishes to, or is obliged to, reduce hours of paid work in order to care for the newly disabled person. Alternatively, pressure on household finances may be such that he or she must increase his or her earnings. Children in the family will also be affected – by changes in the allocation of their parents' time, possibly by taking on new responsibilities, and by changes in household income.

One of the early findings of this research – and one which has also been noted elsewhere (for example, Jenkins and Rigg, 2003) – is that the onset of disability is by no means a random occurrence. On the contrary, those who are already disadvantaged are at significantly greater risk of becoming disabled. There are strong associations between being poor, being out of work, having low educational qualifications and the risk of developing a long-term health problem or impairment. Many of these risk factors are amenable to policy intervention. The onset of ill health or impairment often entrenches and deepens pre-existing disadvantage, and this too is preventable. For these reasons the prevalence and distribution of ill health and impairment in society should be regarded as more akin to a phenomenon which we have chosen to fail to prevent, than to a natural disaster.

It is also worth bearing in mind that some people have identified positive aspects of the experience of becoming disabled, for example through finding a new or stronger sense of identity, or feeling liberated or enlightened through participation in the disabled people's movement (Campbell and Oliver, 1996). While few would choose to become disabled, it is not necessarily an unmitigated bad.

It is the process of becoming disabled and the impact on the individual and his or her family, with which this report is concerned. The emphasis is on changes in activity – paid employment, caring, social and political pursuits – and on changes in income, especially the risk of poverty. Putting it all together, the report aims to illuminate the relationship between becoming disabled and being socially excluded.

1.2 Policy context

Considering disability as a dynamic phenomenon means thinking about policies which might prevent the onset of disability – either by preventing the health problem or impairment arising in the first place, or by preventing such an occurrence leading to economic and social disadvantage. It also means thinking about policies which can alleviate the impact of becoming disabled. Hills (2002) provides a four-way classification of policies in a dynamic framework:

> Prevention – reducing the risk of entering an undesirable state
> Protection – reducing the impact of an event
> Promotion – increasing the chance of exiting an undesirable state
> Propulsion – re-enforcing the benefits of exit and guarding against return to the undesirable state

All these elements can be detected in existing policies relating to the onset of disability. In terms of prevention, one of the objectives which forms part of the Public Service Agreement of the Department of Health is, "To reduce the incidence of avoidable illness, disease and injury in the population", and as part of that objective to achieve, "a narrowing of current inequalities in health status" (DoH 2003, p.10). Preventative strategies have not always been given adequate emphasis in the National Health Service and the majority of services are geared up to treatment rather than prevention. Nevertheless, establishing prevention as a clear target and, in particular, acknowledging that the current level of health inequalities is unacceptable, must be seen as steps in the right direction.

Enforcement of health and safety regulations by the Health and Safety Executive (HSE) forms a second strand of preventative policy. Again, the HSE has been criticised for lacking teeth and being reluctant to prosecute offenders, but it has overseen a gradual decline in non-fatal injuries and in self-reported work-related ill health (Health and Safety Commission, 2002). To what extent this is a result of the HSE's activity and to what extent it is a product of changing patterns of occupation, industry and healthcare remains an open question.

Policies to reduce the impact of developing a serious health condition or acquiring an impairment ('protection' policies) aim to break the link between having an impairment and being socially and economically disadvantaged. One such policy is anti-discrimination legislation, and enforcement through the Disability Rights Commission. Despite the DRC's efforts, however, discrimination against disabled people remains widespread: in employment, in provision of services, and in public attitudes more generally (DRC, 2002). Tackling discrimination is vital, but it is not going to be achieved overnight.

Meanwhile, the social security system and social services provide a combination of financial support and services, designed to alleviate poverty and hardship. Social insurance sickness and disability benefits (now known as Incapacity Benefit) were originally intended to protect against a drop in living standards as a result of being obliged to stop work. The earnings-related element of the benefit was important in this respect, ensuring that the impact of leaving employment was cushioned by a benefit which bore at least some relation to previous earnings. However, since 1979, the earnings-related element has no longer been payable, and the value of the benefit itself has been linked to prices rather than to average earnings, so that the gap between average living standards and the rate of benefit has grown.

Extra costs benefits, such as Disability Living Allowance, aim to help towards additional expenditure which may be incurred as a result of being disabled, and thus also protect living standards. In addition, social assistance (through Income Support) provides a safety net, in principle to ensure that no-one falls below a certain minimum income. The role all these benefits in fact play in protecting people who become disabled, and their families, from poverty will be examined in greater detail in chapters 5 and 6 of this report.

‘Promotion’ policies come into play where preventative policies have failed, and where policies designed to reduce the adverse effects of becoming disabled have provided only incomplete protection. On the medical side, rehabilitation may be available, although services of this kind have traditionally been limited in the UK relative to some of our European neighbours (Riphahn, 1999; Thornton and Lunt, 1997). A new scheme is to be piloted, jointly run by the Department for Work and Pensions and the NHS, giving greater priority to vocational rehabilitation for sickness and disability benefit claimants (DWP, 2002a). On the social side, very little statutory support is directed towards re-integrating disabled people who have become isolated into society; such activity as there is in this area is largely undertaken by voluntary organisations and self-help groups. The state confines its attention mainly to re-connecting disabled people with the labour market. Policy has been developing rapidly in this area since 1997, with a new target for the Department for Work and Pensions to increase employment rates among disabled people, and the inclusion of disabled claimants in welfare to work programmes. The New Deal for Disabled People is now a national programme, offering ‘job brokers’ to assess the barriers disabled claimants face in getting work and helping to match individual claimants with jobs. Participation in the New Deal is – at present – voluntary, but under the auspices of Jobcentre Plus, ‘work-focused’ interviews for new Incapacity Benefit and Income Support claimants are compulsory. By the Department’s own admission, the New Deal for Disabled People has not been as successful as was hoped or expected (DWP, 2002a). Critics have pointed to the emphasis on ‘employability’ and changing the claimant to fit the job as a weakness. In the pilot phase those schemes which devoted more time to working with employers were generally more successful (Hills *et al,* 2001). Most recently, a ‘green paper’ proposed further measures to help disabled people into employment (DWP, 2002a). Once again these focus mostly on offering advice and support to the disabled claimant, together with an incentive in the form of a ‘back to work’ credit of £40 per week, payable for the first 12 months of a new job. Greater efforts are also to be made to disseminate good practice among employers, especially with respect to retention of newly disabled employees.

Finally, one component in the range of policies relating to the onset of disability falls into the ‘propulsion’ category – helping to re-enforce the benefits of exit and reducing the risk of returning to an undesirable state. In this case the undesirable state is not ill health or impairment itself but the economic hardship which may accompany it. The relevant ‘propulsion’ policy is the Disabled Persons Tax Credit, which was incorporated into the Working Tax Credit (WTC) in April 2003. By boosting the incomes of low-paid disabled employees, it is designed to ensure that in-work incomes are higher than out-of-work incomes for disabled people, even if they can work only part-time or in a low-wage job. It should therefore make employment both more attractive and more sustainable. Unfortunately, interaction with unreformed Housing Benefit means that for many social housing tenants, the financial gain from working is negligible, despite the help provided by WTC. In addition, delays and uncertainties in the process of applying for WTC when it was first introduced limited its appeal and its effectiveness.

This brief survey of policies relating to the onset of disability has covered measures aimed at prevention, protection, promotion and propulsion for the individual affected by disability. Support for the families of those who become disabled is much more limited. The only social security benefit specifically designed to address their needs is the Carers Allowance (previously known as the Invalid Care Allowance), payable at a low rate and only under tightly restricted conditions. The National Strategy for Carers, produced by the government in 1999, attempted for the first time to incorporate carers’ own concerns into the formation of policy and bring together issues cutting across traditional departmental boundaries (DoH, 1999). The emphasis was on making it easier for carers to fulfil to their caring responsibilities, possibly in combination with paid work, rather than replacing their care with paid-for services. A small additional fund was announced to help carers to take a break, and the age limit of 65 on Carers Allowance was lifted from October 2002. However, the level of benefit and other eligibility requirements remain unchanged.

As the evidence presented in this report will show, protection and promotion policies are essential to respond to the widespread poverty and social exclusion among people who have become disabled. But if the link between disability and poverty is to be broken, greater emphasis and resources need to be directed towards preventative policies, in particular to address the steep socio-economic gradient in the risk of becoming disabled.

1.3 Existing research

That disabled people in Britain are disproportionately poor, that only a minority are in paid employment, and that many experience social isolation and limited leisure opportunities is widely recognised (eg Burchardt, 2000a). But a series of transitions underlie this cross-sectional picture, including the transitions which may occur when someone becomes disabled: from employment to unemployment, from carer to cared-for, from two-earner to no-earner household. These transitions have received considerably less attention.

One of the earliest studies on the economic impact of becoming disabled was based on US data for the 1970s and 1980s (Burkhauser and Daly, 1996). Their particular interest was in the scope for the 1990 Americans with Disabilities Act (ADA) to increase incomes of disabled men through boosting their employment rates. (The ADA is the US equivalent – and predecessor – of the UK Disability Discrimination Act 1995). They found that the reduction in employment rates and fall in income associated with onset of disability was lower than might be expected, chiefly because the incomes and employment rates of men who became disabled were already low before onset. For example, two years before onset of disability, the average income of those men who went on to become disabled was one-third lower than that of men who did not experience onset of disability.

Burkhauser and Daly followed up their US study with a comparison with Germany (1998). The comparison indicated that Germany achieved higher rates of employment retention and lower earnings differentials after onset of disability than in the US, but that in both countries, the deterioration in economic well-being associated with onset was marked, despite pre-existing low average employment rates and incomes among those who became disabled.

Using the same data to investigate in more detail the operation of the German welfare state in responding to the onset of disability, Riphahn (1999) concludes:

> "[H]ealth shocks not only are more likely to affect the population groups at the bottom of the earnings distribution, they also leave those with the most severe health impairments worst off. Government benefits...do not fully balance and insure against the negative consequences" (p387).

Evidence for Britain is drawn from the British Household Panel Survey (BHPS). Examining disability as a dynamic phenomenon, Burchardt (2000b) showed that intermittent patterns were relatively common, and were especially associated with mental illness. Short durations were also commonly reported, and although it was difficult to assess to what extent this was due to measurement error and to what extent to genuinely brief episodes of incapacity, it was noticeable that one-off reports of limitation in daily activities were associated with less significant disadvantage than longer durations or intermittent patterns. This finding suggested that a two-period definition of disability was preferable – an issue to which Chapter 2 of this report returns.

A number of studies have looked at employment retention following onset of disability in Britain. Using BHPS data, 1 in 6 of those who were in employment at the time they became disabled left employment in the following year (Burchardt, 2000a). Figures from the Labour Force Survey panels for those who became Statutory Sick Pay or Incapacity Benefit claimants were even more stark: 47 per cent had left employment 9 to 12 months after onset (Burchardt, 2003). Meanwhile Bardasi, Jenkins and Rigg (2000) found that overall employment rates among those who became disabled fell from 81 per cent two years before onset, to 60 per cent in the year after onset, and just 36 per cent in the following year – a much steeper decline in employment rates than was found for either Germany or the US.

Finally, Jenkins and Rigg (2003) use the BHPS to disentangle the economic disadvantage associated with disability into ‘selection effects’ (that is, disadvantage which pre-dates the onset of disability), ‘onset effects’, and ‘duration effects’ (disadvantage associated with longer durations of disability). They conclude that both selection and onset effects are important, and that there are variations in risk according to demographic and socio-economic characteristics. More specific findings from the Jenkins and Rigg study will be discussed in the course of Chapters 3-5.

This report builds on existing research by exploring in more detail the circumstances of individuals who become disabled, and how those initial conditions affect the subsequent experience of being disabled. It seeks to incorporate the impact on the rest of the household, especially on the spouse (if there is one), and to broaden the analysis from poverty and employment to other forms of activity (such as caring responsibilities), and other forms of participation (such as leisure activity). Throughout, the focus is on those aspects of the process which are, or could be, affected by the social security system and by broader social policy.

1.4 Structure of the report

Most of the results in this report are based on analysis of existing data – waves 1 to 8 of the British Household Panel Survey (BHPS). This has the advantage of producing generalisable results, since the survey aims to be nationally representative. It can tell us about how many people become disabled and who is at greatest risk, about their incomes before and after onset, about their employment, caring and leisure activities. This approach cannot, however, illuminate the subjective experience of becoming disabled: that would require a qualitative methodology, which was beyond the scope of this study. Some disability theorists are critical of quantitative approaches because they cannot reflect the complexity of what it means to be disabled; others see a role for both qualitative and quantitative research (see Barnes *et al*, 1999, for a discussion). A glimpse of the kinds of issue a qualitative study might uncover are provided in the final chapter, where respondents' self-reported satisfaction with various aspects of their lives before and after onset of disability are considered.

The BHPS itself contains a wealth of data but also has a number of limitations. Two are particularly relevant for this study, and are discussed in more detail at relevant points in the report and in the Data Appendix. The first is the relatively small sample size – around 5,000 households – which means that for some analyses, the results are based on a small number of observations. (The number of observations is indicated where appropriate in the last row of tables).

The second limitation of the BHPS is the range of definitions of disability which are available within it. From an analytical point of view, the absence of direct information on severity of impairment is a significant drawback. Variation in the experience of disability by severity of impairment is wide, as demonstrated by Berthoud (2003) and Grundy *et al* (1999), among others. By grouping disabled people together, and comparing to the non-disabled population, we are likely to *understate* the disadvantage faced by people with more severe impairments. This 'average disadvantage' is closer to the experience of people with less severe impairments because the proportion of less severely disabled people in the disabled population as a whole is much greater. Accordingly, where a difference between the disabled and non-disabled population is found, we can in most cases be confident that the difference between the more severely disabled and the non-disabled would be greater. Some attempt is made in what follows to construct a proxy for severity of disability, but the results need to be treated with caution.

The unique advantage of the BHPS compared to other UK datasets is that it re-interviews the same individuals year on year, thus enabling us to follow their experience over time. This is the reason that most of the results in this report are based on the BHPS, despite the limitations mentioned above.

Chapter 2 begins with a discussion of what ‘becoming disabled’ really means, before going on to investigate the risk of becoming disabled. It probes the relationship between pre-existing poverty and becoming disabled which has been highlighted by previous studies.

Chapter 3 examines changes in income and transitions into and out of poverty, both before and after becoming disabled (using comparisons with similarly-disadvantaged individuals who do not become disabled). By following through the experience of individuals who start out in different circumstances, it is possible to identify the diverse impact becoming disabled can have, and who is least adequately supported by current welfare policy.

Chapter 4 focuses on changes in economic activity which take place when someone becomes disabled – both for the individual him or her self, and, for couples, for the spouse. Particular attention is paid to employment and caring responsibilities, and the interaction between them.

The role of state benefits is examined in Chapter 5. Is Incapacity Benefit effective as insurance against a fall in living standards? Does the scope and take-up of Carers Allowance (previously Invalid Care Allowance) reflect the earnings foregone by spouses when they take on caring responsibilities?

Standards of living are affected not only by the income coming into the household, but also on patterns of expenditure. Chapter 6 considers the extent to which the additional costs incurred by some disabled people as a result of their impairment affect the assessment of the financial impact of the onset of disability on the family. After taking extra costs into account, do the rates of transition into poverty change? Are extra costs benefits (such as Disability Living Allowance) sufficient to offset increased expenditure?

