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Disability in the UK: measuring equality

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In this article we identify the key survey data for examining the issue of equality in the lives of disabled people in the UK. Such data is essential for assessing change in quality of life over time and for the evaluation of the impact of policy initiatives. For each data source we consider definitions, data collection, issue coverage, sample size and data access. It is evident that there is only limited survey data on the lives of disabled people in the UK. A number of national surveys include questions on disability, but many offer only limited coverage. There is a tendency to focus on the medical aspects of disability and a failure to clearly distinguish disability from other health issues. Moreover, disability definitions vary and sample sizes are often too small to compare differences by age, gender, ethnicity or locality. For effective policy development there is a need to identify and measure what leads to change in disabled peoples' lives.

Keywords: disability; equality; survey data

Introduction

The definition of disability accepted by the government for the purposes of assessing equality, including the Public Sector Agreement targets, is that of the 1995 Disability Discrimination Act (DDA) (amended 2005): 'a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities'. The impairment must affect one of the following day-to-day activities: mobility; manual dexterity; physical coordination; continence; ability to lift, carry or otherwise move everyday objects; speech, hearing or eyesight; memory or ability to concentrate, learn or understand; perception of the risk of personal danger. Long-term means that the disability has lasted or can be expected to last at least 12 months.

It is notable that the Disability Rights Commission (DRC) has proposed that the definition should include anyone who has any level of impairment, as this would shift the focus from a medical definition to experience of discrimination (DRC 2006a). The issues of equality affecting disabled people are multiple and include: access to appropriate services for health and welfare needs; equality of opportunities; mobility and social exclusion; personal safety; protection from discrimination in employment and training. The anti-discrimination legislation in relation to disability is less extensive than that in place in relation to gender, ethnicity or religion, although the 2005 DDA extends the definition of disability and places a duty on all public bodies to promote equality of opportunity and positive attitudes towards disability.

In this paper we review the survey data evidence on the lives of disabled people in the UK. The review was conducted using systematic searches of both existing literature and

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secondary data and also consultation with the DRC and the Department for Work and Pensions (DWP).

Population profiles

There is no gold standard measure or estimate of disability rates in the UK and no single definitive source (DWP 2004). Estimates vary according to definition and data source. In 2005 the DRC estimated that there were around 8.5 million disabled people in the UK. The most common impairments of disabled people in order of prevalence are: musculo-skeletal (problems with arms, legs, feet, back or neck); chest and breathing; heart and blood pressure; speech impediments; mental illness; digestive problems; diabetes; the senses (difficulties hearing and seeing). Analysis of the British Household Panel Survey by Burchardt (2000) suggested that in any particular year around one in ten people of working age are limited in their daily activities, three-quarters of whom have long-term disability trajectories. Burchardt (2004) found that on average 3% of people of working age become disabled each year via accident, sudden development or an impairment getting worse. Severity of disability can be measured using the 1997–1998 Family Resources Survey on Disability, although this evidence is now dated (see Berthoud 2006).

Evidence suggests that disabled people from minority ethnic populations may be less likely to formally report that they have a disability and are less likely to take up support services (Prime Minister's Strategy Unit [PMSU] 2005). Analysis of the Labour Force Survey (LFS) suggests that older Asian and black Caribbeans (aged 50–64) generally have considerably higher disability rates than the white population in the same age group. There are no comparable figures for the Chinese population in this age group because of the limited sample size.

Between 5 and 7% of children (or nearly 800,000) are estimated as having a disability (Grewal et al. 2002; PMSU 2005). The Medical Research Council estimates that autistic spectrum disorders affect approximately 60 in every 10,000 children under 8 years old. Detailed evidence on the circumstances of disabled children is limited. More generally, problems surround the definition of disability amongst children, which has led to considerable variations in policies across different service providers. Data is collected by local authorities on children with statements of special educational needs, but the detail is limited. Data on children's disabilities as reported by parents is provided in the General Household Survey, which is a Great Britain wide survey conducted by the Office for National Statistics (ONS). Around 9000 households are interviewed each year. Information on specific conditions is collected and there is scope for analysis by different demographics, however, the coverage of children's circumstances and experiences is limited. Nessa (2004) has also drawn on funding application data to examine the circumstances of disabled children, but the population base is restricted to applicants (see Gordon and Hutchinson 2005; Gordon, Parker, and Loughran 2000; Read 2000; Read, Clements, and Ruebain 2001).

There is no definitive estimate of the number of people with learning disabilities in the UK, although the Foundation for People with Learning Disabilities (2006) has suggested that there are approximately 1 million people with learning disabilities in the UK. An estimated 230,000–350,000 people have severe learning disabilities. Research suggests that overall men are more likely to have a learning disability than women and that learning disabilities are more common amongst those families who are poor and also amongst certain minority ethnic populations, particularly South Asians (see Emerson et al. 2001; Mir et al. 2001).

Key surveys

The Office of Population Censuses and Surveys studies of disability back in the 1980s are thought to have produced some of the first accurate estimates of the prevalence of disability in the UK

(Martin, Meltzer, and Elliot 1989). However, Abberley (1992) questioned the focus on the medical aspects of an individual's condition rather than the barriers that they may encounter. In the national level surveys, such as the census and the LFS, the questions related to disability have also tended to focus on the medical aspects of individuals lives and don't always clearly distinguish disability from other health problems. This is despite the government's claim of the importance of making such a distinction in relation to developing an understanding of the lives of disabled people (PMSU 2005).

