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The Dynamics of Being Disabled

TANIA BURCHARDT*

ABSTRACT

In recent years, the dynamics of poverty and unemployment have come under increasing scrutiny, but another of the risks with which the welfare state concerns itself – disability – is still largely understood only in a static sense. This article uses longitudinal data from the British Household Panel Survey to investigate the complexity behind a cross-sectional snapshot. First, a breakdown is given of the working-age population who are disabled at any one time by the 'disability trajectories' they follow over a seven-year period. Second, the expected duration of disability for those who become disabled during working life is examined. The results show that only a small proportion of working-age people who experience disability are long-term disabled, although at any one time, long-term disabled people make up a high proportion of all disabled people. Over half of those who become limited in activities of daily living as adults have spells lasting less than two years, but few who remain disabled after four years recover. Intermittent patterns of disability, particularly due to mental illness, are common. Failing to distinguish the different disability trajectories people follow has led to policies which marginalise disabled people and are costly to the state.

INTRODUCTION

In recent years, understanding of many of the central concerns of social policy – poverty, unemployment, lone parenthood – has been enhanced by research on their dynamic aspects (Leisering and Walker, 1998). Transitions into and out of poverty are better understood thanks to work on income dynamics (Gardiner and Hills, 1999; Jarvis and Jenkins,

* Research Fellow at the Centre for Analysis of Social Exclusion, London School of Economics
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1997). The problem of cycling between low pay and no pay has been identified (Gosling *et al.*, 1997); the extension of in-work benefits can be seen as a direct policy response. Lone parenthood is no longer seen as a fixed characteristic, since analysis of a panel of lone parents revealed more than one in five re-partnered during a four-year period (Ford *et al.*, 1998).

By contrast, quantitative research on disability has remained preoccupied with differences in the circumstances of disabled people and non-disabled people, conceived as two entirely distinct and fixed populations. It has drawn on cross-sectional government surveys like the OPCS Survey of Disabled Adults in Private Households (Martin *et al.*, 1988) and on analysis of administrative data from the benefit system. The common image of a disabled person as someone blind from birth or permanently in a wheelchair persists, despite representing only a minority of people who qualify for disability benefits or for other state assistance. A snap-shot of disabled people will include some who are temporarily impaired (for example, through injury), some who have been disabled since childhood, and some who have – perhaps recently – developed a condition which is likely to be long term. Being able to distinguish these and other 'disability trajectories' is important both to avoid conflating what may be very different experiences of being disabled, and for the design and evaluation of effective policies.

Disability issues have risen up the political agenda, with a number of significant recent policy initiatives, mostly aimed at disabled people of working age. The 1995 Disability Discrimination Act contained provisions on employment, access to goods and services and the buying or renting of property; its operation is to be monitored by a Disability Rights Commission. The New Deal for Disabled People is funding trial schemes designed to assist incapacity benefit claimants into work, while the controversial 1999 Welfare Reform and Pensions Act overhauled some of the main disability benefits.

A dynamic perspective on disability is crucial to understanding the operation of these policies. A 'welfare to work' strategy for someone disabled in childhood and looking for his or her first entry into the labour market is likely to be very different to that suitable for an employee who has recently developed Repetitive Strain Injury, and different again from the support required by someone with intermittent mental health problems. These distinctions have gone largely unrecognised in the development of policy, in part because even basic breakdowns of numbers in each group are unknown.

This article uses longitudinal data from the British Household Panel

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Survey to illustrate the significance of dynamic measures of disability, with a focus on people of working age since that is the emphasis in current policy debates. The first approach is to determine the prevalence of different 'disability trajectories' and compare these to estimates of disability generated by a static measure. The second approach concentrates on those who become disabled during the course of the panel, and examines the distribution of durations of disability. In both cases, results are analysed by gender and age group.

The section immediately following this introduction reviews existing literature on dynamics of disability. Two approaches to the data used in this study are discussed in the third section and the following section presents the results. The final section considers the implications, first, for measurement and analysis of disability in large-scale surveys, and second, for benefits and employment policy.

LONGITUDINAL STUDIES OF DISABILITY

Of the few longitudinal studies of disability which exist, the majority focus on the elderly and are written from a medical perspective. The principal exception is work by Richard Burkhauser and colleagues, whose interests are the relationship between disability, employment and benefit receipt.

Burkhauser and Daly (1996) use the US Panel Study on Income Dynamics for 1985 and 1986 to examine differences between individuals reporting a work-limiting condition in both years ('disabled'), just one year ('short-term disabled') or neither year ('non-disabled'). They then extend the analysis to define the 'newly disabled', a sub-group of the 'disabled', who are work limited in both 1985 and 1986, but did not report work-limiting conditions in either of the two preceding years. The authors find that the 'newly disabled' are in worse health and have more functional limitations than the 'short-term disabled' and 'non-disabled' groups, but are in better health and functional state than the 'disabled' group in general.

A similar analysis is undertaken by Burkhauser and Wittenberg (1996), using the 1990 Longitudinal Survey of Income and Program Participation. Using a cross-sectional definition of disability, they find 12 per cent of working-age men have a disability, but this proportion falls to 10 per cent if the definition of disability requires positive answers in two consecutive years.

The two-period definition of disability is taken up by Burkhauser and Daly (1998) in their study using US and German panel data to compare employment, earnings and household income of working-age disabled

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men in the two countries, while Burkhauser *et al.* (forthcoming) examine what factors influence the time which elapses between the onset of a work-limiting condition and application for a disability benefit. However neither study discusses the duration or pattern of work-limiting conditions themselves.

Contributions to the medical and rehabilitation literature on changes in disabled states use a number of different time frames. Verbrugge, Reoma and Gruber-Baldini (1994) examine changes in functioning over one year from hospital discharge for 165 patients in a US city. They find considerable alterations in psychological, physical and social functioning over the year, and use graphical methods to demonstrate that these changes are usually non-linear. At the other extreme, Ferraro, Farmer and Wybraniec (1997) use the US National Health and Nutrition Examination Survey covering 6,800 respondents over a period of 15 years. This study is unusual in that the sample includes younger people: aged 25–74 at the first wave. They find that those with restricted activity at Wave 1 are more likely to have higher levels of disability at subsequent waves, and that age, income and self-assessed health status are all significant predictors of disability.