Finally, Chapter 7 looks at the effect of onset of disability on participation more broadly, for example in terms of leisure activities. Do individuals who have been affected by the onset of disability (whether directly or indirectly) express greater or lesser satisfaction with various aspects of their lives – their incomes, employment, relationships, and social life? The concluding section draws together the preceding analysis and considers the policy implications, across a range of areas: employment, social security, enforcement of anti-discrimination legislation and the health inequalities agenda.

2. Who becomes disabled?

2.1 Definitions of 'becoming disabled'

The social model of disability, developed and espoused by organisations of disabled people such as the British Council of Disabled People, draws a distinction between impairments and health conditions on one hand, and 'disability' on the other. 'Disability' is seen as the social and economic disadvantage which results from society's failure to respond to the needs of people with impairments. Impairments may prevent an individual from being able to see or walk, but in a society in which information was standardly presented in alternative formats, and buildings and transport were wheelchair-accessible, being unable to see or walk would not necessarily result in economic hardship or social isolation. This is well illustrated in an account of Martha's Vineyard, a community in the USA which had high levels of congenital deafness (Groce, 1985). Hearing residents were bilingual in English and sign language, local officials were equally likely to be deaf or hearing; in fact being deaf was so unimportant compared to other characteristics that many residents had difficulty in recalling whether particular individuals in previous generations had been deaf or not.

One important consequence of conceptualising disability in this way is a recognition that disability (understood as social and economic disadvantage) is not a necessary consequence of impairment. Correspondingly, acquiring an impairment will not necessarily lead to becoming disabled. Ideally, in analysing the process, we would therefore distinguish between impairment and disability. Unfortunately, neither the data available, nor the current state of society's adjustment to meet the needs of people with impairments, make it easy to draw this distinction in practice. Survey questions confound impairment and disability; acquiring an impairment or developing a serious health condition almost invariably *does* lead to significant disadvantage and discrimination. For this reason in the rest of this report, the term 'becoming disabled' is used to refer to the process of the onset of illness or acquiring an impairment and the economic and social consequences which follow, given the status quo. In recognition of the importance of identifying those aspects of the process which are amenable to policy intervention, the report endeavours to distinguish throughout between factors such as age and gender (which are intrinsic) and factors such as educational qualifications and income (which are contingent – to some extent – on the structure of society).

In the BHPS, the question used to identify people who are disabled is:

> *Does your health in any way limit your daily activities compared to most people of your age?*

The wording is unfortunate: it refers to ‘health’ without mentioning impairment (a blind person may be perfectly healthy), and, by implying that the health condition directly causes limitation in activities, it ignores the role of the social and economic context. However this formulation does have the advantage of simplicity and it addresses the issue of participation in ‘normal’ activities. It has also been used successfully in previous research (for example, Burchardt 2000a, b). Jenkins and Rigg (2000) use a definition based on work-limiting disability, which produces similar results, although there is some concern that whether someone considers his or her condition to be ‘work-limiting’ is influenced by his or her actual employment status at the time.

The analysis concentrates on people of working age: women aged 16-59 and men aged 16-64. On average over eight years of BHPS data (1991-1998), 10.8 per cent of respondents reported limitation in daily activities.[1] There was a slight upwards trend over the period, from 9.4 per cent at Wave 1 to 11.3 per cent at Wave 8.

The simplest definition of ‘becoming disabled’, based on this question, is ‘not disabled at one interview, disabled at the next’. Eight per cent of respondents were already disabled when first interviewed for the survey. Clearly these individuals were not at risk of becoming disabled, since they were disabled already. Restricting our attention to those who were at risk of becoming disabled (in the panel for at least two consecutive waves and not already disabled), on average 4.7 per cent in fact became disabled each year.

We know from findings on the dynamics of disability (Burchardt, 2000b) that for many of these individuals, the experience of limitation in daily activities will be transitory. A definition which requires that an individual reports limitation in daily activities at two consecutive interviews (approximately one year apart), may better capture what we mean by ‘becoming disabled’. According to this two-period definition, 2.0 per cent of those at risk become disabled each year.

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[1] For further details of the BHPS, see data appendix.

This definition might be considered too restrictive, since it may miss those whose condition fluctuates, such that they experience intermittent rather than continuous limitation in daily activities. Widening the definition to include those who report disability in at least one of the two waves following the first report of disability produces a rate of 2.6 per cent becoming disabled each year. This has the advantage of being more inclusive, but the disadvantage of being more demanding of the data: it reduces the number of ‘at risk’ observations (i.e. respondents-at-a-wave) from 34,610 to 26,971. For this reason, the following analysis concentrates on the definition outlined above, requiring disability at two consecutive waves. However we will return later to the possible impact of intermittent patterns of disability.

2.2 Precursors of disability

There are two main routes to acquiring an impairment or long-term health problem as an adult: having an accident, or developing an illness. Onset may be sudden – as is the case for most injuries – or gradual, as if often the case with illness, and there may be times when the condition is better or worse. The BHPS asks respondents whether they have had an accident in the previous year which required attention from a doctor or hospitalisation, and it also asks a series of questions about health problems and conditions.[2] If a respondent becomes disabled, we can therefore identify whether there was a preceding accident or health problem, although we cannot know for certain whether the limitation in daily activities is a direct result.

Table 2.1 shows the breakdown of those who become disabled by type of onset. A ‘sudden’ health problem is defined as one that is reported for the first time in the same year as the onset of disability; a ‘gradual’ health problem is one that was reported in the preceding year. Fifteen percent of those who become disabled have had an accident in the previous year, most of which resulted in (or occurred in the same year as) the development of a health problem or condition. Further analysis indicates that nearly half of these accidents occurred at home. A further 22 per cent occurred on the roads (whether as pedestrians or in a vehicle), and 13 per cent at work.

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[2] For details, see data appendix.

Table 2.1: Precursors of becoming disabled

Two-period definition of becoming disabled

Women aged 16-59 and men aged 16-64

Type of onset	Percent
Accident and sudden health problem	11
Accident and gradual health problem	2
Accident only	2
Sudden health problem only	44
Gradual health problem only	13
None of the above	29
All	100
Number of observations	*702*

Note: 'None of the above' includes those with intermittent health problems, those who have had a health problem for longer than two years previously, and those with no reported health problem or accident

Of those who did not have an accident in the year preceding onset of disability, a large majority report a sudden onset of a health problem, presumably the result of illness (44 per cent of all those who become disabled). A further 13 per cent have a longer-term health problem. The types of problem reported by those with sudden and gradual onset were generally similar.[3] Problems affecting limbs, neck or back were most common (reported by 43 per cent of those with sudden onset and no accident, and 66 per cent of those with gradual onset and no accident). Problems affecting internal organs were also common, reported by 24 per cent and 27 per cent of those with sudden and gradual onset respectively.[4] Problems relating to chest or breathing were reported by 18 per cent of respondents with sudden onset (25 per cent of respondents with gradual onset), and mental health problems were reported by 18 and 15 per cent respectively.[5] Finally, problems affecting sight or hearing were reported by 12 per cent of each group.

As mentioned in the Introduction, there is no direct measure of severity of impairment in BHPS. Following Berthoud (2000), we can construct a proxy indicator based on the number of different health conditions or problems that respondents report. Details are given in the

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[3] Respondents may report more than one type of health problem.

[4] Including problems with heart/blood pressure, blood circulation, stomach or digestion, liver, kidneys, or diabetes.

[5] Problems with chest or breathing includes general chest/breathing problems, asthma, bronchitis and allergies.

Data Appendix. The distribution of this proxy measure for severity of impairment for those who have just become disabled is given in table 2.2, with a breakdown by the type of onset.

Table 2.2: ‘Severity’ of impairment, by type of onset

Column percent

Number of problems reported	All	Accident	Sudden illness	Gradual illness	Other
0 or 1	42	36	28	55	65
2	28	24	33	22	25
3	18	28	21	16	5
4 or more	12	13	18	6	5
No. of observations (= 100%)	*702*	*109*	*322*	*98*	*173*

This variation in the immediate precursors of becoming disabled, and in the number of health problems experienced, is an important part of the context for the following section, which considers how the risk of becoming disabled varies by individual and family characteristics.

2.3 Who is most at risk?

An assessment of who is most likely to become disabled can be made by comparing the characteristics of those who are at risk of becoming disabled but do not do so, with the characteristics of those who do become disabled. Since becoming disabled may itself affect some of the characteristics of interest - for example, by reducing household income - it is important to make the comparison *before* the time of onset. Jenkins and Rigg (2003) do just that.[6] They find that compared to those who do not become disabled, those who will become disabled:

- are older,
- have lower average household incomes,
- are more likely to be in the poorest fifth of the income distribution,
- are less likely to be in paid work, and
- have lower educational qualifications, on average.

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[6] Their definition of ‘becoming disabled’ is two waves of no disability followed by at least one wave of disability, using the ‘work-limiting’ definition of disability. They compare characteristics of individuals two waves before onset.

They find no significant differences by gender, nor by the number of adults or number of children in the household. We know that lone parents experience high levels of ill health and disability (Finlayson, 2000), so we might expect that they would also have high rates of becoming disabled. However this does not appear to be the case, at least not after controlling for age and household income. It could be that the poor health predates becoming a lone parent, or it could be that the association is explained by other factors such as poverty. The variables which *are* significantly associated with becoming disabled suggest that pre-existing economic disadvantage is a major risk factor. Multivariate analysis confirms that being older, having no educational qualifications and not being in paid work are all independently associated with the risk of being disabled.[7]

Variations by region in rates of disability, and in claims for disability benefits, are often remarked upon in cross-sectional analyses (for example, Grundy *et al,* 1999; Evans *et al,* 2002). Does the risk of becoming disabled also vary by region? Figure 2.1 indicates that it does, with Merseyside and Tyne and Wear exhibiting high risks of becoming disabled, and Greater Manchester and the Rest of the North West (excluding Merseyside) at the other end of the spectrum. It is hard to see what features of the regions could explain this pattern: some urban regions show high risks while others do not, some with relatively high rates of employment also have high rates of becoming disabled (like Inner London); some areas which have experienced significant industrial decline have high rates of becoming disabled (Wales), while others do not (Scotland, Greater Manchester).

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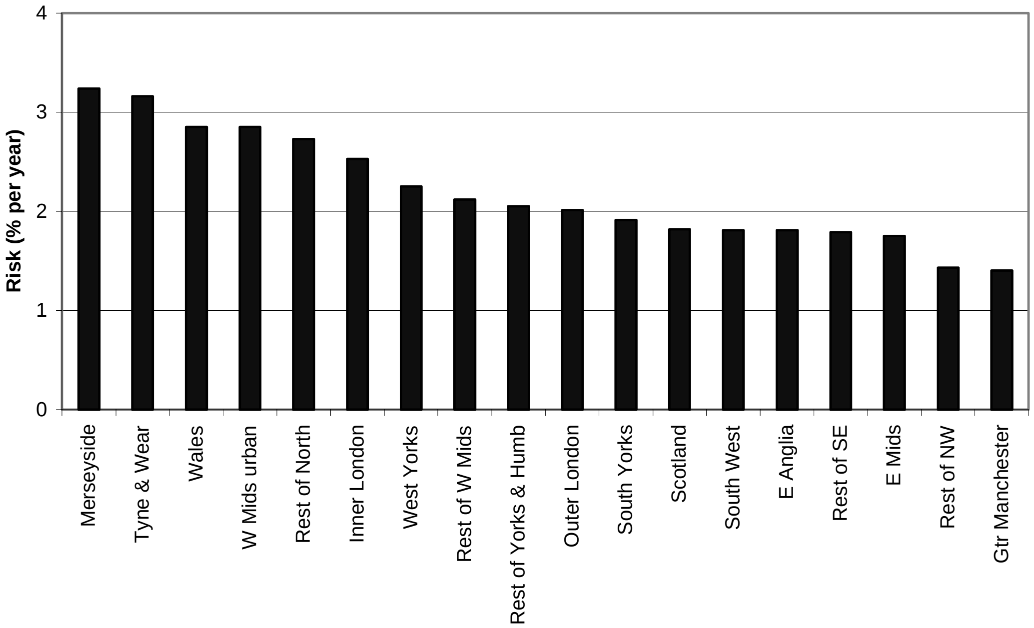
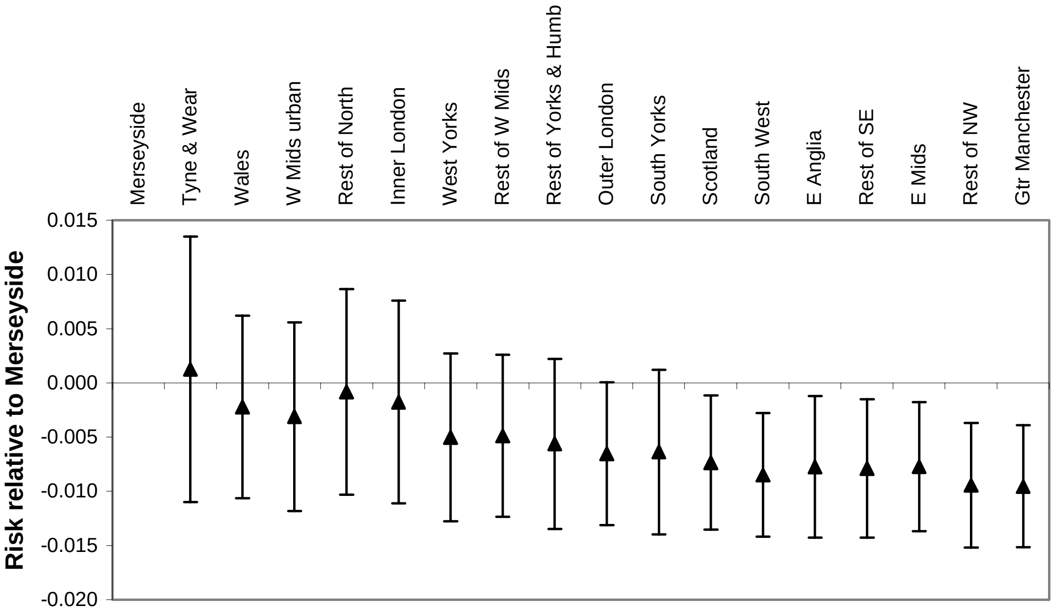
[7] Jenkins and Rigg (2003), Table 2. Probit regression on probability of becoming disabled, with gender, 3 age groups, whether any educational qualifications, whether in paid work, number of adults in household and number of children in household as explanatory variables.

Figure 2.1: Risk of becoming disabled, by region



Part of the explanation could lie in the demographic profile of the region's residents and the structure of the local economy. Accordingly, Figure 2.2 shows the same distribution but this time controlling for the age, employment status and occupation of the residents. The risks are shown relative to Merseyside, with the triangle indicating the point estimate and the bars indicating a 95 per cent confidence interval around the estimate. The first observation to make is that the order of the regions from most to least risky is not much altered by controlling for age, employment and occupation. However, the second observation is that, at least using these data, most of the differences between regions are not statistically significant (as shown by the fact that the bars overlap). Merseyside, Tyne and Wear, Wales, the West Midlands conurbation, the rest of North and Inner London all exhibit similar, and high, risks of becoming disabled. All the other regions are lower risk, and those listed to the right of 'South Yorkshire' in the figure have a significantly lower risk than Merseyside. Although it is difficult to identify what feature the high risk regions have in common that they do not share with at least some of the lower risk regions, there does seem to be a genuine difference between them, which is independent of the demographic profile of residents and their economic activity.