The LFS does offer more scope than the census for examining the circumstances of disabled people. The LFS has a large sample size of 60,000. Information is collected on specific conditions such as, for example, whether a health problem is related to bones and joints, hearing, seeing, speech, chest or breathing problems, heart and circulation problems, depression, learning disabilities and diabetes. However, detailed information on health and disability is not collected for all of those over retirement age in the sample. Variations in the definition of disability have also been used which make comparisons over time very difficult. More fundamentally, little information is collected on the barriers individuals face and how these may change over time. Such a social model-based approach focuses on attitudinal and environmental factors that can act as barriers in peoples' everyday lives. As Oliver (1992, 1996) has argued, it is not the disability that is the sole cause of problems in the lives of people with impairments, but society itself, in terms of peoples' attitudes and such things as building design and transport provision. Moreover, a health problem or impairment can limit activities in some environments and not in others (see also Barnes and Mercer 1997; Crow 1997; Priestley 2000; Riddell and Watson 2003; Zarb 1995).

The Health Survey of England (HSE) is a large-scale survey of medical health. It is a multi-stage random sample of around 10,000 adults and children. It covers a wide range of health issues, physical measurements, nutrition, physical fitness, alcohol consumption and treatment histories. The HSE includes a number of questions on mobility and use of transport and general questions on difficulties and limits on usual activities. However, detailed coverage of the way in which disability affects peoples' lives and the barriers they encounter is limited. Separate national health surveys have also been conducted in Scotland and Wales.

The Family Resources Survey (FRS) is an annual survey which aims to support assessment of the social security programme. It has a sample of around 30,000 households. The survey includes questions on the use of health services, health-related restrictions on the capacity to work and informal care. It can be used to provide breakdowns of the percentage of disabled adults by region, by sex, by age group and by ethnicity (but only white/non-white). The FRS also provides an estimate of the annual spending power of disabled people. As mentioned above, although now dated, in 1996–1997 there was also a disability survey follow-up to the FRS, which asked in detail about cause, type and severity of disability, the extra needs and costs which result and participation in leisure and social activities.

The British Household Panel Survey (BHPS) collects information on disability, ill health and impact on daily activities. The BHPS has the advantage of allowing assessment of how respondents' circumstances have changed over time. 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, but it does not include people who live in institutions. In the sample 1300 respondents were found to be limited in their daily activities at some point (for further discussion and analysis see Burchardt 2000).

The Cohort Studies provide a valuable source of data on the circumstances of disabled people, particularly the British Cohort Study (1970) and the Youth Cohort Study, which covers 16–19 year olds. These surveys trace peoples' changing circumstances and have substantial sample sizes. However there are some aspects which impact on the overall coverage of disabled people. These include inconsistencies in the responses to the questions on

disability, very small samples sizes in relation to respondents who report a disability (such that further breakdown by key demographics and condition can be problematic), higher attrition rates for people who reported an impairment and for people from lower socio-economic groups and also children aged 16+ in special schools are not included. Moreover, in the Youth Cohort Study there is only limited coverage of disability issues (for further discussion see Burchardt 2005).

The Mental Health and Learning Disability Census is a potentially hugely valuable data source. It has a large sample size of around 40,000, but the population is limited to mental health in-patients and those living in learning disability facilities, which therefore limits its representativeness. The first survey highlighted how certain minority ethnic groups had higher rates than average of in-patient admissions to psychiatric services. The recent Survey of Adults with Learning Disabilities in the UK, which is supported by the Department of Health, represents a major shift in the evidence base on the lives of people with learning disabilities in the UK. It includes coverage of the use of services and unmet need (see Emerson et al. 2005).

The Department of Health and the Scottish Executive have also conducted survey research into mental health issues. This began with the 2000 Psychiatric Morbidity Survey in Great Britain and was followed up by a survey of the 2406 people who had been interviewed in 2000. This provides a unique longitudinal perspective on mental health, highlighting, for example, how mental health problems such as anxiety or depression are not always permanent and how peoples' conditions and circumstances change over time. It also includes some respondent perception measures of quality of life and measures relating to the performance of daily tasks (see Singleton and Lewis 2003).

Below we review the key equality issues and quantitative survey evidence in relation to the lives of disabled people in the UK.

Equality issues

Economic circumstances

Disabled people are more likely than non-disabled people to be living in poverty in the UK (Burchardt 2004). Disabled adults are twice as likely as non-disabled people to be in households with low incomes, more likely to live in workless households and they also face additional living costs, including care and transport (Smith et al. 2004; Thornton 2005). Grant (1994) found, in her qualitative study of 79 disabled people, that debt problems were the most significant aspect of their lives. Research by Burchardt (2004) using the BHPS has also shown that people living in poverty are more likely to become disabled. People of lower socio-economic status were also found to be less likely to recover from common mental disorders (such as depression and anxiety disorders) (Singleton and Lewis 2003; see also DRC 2006b; Preston 2006).

