**WP35 Counting on the Social Model of Disability: A case Study of the Measurement of disability in a  Population Survey[1]**

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Introduction

The proportion of people reporting a long-standing illness increased from 20% of the UK population in 1972 to 33% in 1998-99 with a concurrent increase in the proportion reporting a limiting longstanding illness from 15% to 1972 to 20% in 1998-99 (ONS, 2001). Over the same time period there has been widescale development in the politics, understanding and study of disability, impairment and chronic illness. A great deal of social scientific scholarship and social political attention has focused on definitions of disability. Advocacy of social constructionist and phenomenological approaches to the definition and meaning of disability, impairment and chronic illness has been highly successful. Some have argued the shift towards a social constructionist or phenomenological model of disability has gone too far so that the corporeality of these phenomena and their adverse experience at the individual level has to some extent been 'crowded out'. Scambler (2005) for example, argues that disability [social constructivist disability theory] 'has marginalised the embodied experiences of those with multiple or profound disability' (Scambler, 2005, p.144). What is self-evident is that the labels people apply to themselves and their own circumstances rarely match the bio-medical diagnostic labels; nor however do they necessarily have a good fit with legal or social scientific definitions.  Lay understandings of health and disability statuses interact with biomedical, legal and other descriptions over time so that responses obtained to questions about these statuses in surveys are the result in any one case of the individual's specific personal circumstances and biography and general cultural influences.  It is precisely this kind of variability which leads some to argue for the use of very precise biomedical definitions of disability and ill health.  This approach however is rarely satisfactory as diagnostic classification by survey interviewers and/or survey respondents is unlikely to be consistent with those of the researcher setting the questions and answers.

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These disjunctures between lay and biomedical definitions and labels and reluctance to impose definitions, measures and concepts of disability on people has led most social scientific researchers of disability to take a qualitative approach. The qualitative approach is viewed as better able to copy with the inherent fluidity of labelling, self and other definition. There has also been an assumption that for social research to be emancipatory in ethos it must be qualitative in nature.  As a result many social researchers have concluded that it is not feasible to combine the technical approach of quanitative research with the social model of disability.   Consequently research applying the social model of disability has rarely been quantitative in nature. Birkenback et al (1999) suggested that this is because the social model of disability as defined by UPIAS 'is not operationalizable', and that it therefore fails to meet the political strategic need of the Disability Movement to provide a workable model for research and provide advocates with the 'hard' data they need to convince legislators to pass new laws and change old ones (Birkenback, 1999, p.1178).  In this paper we show how it is possible to apply a social model of disability in a short simple suite of questions within a household population survey.  We argue that it is not necessary to engage in the excessively expensive and time consuming biomedical approach to surveying disability which has characterised official statistical practice in the UK.

We take the view that the much rehearsed oppositions between qualitative and quantitative social research with the former perceived to be expert dominated and politically conservative and the latter phenomenological, user oriented and politically radical are naïve and reductionist representations of the complex methodological, ethical and political issues involved in each paradigm.  As White and Pellitt (2004) argue there is no inherent reason why quantitative measurement of social and other phenomena cannot be participatory, radical and emancipatory in ethos whilst also satisfying scientific standards of internal and external validity, replicability and so on.  Nor, we argue is it necessarily the case that qualitative social research is inherently 'better' conceptually or theoretically or politically than quantitative.  Birkenback et al however were right to highlight the 'real politik' that policy makers contrive to show strong preferences for quantitative over qualitative social research 'evidence' (see also McLaughlin, 2005).

In this paper we summarise our recent effort to moderate expert measurement and the biomedical approach to disability and impairment through the development and application of social model informed questions on the presence and experience of disability and chronic

illness within a population survey of poverty and social exclusion (the Poverty and Social Exclusion Study Northern Ireland, first reported as Hillyard et al, 2003). The paper explains the choices made as to question wording and how these sought to integrate the social model of disability within them before exploring how survey respondents categorised themselves for example as ill but not disabled or vice versa.  This analysis contributes to assessment of the internal validity of the questions chosen. The fourth part of the paper explores the validity of the approach taken through external comparison of the results with other population datasets in the case study society. The final part of the paper comments on the methodological choices made by ONS and NISRA recently in respect of the upcoming new UK national survey of Disability which will be undertaken in 2005/2006.  The paper begins with background discussion of definitions of disability and the history of official statistics on disability in the UK.

### *Definitions of Disability*

The definition of disability most often used in the 20th century has been traditionally medical in nature (Drake, 1999).  This type of definition has as its basis a bio-medical interest in the classification of disease and the symptomology of disease.