Figure 2.2: Variation in risk of becoming disabled by region, controlling for age, employment status and occupation of residents



Returning to the Jenkins and Rigg study, they calculate that the odds of an individual with no educational qualifications becoming disabled are 1.4 times higher than someone with qualifications, for any given age and employment status. To examine the association between educational qualifications and becoming disabled in more detail, Figure 2.3 breaks down the risk of becoming disabled by type of onset as well as educational status. Educational qualifications are classified by their approximate equivalent in terms of NVQ levels: level 5 corresponds to a degree, level 4 to professional qualifications like teaching and nursing, level 3 to A levels, level 2 to GCSEs or O levels, and level 1 to qualifications below that level.[8]

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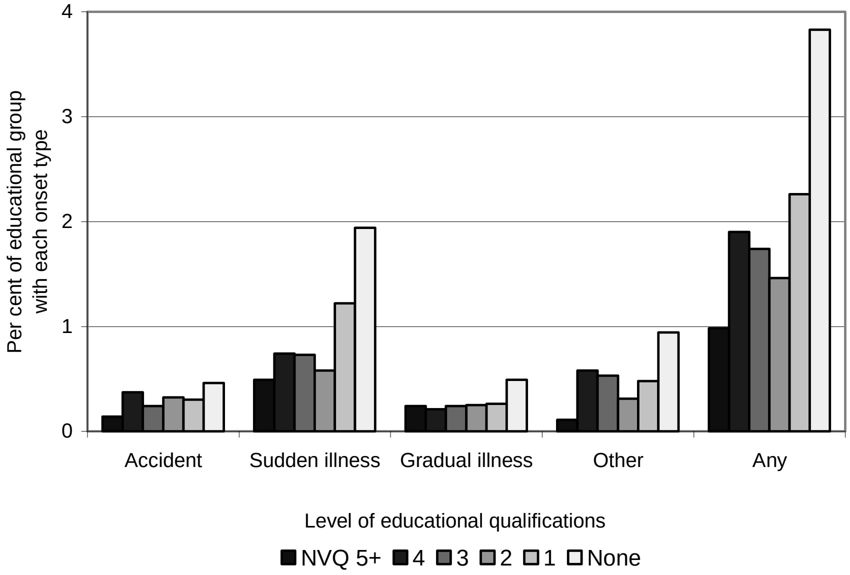
[8] A small number of respondents whose qualifications cannot be classified in this way, for example, because the qualifications are foreign, are omitted from the Figure.

Figure 2.3: Types of onset, by educational qualifications



The figure confirms the strong relationship between educational qualifications and risk of becoming disabled: at the right of the figure, it can be seen that those with no qualifications are nearly four times as likely to become disabled as those with a degree. This difference is apparent for each of the different types of onset, whether an accident, a gradual or sudden illness, or some other cause.[9] The gradient is especially steep for those who report a sudden illness.

However we know that older people are less likely to have formal educational qualifications, and that they are also more likely to become disabled, so it could be age rather than educational qualifications which drive the association. Jenkins and Rigg's results suggest not, and this is illustrated in Figure 2.4. The gradient with respect to educational qualifications in the risk of becoming disabled holds within each age group. Interestingly, even though the overall risk increases with age, the difference in risk between those with no qualifications and those with the highest levels of qualification are larger for the younger ages. Among 16-29 year olds, those with no qualifications are over four and a half times more likely to become

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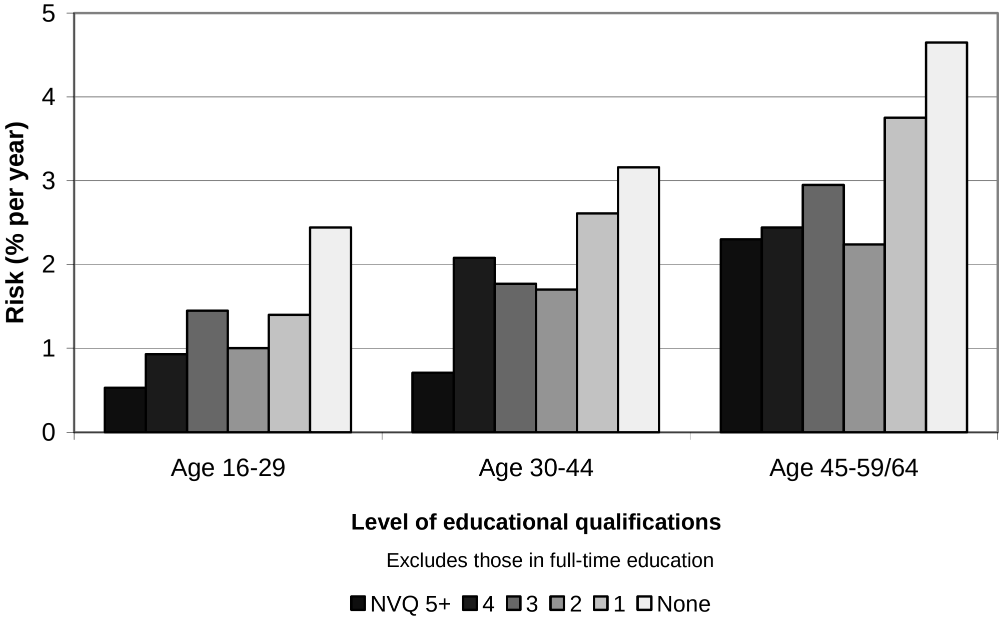
[9] 'Other' type of onset includes those who reported a health problem longer than two years (waves) before onset of disability, and those who do not report any kind of health problem or condition, nor an accident, prior to becoming disabled.

disabled than their counterparts who already have a degree, while among those aged 45 or over, the difference is only two-fold.[10]

Figure 2.4: Risk of onset, by age and educational qualifications



There is a convergence between the top and the bottom of the educational spectrum in terms of the risk of becoming disabled in older age groups. Part of the explanation may be that leaving school with no educational qualifications today is a much more significant economic disadvantage than it was 30 or 40 years ago. Another part of the explanation is that health problems associated with ageing itself account for a higher proportion of onsets of disability at older ages – a process which is independent of social and economic circumstances to a greater extent than the predominant causes of onset of disability at younger ages. At younger ages, although many fewer people become disabled overall, nearly one quarter are the result of accidents. The risk of having an accident is much more closely bound up with one’s living and working environment than the risk of ageing.

Education could have a direct effect on risk of onset through differences in diet, exercise and access to healthcare, but it seems unlikely that this is the chief cause of differences in rates of becoming disabled: more likely is that higher qualifications give better access to employment

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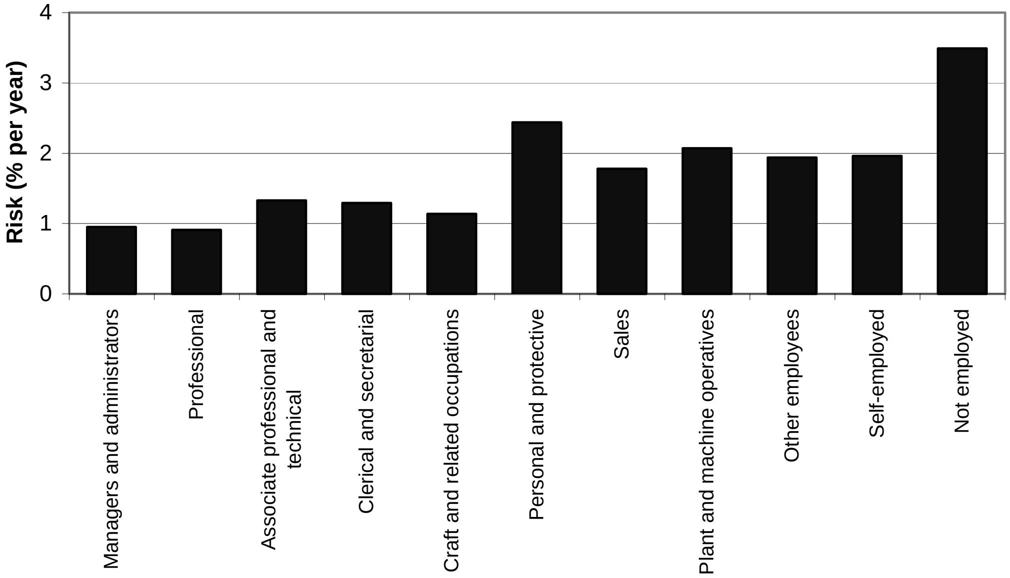
[10] Excluding those who are still in full-time education.

and to better-paid employment and thereby to higher income. Qualifications are also correlated with social class, representing a bundle of characteristics, some of which could affect risk of onset of disability. It is of course difficult to tease apart these various explanations, although Jenkins and Rigg's analysis finds independent effects of employment status and whether the individual has any qualifications.

Figure 2.5 shows the variation in rates of becoming disabled, by employment status and, if an employee, type of occupation. The higher risk faced by those who are not in any kind of employment can be clearly seen – more than twice the average of the other groups. Those who are self-employed or in low-status occupations (plant and machine operatives, sales, personal and protective services) face an intermediate level of risk, while those in professional or middle-ranking occupations are at relatively low risk of becoming disabled.

Some of this difference in risk is related to occupational hazards, but as we have seen, work-related accidents which result in disability account for less than 1 in 7 disabling accidents and accidents themselves account for only a minority of those who become disabled. For this relatively small group, the Health and Safety Commission (2002) calculates that the risk of 'major injuries' is highest among employees in the category of 'other occupations' – which consists of mainly manual, unskilled labour. This is followed by 'plant and machine operatives', and 'craft and related occupations'. These three categories have a rate of major injuries of more than 200 per 100,000 employees, while all other occupational groups have a rate lower than 90 per 100,000 – with 'professionals' experiencing a rate as low as 38 per 100,000. Thus the risk of a major injury at work is strongly related to occupation, and thereby to educational qualifications.

Figure 2.5: Risk of becoming disabled, by employment status and occupation

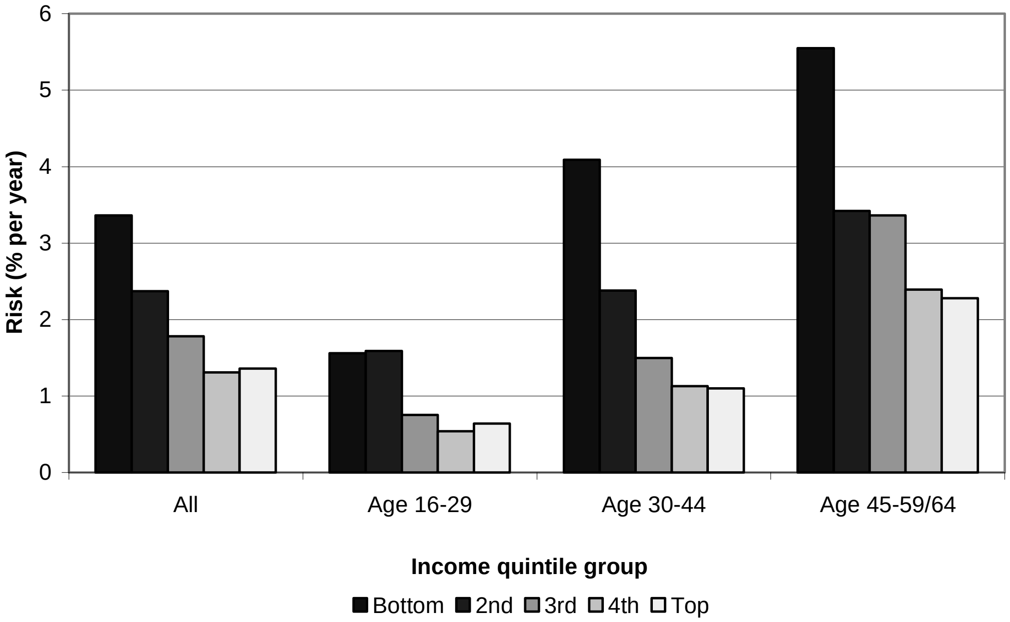


Work-related illnesses are harder to detect because it is not always obvious to what extent a condition was caused by, or made worse by, an individual's employment. Unfortunately, the Health and Safety Executive's series on illness which respondents believe to be work-related is not broken down by occupation. However, it does indicate that while the incidences of some types of condition (for example, deafness) are declining, others such as stress, depression and anxiety are on the increase (HSE, 2002).

Finally, Figure 2.6 shows the association between low household income and high risk of becoming disabled. This holds across all age groups. The difference between the first and second low income groups is greater than between subsequent pairs of income groups; indeed there is hardly any difference at all between the top two groups. This suggests that income matters more at the bottom of the distribution (or, in more formal language, the relationship is non-linear).

Income is the product of employment status and occupation of the individual (which in turn is related to educational qualifications), but also of household composition and the economic activity of other household members. Income can therefore be seen as a summary of many of the other characteristics we have examined above. Low income could also play an important role in its own right as a risk factor for becoming disabled, as the literature on health inequality suggests.

Figure 2.6: Risk of becoming disabled, by income and age group



As far as we can tell from our proxy measure for severity of impairment, individuals in the bottom income group who become disabled also have more severe impairments than those in the top income: an average of 2.2 health problems or impairments, compared to 1.9.[11]

2.4 Discussion

Some of the characteristics we have considered in this chapter are not amenable to policy intervention: the increase in risk of becoming disabled associated with ageing is largely outside the influence of social policy. Similarly, although we cannot be sure what lies behind regional differences, the fact that living in Wales (for example) appears to be associated with higher risks, independently of economic status, may be difficult to tackle with standard policy tools. However, other associations which have been detected in the analysis – the relationship with lack of educational qualifications, with employment status and occupation - are much more susceptible to intervention. This could take the form either of ensuring that fewer people find themselves in high risk categories in the first place, or of breaking the links between, for example, being in low-status occupation and high risk of becoming disabled. More detailed suggestions will be made in the concluding chapter of this report, but for now it may be helpful to illustrate the magnitude of the difference in risk due to characteristics which are amenable to policy intervention.

The examples in the box are based on a model of the risk of becoming disabled, controlling for age group, whether in a high or low-risk region, educational qualifications, employment status, occupation if employed, and household income quintile group.[12] The estimated risks should be taken as illustrative rather than precise since the model can explain only a small proportion of the overall variation in risk of becoming disabled.

Example 1 is chosen as someone with intrinsically high risk – an older man living in a high risk area. But comparing (a) and (b), we can see that the actual risk he faces depends greatly on his economic circumstances. If he is unlucky enough to be without a job or qualifications and to have a low household income, his risk of becoming disabled is 7 times as high as the risk for a wealthy professional.

The individuals in example 2 have intrinsically low risks of becoming disabled – young women living in low-risk areas. But again, the difference between (c) and (d) indicates the significance of education, employment and income. In this case, the woman in disadvantaged circumstances faces a risk more than 10 times as high as her more fortunate counterpart. Policy interventions may not be able to reduce the difference in risk between 1 and 2, but they could certainly narrow the gap between (a) and (b), and between (c) and (d).

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[11] This difference is statistically significant at the 90% level.

[12] Probit regression. High risk regions defined as above. Income is household net equivalised before housing costs income. Predicted values from the model for individuals with the characteristics listed in the examples give the estimated risk of becoming disabled in the following year. Full details available from the author.