There are considerable variations in the rates of disability amongst the working age population across different regions. For example, in the North East 25% of the working age population is long-term disabled, compared with 16% in the South East (DRC 2003a). Analysis below this geographic level is limited because of the small sample sizes.

Education, training and employment

Disabled people are more than twice as likely to have no qualifications compared with the non-disabled population. Amongst 18 and 19 year olds the highest qualification of 48% of disabled young people was equivalent of NVQ level 1 or below (GCSE grades D–G or below), including those with no qualifications, compared with 28% of non-disabled young people (Burchardt 2005).

Grewal et al. (2002) found that a quarter of all people who were disabled during their school years said that they had had a negative experience of mainstream education. In a National Opinion Poll (NOP) poll conducted with disabled young people 20% said that they were discouraged from taking GCSEs because of their impairment (NOP 2003). Research amongst young adults with moderate learning disabilities has shown that in recent years their educational and life ambitions have become comparable to non-disabled young adults of the same age, whereas in the past they tended to have much lower aspirations (Burchardt 2005; Norwich 1997). In 2003 the Higher Education Statistics Agency revealed that the percentage of disabled students in higher education had gone up from 4.1% for 2000–2001 to 4.65% for 2001–2002. However, this was below the rate expected (see Groucher 2004).

Evidence suggests that disabled children have proportionately less access to childcare and early years education than non-disabled children due to the higher costs and a lack of available places. Childminders often lack training to meet disabled children's needs. School-based provision is more widely available, although more than half of providers were found to only have a place for one child at any one time (National Audit Office 2004). As a result families can become socially excluded and be forced to live on reduced income.

The National Adult Learning Survey (NALS) is designed to monitor the effectiveness of adult learning policies. It includes questions on health, disabilities and benefit entitlement and training, so it is possible to examine the learning experiences of disabled people. In the 2001 NALS just under one-third of respondents in the sample had a long-standing illness or disability. The sample size does allow national level analysis, but the scope for regional and local comparisons is limited.

In relation to employment, estimates using the LFS suggest that in 2004 there were 6.9 million disabled people of working age in Great Britain (20% of the total working age population) (DRC 2003a). Disabled people are only half as likely to be in employment as non-disabled people (Goodlad and Riddell 2005). Although the gap is reduced, disabled graduates are less likely to be in employment than non-disabled graduates (HESA 2002). Berthoud's (2006) analysis of the FRS suggested that once socio-demographic characteristics are held constant, disabled people face an employment penalty of 40%. Using data from the British Cohort Study, Burchardt (2005) found that the gap between the proportion of disabled and non-disabled young people out of work widens as they get older.

Employment rates amongst disabled people have increased by 7% since 1998. It is notable that 24% more disabled women and 11% more disabled men are working in the public sector compared with 1998 (Hirst et al. 2004). Although this is still well below the rate of non-disabled people, there is a need to be aware of the impact of modifications to definitions of disability over time. The employment rates of disabled people vary according to the medical conditions they report, according to the types of impairment they experience and according to the overall severity of those impairments (see Berthoud and Blekeseaune 2007).

Analysis of the LFS suggests that 55% of disabled women worked part-time compared with 40% of non-disabled women. Part-time working has been found to be mainly related to balancing domestic responsibilities, but about one-third of disabled people said it was because of concerns about their health (Grewal et al. 2002).

LFS data suggests that disabled people who have had a job have longer periods out of work than non-disabled people. Burchardt (2004) estimated that within of a year of becoming disabled 35% of people who were in employment had left. Further research is required into what might enable people to remain in employment following disability.

Hirst et al. (2004) found that after standardising for age, to take account of the younger age profile of minority ethnic populations, the employment rates of minority ethnic disabled people were lower than disabled white people in the public sector (8% compared with 12%). Disabled

people were also found to be more likely to be in administrative and elementary occupations than in the higher socio-economic groups. They were also found to be less likely to receive on the job training. Sefton, Baker, and Praat (2005) also highlighted how minority ethnic people with a sensory disability are less likely to be in employment when compared with white people with a sensory disability (see also Hussein, Atkin, and Ahmad 2002).

The recent national Survey of Adults with Learning Disabilities in the UK found that 65% of people with learning disabilities who were unemployed and were able to work said that they would like a job (Emerson et al. 2005; Smith and Twomey 2002; Stanley and Regan 2003). However, LFS data has also shown that as little as 2% of the long-term disabled population of working age who were claiming a sickness or disability benefit and would like to work would be available for work within a fortnight (DRC 2003a). Some doubt can be attached to such findings from the LFS, particularly following qualitative research that found variations in how respondents interpret LFS questions about economic activity and their future intentions to work (Guinea and Betts 2003). It is notable that in relation to disability benefits take-up research by Berthoud (1998) concluded that under-claiming is as significant as over-claiming.

There are a number of specific surveys which have examined the issue of employment and disability. Such surveys have comparatively smaller sample sizes, but provide more detailed information. The Attitudes and Awareness Survey conducted on behalf of the DRC focused on issues of fair treatment of disabled people in employment and access to goods, services and facilities. Bunt et al. (2001) conducted a survey of employers and found that physically disabled people and people with mental health problems were, in the view of employers, much less likely to be recruited than lone parents or the long-term unemployed. In research by Graham, Jordon, and Lamb (1990) identical job applications were submitted except that one application declared that the applicant had a non-work-limiting disability. It was found that the disability severely affected the likelihood of the candidate being invited for interview. Grewal et al. (2002) found that 17% of disabled respondents had experienced discrimination in the workplace because of their disability and they also found evidence that disabled people frequently believed that they had encountered prejudice in the application process.