A common theme which emerges from these and other studies is that while disability in one period is associated with higher risk of disability in later periods, there is by no means a universal or uniform decline from first onset. For example, Mor *et al.* (1994) find that the functional status of 12 per cent of men and women in their seventies, who were impaired at the first observation, improved over a six-year period, using the US Longitudinal Study of Aging. Similarly, Boaz (1994) uses the US National Long-Term Care Surveys of 1982 and 1984 to show that 19 per cent of elderly disabled people had fewer 'Activities of Daily Living' (ADL) limitations at the end of the period than at the beginning.[1] Using the same data source, Laditka and Wolf (1998) develop a microsimulation model of functional statuses and derive statistics on the distribution and duration of spells of impairment. These suggest that multiple spells of moderate impairment are common among older people. Lagergren (1994) shows that for users of care services in his case study, annual rates of change in disability were positive on average (i.e. disability tended to increase over time), but that younger clients had higher probabilities of improvement. Over a third of Maddox, Clark and Steinhauser's (1994) panel of 11,000 adults initially aged 58–63 made one or more transitions between impaired and non-impaired states over a decade.

In the UK, longitudinal studies have focused on disability benefit receipt rather than disability itself. Transitions on and off benefits may of

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course be affected by changes in employment status, income or eligibility rules, as well as by changes in disability. Holmes, Lynch and Molho (1991) found that demographic effects (age and health) were the main determinant of inflows and durations on Invalidity Benefit (IVB) during the late 1970s and early 1980s, though local labour and housing market conditions also had marginal impacts. Erens and Ghate (1993) also examined IVB, but their interest was people leaving the benefit, and for a later period (spells beginning in 1991/92). They found gender, age, type and severity of incapacity, qualifications, presence of children in the household and 'attachment' to the labour market were all associated with the probability of leaving IVB, but the relative importance of these factors was not assessed. Finally, Swales (1998) and Dorsett *et al.* (1998) report a study which tracked individuals leaving Incapacity Benefit (the successor to IVB). Around 100,000 stopped receiving Incapacity Benefit each quarter in 1995/6 (excluding those who transferred to retirement pension), out of a 'stock' of 1.7 million claimants. Leavers were younger and more likely to be women than those remaining on the benefit. High proportions of leavers reported continuing disabilities – 82 per cent of those who found work and nearly all of those who did not.

This brief review suggests that while there is ample evidence in the medical literature that disability is not a static state (even among the elderly), the dynamics of disability from a social policy perspective remain underexplored. The implications of using a cross-sectional measure for a dynamic phenomenon has begun to be examined in the USA by Burkhauser and colleagues, although it has not been their primary concern. Detailed analysis of the dynamics of disability – the relative frequency of short and long spells, or of continuous and repeated patterns – has yet to emerge. This article places these issues at centre-stage, and breaks new ground by analysing UK data.

DATA AND METHODOLOGY

Data and definitions

To analyse movements in and out of disability, relatively fine-grained longitudinal data are required. For this reason, data from the British Household Panel Survey (BHPS) were used, for the years 1991–97. The BHPS sample consists of around 10,000 adults who are re-interviewed each year, and is nationally representative of the household population of Great Britain. People living in institutions are excluded; however at the 1991 Census only 2 per cent of the working-age population were in communal establishments (OPCS, 1993).[2]

Of the 9,912 adults who gave full interviews at Wave 1 of BHPS, 6,140

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(62 per cent) went on to give full interviews at every subsequent Wave. Of the 6,140, 4,751 were of working age (defined as 16–64 for both men and women) throughout the 7-year window, and it is these that form the main sample used for analysis. This includes approximately 1,300 who are disabled at some point. (Definitions of disability are discussed more fully below.)

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. In order to try to correct for bias that may arise from initial non-response, the obtained sample is weighted to reflect population characteristics such as age, sex, type of dwelling, household size, and number of cars (as a proxy for wealth), as closely as possible. 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. A second set of weights, using the much more detailed information about individuals' characteristics available from their most recent interview, are used to counter possible attrition bias. All analyses reported in this article are weighted using the longitudinal weights supplied with the data.[3]

Questions asked in the survey which might yield indicators of disability are listed in Table 1. All the questions refer to the time of interview, so responses are at approximately annual intervals.[4] Choice of indicator depends both on one's position in conceptual debates and on practical concerns about validity and reliability. One distinction is between ill health and disability: a person may be disabled and perfectly healthy, or be suffering from an illness but not be disabled by it. Some would regard any condition which is not permanent as ill health or injury; others regard any long-term ill health as disabling. BHPS indicators mix the two: 'Conditions' explicitly covers both; 'ADL' and 'Work' refer to health but seem designed to establish disability. The latter are asked immediately after the section on specific impairments, so it can be hoped that respondents with limiting impairments will give positive responses. 'ADL' asks respondents to compare themselves to others of their own age, and this has been found to decrease reporting of disability (Thomas and Dobbs, 1998), but the effect should be less significant for people of working age.

The Disability Discrimination Act (DDA) definition covers disabilities and health problems which have a 'substantial' effect on day to day activities, and which have lasted or are expected to last for at least 12 months (DfEE, 1995). The 'ADL' question in BHPS refers to limitation in daily

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TABLE 1. *Variable names and text of questions on disability in BHPS*

Variable name	Short name	Description
hllt	ADL	Does your health in any way limit your daily activities compared to most people of your age?
hlltw	Work	Does your health limit the type or amount of work you can do?
hlghq2	GHQ	(Score from 0 to 12 on basis of responses to standard set of 12 questions, usually taken as indicator of mental health. Eg, 'Have you recently been able to concentrate on whatever you're doing? Better than usual/ same/ less/ much less than usual'.)
hlprb	Conditions	Do you have any of the health problems or disabilities listed on this card? (List of 12 conditions/impairments, and an 'other' category)
hlsv	Services	Here is a list of some health and welfare services. Have you yourself made use of any of these services since September 1st last year? (List includes home help and meals on wheels)
hldsbl	Registered	Can I check, are you registered as a disabled person, either with Social Services or with a green card?
f116 – f125	Benefits	Have you yourself or jointly with others since 1st September last year received... (list of benefits including all the main disability benefits)

activities, although it does not assess how substantial the limitation is. For the DDA definition, answers in two consecutive years would be needed to establish disability.