Example 1: *man aged 55-64, living in a high-risk region*

(a) a professional, with a degree, and household income in the top fifth of the distribution

Risk of becoming disabled in the next year: ***1.7 per cent***

(b) not working at present, no educational qualifications, household income in the bottom fifth of the distribution

Risk of becoming disabled in the next year: ***11.9 per cent***

Example 2: *woman aged 25-34, living in a low risk region*

(c) a professional, with a degree, and household income in the top fifth of the distribution

Risk of becoming disabled in the next year: ***0.3 per cent***

(d) not working at present, no educational qualifications, household income in the bottom fifth of the distribution

Risk of becoming disabled in the next year: ***3.7 per cent***

3. Risks of poverty following onset of disability

3.1 Introduction

One consequence of someone becoming disabled can be a change in household income. As discussed in the Introduction, this may arise for a number of reasons – because the individual him or herself ceases employment or changes job, because other household members increase or decrease their hours of paid work to adjust to the new situation, or because benefit entitlement changes. In addition, the household may have to spend money on items which were not previously part of the budget – aids and adaptations or personal assistance, for example. Each of these processes is considered in greater detail in subsequent chapters; the task in this chapter is to describe overall changes in income and in particular, to consider the risks of entering poverty, and the chances of leaving poverty, associated with becoming disabled.

This chapter uses the two-period definition of becoming disabled identified in the previous chapter (that is, becoming limited in activities of daily living and remaining so for at least two consecutive annual interviews), in order to identify individuals in households where someone becomes disabled. Changes in income for this group are compared to changes in income for individuals in households where no-one becomes disabled.[13] As a short-hand, these groups are referred to as individuals in "affected" and "unaffected" households respectively. Individuals may leave one household and form or join another; accordingly the analysis follows individuals rather than households over time.

Even though the risk of becoming disabled does not vary significantly by gender or household composition, as discussed in the previous chapter, the economic impact for an unemployed single mother and for a husband in a two-earner professional couple can be dramatically different. Accordingly, much of the analysis in this chapter is presented with a breakdown by household type.

Since we are interested in income as representing standards of living, a measure of net income, rather than gross income, is appropriate: current net household income before

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[13] Either kind of household may contain individuals who were already disabled.

housing costs, equivalised for household size using the McClement's scale.[14] Change in household income is measured from one interview to the next, approximately one year apart. In order to be able to make comparisons across the years (1991 to 1998), all incomes are deflated to January 1998 prices.

There is no consensus on measurement of poverty, but a poverty line of 60 per cent of median income is increasingly widely used in both European Union and UK official statistics. This threshold is applied here.

3.2 Overall changes in income

Jenkins and Rigg (2003) find that the mean household income of those who became disabled was already falling prior to the onset of disability, and that it recovered somewhat in the subsequent two years (although not returning to pre-onset levels). Between the interview approximately two years before onset and the interview immediately after onset, mean income fell by 8 per cent, and the proportion of individuals with income in the lowest fifth of the income distribution rose by 5 percentage points.

Using the slightly different definitions of disability and income employed in this report,[15] the mean change in weekly household income for individuals in households in which someone becomes disabled is – £12 (comparing year of onset to preceding year), while the corresponding change for individuals in unaffected households is +£6. However, these summary statistics hide considerable variation, as indicated by Figure 3.1. A higher proportion of individuals in affected households experience static or falling incomes than individuals in unaffected households, but almost half experience a gain in income.

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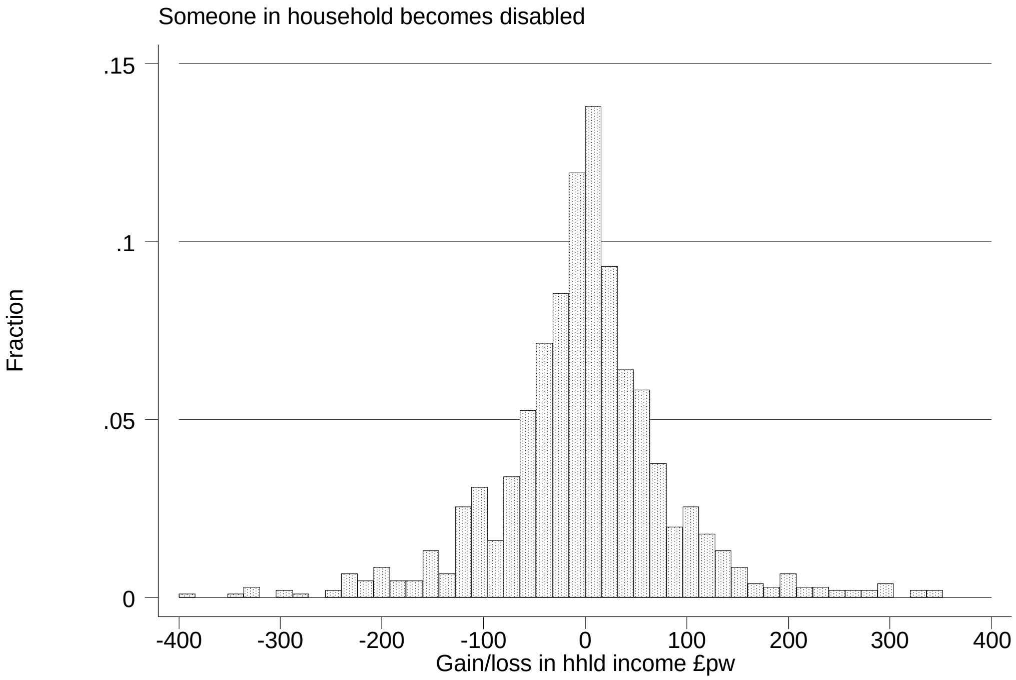
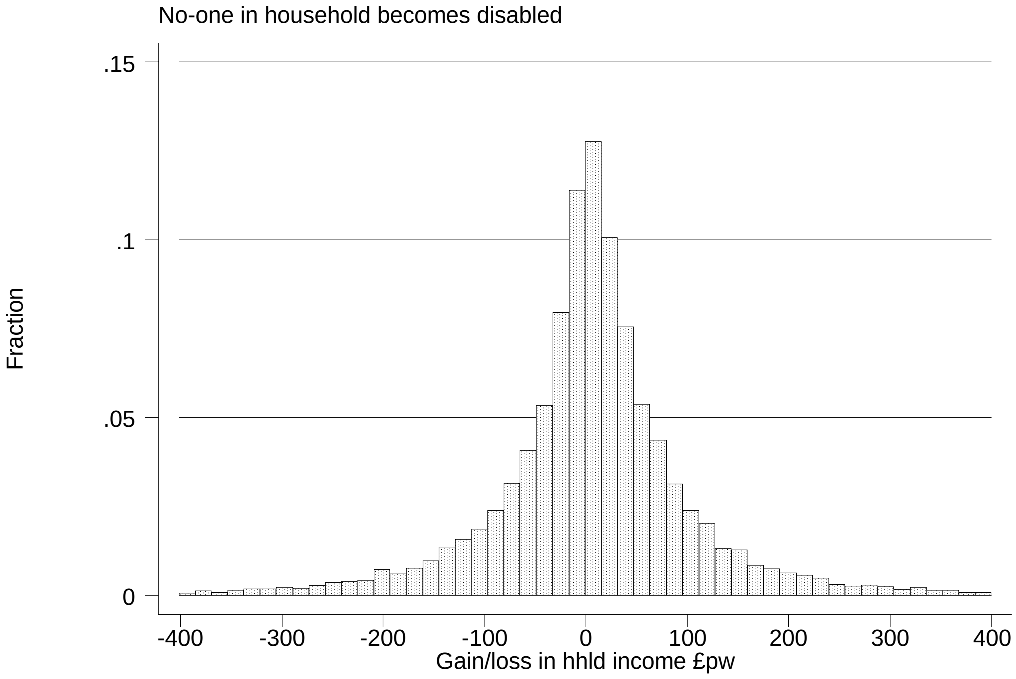
[14] Neither 'before housing costs' nor 'after housing costs' measures of income are ideal. The former treats expenditure on housing as discretionary, which of course it may not be, while the latter risks equating someone living in a mansion with someone living in a bedsit, if they have the same income after paying the rent.

[15] Jenkins and Rigg's measure of income is based on annual income (as opposed to the current income measure used in this report), and their definition of disability requires two observations of 'non-disabled' followed by at least one observation of 'disabled' (in contrast to requiring one observation of 'non-disabled' followed by at least two of 'disabled').

Figure 3.1: Distribution of individuals by year-on-year change in weekly household income





Note: distribution of changes in household income trimmed at 1st and 99th percentile

There are numerous reasons for this variation, not all of them related to becoming disabled at all. Household composition, whether the individual who becomes disabled was working and whether anyone else in the household was working are all important factors, as shown in Table 3.1.

Table 3.1: Year-on-year change in household income, by household type and whether someone becomes disabled

£ pw in 1998 prices

Initial household status	**Individuals in affected households** 1	**Individuals in unaffected households** 2	**Difference** 1 minus 2
Single adult, not employed	-16	+24	-40***
Single adult, employed	-20	+ 4	-24
Couple, neither employed	+16	+14	+ 2
Couple, one employed	- 6	+ 7	-13**
- *person who becomes disabled*	*-19*	--	
- *partner*	*- 2*	--	
Couple, both employed	- 7	0	-7
Other	+ 6	+11	- 5
Number of observations	*1,065*	*27,104*	

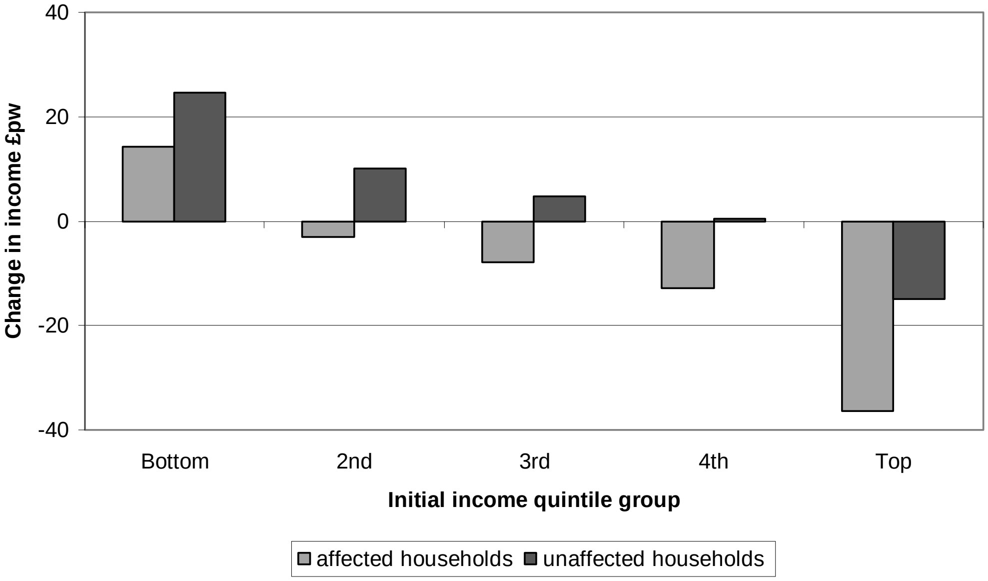
Note: based on distribution of changes in household income trimmed at 1st and 99th percentile.

** statistically significant at 5 % level *** statistically significant at 1 % level

Single adults who become disabled, whether or not they are initially employed, appear to be susceptible to significant falls in income. Among those not employed, the fall in income is much larger than for single adults who do not become disabled: perhaps because the latter are more likely to move into employment. The consequences for couples of one partner becoming disabled vary greatly by their employment status. Where neither partner is initially employed, the outcome is a gain in income, on average, presumably as a result of increased benefit entitlement. By contrast, if the partner who becomes disabled was employed, the fall in income can be substantial. These changes in benefit and employment status will be examined in more detail in the following two chapters.

Another source of variation in the gains and losses experienced following onset of disability is the level of household income initially. Figure 3.2 indicates that in general, households with income in the lowest fifth of the distribution initially tend to experience an increase in income over the period of a year.[16] This finding is common to analysis of income dynamics. It holds whether or not someone in the household becomes disabled, although those in unaffected households experience a larger gain in income, on average, than do individuals in affected households. As we move up through the second, third and fourth fifths of the income distribution, those in unaffected households continue to increase their income over a year, albeit by modest amounts, while those in households in which someone becomes disabled experience small losses. Finally, in the top income group, household income tends to fall over the period of a year, whether or not someone in the household becomes disabled. The average fall in income is more than twice as large for affected households, however.

Figure 3.2: Change in household income, by initial income and whether someone becomes disabled



Jenkins and Rigg (2003) indicate that for many households, income is already falling before onset of disability, and consequently the drop in income at the time of onset itself may not be so great. This can be interpreted in two ways. Either the falling income is itself a risk factor

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[16] The figure shows the median increase (or decrease) in income for individuals in that category. If changes in income are arranged from biggest decrease to biggest increase, the median value is the middle value.

for onset of disability, or health problems which do not yet constitute disability nevertheless contribute to lower earning power (or, of course, both processes may occur simultaneously). One way of checking this hypothesis is to analyse the change in income by type of onset, as in Table 3.2.

Table 3.2: Change in household income, by type of onset of disability

Individuals who become disabled

Type of onset	Change in income (£pw 1998 prices)
Accident	-7
Sudden illness	-5
Gradual illness	+1
Other	-5
Number of observations	*558*

Note: distribution of changes in household income trimmed at 1st and 99th percentile

The table confirms that those who experience an unexpected deterioration in health or an accident have larger falls in household income than those whose condition has developed gradually. To examine this further, we can look at the income trajectory of the household in the years before onset of disability. The classification of income trajectories used here follows that devised by Gardiner and Hills (1999). In each year (or ‘wave’ of the survey), individuals are categorised by which 100th (percentile group) of the income distribution they fall into. If individuals move up 15 or more percentiles over a period of three years, and do not ever fall more than 15, they are said to have a ‘rising’ income trajectory. Conversely, if they move down through 15 or more percentiles, and do not ever move up more than 15, they are said to have a ‘falling’ trajectory. If they neither rise nor fall more than 15 percentiles, they are classified as a ‘flat’ trajectory. All other patterns, for example, moving both up and down, are left as a residual category. The results are shown in Table 3.3.

Table 3.3: Income trajectory over three previous waves

(immediately prior to onset of disability for those who become disabled)

Row percentages

Type of onset	Income trajectory over previous 3 waves				
	Rising	Flat	Falling	Other	*Number of cases* = 100%
Accident	14	55	15	16	*73*
Sudden illness	18	37	12	33	*187*
Gradual illness	12	32	22	34	*68*
Other	13	43	18	26	*72*
Any onset	15	41	16	29	*400*
No onset	14	44	16	26	*19,727*

The results confirm that those who experience gradual onset are more likely than other groups to be on a ‘falling’ income trajectory over the three years previous to when they first report being disabled. By contrast, those who experience an accident are more likely to have been on a ‘flat’ income trajectory, perhaps reflecting the younger age profile of these individuals. Those who experience a sudden illness are slightly more likely than other groups to have been on a rising trajectory prior to onset. Combining the different types of onset together, there is little difference between the income trajectories of those who become disabled and those who do not over a comparable period.

There is also a relationship between change in income following onset of disability, and severity of impairment, as far as we can tell. Those who report either no or only one health problem, experience a small gain of £4 in household income, those who report two or three conditions experience a small loss, and those who report four or more conditions experience a loss of £17, on average.[17]

3.3 Transitions into and out of poverty

In chapter 2, it was shown that people with low income were more likely to become disabled (other things being equal) than those with higher incomes. We have also seen that the immediate financial impact of someone becoming disabled can be an increase or a decrease

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[17] Calculated on the basis of the trimmed distribution of changes in household income.

in income, depending on the circumstances of the household: households with initially low income tend to experience an increase. This might lead us to expect that for poor households, someone becoming disabled would be associated with increased chance of exiting poverty. Table 3.4 summarises the transitions into and out of poverty made by households with and without someone becoming disabled.