Other small-scale studies have examined the experiences of disabled people in employment and in relation to a range of social issues, e.g. DRC case studies of service users in four cities (DRC 2004a), a study of the experiences of deaf teachers (Young, Ackerman, and Kyle 1998), a study of visually impaired health professionals (French 2001), a qualitative study of the barriers minority ethnic people with disabilities face in gaining employment (Ali et al. 2006), a study of the discrimination encountered by disabled women (Ellis 1995), a social profile of lesbian, gay and bisexual disabled people (Brothers 2003), research into accessibility of polling stations (Capability Scotland 2003) and a review and analysis of the data available on the circumstances of minority ethnic people with sensory disabilities (Sefton, Baker, and Praat 2005).

For further discussion of the barriers disabled people face in finding employment see Arthur and Zarb (1995), Barnes, Thornton, and Maynard Campbell (1998), Blackaby et al. (1999), Hurstfield et al. (2004) and Barham and Leonard (2002).

Housing and health care

The Department of Health Survey of Adults with Learning Disabilities has revealed a number of housing issues affecting disabled people (Emerson et al. 2005). Around 3000 adults were interviewed. Specific areas of concern included suitability of accommodation, level of independence, communal living and privacy. Of people with learning disabilities 64% stated that they did not have a choice over where they lived or who they lived with; 39% stated they did not have enough privacy; 50% of adults with learning disabilities were still living with their parents and a further

12% were living with other relatives (for further discussion see Ahmad 2000; Salvage and Zarb 1995a). The Foundation for People with Learning Disabilities (2006) has highlighted the growing challenge for people with learning disabilities who wish to leave the family home and the importance of planning for these housing needs. However, again the available data on expected demand is dated. Research by the DRC has shown that 50% of parents with learning disabilities have their children taken into care (DRC 2006c).

In relation to healthcare, a wide range of inequalities are evident. Research suggests that preventable deaths of people with learning disabilities are four times higher than for the rest of the population (DRC 2003a). Disabled people have been found to be less likely to take up preventative care services. For example, compared with the national uptake of breast screening the rates are strikingly lower amongst disabled women with learning disabilities. Medical problems can also be overlooked, because medical care focuses on the patient's disability or age (Mencap 2004). Disabled people are much more likely than non-disabled people to find key services inaccessible (DRC 2002; Leonard Cheshire Disability 2003). In a survey conducted by Sport England 64% of respondents stated that they would have liked to play sport but found it difficult or impossible (Sport England 2001).

Small-scale qualitative research and sample surveys on barriers to accessing services on behalf of the DWP by Grewal et al. (2004) found that one in five survey respondents had experienced difficulties accessing goods and services (see also Hatton et al. 1998; Mir et al. 2001). Research has also identified high levels of unmet need in terms of public transport and mobility (see Salvage and Zarb 1995b). The National Travel Survey includes a section on disability, with questions relating to difficulties in travelling to work, the shops, visiting friends and public transport. Research by the Scottish Executive (1999) has found that only 15% of Scotland's bus fleet has a low floor, certain key bus stations are inaccessible to disabled people, many trains are inaccessible due to lack of ramps and only 51 of over 300 stations are accessible to all areas for wheelchair users. Research by Emerson et al. (2005) highlighted the social isolation faced by many people with learning disabilities. People with learning disabilities were found to be much less likely to see their families and friends than people without learning disabilities.

As outlined above, in relation to mental health, research has shown that certain minority ethnic groups have much higher rates than average of in-patient admission and detention in psychiatric services when compared with the white population. The rates of admission into mental health hospitals were at least three times higher for black populations than the average. Such populations were also more likely to be detained under the Mental Health Act and more likely to experience sedation or physical restraint (see Chamba, Ahmad, and Jones 1998; Healthcare Commission 2007). Research by Mir et al. (2001) has found that negative stereotypes and attitudes held by service professionals can contribute to the disadvantage minority ethnic people face.

Crime and safety

There is only limited evidence on disabled people's experiences of crime and criminal justice. Research by the Department of Health found that 32% of people with learning disabilities had encountered 'rudeness' or 'offensive behaviour' from people because of their learning disability in the last year; 23% of adults with learning disabilities had experienced physical abuse, while 32% also stated that they did not feel safe in their own homes, their local area or when using public transport and 9% of respondents stated that they had been a victim of crime in the last year (see Emerson et al. 2005). More generally, the ONS Omnibus Survey, which began in 1990, included a range of questions on attitudes towards disabled people. The survey is a repeated cross-sectional study and includes around 1800 respondents.

In Scotland evidence from the Scottish Disability Awareness Survey 2003 has revealed that one in five disabled Scottish people had experienced harassment because of their disability. Follow-up qualitative research found that half the respondents had experienced a hate crime (although the actual numbers of respondents in the survey are small) (DRC 2003b).