Organisations run by disabled people (under the umbrella of the British Council of Disabled People) advocate the social model of disability, emphasising the role society plays in creating disabling barriers (Barnes, 1991; Oliver, 1996). According to the social model, 'impairment' refers to a physical or mental condition (for example, blindness), while 'disability' refers to the social disadvantages associated with being impaired (for example, being out of work), due to society's failure to facilitate the full participation of people with impairments. This is in contrast to the medical or individual model of disability, which focuses on underlying conditions (for example, paralysis) and the functional limitations which are seen as a direct result (for example, being unable to walk). Of the questions on disability asked in the BHPS, 'Conditions' relates most closely to the individual model. None is fully consistent with the social model: all place the individual's impairments rather than the social environment at centre stage. Two variables, 'ADL' and 'Work', address the extent to which the individual can participate in 'normal' activities, and in that respect do reflect the social model of disability.

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Turning to issues of validity and reliability, benefit receipt and use of services depend on characteristics other than disability (for example, income and availability of informal care). Similarly, those who are registered disabled are only a small subset of disabled people. On the other hand, the remaining questions, 'ADL', 'Work', 'GHQ' and 'Conditions', may be thought too subjective. Self-assessment may not be a good guide to disability status, especially since perceptions of disability may be influenced by whether the individual is currently in work or not (Chirikos and Nestel, 1984). There are two reasons to believe that this problem is not as serious as it might seem: first, there is some evidence that self-assessed disability is closely related to 'harder' measures of disability (Verbrugge *et al.*, 1994; Ferraro *et al.*, 1997), and second, self-assessment may be a *better* way of picking up the complex barriers to participation faced by disabled people than assessment by a third party based on fixed criteria.

Considering the conceptual and measurement issues together, 'ADL', 'Work' and 'GHQ' were chosen as indicators of disability for this study. In analysis, results for 'ADL' and 'Work' were similar, so only those for 'ADL' are presented here. 'GHQ' was included to correct the possible physical bias of the other variables. It is based on a standard mental health questionnaire (administered as part of the BHPS self-completion booklet) which has been extensively validated; the usual cut-point, also adopted here, is between 2 and 3 positive answers out of 12.[5] Each of the variables was taken to indicate simply whether the individual was 'disabled' or 'not disabled'; the degree or type of limitation was not considered. This is somewhat crude but has the advantage of simplicity.

Cross-sectional prevalence rates of disability among the working-age population according to the chosen indicators are 11 per cent limited in activities of daily living ('ADL limited') and 26 per cent scoring more than 2 on the mental illness questionnaire ('GHQ>2'). These estimates may seem high but are in line with results from other surveys.[6]

The two indicators are positively and significantly correlated. Of those who are ADL limited, about half have GHQ>2, and just over one fifth of GHQ>2 are ADL limited. Table 2 shows the overlap between the selected indicators of disability and other indicators in the BHPS.

The associations between ADL and the other indicators are in the expected direction. Nearly all those who are ADL-limited also report some specific condition or health problem. On the other hand, not all those who have specific conditions regard them as limiting. Around one in five of those who are ADL-limited receive extra costs benefits, and just over one in three receive income replacement disability benefits. Very small proportions of those who are not ADL-limited are in receipt of disability

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TABLE 2. *Overlap between different indicators of disability in BHPS Working-age population, Wave 4*

	Percentage of:	
	ADL-limited	Not ADL-limited
Who are disabled according to:		
GHQ>2	51.2	22.5
Work	86.7	4.8
Conditions	99.0	44.2
Services	2.3	0.1
Registered	22.8	0.5
Benefits* – extra costs	19.2	1.1
- income replacement	35.8	1.5
Base	*515*	*4235*

	Percentage of:	
	GHQ>2	Not GHQ>2
Who are disabled according to:		
ADL	21.5	7.1
Work	24.3	9.9
Conditions	64.0	45.1
Services	0.7	0.2
Registered	5.6	2.0
Benefits* – extra costs	5.5	2.2
– income replacement	10.3	3.5
Base	*1205*	*3498*

For definition of indicators, see Table 1.
* Extra costs benefits are Attendance Allowance and Disability Living Allowance (or its predecessor); Income replacement benefits are Incapacity Benefit and Severe Disablement Allowance (or their predecessors).
Source: author's calculations using BHPS Wave 4.

benefits. This suggests being ADL-limited has the advantage of being a broad, inclusive measure, but by the same token, the category includes both more and less severely impaired individuals.[7] Focusing on a smaller group of more severely impaired individuals would be likely to decrease estimates of exit-rates from disability.

GHQ>2 has generally smaller overlaps with other indicators, perhaps because unlike many of the others, it picks up on mental rather than physical conditions. Only around one in twenty respondents with GHQ>2 are in receipt of extra costs benefits, and one in ten are receiving income replacement disability benefits.

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Approaches to describing dynamics

Two approaches are pursued. The first, following Gardiner and Hills (1999) and somewhat akin to Burkhauser and Daly (1996), is to derive summary statistics for various 'trajectory types'. Trajectories are determined by the pattern of 'disabled' (1) and 'not disabled' (0) observations for each individual over the seven years of the panel. After examining the distribution of duration of spells and the pattern of repeat spells for each of the disability indicators, the types of trajectory described in Table 3 were defined. The possibility of measurement error cannot be ignored (an individual incorrectly recorded as disabled, or as not disabled, in a particular year), but is difficult to distinguish from genuine changes in disability status. The grouping of trajectory types, in particular treating 'One off' as a separate category, is designed to minimise the problem.