Table 3.4: Transitions into and out of poverty in year following onset of disability

		Individuals in affected households	Individuals in unaffected households
Not initially in poverty		*75 % of all*	*83 % of all*
of whom	% remain non-poor	86	93
	% enter poverty	14	7
Initially in poverty		*25 % of all*	*16 % of all*
of whom	% exit poverty	31	39
	% remain in poverty	69	61
All		*100*	*100*
Number of observations		*1,320*	*33,425*

Note: poverty is defined as income less than 60 per cent of median income for individuals of working age. Income is current net household income before housing costs, equivalised for household size.

Initially, one-quarter of individuals in households in which someone will become disabled are in poverty, a higher proportion than of unaffected households. Of this one-quarter, just under 1 in 3 exit poverty in the year after someone has become disabled. This is a high proportion, but not as high as the proportion of individuals in poor households not affected by onset of disability who exit poverty over a comparable period. In other words, although an increase in income can occur as a result of someone becoming disabled (for example due to increases in benefit entitlement), it does not result in as many households leaving poverty as is achieved in unaffected households by means of other routes (for example through someone getting a job or a change in household composition). Of those not initially in poverty, twice the proportion of individuals in affected households enter poverty than individuals in unaffected households.

3.4 Risks of poverty before and after onset

Jenkins and Rigg (2003) identified that individuals who were not in paid employment, or who lived on their own or in a household containing two or more dependent children, were more likely to enter poverty than other individuals who became disabled. Of course, these characteristics are also associated with risk of entering poverty, even without the onset of disability. There may also be other, hidden, characteristics which are associated with greater risk of poverty. In order to try to isolate the effect on risks of poverty of becoming disabled, it is necessary to compare the risk of being in poverty prior to becoming disabled with the risk for the same individual of being poor when he or she becomes disabled. This can be achieved by means of technique known as fixed effects regression. An ordinary regression seeks to explain variation in the risk of poverty *between* individuals. A fixed effects regression seeks to explain variation in the risk of poverty for the same individual over time. A very simple version is shown in Table 3.5.

Table 3.5: Risk of being poor, before and after onset of disability

Fixed effects logit regression on ‘below 60 per cent median income’; individuals who become disabled at some point during panel

Characteristic		**Odds ratio**
Before onset		1.00
At or after onset		1.33*
Age		0.95
Household type	single no children	1.00
	couple no children	0.36***
	couple with children	0.79
	lone parent	1.61
	other	0.36***

Statistically significant at * 10% ** 5% *** 1%

Log likelihood –816 Number of observations 2130

The sample is restricted to those who become disabled at some point during the period for which we observe them. The risk of being poor (defined as above) is calculated separately for each individual, and controls are included for any characteristics which are likely to *change* during the course of the panel. These include, importantly, disability status, but also age, and household type. Other characteristics such as gender, educational qualifications and region of residence may also influence an individual's risk of being poor, but in only a few (or no) cases do they change during the period of observation, so they do not affect the *change* in risk of poverty associated with becoming disabled.

The results indicate that individuals are indeed at an increased risk of being poor after onset of disability, relative to their own previous risk of being poor and given all their (fixed) characteristics such as gender and educational qualifications. This is shown by the odds ratio associated with 'at or after onset' being greater than 1 (and statistically significant). Getting older – at least over a period of a few years – does not make a significant difference to risk of being poor, but acquiring a partner (without children) decreases an individual's chance of being poor, as does entering a household with more than one other adult. Becoming a lone parent increases the risk of being poor, but there are not enough individuals in the sample to make this significant.

3.5 Discussion

This chapter has explored the wide variation in the impact of the onset of disability on a household's income and poverty status. Part of this variation is due to initial circumstances: while those who become disabled are disproportionately drawn from low-income groups, nevertheless a majority are not below the poverty line before the onset of disability. There is also significant variation by household type, the employment status of the individual and of the spouse (if there is one), and by the type and severity of onset.

Despite this variation, some overall conclusions can be drawn. Firstly, compared to households unaffected by the onset of disability, individuals in affected households face an increase in the risk of entering poverty, and a decrease in the risk of leaving poverty. This suggests that the help currently provided through the social security system is not sufficient to avert poverty. Secondly, those with sudden onset (as a result of an accident or illness) experience a larger drop in income, on average, than those whose condition has developed gradually. The latter are more likely to have already been on a falling income trajectory in the preceding years. This has implications for the kind of support that is required, both financial and practical.

4. Changes in paid and unpaid work

For many households, the largest share of income comes from earnings, and one part of the explanation of the fall in income experienced by some of those who become disabled is a drop in earnings – or even a cessation of employment altogether. By no means all of those who become disabled leave employment, however, and it is interesting to explore who is able to keep their job and who is not. Changes in the employment status of one individual can have knock-on effects on other household members too, especially a spouse. He or she may try to increase his or earnings to compensate for the loss in income from the newly-disabled person. He or she may wish to, or be obliged to, give up paid work in order to provide care or assistance at home. The couple may also find that the benefits system does not provide adequate means to support a one-earner family and that they are better off if neither of them work. These changes in employment status and unpaid caring responsibilities are the subject of this chapter.

4.1 Own employment and earnings

One outcome of becoming disabled can be loss of employment, a reduction in hours, or a reduction in earnings. Often such loss could be avoided given appropriate support from the employer, adaptations to the workplace or job, or better integration of other support, for example from social services or the benefits system. Nevertheless, loss of employment is all too frequently the upshot.

In earlier work for the Joseph Rowntree Foundation (Burchardt, 2000a), it was shown that around 1.5 per cent of those in paid work (approximately 375,000 individuals) became disabled each year. Of these, around 1 in 6 (17 per cent) left employment in the first year after becoming disabled. The rate of exit from employment decreased as time went on, so that after five years had elapsed, a total of 36 per cent had left employment. Of course, non-disabled people also leave employment for various reasons (redundancy, dismissal, childcare responsibilities, etc), but multivariate analysis indicated that the risk of leaving employment following onset of disability was higher by one-and-a-half to three times, even after controlling for a range of personal, job and workplace characteristics.[18]

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[18] Cox proportional hazards models stratified by age and gender, with controls for marital status, ethnicity, occupation, industry, size of workplace, availability of occupational pension scheme, hourly pay, hours of work, and job tenure.

Among men, those who worked in manual occupations and those who worked at a small workplace were more likely to leave employment following onset of disability, and these risk factors were greater than they were for men who did not become disabled. Among both men and women, those who reported musculo-skeletal problems, those with sensory impairments, and those with mental health problems were more likely to leave employment than others who became disabled.

Similarly, Jenkins and Rigg (2003) found that overall employment rates among those who became disabled fell from 73 per cent in the year before onset, to 55 per cent in the year of onset itself, and then further to 52 per cent the year after.[19] Employees who did not have any educational qualifications were more likely to leave paid work.

Further analysis using panel data from the Labour Force Survey was able to examine in more detail the months immediately after someone became disabled (Burchardt, 2003). This showed that estimates of job retention were highly sensitive to the precise definition of onset of disability used. Those who became disabled according to the Disability Discrimination Act definition did not necessarily take a extended period off work, and on average were much more likely to retain their employment than those who became sick or disabled and were obliged to take time off. Most factors which were associated with increased risk of leaving employment within a year of onset of sickness or disability were also associated with increased risk of leaving employment in general. These common factors were low human capital (lack of educational qualifications, short job tenure) and poor employment protection (small workplace, female gender or part-time employment, manufacturing or construction industry). Three risk factors specific to the onset of sickness or disability were also identified: having mental health problems (a particularly strong effect), being aged 45 or over, and living in a region with low labour demand.

These three studies present a fairly clear picture of the risk of leaving employment following onset of disability, and who is most at risk. The financial impact of employment loss of course depends on what the individual was earning in the first place. Jenkins and Rigg (2003) found that average gross weekly earnings (including zero earnings for those not in employment) of all those who became disabled and remained disabled for at least two years

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[19] The results quoted are for those individuals who remained disabled for at least two years.

fell from £167 per week two years before onset, to £113 per week in the year after onset (in year 2000 prices).

Breakdowns by household type of changes in employment status, and in earnings, are given in Tables 4.1 and 4.2 respectively.

Table 4.1: Year-on year change in own employment status, by household type

	Individuals in single-adult households		**Individuals in two-adult households**	
	Becomes disabled at y = 2	Does not become disabled at y = 2	Becomes disabled at y = 2	Does not become disabled at y = 2
Status at year y = 1				
% employed	44	70	61	81
% not employed	56	30	39	19
Of those employed at y = 1, status at year y = 2:				
% remain employed	65	94	78	94
% leave employment	35	6	22	6
Of those not employed at y = 1, status at year y = 2:				
% remain non-employed	96	79	90	74
% enter employment	4	21	10	26
Number of observations	*90*	*3,708*	*380*	*18,029*

Note: employment status classified on the basis of whether has any earnings, not reported employment status. Individuals in neither single-adult nor couple households are not included in the table.

Looking at single adults first, we can see that, as expected, fewer of those who will become disabled are in employment initially than those who will not experience onset of disability. Moreover, as shown in the bottom panel of Table 4.1, very few of those who are not initially in employment and become disabled move into employment, while around 1 in 5 of those who do not become disabled move into work.

Table 4.2: Year-on-year change in earnings, by household type

	Individuals in single-adult households		**Individuals in two-adult households**	
	Becomes disabled at y = 2	Does not become disabled at y = 2	Becomes disabled at y = 2	Does not become disabled at y = 2
Median earnings at year y = 1				
Employed	£254	£271	£206	£264
All	£ 0	£180	£ 91	£215
Median change in earnings by year y = 2				
Those who remain employed	£ 0	+£11	+£ 5	+£12
Those who leave employment	-£129	-£130	-£186	-£180
All	£0	£0	£0	+£4

Note: All figures in January 1998 prices.

Among single adults who are initially in employment, the proportion who leave employment is nearly six times higher among those who become disabled than among the non-disabled.

The situation for individuals who are part of a couple is slightly better: a higher proportion are in employment initially, and of those, a higher proportion retain their employment after becoming disabled. Nevertheless, more than 1 in 5 leave employment.

Change in earnings tells a slightly different story (Table 4.2). Those who leave employment *not* as a result of becoming disabled experience similar falls in earnings to those who leave following onset of disability. However, the latter have lower average earnings to start with, so proportionately, their loss is greater.

The impact of a fall in earnings of the individual who becomes disabled depends in turn on the response of other household members, where there are other adults in the household. Single-adult households, including lone parents, are more vulnerable in this sense, because there is no-one who can compensate for their lost earnings.

There is also a relationship between severity of impairment and changes in earning status. To begin with, those who become severely disabled (as gauged by the number of different health problems or impairments they report) are less likely to have been working before onset of disability: 54 per cent of those who report four or more problems were previously working, compared to 64 per cent of those who report no or only one problem. Furthermore, among those who were working, a large majority (84 per cent) of those with apparently the least severe impairments retain their employment, while only just over half (56 per cent) of those with four or more health problems do so.

4.2 Spouse's employment and caring activity

A recent study for the Joseph Rowntree Foundation of people in their fifties and sixties with caring responsibilities found that few wanted to give up paid work, although a combination of financial, health and job-related considerations sometimes meant that they did (Mooney et al, 2002).[20] Many of those who continued to work reported significant personal costs, including tiredness, ill health and lack of leisure time.

Table 4.3 summarises the transitions between different combinations of employment status made by couples. The top panel shows what happens for couples when one partner becomes disabled. For comparison, the lower panel shows the changes which occur year-on-year for couples in which no-one becomes disabled.

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[20] Not all of the carers in the Mooney et al study looked after disabled partners; many looked after grandchildren or parents.

Table 4.3: Transitions between no-earner, single-earner and two-earner couples

Individuals who remain in couple households only

(a) Someone becomes disabled

column %	**Initial status at year y = 1**	**Status after onset of disability at year y = 2** *row percentages* No-earner	1-earner	2-earner	All
23	No-earner	90	7	4	100
31	1-earner	22	64	14	100
11	*becomes disabled*	*28*	*58*	*15*	*100*
19	*doesn't become disabled*	*19*	*67*	*13*	*100*
46	2-earner	2	22	76	100
100%	*Number of observations*	*199*	*217*	*283*	*699*

(b) No-one becomes disabled

column %	**Initial status at year y = 1**	**Status at year y = 2** *row percentages* No-earner	1-earner	2-earner	All
9	No-earner	76	18	5	100
27	1-earner	7	70	23	100
65	2-earner	1	10	90	100
100%	*Number of observations*	*1628*	*4800*	*11788*	*18216*

The first point to note is that no-earner couples make up a higher proportion (23 per cent) of couples in which someone will become disabled than of unaffected couples (first column, extreme left of table). This is as we would expect, since we know that those who are not employed are more likely to become disabled. The proportion of single-earner couples is similar in the two groups however.

Of those initially in no-earner couples, nearly all remain in that position when one of the partners becomes disabled. The chances of either partner entering employment in the year in which one becomes disabled are small. By contrast, among individuals in no-earner couples unaffected by the onset of disability, 24 per cent gain employment by the following year.

Among single-earner couples, the experience of onset of disability depends importantly on whether it is the earner who becomes disabled or his/her partner. In just over 1 in 5 cases where the earner becomes disabled, the couple becomes a no-earner couple. The individual who becomes disabled leaves employment and there is no compensating gain in employment for the spouse. Interestingly, even where the earner is not the one who becomes disabled, he or she is quite likely to leave employment, and the couple becomes a no-earner couple. (This is a significantly higher proportion of exits from employment than occurs in couples unaffected by the onset of disability). The most likely explanation is that he or she has to take on unpaid caring responsibilities, although it is also possible that the risks of employment loss is higher for these individuals because of their other characteristics (age, educational qualifications, etc).

Finally, among individuals in two-earner couples, just over 1 in 5 become part of a single earner couple when one partner becomes disabled, and a small but not insignificant proportion become no-earner couples.

We can examine the issue of caring responsibilities more directly using the questions asked in the survey about hours spent looking after others in the household (except children). Overall, 5 per cent of individuals in couples report some caring responsibilities. Of these, 45 per cent spend less than 20 hours per week caring, but 30 per cent spend 100 hours or more.

Ten per cent of individuals whose spouse becomes disabled report that they have taken on caring responsibilities at that time, and two-thirds of those who already had caring responsibilities continue to do so. Among those who take on new responsibilities, or continue with existing arrangements, half spend less than 20 hours per week caring, but nearly 1 in 4 spend 100 hours or more: an enormous commitment of time. Of those who were in employment before taking on their new caring role, one quarter leave employment. Clearly, full-time (sometimes round-the-clock) caring responsibilities are incompatible with continued paid employment.

Table 4.4: Change in caring responsibilities for those whose spouse becomes disabled

Individuals in couple households only

	Begins or continues caring	**Other**
Row percentage	13	87
Hours caring per week[†]	*col. %*	
1-19 hours	50	-
20-35 hours	19	-
35+ hours	31	-
Percentage of those in employment who leave	24	5
Number of observations	*37*	*254*

[†] The response 'Varies 20+ hours' (= 9 per cent) is split between '20-35 hours' and '35+ hours' in the same proportions as responses indicating non-varying hours per week.
Includes hours caring for others outside household, if any.