The bio-medical model has its roots in theories about health and disease which emerged during the 19th century.  These theories challenged preceding understandings of health and disease in which disease was perceived in moral terms - as a form of retribution for individuals' sinful, immoral or deviant behaviours (Stone, 1985). By separating organic disease from individuals' moral agency and establishing organic cause and effect links, ill health and disability became allied with emergent medical and clinical understandings of disease as something which could be transmitted and or caused by agents without as well as within the individual human organism.  Drake (1999) argues that the current bio-medical model and popular understandings of disability retain some of the influences of this earlier moral concept of disease.  In more recent times this has been congruent with moralistic ideas on genetics. Drake argued that biblical stories about the healing of the sick and exemption from certain religious obligations for disabled people within the world's major religions have reinforced the notion that disabled people are morally different from 'normal' members of society.  Certainly, the moral status of disabled people in liberal societies has been deeply problematic (Silvers, 1992).  Insofar as the study of genetics attributes differences between individuals to their genetic inheritance and ascribes relative social value

according to these inheritances, there is congruence with the pre 19th century moral paradigm of health and illness.  It is for this reason that advocacy of genetic engineering is perceived by many disabled people to have potentially sinister implications.

The 20th century witnessed the emergence of social groups which organised themselves into movements protesting against exclusion and discrimination, prejudice and disempowerment, and demanded political change.  For example, black Americans, nationalists in Northern Ireland, women, lesbians and gay men and more recently disabled people all began to assert their claims to full civil, political and social rights. Shakespeare and Watson (2001) argue that these new social movements also helped to create positive political and social identities on a local level.  In the case of the disability movement, a body of literature emerged written by disabled activists and scholars which identified disability as a form of social oppression and institutional or systematic discrimination.  For example, activists and scholars highlighted the disabling nature of inaccessible building and transportation systems and pointed out that many impairments have disabling consequences only because our social, economic and physical systems and structures are modelled on and for use by those without impairments.  This alternative perspective - the Social model of disability was adopted by most social scientists studying disability and less often chronic illness and makes a distinction between 'disability' and 'impairment'.  In Jenny Morris's words:

*"My impairment is the fact that I can't walk; disability is the fact that architects think that steps are a wonderful design feature.  Not being able to see is an impairment; disability is the failure to provide printed material on audio tape, in braille etc." (Morris, 2000).*

Unlike the biomedical paradigm which focuses on classification of the individual's diseases and/or injuries and the functional consequences of these, the social model assumes that disabled peoples' individual and collective disadvantages and social exclusion are due to complex forms of institutional discrimination still commonplace in society as sexism, racism or heterosexism (Rieser, 2002), in effect to 'the tyranny of the majority' (Byrne & McLaughlin, 2005) in whose interests and for whom our social and economic structures and systems are and have been devised.  The Social model is concerned with the lived experience of disability and chronic illhealth rather than with classification of the causes of those experiences.

Bury (1996) has identified the emergence of a 'socio-medical' model of disability arising from collaborative research between public health oriented rehabilitation specialists and sociologists (see also Priestley 2002). This research has however also been primarily concerned with estimating need for medical and other public services. According to Bury, it was this socio-medical model which culminated in the first UK study of 'impairment and handicap' by The Office of Population Censuses and Survey (OPCS) in 1971.

### The definition and measurement of disability in UK official statistics

The OPCS survey published in 1971 was the first attempt in the UK to measure the extent of impairment in the population. The survey contained inconsistencies in definitions of impairment and handicap. Subsequently the World Health Organisation (WHO) published a system of classification - the International Classification of Impairments, Disabilities and Handicaps (ICIDH) which distinguished between the terms 'impairment', 'disability' and 'handicap' and provided a more consistent system of definitions than had OPCS in 1971. Impairment was defined by WHO as 'any loss or abnormality of psychological, physiological or anatomical structure or function' (WHO, 1980: 27). Reflecting the influence of the social model of disability the term disability was used by WHO to describe the impact of an impairment on everyday life. Impairment and disability according to WHO related to the disadvantage an impaired person suffered by not being able to carry out certain 'survival roles'. The consequence of having a disability or an impairment resulted in a 'handicap' socially. The implication was that handicaps were socially constructed disadvantages and the ICIDH thus incorporated at least some of the social model paradigm (Bickenback et al, 1999).