The main limitation of this approach is that were one able to observe what happened before or after the 'window' provided by the panel, the classification of an individual's trajectory type might change. For example, an individual who is disabled at Waves 1 and 2, but not for the rest of the panel, would be classified as having a short continuous spell (ShortCon). But if the individual had in fact been disabled for three years immediately preceding the panel, it would look more like a long continuous spell. On the other hand, the strength of this approach is that it provides a readily comprehensible picture of the variety of paths individuals follow through the panel, and indicates their relative frequency. It can also provide a detailed breakdown of the population who are disabled at any one time (the 'stock' of disabled people) by the kind of disability trajectories they follow.

The second approach is to focus on those spells which are observed to start during the panel (the 'inflow' to disability). The proportion of spells which last for one, two or more periods can then be analysed, giving an estimate of the expected duration of disability once a spell has begun. Those whose spell of disability begins before the panel, including those who are disabled throughout, are excluded from this analysis. The results are therefore representative of individuals *becoming* disabled as adults, but say nothing about those who became disabled in childhood.[8] The collection of statistical techniques employed were developed for investigating life expectancy and are known as survival analysis (Cox and Oakes, 1984).

RESULTS

Disability trajectories

Just under three-quarters of working-age respondents (73 per cent) report no ADL-limitation during the panel, and just over one third of

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TABLE 3. *Definition of trajectory types*

Name	Definition	Example patterns
Never	Not disabled in any year	0000000
One off	Disabled in just one year	0100000 0000001
Short repeated ('ShortRep')	Disabled in two or three years in total, but not consecutively	0101000 1100100
Short continuous ('ShortCon')	Disabled in two or three years in total, consecutively	0110000 0000111
Long repeated ('LongRep')	Disabled in four, five or six years in total, but not consecutively	0110110 1011111
Long continuous ('LongCon')	Disabled in four, five or six years in total, consecutively	0111100 1111110
Always	Disabled in seven years consecutively	1111111

respondents (34 per cent) report no spells of GHQ>2. The patterns of disability experienced by other respondents are shown in Figure 1.

Those who report being ADL-limited at every interview during the panel represent only a small proportion of those who experience disability at some point. Just over 10 per cent of individuals report a 'One-off' spell of ADL-limiting disability, while between 3 per cent and 4 per cent report each of the other trajectory types. About the same proportion experience disability in consecutive years as experience disability intermittently or with some respite (ShortRep is a similar proportion to ShortCon, and similarly for long spells).

By contrast, for GHQ>2, both short and long total durations of disability experienced non-consecutively are common relative to the experience of consecutive spells, and relative to ADL-limiting disability. 'ShortRep' and 'LongRep' between them account for nearly one-third of individuals, compared to 13 per cent who experience disability in consecutive years for a short or long period. The proportion who experience one-off spells is double that for ADL limited. Just 2 per cent report GHQ>2 in all seven years of the panel.[9] It is widely acknowledged that mental illness is often intermittent (Lonsdale *et al.*, 1993; Mind, 1997), and these results confirm that impression.

The trajectories experienced by men and women are somewhat different. In the first instance, more women than men have some ADL-limiting disability during the panel (31 per cent compared to 23 per cent), and

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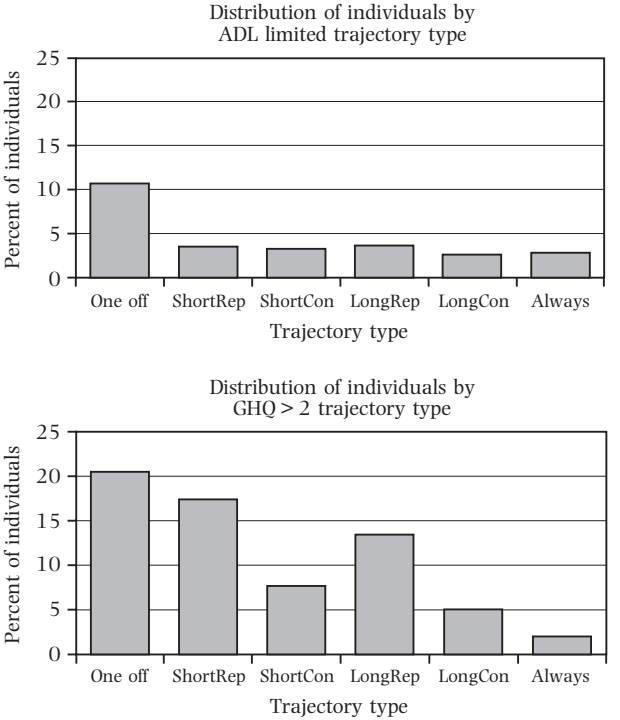


Figure 1. *Source*: Author's calculations using BHPS Waves 1–7.

many more women than men have at least one spell of GHQ>2 (75 per cent compared to 59 per cent). The gender breakdown by type of trajectory is shown in Figure 2. For ADL-limiting disability, women and men are about equally likely to be disabled throughout the panel or to have a long continuous spell, but women are more prominent in each of the other trajectory types. For GHQ>2, women predominate in all categories; the gap between men and women is largest in the trajectories representing non-continuous spells.

Average ages of men and women by trajectory type are shown in Table 4. For both men and women, those following longer ADL-limited trajectories tend to be older. The average age does not differ significantly by gender within each trajectory type, with one exception: men who are ADL-limited throughout the panel are significantly older than their female counterparts. These men are also substantially older than men who have long continuous spells.

Average ages are less differentiated across GHQ>2 trajectory types,

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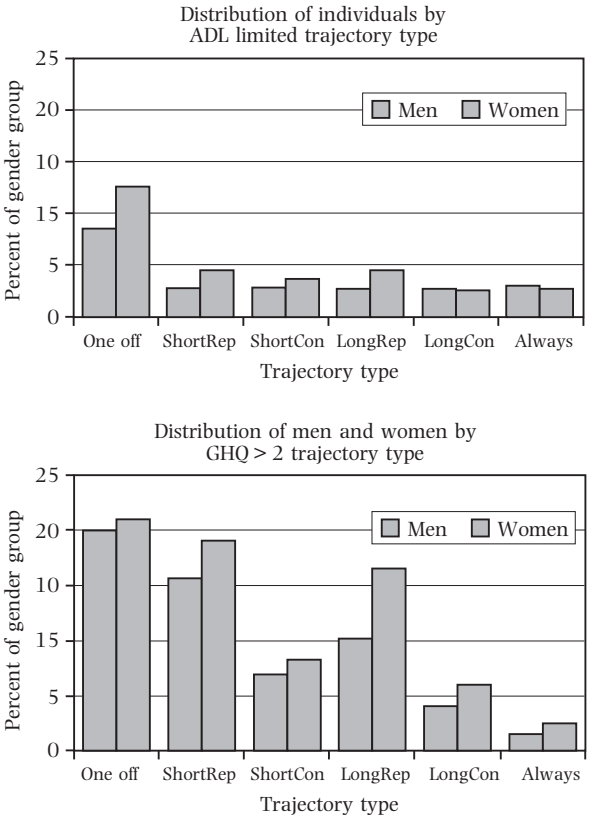