The British Crime Survey (BCS) is primarily a survey of perceptions and experiences of crime in England and Wales. The BCS includes questions related to whether the respondent has a long-term illness or disability and whether an incident of harassment, crime or fear of crime was related to disability. The BCS provides good scope for examining issues of victimisation in relation to disabled people and in relation to mobility and use of certain services, such as public transport. In the 2005 BCS just under one-third of respondents in the sample had a long-standing illness or infirmity. As such, the BCS provides a valuable resource for exploring the attitudes and experiences of this population in relation to crime and criminal justice. However, the detail in the BCS on the lives and experiences of disabled people more generally is limited.

Conclusions

There is only limited survey data on the social and economic circumstances of disabled people in the UK. For certain groups (including children) there aren't even agreed estimates of the numbers of disabled people. There is no specific survey designed to capture the circumstances of disabled children and young people and few of the national surveys capture this information effectively. This is a major gap in the evidence base for monitoring equality and hinders effective evidence-based policy development and service provision.

Definitions of disability vary across surveys and sample sizes are often too small to examine differences across populations. In a number of national social surveys there is a tendency to focus on the medical aspects of disability and a failure to clearly distinguish disability from other health problems. The underlying approach seems to be focused on the extent of dependency rather than one of quality of life. Moreover, many UK national sample surveys are not even inclusive of all disabled people. For example, in numerous surveys people in residential care or communal establishments are not included in the sampling frame. Yet, as Priestley (2000) and Grewal et al. (2002) have highlighted, a majority of people with impairments are over retirement age. Disability is a way of life for older people, but they are rarely seen as disabled. It is notable that many developed countries (including France, Canada, Australia and the USA) have dedicated specialist surveys on disability.

As a priority, cross-sector and internationally harmonised survey questions on disability need to be established that capture the circumstances, severity of impairment and barriers faced by disabled people, including children, young people, adults and the retired (World Health Organisation 2003). The current ONS harmonized question relating to disability (limiting long-standing illness or disability question) does not provide a satisfactory definition of disability based on the DDA. It is promising that the 2007 census test includes a more detailed question on type of disability (ONS 2007). It is also certainly highly desirable that detailed disability information is to be collected in the Integrated Household Survey to be conducted by the ONS.

More evidence is required on the impact of multiple impairments in the lives of disabled people. Research by the DWP (Grewal et al. 2004) has shown that almost three-fifths of disabled people reported three or more impairments. While data is collected on multiple impairments, they are not commonly reported. This can lead to considerable under-representation of the size of the population with multiple disabilities. For example, Harris and Thornton (2005) noted a stark contrast between the DRC published data based on the spring 2002 LFS, giving an estimated 127,000 people of working age whose main condition was 'difficulty in hearing', compared with the Royal National Institute for the Blind estimate of over 2.25 million deaf and

hard of hearing people of working age, based on the standard epidemiological source (Davis 1995).

Under-reporting is a major problem in relation to understanding the circumstances of disabled people. For example, Grewal et al. (2004) found that only 48% of disabled respondents classified themselves as having a disability. People are often reluctant to report past or present mental health problems (Rooke-Mathews and Lindow 1998). Research by Dex and Purdam (2005) has shown that in the workplace employers find it very difficult to collect such information, as employees are unwilling to provide it. This maybe related to concerns about confidentiality and prejudice, which again need to be overcome.

The impact of other factors, such as poverty, gender, ethnicity, unemployment and working part-time, on the lives of disabled people also need to be considered. There is no current reliable comprehensive measure of disabled people's economic circumstances apart from those of working age and no reliable estimates exist of the number of disabled people from minority ethnic populations by detailed ethnic categories. More information is also required on access to health services, reproduction and child birth amongst disabled women. Mir et al. (2001) highlighted that there is very little data on the views of people with learning difficulties themselves. Moreover, whilst the needs of people from South Asian communities have been more intensively researched than those from African-Caribbean backgrounds, only limited information is available about the needs of people with learning difficulties from other populations, such as the African, Chinese, Irish or Jewish communities, refugees or travellers (see Healthcare Commission 2007; Mir et al. 2001).

Measuring change over time is vital in examining the extent of inequalities and the impact of new policy initiatives. There is a need for survey evidence on how peoples' circumstances change when they become disabled. The Census Longitudinal Study does allow comparisons of circumstances over time, but is limited by the census coverage of disability issues. The English Longitudinal Study of Ageing, which began in 2002, is a longitudinal survey that explores the dynamic relationships between health and activity, social networks and participation and economic position as people plan for, move into and progress beyond retirement. However, the sample size means that detailed analysis below the national level is limited. The small number of minority ethnic respondents also makes detailed comparisons across different populations problematic. The DWP is currently looking at the feasibility of conducting a longitudinal survey of disabled people. For a detailed overview of a possible longitudinal design for a survey of disabled people see Purdon (2005).