In section 4.1, the evidence on who was most likely to leave employment following onset of disability was reviewed. Less is known about who is most likely to leave employment following a spouse becoming disabled. Factors likely to be relevant include the individual's age and gender, the characteristics of his or her employment (for example, hours worked, weekly earnings, and how long he or she has held the job), and the circumstances of the spouse who becomes disabled (whether he or she was in employment, whether he or she needs to be cared for). Table 4.5 presents the results of multivariate analysis of the likelihood of retaining employment, controlling for these characteristics.

The middle column is for all individuals in couples who are initially in employment, and includes a variable indicating whether or not the spouse becomes disabled (bottom row of main panel). The fact that the coefficient on this variable is negative and significant, indicates that individuals whose spouse becomes disabled are indeed less likely to retain their employment, even after controlling for various job and personal characteristics. They face generally lower rates of employment retention because of their lower earnings and older age, but the fact that their spouse becomes disabled is an additional factor.

Table 4.5: Likelihood of retaining employment (when a spouse becomes disabled)

Individuals initially in employment, with a spouse

		All Marginal probability	**Those whose spouse becomes disabled** Marginal probability
Gender	female	reference category	reference category
	male	-0.006	+0.012
Age group	16-29	reference category	reference category
	30-44	+0.019***	+0.000
	44-59/64	-0.005	+0.028
Usual hours pw	< 16	reference category	reference category
	16-34	+0.017***	+0.068
	35+	+0.012*	+0.092
Log of weekly earnings		+0.031***	+0.024
Duration of job	< 1 year	reference category	reference category
	1-3 years	+0.004	-0.028
	3+ years	-0.051***	-0.356***
Spouse was working	no	reference category	reference category
	yes	+0.061***	+0.082*
Spouse's care needs	none	-	reference category
	new	-	-0.144*
	continuing	-	-0.078
Spouse becomes disabled	no	reference category	-
	yes	-0.029**	-
Number of observations		14,295	250
Log likelihood		-3129	-76
Mean predicted probability		0.95	0.91

* significant at 10% level ** significant at 5% level *** significant at 1% level

There are not many statistically significant results when we look for differences among those whose spouse becomes disabled (right-hand column). This may be because differences genuinely do not exist or because the BHPS sample size is not large enough to detect them. The results do confirm, however, that if the spouse was also working (in other words, if it was a two-earner couple initially), the chance of the non-disabled spouse retaining his or her employment is higher. The results also suggest the importance of taking on new caring responsibilities: compared to those whose partner does not have care needs, those who take on new responsibilities are much more likely to leave employment.[21] Again, this holds even after controlling for other job and personal characteristics.

4.3 Changes in combined earnings of couples

Jenkins and Rigg (2003) found that on average, 'other household labour income' – that is, the earnings of household members other than the individual who became disabled – fell immediately after onset, but recovered somewhat in the following year. It appears that new caring responsibilities, and the greater vulnerability of individuals with these kinds of characteristics to loss of employment, more than offsets the pressure to compensate for lost earnings of the newly disabled partner. Table 4.2 showed what happens to the earnings of individuals who become disabled themselves, and Table 4.3 showed the changes in the spouse's employment status. Table 4.6 shows the combined impact of changes in employment status and caring responsibilities of both partners on the earnings of couples. Both mean and median earnings are given because of concerns about outliers and measurement error.

Table 4.6: Changes in combined earnings for couples,
by initial employment status

(a) Someone becomes disabled *£ per week*

	Initial earnings		Change in earnings		
Initial status	median	mean	median	mean	*No. of observations*
No earner	0	0	0	+18	*168*
1-earner	219	311	0	-69	*238*
becomes disabled	*172*	*235*	*-15*	*-57*	*92*
doesn't become disabled	*244*	*359*	*+1*	*-77*	*146*
2-earner	476	563	-8	-72	*374*

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[21] We cannot be sure whether taking on caring responsibilites pre-dates or post-dates the departure from employment. So it could be that those who leave employment for non-care-related reasons are more likely to take up caring than those who remain in employment.

(b) No-one becomes disabled *£ per week*

Initial status	Initial earnings median	Initial earnings mean	Change in earnings median	Change in earnings mean	*No. of observations*
No earner	0	0	0	+54	*1,793*
1-earner	296	357	+20	+37	*5,466*
2-earner	531	591	+20	+7	*13,096*

Note: all earnings in January 1998 prices

As expected, initial earnings are lower among couples affected by onset of disability, and subsequent changes in earnings are either smaller increases than is the case for unaffected couples, or larger decreases. In absolute terms, the drop in earnings is greatest for 2-earner couples followed by single earner couples where the earner becomes disabled, but single earner couples lose a greater percentage of initial earnings.

4.4 Discussion

In examining the impact of someone becoming disabled on employment status and earnings it has become clear that the changes which are experienced depended greatly on initial circumstances. For some, existing disadvantage – low earnings or lack of employment – is compounded by becoming disabled. The chance of gaining employment falls and earnings rise less quickly than for non-disabled counterparts. For others, a relatively comfortable employment position is disrupted, and a significant fall in earnings occurs. For yet others, particularly those who are part of a couple, the impact on employment and earnings may be slight.

Being part of a couple can afford some protection against fall in income, but equally, one partner becoming disabled can impact on the other partner’s ability to continue in employment. Decisions about paid and unpaid work interact, so it is important to consider the impact on the household as a whole, not just the person directly affected.

5. Changes in benefit income

5.1 Overview

One of the purposes of a social security system is to protect against shocks to a family's standard of living as a result of events like the onset of disability, unemployment or retirement. In fact, this redistribution across an individual's lifetime, as opposed to redistribution from rich to poor, accounts for a large proportion of all benefit spending (Falkingham and Hills, 1995). This chapter considers whether the benefit system is doing its job properly in this respect, by compensating for lost earnings when someone becomes disabled.

The UK system has three elements, in addition to the general means-tested safety net (Income Support), which are designed to address the needs of people who become disabled. The first is a social insurance benefit, Incapacity Benefit (IB), which is insurance against being unable to work due to long-term sickness or disability. In its origins, IB is an 'earnings replacement benefit', that is, non-means-tested, earnings-related and paid on an individual basis. In practice, since 1979 the earnings-related element has been discontinued, and since 2001 the amount paid is reduced if the claimant is also in receipt of occupational or private pension income. The question posed in the next section, therefore, is to what extent IB is still effective as an insurance against lost earnings.

As discussed in Chapter 4, someone becoming disabled can also have significant implications for the employment capability of his or her spouse. When Beveridge was devising National Insurance, this was not a risk which he took into account – not surprisingly, since the 'male breadwinner, female housewife' model was prevalent at the time. Belatedly, an Invalid Care Allowance (ICA) was introduced in 1976, although it was not until 1987 that married women were able to claim it. ICA was never integrated into the National Insurance system and remains payable at lower rates than NI benefits. In April 2003 it was renamed Carers Allowance. Section 5.3 assesses the extent to which ICA/Carers Allowance compensates spouses for loss of earnings when they leave employment to look after a disabled partner. One of the issues which arises is the limited eligibility for, and take up of, ICA.

The third element of the benefits system specifically designed to assist disabled people are 'extra costs benefits', primarily Disability Living Allowance (DLA, for people who become disabled during childhood or working life) and Attendance Allowance (AA, for people disabled during retirement). These benefits are paid in recognition of the additional expenditure some disabled people incur, for example, on aids and adaptations, personal assistance, transport, heating, special clothing or diets. Consideration of the role these benefits play is held over to Chapter 6, in which the actual additional costs disabled people face are estimated, and compared to the levels of benefit they receive.

In looking at overall changes in the composition of household income when someone becomes disabled, Jenkins and Rigg (2003) conclude that social security does indeed ameliorate the financial impact of lost earnings. Both disability benefits and other benefits increase as a share of household income following onset of disability, and they also increase in absolute amounts. Individuals who became disabled received an average of £12 per week in disability benefits in the year of onset, rising to £16 the following year, while other benefit income for the household as a whole rose from an average of £39 per week two years before onset, to £47 in the year of onset, and £51 the year after (all in 2000 prices). However, these increases are not sufficient to bring total income back to pre-onset levels.

5.2 Incapacity Benefit: replacing lost earnings?

To be eligible for Incapacity Benefit, a claimant must pass a ‘personal capability assessment’ – which is to say, they must score above a certain threshold on a test of their inability to carry out various physical and mental functions. In addition, they must be currently out of work and have paid sufficient National Insurance contributions in the relevant years.[22]

To get an impression of the coverage of IB, we focus on BHPS respondents who are most likely to be eligible: those who were employed in the previous year, and who have now become disabled and left employment. Just under 1 in 3 respondents in this situation report receipt of Incapacity Benefit.[23] There are a range of explanations for those not getting IB. One relatively innocuous explanation is that they are receiving Statutory Sick Pay through their employer, usually payable for up to the first six months of sick leave. Unfortunately these individuals cannot be identified separately in the BHPS. Of more concern are those that have insufficient National Insurance contributions to qualify for IB (for example because

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[22] In certain circumstances, claimants are permitted to work, provided their weekly earnings are less than a low threshold.

their employment was very low paid or part-time, of short duration, or interrupted). Claimants who pass the personal capability assessment but do not meet the National Insurance contribution conditions may be entitled to other benefits like Income Support or Severe Disablement Allowance, although these have further conditions attached and are likely to be paid at a lower rate than IB.[24] There may also be some who are disabled according to the general definition used by BHPS but not according to the narrower definition used in the personal capability assessment. Claimants who fail the personal capability assessment may be able to claim Jobseekers' Allowance, subject to agreeing to undertake intensive job search activity. Finally, and most problematically, some individuals may make a claim and be incorrectly refused benefit. According to figures from the Department for Work and Pensions, there were around 3,600 successful appeals against Incapacity Benefit decisions in the first quarter of 2002 – over 14,000 per year (DWP, 2002b).

In April 2002, average gross weekly earnings for all employees were £386.50 (men and women, full- and part-time employees; Bulman, 2002). The short term higher rate of IB – the rate for which most claimants would qualify initially - was £63.25 per week. Additions for an adult dependant and two children could bring that up to £117.35 per week. In other words, these rates of benefit are between 16 per cent and 30 per cent of *average* earnings. But of course, claimants actual earnings can be higher or lower than the average, and their precise benefit entitlement depends on a range of factors.

Using the BHPS data to look at those who do successfully claim IB following onset of disability, the amount of benefit they receive varies from 16 per cent of their previous earnings to 147 per cent (although these figures should be treated with caution since they are based on just 40 cases). The median amount received is 41 per cent of previous earnings. Those with high replacement rates are individuals with low previous earnings, and who are entitled to additions to their benefit for dependants. Conversely, those with low replacement rates are individuals with relatively high previous earnings. If we take a 70 per cent replacement rate to be a reasonable objective for protection of living standards, fewer than 15 per cent of new IB claimants are able to achieve this objective.

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[23] Called Invalidity Benefit until 1995. For a discussion of the accuracy of benefits data in BHPS, see Data Appendix.

The combination of relatively limited coverage of IB and low replacement rates for those able to claim, means that overall, IB replaces 16 per cent of previous earnings, for individuals who become disabled and leave employment. For households with low or no income from IB, other sources may make up some of the shortfall (for example Income Support), so the most extreme poverty is prevented. But if the intention of IB is to protect living standards by insuring against loss of earnings, this function is clearly not being fulfilled.

5.3 Carers Allowance: compensating for lost earnings?

Despite the fact that eligibility for Carers Allowance has been extended since its introduction in 1976 (then known as Invalid Care Allowance or ICA), entitlement remains limited. Claimants must spend at least 35 hours per week caring for someone, and the ‘cared for’ person must be in receipt of the middle or higher rate of Disability Living Allowance care component or Attendance Allowance (for which of course there are also strict eligibility criteria). Furthermore, the carer must not earn more than a low threshold (£50 per week in 2000/1, or about 12 hours at the National Minimum Wage; increased to £77 per week in 2003). Consequently many individuals who have significant caring responsibilities do not qualify for the allowance.

The BHPS does not contain sufficiently detailed information to model eligibility for ICA accurately, so take-up is difficult to estimate, but some indication of the coverage of ICA - the proportion of carers who are in receipt of ICA - can be gained, as shown in Table 5.1.

Table 5.1: Coverage of Invalid Care Allowance

Individuals of working age

	% receiving ICA	*Number of observations = 100%*
All who report caring for someone else in the household	14	*2,264*
Those who spend more than 35 hours per week caring	32	*876*
Those who spend more than 35 hours per week caring and earn less than threshold	36	*421*

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[24] Severe Disablement Allowance has now been abolished for new claimants, but at the time of the survey it was still in existence.

Mimicking the criteria for ICA as closely as possible, the bottom row of the table suggests that just over 1 in 3 potentially eligible carers are in receipt of ICA. (The match is not exact because we do not know whether the person they are caring for is in receipt of DLA or AA at the appropriate rates). It is interesting to note that of those who are apparently eligible but are not claiming, the majority (62 per cent) report that they spend more than 100 hours per week caring.

If the limit on earnings of carers is considered irrelevant – after all, it is not clear why someone who is managing to combine earning with full-time caring should not be compensated for their effort – estimated coverage falls to 32 per cent. Finally, since the analysis in chapter 4 indicated that many spouses who take on caring responsibilities of less than 35 hours per week when their partner becomes disabled also leave employment, it might be appropriate to included ‘part-time’ caring within the scope of a benefit designed to compensate for lost earnings of carers. On this basis, ICA covers just 14 per cent of the relevant population.

The median amount of ICA received by successful claimants is £37 per week (mean £42 per week). Among those who were previously employed, this represents only 16 per cent of their previous earnings.

5.4 Discussion

In recent years, commentators have begun to question what the role of National Insurance is within our social security system, and what it should be (Hills, 2003). Some see it as based on an out-dated and gendered model of labour market participation, and point to its inefficiency as a redistributive tool. Others regard it as the foundation of a universal welfare state, offering protection ‘from the cradle to the grave’. There is not space to enter into these more fundamental arguments here, but this chapter has attempted to show two things: firstly, that there is a continuing need for benefits which protect against a shock to income as a result of sickness or disability, and secondly, that in their current form, National Insurance and other benefits are failing to meet that need. Whether this points to reforming and revitalising social insurance for people of working age, or whether the need for protection should be met by some other means, is a debate which needs to be had. In either case, the present unmet need is large, for both disabled people and their carers.

6. Changes in the cost of living

6.1 Introduction and methods

Onset of disability may bring changes in the level and composition of household income, as the previous chapters have explored. But it may also bring changes in the way money is spent. New items of expenditure may occur (for example taxi fares, information in Braille, paying for personal assistance) and some types of existing expenditure may rise (like heating, medicines or food for special diets). The amount of extra costs incurred is likely to vary by type and severity of impairment, as well as the living circumstances of the disabled person, and according to how much is provided by the state for free or at a subsidised rate.

Extra costs benefits, like Disability Living Allowance, are designed to help towards these extra costs. They are paid at different rates according to various tests of mobility and whether the claimant needs someone to assist with activities of daily living. The original benefits were created in 1971 and 1975 but the current regime dates from 1992. The rates of benefit were informed by a series of studies which attempted to estimate the additional costs of living disabled people faced (Harris, 1971; Martin and White, 1988; Matthews and Truscott, 1988), but they were not set as a fixed proportion of these costs, let alone to cover them completely.