Figure 2. *Source*: Author's calculations using BHPS Waves 1–7.

although again those who are disabled throughout the panel have distinct characteristics: both men and women in the 'Always' trajectory type are significantly older, on average, than men and women in other trajectory types.

Comparison between cross-sectional and longitudinal disability measures

A cross-sectional measure of ADL-limiting disability at Wave 4 produces a prevalence rate of 11 per cent, but this 11 per cent is made up of people following quite different trajectories of disability.[10] Table 5 compares cross-sectional and longitudinal measures for ADL and for GHQ>2. Of those who are ADL limited at Wave 4, just over one quarter are 'Always' disabled. Another quarter have LongCon (four to six years consecutively), and a fifth have been disabled for a long period with some intermission. This highlights the contrast between looking at those who are disabled at

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TABLE 4. *Average age of men and women by disability trajectory type*

ADL-limited trajectory type	Men	Women
Never	34.8	35.0
One off	35.6	33.4
ShortRep	36.0	37.2
ShortCon	38.4	37.4
LongRep	43.7	41.6
LongCon	42.8	43.4
Always*	49.8†	44.8
All	35.9	35.8
GHQ>2 trajectory type	**Men**	**Women**
Never	36.1	37.6
One off	34.4	35.2
ShortRep	35.6	33.8
ShortCon	36.5	35.6
LongRep	36.4	34.9
LongCon	37.1	35.8
Always	43.4†	43.1†
All	35.9	35.8

For definition of trajectory types, see Table 3.
* Difference between men and women significant at 5 per cent level.
† Difference between Always and LongCon trajectory types significant at 5 per cent level.
Source: Author's calculations using BHPS Waves 1–7.

a moment in time (as in this table), and looking at all those who experience disability over a period of time (as in Figure 1). At any particular time, the proportion of disabled people who are on long-term disability trajectories is nearly three-quarters, but over a period of seven years, the proportion of people who experience any disability who are long-term disabled is under one-third.

In addition, there are some who might be considered disabled despite not reporting disability in the particular year in question. Looking at the right-hand column of Table 5, 82 per cent are never ADL limited during the panel, so these seem 'correctly' classified. However 2 per cent of those not ADL limited at Wave 4 experience long spells of disability. While it may be accurately reported that they are not ADL limited at Wave 4, their experience of disability is nevertheless considerable: four to six years out of a seven year period.

For GHQ>2, the largest group of those who are disabled at Wave 4 are those who experience intermittent GHQ>2 over a long period (one third).

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TABLE 5. *Comparison of cross-sectional and longitudinal disability measures*

Cross-sectional ADL measure at Wave 4		ADL limited 515 (11%)	not ADL limited 4,235 (89%)
		of which (%):	of which (%):
Longitudinal measure	Never	0	82
	One off	9	11
	ShortRep	11	3
	ShortCon	6	3
	LongRep	21	2
	LongCon	25	0
	Always	27	0
	All	*100*	*100*
Cross-sectional GHQ>2 measure at Wave 4		GHQ > 2 1,205 (26%)	not GHQ > 2 3,498 (74%)
		of which (%):	of which (%):
Longitudinal measure	Never	0	45
	One off	9	25
	ShortRep	21	16
	ShortCon	9	7
	LongRep	33	7
	LongCon	20	0
	Always	8	0
	All	*100*	*100*

Source: Author's calculations using BHPS Waves 1–7.

The two next largest groups – each representing one fifth of those disabled at Wave 4 – are those who have a long continuous period of disability and those who have shorter period of intermittent disability. The cross-sectional GHQ>2 measure misses quite a high proportion of those who might be considered disabled looking over a longer period: nearly a quarter of those not classified as disabled on the cross-sectional measure have short or long repeated spells of GHQ>2, and a further 7 per cent have a short continuous spell during the seven years.

Duration of spells beginning within the panel

We now turn from examining the 'stock' of disabled people to examining the 'inflow', in other words, those whose spell of disability begins during the panel. If a spell begins and ends within the panel, the duration can be determined. If a spell begins and is not observed to end, the duration is unknown but it can be said that the spell lasted at least to the end of the panel (for example, if the spell began at Wave 2, it would have lasted

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at least five waves). Duration within the panel cannot be precisely measured, since observations are at yearly intervals and it is not known whether the individual was disabled throughout the intervening period, but the count of consecutive observations of disability serves as an appoximation.[11]

In Figure 3, the horizontal axes show the number of waves which have elapsed since the onset of disability and the vertical axes show the proportion remaining disabled. For ADL-limiting disability, the number remaining disabled falls sharply initially: just over half remain disabled after one wave. The 'curve' then flattens out, indicating that the rate at which individuals are ceasing to be disabled has decreased. Very few cease to be disabled after four waves have elapsed, although only one-third of those who begin a spell will remain disabled for this long. Since the maximum duration which can be observed for a spell beginning within the panel is six waves, what happens after this cannot be ascertained, but there is no reason to believe that the gradient of the curve will change dramatically. The interpretation of these results is that while over half of those who become ADL-limited as adults have a short spell, few of those who remain disabled after four years recover.[12]

The gradient on the graph for GHQ>2 is slightly steeper initially and flattens out less rapidly, with the result that only one in three of those who begin a GHQ>2 spell are still disabled after two waves, and only one in ten are still disabled after six waves. What this graph does not show, but is apparent from the previous section on disability trajectories, is that many of those who have a short GHQ>2 spell will go on to have a repeat spell within a relatively short period of time.