A second survey of disability in Great Britain was carried out by OPCS in 1984, mainly to inform a review of social security disability benefits. This survey used the definitions of disability set out in the WHO classification. The OPCS study was restricted to Great Britain rather than the UK, that is it did not include Northern Ireland for reasons which were not clear. Abberley (1992) suggested it may "possibly [have been] because it was feared high rates of injury associated with English occupation would become apparent, possibly because of associated difficulties in carrying out research" (1992: 142). In 1990 the then Policy, Planning and Research Unit (PPRU) in Northern Ireland (the equivalent of OPCS in Britain) was commissioned by the then Departments of Health and Social Services; Economic Development; Education and Environment to carry out a series of surveys on disability in

Northern Ireland. These were intended to parallel the British OPCS surveys so that comparisons could be made between Northern Ireland and Britain. Comparisons were and remain limited in scope and constrained by the five year time gap between the datasets, Monteith et al., 2003; Bernard et al., 1998 provide two of the very few comparative analyses undertaken. The PPRU survey adopted the same concepts and definitions as the OPCS surveys.

In his critique of the OPCS Disability Surveys Abberley (1992) outlined the weaknesses of estimates of disability which ignore peoples' social and environmental circumstances, arguing that the functional definitions within the OPCS surveys were administrative definitions and measures rather than scientific ones because they arose from administrators' concerns about the abilities of individuals to produce and to work and to the extent of needs for public provision to make up for incapacities in the population.

The OPCS 1971 Disability Survey was concerned with physical impairments which severely limited activities. The subsequent OPCS survey in 1985 used different question wording and a much wider definition of disability than before. The second survey set out to include more wide ranging types of disability and set a lower threshold for disability by utilising a hierarchy of severity ranging from 1 (the least severe) to 10 (the most severe). The number of disabled adults living in Britain was measured as three million in 1971 compared to nearly six million in 1985. The Northern Ireland PPRU survey (McCoy & Smith, 1992) and the 1985 OPCS survey attempted to be even more wide ranging by distinguishing between thirteen different types of disabilities [impairments] and establishing a ten-point severity scale. The method used to judge severity was complex and rested on the subjective judgement of a panel, some of whose members were themselves disabled. However, Abberley argues that the panel were being asked to say which impairments they regarded as more or less severe, without regard to the situation or contexts in which the impairment was experienced. He concluded that it is not possible to provide a 'true' measure of the extent of disability in the population since disability is a social construct. The definition and measurement of disbaility is dependent on the beliefs and intentions of those who have the power to define it administratively and culturally. Both the administrative and lay health/disability boundaries shift over time and space. Since disability is so contingent how can a survey methodology hope to measure it reliably but also meaningfully (that is, in a way which those concerned would recognise as being a truthful representation of their circumstances)?

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*The Poverty and Social Exclusion Survey, Northern Ireland (PSENI)*

In this section we review the authors' efforts to answer the above question.  We sought to incorporate a contingent and social understanding of disability, impairment and chronic illness in a recent population survey.  The survey was the Poverty and Social Exclusion survey Northern Ireland[2] (hereafter PSENI) carried out to provide the first reliable measurement of poverty in Northern Ireland. The aims of the research were to provide the first baseline measurement of poverty and social exclusion that could be updated periodically and to compare poverty rates in Northern Ireland with those in Britain and the Republic of Ireland (Hillyard et al, 2003: 13) (see also McAuley et al: 2003).

The PSENI survey largely replicated the methodology of the JRF funded Millenium Survey of Poverty and Social Exclusion in Britain (see Gordon et al., 2000).  The survey involved a two-stage methodology. The first stage established public opinion on what constitutes an acceptable standard of living in modern society. The second survey stage collected information on households, incomes and the extent of deprivation or enjoyment of necessities as well as collecting information on a wide range of circumstances including income, employment and social participation.  Information about the household as a whole was sought from a household respondent and information was obtained from individuals within the household aged 16 years or more.  A random sample of 3,490 addresses was drawn from the Valuation and Lands Agency rating list.  A household response rate of 64 per cent was achieved resulting in 1,976 household interviews and 3,104 individual interviews. The achieved sample was robust matching the socio economic and demographic characteristics of the population in general.

*Ill health, impairment and disability questions in the PSENI*

One of the aims of the PSENI and a difference between it and the JRF British Millenium study was that PSENI set out to provide reliable data on how the risk of poverty and social

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[2] The research was co-funded by OFMDFM and the UK Exchequer.  The survey was designed and directed by Professors Hillyard and McLaughlin and Mr Mike Tomlinson of Queens University Belfast in 2002/2003.

exclusion varied across the nine dimensions of (in)equality set out under Section 75 of the Northern Ireland Act (1998).  These dimensions include disability.