Using a longitudinal survey methodology means that transitions into disability can be understood and factors that shorten or lengthen a period of disability can be discerned. As Burchardt (2003) highlighted, intermittent patterns of disability, particularly due to mental illness, are not uncommon, although, because of definitions, it maybe that some periods of short-term illness are also being captured in this analysis. Hirst et al. (2004) argued that there is a need for longitudinal data that identifies what leads to change in disabled peoples' lives. Thornton (2005) cited the concept of 'participation restriction' in relation to measuring inequality, as is being pioneered by the World Health Organisation and in the Canadian Participation and Activity Limitation Survey (Thornton 2005; see also DRC 2004c; Grewal et al. 2004). It is notable that the recent public consultation conducted by the government's Social Exclusion Unit (2004) has highlighted the importance of mental health services focusing on the social dimension of mental illness, rather than simply the medical aspects of the condition. The Washington Group on Disability Statistics,¹ an international group of researchers, and also the highly regarded Institute on Disability at the University of San Francisco have argued that research examining equalisation of opportunity should focus on limitations on activities such as seeing, hearing and walking. In the UK a longitudinal survey could include a comparison with non-disabled people and so provide evidence for

the assessment of the success of the DDA in reducing employment and education barriers. Without such an approach there is an over-reliance on small-scale ad hoc studies to provide insights, but without any real measure of social change.

Disability is not a fixed state. Men and women and different populations can experience different trajectories. Policies aimed at tackling inequalities need to take account of such differences if they are to be successful. In addition, in order to address these issues it is important that disabled people themselves have an input in shaping the research agenda and designing the appropriate methodologies.

In Scotland and Wales a number of other concerns have been raised in relation to evidence gaps at the country level. UK/GB-wide research is often of very limited use because samples are usually too small to allow robust analysis. The DRC in Scotland does not have one definitive source for the number of disabled people in Scotland, although it is estimated that there are around 1 million (DRC 2004b; submission to the authors by the DRC 2005). Whilst evidence is limited, there are a number of small-scale studies such as, for example, research into the experiences of minority ethnic people in Wales with diabetes (see also Riddell et al. 2004).

Only limited comparative analyses have been conducted on the lives of disabled people across different countries internationally. Again, one of the main barriers is the lack of harmonisation of categories and the differences in reporting. The English Longitudinal Study of Ageing dataset forms part of the Survey of Health, Ageing and Retirement in Europe. Although questions are standardised, variation in the prevalence of disability across countries is sufficient to suggest that individuals in different countries interpret standard questions in different ways.

More innovative uses of administrative record data could be made, including, for example, records of people who are claiming incapacity benefit or accessing medical care—see for example Nessa's (2004) use of funding application records and Gordon and Hutchison's (2005) use of medical records to develop estimates of the prevalence of disability amongst children. With new public duties on monitoring equality in relation to disabled people such data will be vital in driving forward the social justice agenda. However, Mir et al. (2001) argued that monitoring procedures are currently insufficiently able to identify unmet need or comparative service performance (see also concerns raised by the Healthcare Commission 2007).

For effective policy development that ensures the rights and freedoms of disabled people there is a need to identify the ways in which the barriers society creates can be overcome and to understand what leads to positive change in peoples' quality of life. It is of primary importance to know how disabled peoples' different circumstances and experiences change over time in relation to policy interventions. The lack of robust evidence and effective survey research methodologies pose major barriers to driving forward an agenda of social justice in relation to disabled people.

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Note

1. The Washington Group on Disability Statistics was formed as a result of the UN International Seminar on Measurement of Disability held in June 2001.

References

- Abberley, P. 1992. Counting us out: A discussion of the OPCS disability surveys. *Disability, Handicap and Society* 7: 139–55.