Figure 4 shows the same duration estimates, broken down by gender. Men are slightly less likely to stop being ADL-limited than women initially, but the gradient after three waves have elapsed is similar. Overall, the difference by gender is statistically significant at the 5 per cent level.[13] The curves for men and women who become GHQ>2 during the panel are very close.

The breakdown by age group is shown in Figure 5. The 31–45 and 46–58-year-old age groups present a similar profile on ADL-limiting disability. The oldest age group is much more likely to become disabled in the first place, but if someone in the 31–45 age range does become disabled, the prospects for the duration of their spell are similar to that of the older age group. Both 31–45 and 46–58-year-olds are much more likely to remain disabled for longer than younger people. Only one in five young people who become ADL-limited remain so for four waves. On GHQ>2, all three age groups follow similar patterns.

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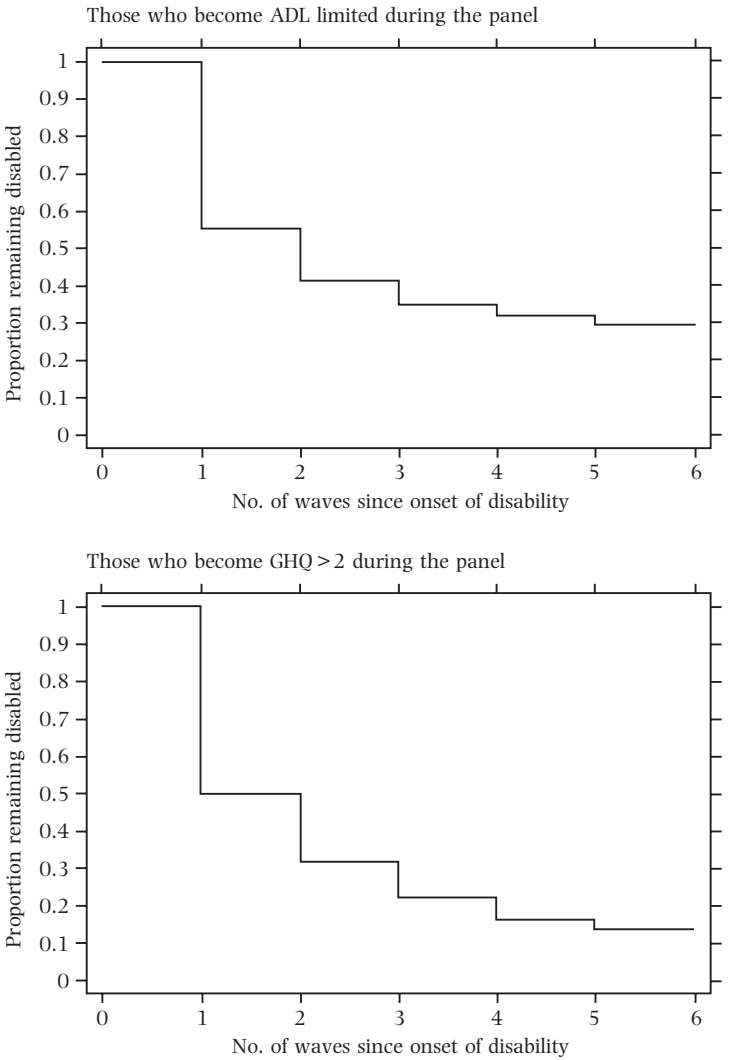


Figure 3. Kaplan–Meier survival estimates. *Source*: Author's calculations using BHPS waves 1–7.

DISCUSSION

Results from analysis of the British Household Panel Survey confirm the hypothesis that only a small proportion of working-age people who experience disability are long-term disabled, despite the fact that at any one time, long-term disabled people make up a high proportion of all disabled people. This coincides with general findings from US studies: the common

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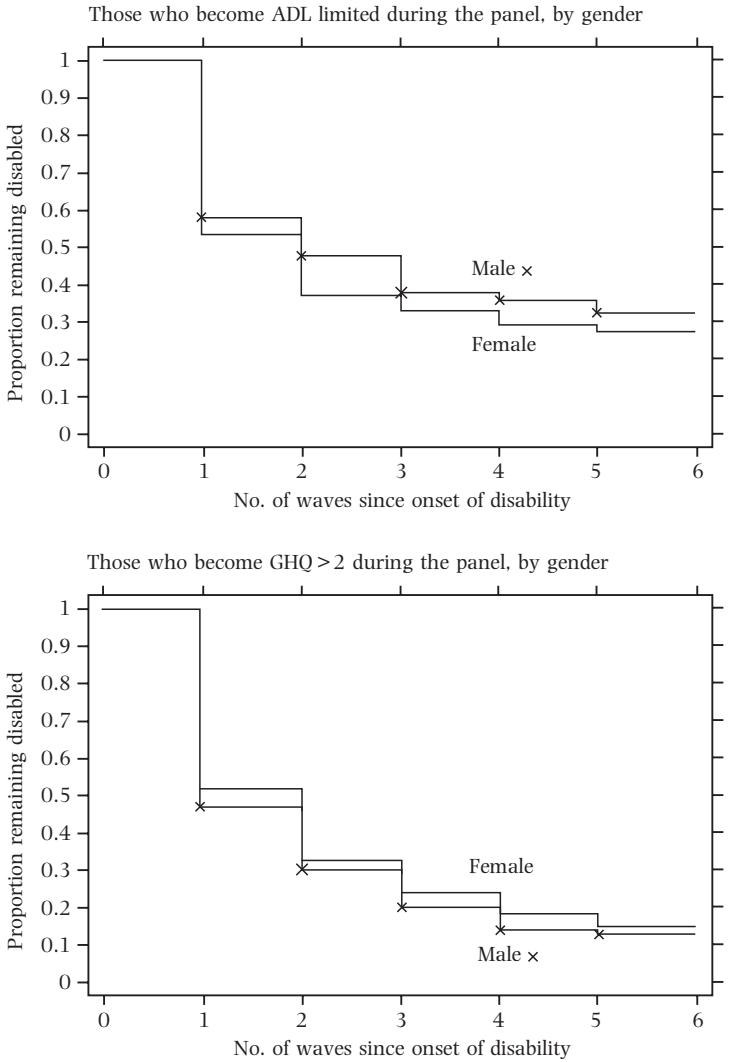


Figure 4. Kaplan–Meier survival estimates, by gender. *Source*: Author's calculations using BHPS waves 1–7.

perception that disabled and non-disabled people make up two entirely distinct and fixed groups in the population is misleading. In Britain in a particular year, around one in ten people of working age are limited in their daily activities, of whom three-quarters are on long disability trajectories. But over a seven-year period, as many as one in four experience some limitation, of whom only 10 per cent are disabled throughout.