This situation has led to two problems in the way poverty among disabled people is usually calculated, and in comparisons of the position of disabled and non-disabled people in the income distribution. The first problem is that benefits like Disability Living Allowance (DLA) are commonly included as part of disabled people's disposable income. So a disabled person who receives £100 per week plus £56 DLA is considered to be better off than a non-disabled person on £100 per week. However, since DLA is designed to help towards the *additional* costs generated by being disabled, it should not be counted as disposable income unless an equivalisation for disability is also applied. It is like saying that because a family of four receives £166 on Income Support, they are better off than a single person who gets £54: it fails to recognise that the additional income is required to meet the additional needs faced by the larger family. The additional income does not translate into a higher standard of living for the larger family, or, for that matter, for the disabled person.

The second problem is that DLA does not cover the additional costs of disability in full, for many people. Some people with extra costs are not eligible for DLA at all, others face costs which are higher than the rates set for DLA.[25] So even if DLA were not included as disposable income, a disabled person and a non-disabled person with the same income (excluding DLA) would not be able to achieve the same standard of living. Some of the disabled person's remaining income might have to be spent on meeting the costs of his or her disability.

In section 6.3 below, therefore, the incomes of people who have become disabled are adjusted in two ways, and the results compared to the unadjusted figures which were presented in Chapter 3. The first adjustment is straightforward and should be uncontroversial: income from Disability Living Allowance (and any other extra costs benefits) is subtracted from disposable income. This is of course unsatisfactory because the match between DLA and actual extra costs incurred is far from exact. The second adjustment is an equivalisation for the extra costs of disability, similar to the equivalisation for household size which is commonly applied in poverty analysis.[26] Equivalisation means that individuals (or households) with additional needs, for example due to disability, are assigned a factor which represents how much additional income they would need to achieve the same standard of living as individuals without additional needs. Their incomes are then divided by this factor, so that comparisons between groups with different needs can be made on an 'equivalent' basis.

The disability equivalisation used here is based on estimates produced by comparing the incomes required for a disabled and non-disabled person to achieve a similar standard of living. The method was first implemented by Berthoud, Lakey and McKay (1993) and full details of the estimates used here are given in Zaidi and Burchardt (2003). Various indicators of standard of living were used, including an index of ownership of consumer durables, whether the household has any savings, and a subjective assessment of financial well-being. Data were drawn from the 1996/7 Family Resources Survey (FRS) Disability Follow-up, which contains detailed information on over 3,000 disabled adults in non-pensioner households, including the nature of their disability, income and household circumstances. Estimates were calculated separately for pensioners and non-pensioners, and for individuals living in single-adult households, couples in which one person was disabled and couples in

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[25] It is probably also the case that some DLA recipients incur lower extra costs than the benefit they receive. DLA criteria do not closely match the existence or amount of extra costs.

[26] The equivalisation for disability is applied to total incomes, i.e. income including DLA.

which both adults were disabled. Factors other than severity of impairment and level of income which might affect the relationship between income, standard of living and disability, were also controlled for (such as the number and ages of children, region of residence, and housing tenure).

Table 6.1 applies the results of this estimation to data from the BHPS. This is not straightforward because the BHPS and FRS use different definitions of disability and different gradings of severity. The approach taken is to look at the distribution of disabled people in the BHPS by the best proxy of severity which that dataset provides (the number of health conditions or impairments which they mention), and then match this to thresholds in the distribution of OPCS severity scores provided in the FRS.[27]

In the final column, the extra costs corresponding to the mean OPCS severity score for each group are calculated. These are expressed as a percentage of income because the model specification with the best fit in Zaidi and Burchardt's work suggested that extra costs are proportional to income. This approach is in line with commonly-accepted methods of taking account of the extra costs of children.

Table 6.1: Estimates of extra costs of disability (for people of working age), combining information from BHPS and FRS

BHPS proxy for severity: number of conditions / impairments	Distribution of BHPS sample by severity (column %)	Range of OPCS severity scores corresponding to same % of sample in FRS	Mean value of OPCS range	Estimate of extra costs as per cent of income
0/1	37	0.50 - 5.50	2.58	11
2	28	5.55 - 10.55	8.08	35
3	17	10.60 - 13.85	12.15	52
4+	18	13.90 - 21.10	16.00	69
All	100	0.50 - 21.10	8.14	35

Sources: author's calculations using BHPS and 1996/7 FRS Disability Follow-Up;
Zaidi and Burchardt (2003) Table 5.

There is no consensus as to the additional costs of disability, and the estimates in Table 6.1 are higher than some previous estimates, but they have the advantage of being based on a rich

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[27] For details of how OPCS severity scores are calculated, see Martin, Meltzer and Elliott (1988).

data source with a relatively large sample, which allows sensitivity tests to be carried out and comparisons between different sub-groups to be made. There are also good reasons to believe that extra costs have risen over time: for example, a charge is now made for a higher proportion of social services than was the case 10 years ago; prescription charges have risen faster than inflation, and so on.

6.2 Comparing extra costs incurred with benefits received

Zaidi and Burchardt (2003) compare their estimates of the extra costs incurred by disabled people with the extra costs benefits (like Disability Living Allowance) which disabled people receive. They use the 1996/7 Family Resources Survey Disability Follow-Up, which includes information on severity of impairment, allowing a reasonable match between DLA criteria and the characteristics of individuals in the survey to be made. On that basis, they find that three-quarters of disabled people in non-pensioner households do not receive any DLA. A further 17 per cent receive less DLA than their estimated extra costs, while 8 per cent receive more than their estimated extra costs. Overall, just over one-quarter (27 per cent) of estimated extra costs are met by DLA.

These figures are for all disabled people. Our particular interest in this report is those who have recently become disabled. Unfortunately, these individuals cannot be identified in the Family Resources Survey because it is does not contain longitudinal data. They can be identified in the BHPS, but the BHPS has less detail on severity of impairment. Consequently, estimates of the extra costs for people in the BHPS who become disabled are based on averages for four severity groups, as shown in Table 6.1.

Among those who became disabled in the previous year, a large majority (85 per cent) are not receiving any extra costs benefits. Some may be awaiting the outcome of a claim, some will be unaware that they are able to claim, and yet others may not meet the eligibility criteria. The situation is slightly better for those who have been disabled for longer, of whom 30 per cent are receiving some DLA. Among those who are receiving DLA, the proportion of average extra costs which are covered by the benefit varies widely. This may be partly because back-payments of DLA reported by individuals are not identified separately in the data, and so raise the average value of DLA payments above its proper level. This is likely to affect the results for those who have recently become disabled in particular. Overall, 12 per cent of the estimated extra costs of newly disabled people are covered by DLA, while 9 per cent of extra costs for those already disabled are met.

6.3 Risk of poverty, adjusting for extra costs

Taking account of changes in expenditure (or needs) as well as changes in income affects the estimated risks of poverty. Table 6.2 shows three different ways of estimating the risk of poverty. The first, 'Unadjusted', shows the results if no account is taken of the extra costs of disability. The second, 'Income minus DLA', follows the simple rule of subtracting any extra costs benefits received by the household from their income before calculating the poverty line and whether the household is above or below it. Finally, the last column shows poverty calculated on the basis of fully equivalised incomes.

Table 6.2: Transitions into and out of poverty,
with and without adjustment for extra costs

Individuals in households in which someone becomes disabled

	Unadjusted	**Income minus DLA**	**Income equivalised for disability**
Not initially in poverty	*76 % of all*	*72 % of all*	*72 % of all*
of whom % remain non-poor	86	83	59
% enter poverty	14	17	41
Initially in poverty	*24 % of all*	*28 % of all*	*28 % of all*
of whom % exit poverty	31	27	14
% remain in poverty	69	73	86
All	*100*	*100*	*100*
Number of observations	1,088	1,088	1,088

Poverty rates before onset of disability, shown in italics, differ little across the three different measures, because before onset, there is no adjustment for extra costs to be made. (The slight difference between the unadjusted figures and the other columns is because other household members may already be in receipt of DLA).

The rates of transition into and out of poverty following onset of disability vary markedly. While the unadjusted figures suggest that 14 per cent of those not initially in poverty enter poverty, the fully equivalised figures indicate that the proportion is as high as 41 per cent: two-fifths. Similarly, while the unadjusted figures show that just under 1 in 3 of those initially in poverty are helped to escape poverty following onset (for example through increased benefit income), the equivalised figures suggest that this is a large overestimate. Once extra costs are taken into account, the percentage whose income rises above the poverty line is found to be only 14 per cent.

6.4 Discussion

This chapter has illustrated the importance of taking into account changes in expenditure as well as changes in income when considering the financial impact of someone becoming disabled. A full investigation of this issue would require longitudinal data on spending and disability, which are not available, but by matching data as carefully as possible between two datasets (the detailed Family Resources Survey and the longitudinal British Household Panel Survey), some estimates can be produced. The results indicate that adjusting for extra costs makes a substantial difference to the estimates of the numbers of people who enter or leave poverty following onset of disability.

7. Becoming disabled, being socially excluded?

In this final chapter, the impact of becoming disabled on broader aspects of participation in society and on subjective well-being of the individual are considered. Is it the case that becoming disabled also means becoming excluded from interaction with friends and family, or from leisure pursuits previously enjoyed? These considerations are put together with a summary of results from previous chapters on income and poverty, employment and caring, benefits and the cost of living, to give an overview of the impact of becoming disabled. Finally, the implications for various aspects of employment, social security and broader social inclusion policy are discussed.

7.1 Subjective well-being and the onset of disability

The many practical and economic consequences of becoming disabled are in themselves likely to affect how an individual feels about his or her circumstances. Becoming disabled may also have a direct effect on psychological well-being and satisfaction with life. These are no less important than the purely financial dimensions of a change in circumstances, and Table 7.1 explores some of the subjective assessments respondents who have become disabled make. Because people may change their assessments over time anyway, regardless of becoming disabled, the responses are compared to those of individuals who have remained non-disabled.

The first two rows in the table consider how well-off the individual feels financially. The figures confirm that those who become disabled are disproportionately drawn from the less well-off – subjectively as well as objectively. Even before becoming disabled, those who will become disabled are less likely to feel well-off, and are less likely to feel they are on a steady or improving income trajectory, than are those who will not be affected by onset of disability in the near future. Moreover, while the unaffected improve their assessment of their financial situation in the following year, there is a marked decline in the proportions of those who have experienced onset of disability who can make a positive assessment of their financial circumstances.

Table 7.1: Satisfaction with various aspects of life,
before and after onset of disability

	Individual becomes disabled		**Individual does not become disabled**	
	Year before onset	Change by year after onset	Year y =1	Change by year y = 2
Financial situation: % “living comfortably” or “doing alright”	44.1 %***	-3.4***	61.4 %***	+1.4***
Change since last year: % “better off” or “about same”	63.3 %***	-4.6***	72.2 %***	+0.8***
Job satisfaction (if employed): mean score[†]	5.5	-0.2**	5.5	0.0**
Active in any listed[♣] organisation: %	51.6 %	-2.7	51.5 %	-0.1
Satisfaction with social life: mean score[†]	4.6***	-0.2***	5.0***	0.0***
Satisfaction with use of leisure time: mean score[†]	4.7	-0.5***	4.9	0.0***
Psychological well-being: mean score[♣]	2.8***	+1.2***	1.7***	0.0***
Satisfaction with life overall: mean score[†]	4.7***	-0.2***	5.3***	0.0***
Number of observations	*682*	*673*	*32,921*	*32,956*

Difference between ‘becomes disabled’ and ‘does not become disabled’ statistically significant at level of *** 1 % ** 5 % * 10 %.

[†] On scale of 1 (completely dissatisfied) to 7 (completely satisfied).

[♣] Asked at waves 1-5 and 7. List is: Political party, Trade Unions, Environmental group, Parents'/School Association, Tenants'/Residents' Group or Neighbourhood Watch, Religious group or church organisation, Voluntary services group, Other community or civic group, Social Club/Working men's club, Sports Club, Women's Institute/Townswomen's Guild, Women's Group/Feminist Organisation, Other group or organisation. Added at wave 3: Professional organisation, Pensioners group/organisation, Scouts/Guides organisation.

[♣] Based on 12-point General Health Questionnaire; higher score indicates lower well-being.

The BHPS also asks follow-up questions on why people feel they are better off (or worse off) than the previous year. Among those who have become disabled and say they are worse off, 44 per cent cite a fall in earnings, and 35 per cent say their expenses have increased. This confirms the results of the previous chapters, showing that loss of employment, and a rise in the cost of living associated with disability-related items, are two main sources of financial hardship following onset of disability.

The next row in the table shows the results for job satisfaction, among those who are employed. Initially there is no difference between those who will become disabled and those who will not. However, after onset of disability, those who remain in employment are less satisfied than their non-disabled counterparts. This is particularly striking since one might expect the most dissatisfied to be the first to leave employment, with the more satisfied remaining in work. Could this be evidence of employers failing to make the necessary adaptations to ensure that continuation in employment following onset of disability is not only possible, but satisfying? It could also reflect changes in the attitudes of colleagues – which might include embarrassment, becoming patronising, or lowering their expectations of the newly disabled person's abilities – but without more detailed evidence, this remains speculative.

The middle section of the table looks at various measures of involvement in, and satisfaction with, leisure activities and social life. There is little difference initially between those who will become disabled and those who will not in the proportion who are active in some kind of community or leisure organisation (for example, a youth group, trade union or sports club). There is a decline for those who become disabled, but even so the difference between the groups is not statistically significant in this respect. However, in terms of satisfaction with leisure and social life, those who will become disabled are already less satisfied, and the gap between them and the non-disabled widens after onset of disability. The increased dissatisfaction may reflect a lack of accessibility and opportunity to socialise, or a more general dissatisfaction with life. The higher (and increased) rate of poverty among those who have become disabled is also contributory factor.

The last rows in the table give two general indicators of overall well-being, one based on a widely-used survey instrument called the General Health Questionnaire (or GHQ) which measures psychological well-being, and the other a question about the respondent's satisfaction with life overall. There is no change over time in the average of either of these measures for the non-disabled group, and they start with lower levels of mental ill-health and higher levels of satisfaction. Meanwhile, the subjective well-being of those who experience onset of disability, starts low and deteriorates further.

Once again it is important to stress that there is nothing inevitable about these results. Becoming disabled is without doubt a major life-event and it may well take some time to come to terms with its impact emotionally. However, the financial hardship and exclusion from participation in employment, leisure and social life which too often occurs as a result, is an additional, and unnecessary, burden.

7.2 Changes to the household

Some previous research has suggested that someone becoming disabled can produce a strain on relations between a couple (Biegal *et al*, 1991). Changes in a couple's economic circumstances are known to affect the probability of partnership dissolution (Böheim and Ermisch, 1999). In addition there may be changes in the care one partner needs or chooses to provide for the other, and reduced opportunities for leisure activities. On the other hand, a relationship may be strengthened by facing, and surviving, a crisis of this kind. Evidence from the BHPS in this respect is limited: the number of people changing their marital status is too few to be able to draw any definite conclusions, and the panel is not long enough to follow people for as many years as it might take after onset of disability for the any effect to show up. During the two years following onset of disability, 95 per cent of those who had a spouse (married or cohabiting) remain with their partners, and 89 per cent of those who were single remain so. These figures are almost identical for those who do not become disabled.