- Ahmad, W., ed. 2000. *Ethnicity, disability and chronic illness*. Buckingham, UK: Open University Press.
- Ali, N., K. Atkin, G. Craig, A. Dadze-Arthur, C. Elliott, and A. Edwards. 2006. *Ethnicity, disability and work – examining the inclusion of people with sensory impairments from black and minority ethnic groups into the labour market*. London: Royal National Institute for the Blind.
- Arthur, S., and G. Zarb. 1995. *Measuring disablement in society*, Working Paper 4, *Barriers to employment for disabled people*. Leeds, UK: Measuring Disablement in Society.
- Barham, C., and J. Leonard. 2002. Trends and sources of data on sickness absence. *Labour Market Trends* 110: 177–85.
- Barnes, C., and G. Mercer, eds. 1997. *Doing disability research*. Leeds: The Disability Press.
- Barnes, H., P. Thornton, and S. Maynard Campbell. 1998. *Disabled people and employment: A review of research and development work*. Bristol, UK: The Policy Press.
- Berthoud, R. 1998. *Disability benefits: A review of the issues and options for reform*. York, UK: Joseph Rowntree Foundation.
- . 2006. *The employment rates of disabled people*, DWP Research Report no. 298. London, UK: Department for Work and Pensions.
- Berthoud, R., and M. Blekeseaune. 2007. *Persistent employment disadvantage*, DWP Report no. 416. London, UK: Department for Work and Pensions.
- Blackaby, D., K. Clark, S. Drinkwater, D. Leslie, P. Murphy, and N. O'Leary. 1999. *Earnings and employment opportunities of disabled people*, Department for Education and Employment Research Report no. 133. Nottingham, UK: Department for Education and Employment.
- Brothers, M. 2003. *It's not just about ramps and braille*. London: Disability Rights Commission.
- Bunt, K., J. Shury, D. Vivian, and F. Allard. 2001. *Recruiting benefit claimants: A survey of employers in one pilot areas*, Department of Social Security Research Report no. 139. Leeds, UK: Corporate Document Services.
- Burchardt, T. 2000. *The dynamics of being disabled*, CASE paper 36. London: London School of Economics Centre for Analysis of Social Exclusion.
- . 2003. *Employment retention and the onset of sickness or disability: Evidence from Labour Force Survey Longitudinal Study*, DWP In-house Report no. 109. London: Department for Work and Pensions.
- . 2004. *Being and becoming: social exclusion and the onset of disability*. London: London School of Economics Centre for Analysis of Social Exclusion.
- . (2005) *The education and employment of disabled young people*. York, UK: Joseph Rowntree Foundation.
- Capability Scotland. 2003. *Disability access review in connection with the Scottish Parliament and Local Government Elections 2003*. Edinburgh, UK: Capability Scotland).
- Chamba, R., W. Ahmad, and L. Jones. 1998. *Improving services for Asian deaf children*. Bristol, UK: Policy Press.
- Crow, L. 1997. Including all of our lives: Renewing the social model of disability. In *Doing disability research*, ed. C. Barnes and G. Mercer. Leeds, UK: The Disability Press.
- Davis, A. 1995. *Hearing loss in adults*. London: Whurr.
- Department for Work and Pensions (DWP). 2004. *User's guide to disability estimates and definitions*. Research Report. London: Department for Work and Pensions.
- Dex, S., and K. Purdam. 2005. *Implementing equal opportunities*. York, UK: Joseph Rowntree Foundation.
- Disability Rights Commission (DRC). 2002. *Creating and inclusive environment*. London: DRC.
- . 2003a. *DRC disability briefing: February 2003*. London: DRC.
- . 2003b. *Scottish disability awareness survey 2003*. Disability Rights Commission. <http://www.drcgb.org/scotland/publicationsandreports/research.asp17>.
- . 2004a. *Measuring physical access barriers to services: Snapshot research in 4 town/city centres in Britain*, Part 1, *Establishing baseline measurements*. London, UK: JMU Access Partnership.
- . 2004b. *Disability in Scotland 2004*. London: DRC.
- . 2004c. *Health and independent living*. London: DRC.
- . 2006a. *Consultation on definition of disability in anti-discrimination law*. London: DRC.
- . 2006b. *Ending child poverty – the disability dimension*. London: DRC.
- . 2006c. *Are we taking the dis? Key facts*. London: DRC.
- Ellis, B. 1995. *The experiences of disabled women, findings from the Disabled Women's Project*. London: Greater London Association of Disabled Women.
- Emerson, E., C. Hatton, D. Felce, and G. Murphy. 2001. *Learning disabilities the fundamental facts*. London: Foundation for People with Learning Disabilities.

- Emerson, E., S. Malam, I. Davies, and K. Spencer. 2005. *The first national survey of adults with learning disabilities in England, 2003/4*. London: Department of Health.
- Foundation for People with Learning Disabilities. 2006. *The lives of people with learning disabilities – a policy briefing, July 2006*. London: Foundation for People with Learning Disabilities.
- French, S. 2001. *Disabled people and employment: A study of visually impaired physiotherapists*. Aldershot, UK: Ashgate.
- Goodlad, R., and S. Riddell. 2005. Social justice and disabled people: Principles and Challenges. *Social Policy and Society* 4: 45–54.
- Gordon, D., and T. Hutchison. 2005. Ascertaining the prevalence of childhood disability, *Child: Care, Health & Development* 31: 99–107.
- Gordon, D., R. Parker, and F. Loughran. 2000. *Disabled children in Britain*. London: The Stationery Office.
- Graham, P., D. Jordon, and B. Lamb. 1990. *An equal chance or no chance*. London: The Spastics Society.
- Grant, L. 1994. *Debt and disability*. York, UK: Joseph Rowntree Foundation.
- Grewal, I., S. Joy, J. Lewis, K. Swales, and K. Woodfield. 2002. *Disabled for life. Attitudes towards and experiences of disability in Britain*. London: Department for Work and Pensions.
- Grewal, I., S. McManus, S. Arthur, and R. Leith. 2004. *Making the transition – addressing barriers in services for disabled people*. London: Department for Work and Pensions.
- Groucher, K. 2004. What happens next? A report on the first destinations of 2002 graduates with disabilities. *The Skill Journal* Issue 79: 1–3.
- Guinea, D., and P. Betts. 2003. How people answer Labour Force Survey questions about economic activity. *Labour Market Trends* October: 513–9.
- Harris, J., and P. Thornton. 2005. Barriers to labour market participation: The experience of deaf and hard of hearing people. In *Working futures? Disabled people, policy and social inclusion*, ed. A. Roulstone and C. Barnes. Bristol, UK: The Policy Press.
- Hatton, C., S. Azmi, A. Caine, and E. Emerson. 1998. Informal carers of adolescents and adults with learning disabilities from South Asian communities. *British Journal of Social Work* 28: 821–37.
- Healthcare Commission. 2007. *Count me in – results of the 2006 national census of inpatients in mental health and learning disability services in England and Wales*. London: Health Care commission.
- Higher Education Statistics Agency (HESA). 2002. *First destination survey*. London: HESA.
- Hirst, M., P. Thornton, M. Dearey, and S. Maynard Campbell. 2004. *The employment of disabled people in the public sector: A review of data and literature*. London: Disability Rights Commission.
- Hurstfield, J., N. Meager, J. Aston, J. Davies, K. Mann, H. Mitchell, S. O'Regan, and A. Sinclair. 2004. *Monitoring the Disability Discrimination Act*. London: Institute of Employment Studies.
- Hussain, Y., K. Atkin, and W. Ahmad. 2002. *South Asian young disabled people and their families*. Bristol, UK: Policy Press.
- Leonard Cheshire Disability (2003) *Social exclusion report*. London: Leonard Cheshire Disability.
- Martin, J., H. Meltzer, and D. Elliot. 1989. *The prevalence of disability among adults*, OPCS Surveys of Disability. London: HMSO.
- Mencap (2004) *Treat me right! Better healthcare for people with a learning disability*. London, Mencap.
- Mir, G., A. Nocon, and W. Ahmad, with L. Jones. 2001. *Learning difficulties and ethnicity*. London: Department of Health.
- National Audit Office. 2004. *Early years: Progress in developing high quality childcare and early education accessible to all*. London: National Audit Office.
- National Opinion Polls. 2003. *A survey of the views and experiences of young disabled people*. London: DRC.
- Nessa N. 2004. Disability. In *The health of children and young people*, ch. 10. London: HMSO.
- Norwich, B. 1997. Exploring the perspectives of adolescents with moderate learning disabilities on their special schooling and themselves: stigma and self perceptions. *European Journal of Special Needs Education* 12: 38–53.
- Oliver, M. 1992. Changing the social relations of research production? *Disability, Handicap & Society* 7: 101–14.
- . 1996. Defining impairment and disability: Issues at stake. In *Exploring the divide: Illness and disability*, ed. C. Barnes and G. Mercer, 39–54. Leeds, UK: The Disability Press.
- Office for National Statistics (ONS). 2007. *Census test 2007*. London: ONS.
- Preston, G., ed. 2006. *A route out of poverty? Disabled people, work and welfare reform*. London: CPAG.
- Priestley, M. 2000. Adults only: Disability, social policy and the life course. *Journal of Social Policy* 29: 421–39.