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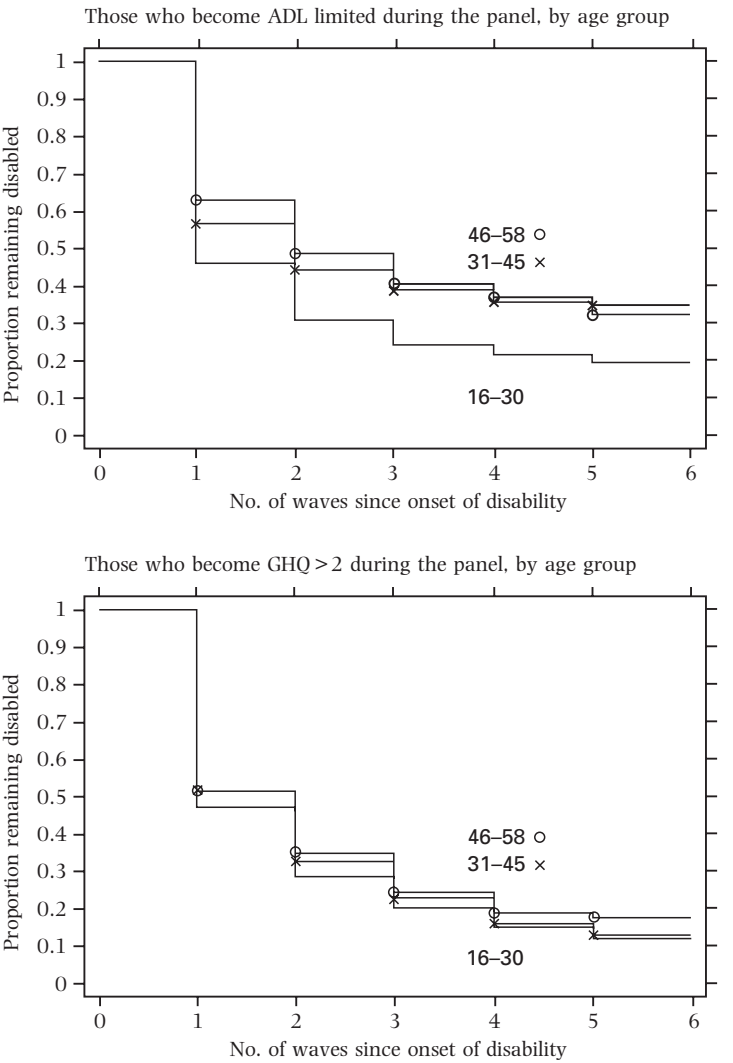


Figure 5. Kaplan–Meier survival estimates, by age group. *Source*: Author's calculations using BHPS waves 1–7.

Cross-sectional measures in some respects over-estimate, and in other respects under-estimate, disability looked at with a longer view. For around one in ten of those limited in activities of daily living according to a cross-sectional measure, that disability is a one-off observation (within a seven-year window). On the other hand, about 5 per cent of those not classified as disabled in the year in question have intermittent patterns of

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disability; their inclusion would increase the cross-sectional count of disability by nearly one-third. Aside from the question of accuracy, a static measure of disability conflates entirely different experiences under one indicator – a brief spell of incapacity perhaps following an accident, with a chronic, long-term problem that offers only occasional respite.

Detailed analysis of those who become limited in activities of daily living as adults reveals that over half have spells lasting less than two years, but that few who remain disabled after four years will recover. The core of long-term disabled have low exit rates. For mental illness, just one in ten who begin a spell are still ill after six years, though many more have repeat spells. Intermittent disability of this kind is very common – nearly one-third of the sample experienced more than one spell of mental ill health – while long continuous spells are rare in comparison to disability picked up by indicators of functional limitation.

More women than men of working age experience disability, and the difference is especially noticeable in mental health. But men who become limited in their activities of daily living are slightly more likely than women to remain disabled for a longer period. Older people of both sexes are more likely to become disabled than younger people and those who are disabled throughout the seven-year window provided by the panel are significantly older, on average, than individuals following any other trajectories. However, 31–45-year-olds who do become disabled face similar probabilities of long spells as 46–58-year-olds.

The results have implications for survey design and analysis. First, given the sensitivity of estimates to different indicators of disability, attention needs to be given both to the underlying concept of disability and to the phrasing of questions. While organisations of disabled people have moved towards a social model of disability, recognising institutional barriers to participation as well as individuals' impairments, large-scale surveys have been slow to respond. There is also unhelpful ambiguity over ill-health and disability.

Second, disability is not a fixed characteristic of individuals, at least within the working-age population. Treating one-off observations of disability separately – the method adopted in some recent American studies – is one possibility, but a simple cut-off by number of consecutive observations is misleading, and excludes those whose disability is intermittent. The 'trajectories' approach taken here, distinguishing between short and longer-term disability, and between continuous and repeated spells, comes closer to reflecting the complexity of disability dynamics. Longitudinal measures reveal considerable variation in the experience of disability which is hidden in a cross-sectional measure.

The results also suggest a need to revise our understanding of who and

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what disability policy is about. Looking at the population over time, disabled people make up a larger constituency than might previously have been acknowledged: a significant proportion of people are affected by disability at some point during the course of their working lives. Disability issues can no longer be seen as a minority interest; their continuing prominence on the political agenda is lent support by a longitudinal perspective.