Becoming disabled may also mean that the present accommodation becomes unsuitable - whether because of its location, external access or internal features. In fact in the BHPS a slightly lower proportion of those who had become disabled in the previous year had moved house during the year than of those who did not become disabled (10 per cent compared to 12 per cent: a difference which is not statistically significant). But among those who had moved, 14 per cent cited the fact that the new property did not have stairs or health-related reasons for moving.[28]

A higher proportion of those who became disabled in the previous year state that they would like to move house (46 per cent compared to 42 per cent of non-disabled people. This difference is statistically significant at the 5% level). Many of the reasons for wanting to

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[28] The question was open-ended, and coded retrospectively by the BHPS team.

move house pre-date the onset of disability, but of those who want to move, 5 per cent cited needing accommodation without stairs, or other health-related reasons.

7.3 Being socially excluded and becoming disabled

We are now in a position to review the connections between becoming disabled and social exclusion, drawing on the results in this and the previous chapters. One crucially important feature of the relationship is that it is two-way: someone who is socially excluded is at greater risk of becoming disabled, and someone who becomes disabled is at greater risk of becoming socially excluded.

The first link in the chain has been demonstrated by Jenkins and Rigg (2003) and is explored in chapter 2 of this report. It is perhaps most obvious in looking at the relationship between pre-existing low income and becoming disabled: those in the bottom fifth of the income distribution face each year a risk of becoming disabled two-and-a-half times as high as those in the top fifth of the distribution. In fact the difference between the bottom two income quintile groups is larger than the difference between each consecutive pair of quintiles further up the distribution, suggesting that additional income makes more difference to the risk of becoming disabled at lower incomes.

The link between pre-existing disadvantage and the risk of becoming disabled is also apparent with respect to other characteristics: those with no qualifications are nearly four times as likely to become disabled as those who hold a degree. Interestingly, the difference in risk between those with no qualifications and those with the highest levels of qualification are larger for younger age groups. One possible explanation is that health problems associated with ageing itself account for a higher proportion of onsets of disability at older ages while accidents predominate at younger ages. The effects of ageing are independent of social and economic circumstances to a greater extent than the risk of having an accident, which is closely bound up with one’s living and working environment. Overall, 15 per cent of those who become disabled have had an accident in the previous year, but for people aged 16-29, this figure rises to 22 per cent.

The second link in the chain is between becoming disabled and either remaining, or becoming, socially excluded. The effect of becoming disabled on household income varies widely by individual circumstances, as shown in chapter 3. In one sense, those who live alone are more vulnerable, since there is no-one who can compensate for a fall in earnings by increasing their own labour market activity. In another sense, two-earner couples are more vulnerable, since the income they stand to lose is in many cases greater. If the non-disabled partner also leaves employment, either because the benefit system makes that the best option, or because he or she wishes to (or is obliged to) provide unpaid care for the newly-disabled partner, the fall in income and consequent shock to living standards can be substantial.

Table 3.4 in chapter 3 showed that despite the pre-existing high rates of poverty among those who became disabled, the onset of disability was itself associated with a further risk of entering poverty, and a decrease in the proportion of people leaving poverty. More than 1 in 7 of those not initially in poverty, entered poverty following the onset of disability (with poverty defined as below 60 per cent of median income), and over two-thirds of those who were already poor, remained so – a higher proportion than for the non-disabled poor. Although an increase in income can occur as a result of someone in a poor household becoming disabled (for example due to increases in benefit entitlement), it does not result in as many households leaving poverty as is achieved in unaffected households by means of other routes.

One of the major reasons for a fall in income following onset of disability is that the individual or his/her spouse leaves employment. This was explored in chapter 4. Just over 1 in 3 single adults who were employed leave employment after becoming disabled. Among single-earner couples, even where the earner is not the one who becomes disabled, 1 in 5 leaves employment, and the couple becomes a no-earner couple. A contributory factor is that 7 per cent of individuals whose partner becomes disabled report that they have taken on new caring responsibilities at that time, ranging from under 20 to over 100 hours per week.

One of the aims of the social security system is to protect individuals against falls in income due to unemployment, disability and old age. This is the insurance principle which Beveridge attempted to establish as the foundation of the welfare state after the Second World War. The analysis in chapter 5 indicated that although benefit income does indeed become a more important component of household income following onset of disability, it is sufficient to compensate for lost earnings only in a small minority of cases. Coverage is one problem. Just under 1 in 3 respondents who leave employment in the year following onset of disability report receipt of Incapacity Benefit and for those who do receive it, the median percentage of previous earnings replaced by the benefit is just 41 per cent. The situation is even worse for the partners of those who become disabled, many of whom also leave employment. Their needs have been only belatedly and partially recognised by the social security system. Fewer than 1 in 3 full-time carers receive Invalid Care Allowance, and among those previously employed, the benefit replaces a paltry 16 per cent of previous earnings.

In addition to changes in income, there may be changes in expenditure as a result of becoming disabled. The extra costs of disability were explored in chapter 6. Here again, the benefits system provides some help, but neither the coverage nor the amounts paid are adequate to level the playing field between disabled and non-disabled people, or to protect those who become disabled from a sharp fall in living standards. This was confirmed by the subjective assessments of financial well-being reported in Table 7.1. Among those who have become disabled and say they are worse off, 35 per cent said the main reason was that their expenses have increased.

Although much of this report has focused on the precursors and consequences of becoming disabled in terms of income, employment and other economic activity, broader aspects of social inclusion should not be forgotten. Those who become disabled are already less satisfied with their social life and leisure activities prior to becoming disabled, but the gap between them and the non-disabled in terms of these measures widens following onset of disability. We cannot be sure of the reasons, but problems of inaccessibility, limited opportunities and lack of disposable income are likely explanations.

7.4 Preventative and protective policies

The two-way relationship between social exclusion and becoming disabled has several implications. Firstly, the very strong associations between becoming disabled on the one hand and low income, lack of employment and low educational qualifications on the other, should themselves become the focus of policy intervention. Contrary to the popular myth that the onset of disability is a random occurrence, it is strongly patterned by social and economic circumstances. We may be able to do relatively little about the increased likelihood of ill health at older ages, but we certainly can do something about the risk of accidents at home, on the roads and at work, not to mention the prevalence of illnesses and conditions which are caused or exacerbated by poor living and working conditions.

Secondly, recognition of the factors which increase the risk of becoming disabled leads to the realisation that the most vulnerable among us are the least well protected. In so far as the social security system does retain an insurance element, those who are most effectively insured are better-paid employees in stable jobs. They have access to relatively generous occupational sick pay schemes and are eligible for higher rates of state benefits. By contrast, the unemployed or ‘economically inactive’, low-paid employees, the self-employed, and those with broken work histories - all of whom face higher risks of becoming disabled - are unlikely to get much in benefits above the means-tested minimum should they become disabled.

Thirdly, the changes in income, employment and earnings, caring responsibilities, leisure and social opportunities (both for the individual and any partner), which often accompany the onset of disability draw attention to the importance of providing particular help at the time of transition from being non-disabled to being disabled. Whether the individual comes from a relatively well-off background, in which case the difference in living standards before and after onset may be dramatic, or whether he or she experiences a compounding of existing disadvantage, coming to terms with the new situation, negotiating access to new services and benefits, and re-assessing employment options will require intensive and specialist assistance.

There are implications for health, welfare and employment policy. Firstly, there is a clear case for joining up the health inequalities agenda with efforts to raise the employment rate among disabled people. As long as it remains the case that someone with no educational qualifications is one-and-a-half times more likely to become disabled than someone with any qualifications, disabled people of working age will remain disproportionately low-skilled and unqualified. In today’s labour market, that means it is an uphill struggle to raise significantly their employment rates. Only in a period of heightened labour demand – such as during the Second World War – are large numbers of unskilled and disabled workers likely to be taken on by employers. Labour made a commitment to tackling health inequality when it came into power in 1997, establishing Health Action Zones and setting targets for reduction of diseases which particularly afflict poorer people, but since then the issue seems to have slipped down the political agenda. Links with the welfare to work agenda have been made only at the point of rehabilitation, failing to take advantage of the opportunity to intervene preventatively.

A vigorous pursuit of the health inequality agenda might help to prevent ill health and impairment arising in the first place, but there are also possibilities for preventing impairment leading to disability. As discussed in chapter 2, the disadvantage which people with impairments experience in terms of participation in society is not a necessary outcome of impairment, and can be reduced with appropriate social and economic policies. First among these should be addressing the lack of employment retention for those who have a job when they become disabled. A pilot job retention and rehabilitation scheme is currently underway under the auspices of the New Deal for Disabled People, but this is relatively small scale and the results of the evaluation will not be available for at least another two years. A number of other options could be explored simultaneously. For example, some disability organisations have proposed that a system of 'disability leave' should be established alongside existing sick leave and maternity/paternity leave provisions. This would enable employees who became disabled to take time off work to adjust to the onset of disability, possibly to undertake some rehabilitation, and to discuss with the employer what facilities or changes to the job would enable him or her to return to work. Importantly, employers would be prevented from dismissing the employee during the period of disability leave, so ensuring that both parties have an interest in arranging a return to work.

The Disability Discrimination Act already requires employers to make 'reasonable adjustments' to accommodate employees who become disabled, and this part of the Act has been used by disabled people to gain redress. However, the Disability Rights Commission, set up to oversee the enforcement and implementation of the legislation, is restricted by lacking the power to take cases against employers unless an individual ex-employee is willing to pursue a case – a process which can be time-consuming and stressful. If the DRC were empowered to take issue with employers who failed to establish adequate retention policies, employers might be prompted to take more effective action.

Paid work is not the be-all and end-all of social inclusion, but lack of employment retention is one of the main routes by which those who were previously 'included' become 'excluded': an increased risk of poverty, a possible reduction in the chance of taking up other productive activities in the future, and more restricted social and leisure opportunities. Policies to prevent the onset of disability leading to social exclusion are only one part of the story however. There is also a need to provide protection for those who are already (or who are already at risk of) social exclusion, and who experience the additional burden of becoming ill or acquiring an impairment.

Policies which protect those vulnerable to social exclusion can take many forms but one of the most fundamental is providing a stable and adequate income. As the analysis in chapters 5 and 6 indicated, social security is at present not meeting that objective for those who become disabled or their families. Incapacity Benefit and Carers Allowance need to be revitalised if they are to be effective in insuring against loss of income due to sickness or disability, whether the individual who leaves employment is the one who becomes disabled, or his/her spouse, or both. Combining the benefits and re-introducing an earnings-related element is one possibility, or setting a flat rate at a higher level. Extra costs benefits need to be more closely matched to the cost of living with disability – which means both revising the criteria for receipt to ensure some groups are not inadvertently excluded, and increasing the levels of payment for those who incur greatest additional costs.

Becoming disabled is always likely to be a major life-event. But the financial hardship and exclusion from participation in society which often occurs as a result is an additional, and unnecessary, burden: one to which it is high time policymakers turned their attention.

Data appendix

The British Household Panel Survey

The original BHPS sample consisted of adults in around 5000 households, and was designed to be nationally representative of the household population of Great Britain.[29] These original sample members have been re-interviewed in each subsequent year ('wave'), together with any adults who have moved into a household containing an original sample member, and household members who turn 16. The questionnaire covers topics such as household composition, housing, economic status, education, health and impairment, caring responsibilities, and social attitudes. Although 10 waves of BHPS data are now available, the questions on disability asked at Wave 9 were not consistent with preceding waves. For this reason, analysis of 'becoming disabled' is limited to waves 1 to 8.

Sample attrition and weighting

As with any survey, some households do not yield an interview. At the first wave of the BHPS, at least one interview was obtained in 74 per cent of eligible households, a response rate comparable to that of other large-scale British surveys. A further problem of non-response specific to panel surveys arises because some respondents at the first wave fail to give an interview at subsequent waves, so that the remaining sample is no longer representative - a process known as attrition. Of the 9912 adults who gave full interviews at Wave 1 of BHPS, 6332 (64 per cent) went on to give interviews at every wave up to and including Wave 8, and a further 584 (6 per cent) gave an interview at Wave 8 but not at all the intervening waves. In order to try to correct for bias that may arise from initial non-response and subsequent attrition, the obtained sample can be weighted to reflect population characteristics and original sample characteristics as closely as possible. Some longitudinal analysis does not require respondents to be present at all waves (for example, year-on-year transition probabilities can be calculated for any respondent present at at least two consecutive waves), and the strategy followed in this paper is to include as many respondents as possible in any given analysis.[30]

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[29] People living in institutions are excluded; however at the 1991 Census only two per cent of the working age population were in communal establishments, of whom one-quarter had a limiting long-standing illness or disability (OPCS, 1993).

[30] For discussion of weights in the BHPS, see Taylor (1999). It is possible that disabled people have characteristics not controlled for in the weighting procedures which make them more likely to drop out of the Panel. However for people of working age, the difference is not statistically significant.

Questions on health problems, impairments and accidents

The main question used to define disability in this report, based on limitation in daily activities, is discussed in Chapter 2. Two further sets of questions are described here: those used to define type of onset, and those used to define a proxy measure of severity of impairment.

Type of onset

BHPS respondents are asked:

> *Since September 1st* [last year]*, have you had any kind of accident as a result of which you saw a doctor or went to hospital?*

If a respondent becomes disabled, we can therefore identify whether there was a preceding accident, although we cannot be sure whether the limitation in daily activities is a direct result.

Respondents are also asked to identify all of the “health problems or disabilities” which they have, selecting from a list presented to them on a card. The list is as follows:

> *Problems or disability connected with: arms, legs, hands, feet, back, or neck*
> *(including arthritis and rheumatism)*
> *Difficulty in seeing (other than needing glasses to read normal size print)*
> *Difficulty in hearing*
> *Skin conditions/allergies*
> *Chest/breathing problems, asthma, bronchitis*
> *Heart/blood pressure or blood circulation problems*
> *Stomach/liver/kidneys or digestive problems*
> *Diabetes*
> *Anxiety, depression or bad nerves*
> *Alcohol or drug related problems*
> *Epilepsy*
> *Migraine or frequent headaches*
> *Other health problems*

To distinguish between sudden and gradual onset of a health problem or impairment, the list was first grouped into six categories. Then any respondent who experienced a problem in one of those six categories for the first time in the year of onset of disability was classified as having had sudden onset, and a respondent who experienced a problem for the first time the previous year was classified as having had gradual onset.

Proxy for severity

The same list of health problems or conditions forms the basis for the proxy for severity of impairment. Although in principle there is no relationship between the number of different health problems or impairments an individual has, and the severity of his or her overall condition, Berthoud found in previous work that a count of the number of different conditions appeared to perform quite well as a proxy (Berthoud, 2000, 2003). This approach is followed here, with the number of different health problems reported grouped into four categories: none or 1 reported problem, 2 problems, 3 problems, and 4 or more problems.

Questions on receipt of benefits

Detailed information on benefits is collected in BHPS. Respondents are first asked to identify which of a comprehensive list of benefits they have received since September the previous year. Then for each benefit identified, they are asked over what period they received it, how much the most recent payment was, and whether it is received jointly or individually.

It is not entirely straightforward to check the accuracy of benefits data in the BHPS. However, one illustrative comparison can be made. In Wave 8 (Autumn 1998) of BHPS, 3.79 per cent of people of working age were receiving IVB or IB. According to DWP benefit statistics and the Government Actuary Department’s population estimates, 4.28 per cent of the working age population was receiving IVB or IB in Autumn 1998. So it appears that the BHPS figure is a slight underestimate of the rate of claiming according to administrative statistics, but the two figures are quite close. Both series show a slight increase in the rate of claiming over the period 1991 to 1998.

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