- Prime Minister's Strategy Unit (PMSU). 2005. *Improving the life chances of disabled people*. London: PMSU.
- Purdon, S. 2005. *Meeting DWP's long-term information needs on disability – a feasibility report*, DWP Research Report no. 267. London, UK: Department for Work and Pensions.
- Read, J. 2000. *Disability, the family and society: Listening to mothers*. Oxford: Oxford University Press.
- Read, J., L. Clements, and D. Ruebain. 2001. *Disabled children and the law: research and good practice*. London: Jessica Kingsley.
- Riddell, S., P. Banks, and T. Tinklin. 2004. *Disability and employment in Scotland: A review of the evidence base*. Edinburgh, UK: Scottish Executive.
- Riddell, S., and N. Watson, eds. 2003. *Disability culture and identity*. Harlow, UK: Pearson Education.
- Rooke-Mathews, S., and V. Lindow. 1998. *The experiences of mental health service users as mental health professionals. Findings 488*. York, UK: Joseph Rowntree Foundation.
- Salvage, A., and G. Zarb. 1995a. *Measuring disablement in society*, Working Paper 2, *Gaining access: Disabled people and the physical environment*. Leeds, UK: Measuring Disablement in Society.
- Salvage, A., and G. Zarb. 1995b. *Measuring disablement in society*, Working Paper 1, *Disabled people and public transport*. Leeds, UK: Measuring Disablement in Society.
- Scottish Executive. 1999. *Transport provision for disabled people in Scotland*. Edinburgh, UK: Scottish Executive/Reid-Howie Associates.
- Sefton, T., M. Baker, and A. Praat. 2005. *Ethnic minorities, disability and the labour market: A review of the data*. London: Royal National Institute for the Blind.
- Singleton, N., and G. Lewis. 2003. *Better or worse: A longitudinal study of the mental health of adults living in private households in GB*. London: HMSO.
- Smith, N., S. Middleton, K. Ashton-Brooks, L. Cox, B. Dobson, and L. Reith. 2004. *More than you think*. York, UK: Joseph Rowntree Foundation.
- Smith, A., and B. Twomey. 2002. Labour market experience of people with disabilities. *Labour Market Trends* August: 415–27.
- Social Exclusion Unit. 2004. *Mental health and social exclusion*. London: Social Exclusion Unit.
- Sport England. 2001. *Disability survey: Young people with a disability and sport*. London: Sport England.
- Stanley, K., and S. Regan. 2003. *The missing million supporting disabled people into work*. London: Institute for Public Policy Research.
- Thornton, P. 2005. Disabled people, employment and social justice. *Social Policy and Society* 4: 65–73.
- World Health Organisation (WHO). 2003. *International classification of functioning, disability and health*. Geneva: WHO.
- Young, A., J. Ackerman, and J. Kyle. 1998. *Looking on: Deaf people and the organisation of services*. Bristol, UK: The Policy Press.
- Zarb, G. 1995. Modelling the social model of disability. *Critical Public Health* 6: 30–37.