A longitudinal view also facilitates the development of a more sophisticated understanding of who is disabled. On the one hand, those with intermittent or fluctuating conditions – especially mental illness – are seriously under-counted in cross-sectional measures. On the other hand, a cross-sectional measure includes many people whose spell of disability will be short. If, as seems likely, people who are disabled for a relatively short period face less severe pressures on their income and in general experience less severe dislocation from the mainstream, the disadvantage disabled people encounter will be underestimated if groups within the disabled population following different trajectories are not differentiated.

Even more importantly, considering disability in a dynamic setting allows us to analyse different processes by which disabled people become socially excluded. Key points in the trajectories individuals follow may be identified and interventions targeted at them: the transition to adulthood for those who become disabled in childhood, perhaps; or for those who become disabled while in work, the period immediately after they develop a health problem or impairment but before they lose their job. It may be possible to identify factors prior to someone acquiring an impairment which increase or decrease the risk of subsequent exclusion. The dynamic perspective allows the focus to be on preventing undesirable outcomes as well as ameliorative strategies.

Future work will relate the dynamics of disability to patterns of benefit receipt and employment. But the underlying complexity of disability has in itself implications for the design of social security and employment policy. Until recently, benefits were based on the understanding that disability was a one-way street. Disability Living Allowance awards were often made for life and not reviewed. Incapacity Benefit claimants were not encouraged to participate in back-to-work schemes and in some cases did not have access to the job-search facilities available to other claimant groups. The approach can be summed up as 'once disabled, always disabled' – and subsequently ignored by 'the system'. The outcome has been a ratchet effect on benefit expenditure (Berthoud, 1998) and has re-enforced the marginalisation of disabled people on benefits, many of whom express the desire to return to work.

Re-connecting Incapacity Benefit claimants with the mainstream of out-of-work benefit claimants through the New Deal for Disabled People is for this

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reason to be welcomed. But personal advisers will need to be sensitive to the range of disability trajectories their clients may follow. Recognition that some, but not all, disabled people will be disabled over the longer term means solutions need to be found which accommodate their needs – whether through vigorous application of the Disability Discrimination Act to employers or through enhanced support from the benefit system, or a combination of the two. For those who want to work, the emphasis may need to be on changing the workplace and organisation of the job in question, rather than expecting the individual him or herself to change. Special consideration may need to be given to a minority of people who become long-term disabled at a younger age, such as the 31–45 year olds identified in this study who face similar probabilities of their disability becoming long term as 46–58 year-olds.

Another important group among the personal advisers' clients will be those who have intermittent conditions, especially since mental illness is increasingly cited as the cause of incapacity by Incapacity Benefit claimants. Benefits and employment support need to reflect the non-continuous nature of some disability: an eligibility test which takes no account of fluctuating conditions will exclude large numbers of people. For those who wish to work, it may be necessary to adapt the work environment to make it amenable to varying levels of attendance or output; self-employment and other flexible forms of working may be appropriate.

For those who are short-term disabled, the most important function of the personal adviser is likely to be smoothing the transitions between employment and benefit receipt in both directions. Early intervention to retain links with any existing employer or field of work is more likely to be successful than attempting to re-establish connection with the labour market after months or years have elapsed.

For all disabled people, identifying and removing barriers to their full participation in society – a decent standard of living and opportunities for meaningful activity, political engagement and social interaction – must be the objective of social policy. But policies which fail to distinguish between the different trajectories which disabled people follow are unlikely to be successful.

NOTES

1 ADLs are activities such as bathing, dressing, going to the toilet, climbing stairs, and eating. Being ADL limited is usually defined as needing the assistance of someone else to perform one or more of these activities. See Katz *et al.* (1963).

2 It is not known how many were disabled; about one quarter had a limiting long-standing illness.

3 For discussion of weights in the BHPS, see Taylor (1998). 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. Furthermore, the analysis sample is not identical to the sample on which the longitudinal weights are based. The latter includes those who become of age at some point in the Panel and those who return after missing one or more Waves. However the numbers in these categories are small.

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4 Some variation arises from timings of interviews within the fieldwork period.
5 Two kinds of scores are commonly derived from the questionnaire, the Likert scale (responses to each of the 12 questions coded 'Better' = 0, 'Same' = 1, 'Worse' = 2, 'Much worse' = 3, and then summed) and the Caseness (responses coded 0, 0, 1, 1 respectively). McDowell and Newell (1987) report no advantage to the Likert scale, so Caseness is used here.
6 The 1991/92 Health and Lifestyle Survey used an extended scale, GHQ30, and found 25 per cent of men and 30 per cent of women were above the cut-point (Huppert and Whittington, 1993). The Health Survey for England 1993–95 found 13 per cent of men and 19 per cent of women scored 4 or above on GHQ12 (a higher cut-point than is usual) (Prescott-Clarke and Primatesta, 1997). The BHPS figure for proportion of working-age people who are work limited is 14 per cent, close to that found in the Spring–Winter 1997 Labour Force Surveys (13 per cent) (Cousins *et al.*, 1998).
7 35 per cent of those who are ADL limited are limited in more than one of: doing the housework, climbing stairs, getting dressed and walking for more than 10 minutes.
8 In the 1996/97 Family Resources Survey Disability Follow-Up, one fifth of those of working age who are disabled say the onset of their condition was at birth or during childhood (author's calculations).
9 It could be that a questionnaire originally designed to measure *change* in mental health does not pick up those with long-term problems but tests have shown that it does in fact do so (McDowell and Newell, 1987).
10 The mid-point of the panel was chosen for the comparison since cross-sectional prevalence rates rise through the panel, and therefore the proportion in each trajectory type changes.
11 A single observation of disability (e.g., 0100000) means the individual was disabled for a maximum of almost two years (from immediately after Wave 1 interview to immediately before Wave 3 interview), and a minimum of one day (the day of the Wave 2 interview).
12 Some caution is needed since cell sizes are small for long spells. Although 1,228 ADL spells begin within the panel, only thirty-eight are observed to continue for a full six waves. On GHQ>2, 3,480 spells begin within the panel, and thirty-one are observed to continue for a full six waves.
13 Log-rank test for equality of survivor functions.

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