In order to measure disability in the PSENI study, the researchers put questions to both the household respondent (HR) and individual members of the household.  Thus individuals over 16 years were asked 3 questions which could potentially classify their disability status.  First the standard limiting illness question:

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

Second the standard self-assessed health status question:

- ‘Please think back over the last 12 months about how your health has been.  Would you say your health has been excellent, good, fair, poor, very poor or varies a lot?’
-

Thirdly a potential impairment question

- Have you had any of the following health problems or disabilities listed, for 12 months or more? (see appendix A)

The impairment question was followed by two supplementary questions probing the effects of the impairment on aspects of daily life and the severity of this.

Derived variables were subsequently created for health status based on responses to these 3 questions.  In the next section we compare responses across the questions

Despite the difficulties of obtaining data from third parties it was decided to ask the household respondent about other members of the  household because it was not intended to interview under 16s, and successful interview of individual household members may not subsequently have been achieved.

The household respondent was asked:

- ‘Do you or anyone in your household including children under 16 have a disability?’

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The report on disability and poverty rates for the initial equality analysis of the dataset in chapter 6 of Hillyard et al (2003) relied on the responses of household respondents to this question.  Subsequent analyses have explored the disability poverty relationship in the dataset more fully (McLaughlin et al, 2005).  For analysis of the relationship of disability to poverty in the UK as a whole see Burchardt (2000) and Berthoud (2003).

Hillyard et al (2003) reported key PSENI findings analysed in terms of the characteristics of the household respondent and poverty rates as percentages of households, except for gender and disability where poverty rates based on the total numbers of men and women within households were calculated.  The research presented the analysis on equality and poverty in two ways.  Firstly, poverty rates for different sub-groups within a chosen dimension were illustrated (the poverty rate is the prevalence of poverty within that category).  Secondly, the share of poverty for each sub-group within the dimension was given (the poverty share is the proportion that category is of all those in poverty).  For example, in respect of marital status the report showed that widowed people have a poverty rate of 28 per cent and they make up 11 per cent of all people in poverty.  The measure and definition of poverty used was the consensual poverty measure see McLaughlin and Monteith, 2005 and Hillyard et al., 2003 for discussion of poverty measures and Gordon, 2000 for an explanation of the consensual poverty measure method.

Over half (56 per cent) of households containing one or more people with a disability were in poverty compared with 29 per cent of those containing no one with a disability. Household respondents who reported the presence of at least one member in the household with a disability made up only 6 per cent of all those in poverty.  The overall prevalence of long-term illness and disability reported in the survey by individuals was 31 per cent, 15 per cent reported poor health.  Hillyard et al concluded 'There may have been some under-reporting of disability by survey household respondents in poor households' (2003: 51).
Low expectations of health and quality of life among disadvantaged and poor populations is a well known problem in population surveys and in subjective or self-reporting of morbidity and impairment in population surveys.

Aware of the methodological and conceptual problems inherent in measuring what is essentially a contingent social construct with considerable fluidity, we included additional

questions in the survey when asking individuals whether they themselves had suffered from one or more of a list of detailed health problems or disabilities for 12 months or more.

Those who answered 'yes' were asked which of the conditions affected their daily life most. Respondents were then asked how much and whether the difficulty affected their daily lives in 5 domains of life: paid work; personal care; domestic work; social life and leisure.

These supplementary questions were to encourage respondents to identify disability as the consequence of specific impairments in specific social circumstances and to assess severity of the disablement in their own terms. Thus the specification of domains was intended to prompt respondents to use a social model of disability to consider how or if an impairment or chronic illness interacted with their environment in such a way as to result in a disability for them. The domain approach was similar to the methodology used in Kind et al's survey and research on ways of measuring health related quality of life (Kind et al, 1998). Subsequent analysis of the PSENI dataset has created derived variables based of counts of all those who reported they had difficulties in any or more than one domain if these were either 'severe' or 'very severe'. Analysis using the derived disability variables produced significantly different poverty rates (which will be discussed in more detail in a separate paper). Here however we focus on the ways in which respondents did or did not classify themselves as disabled. Analysis was carried out to ascertain if households containing a disabled individual, counted under the original Household Respondent measure, were also captured within the new individual respondent measure. Twenty one per cent of households where the household respondent reported that their household contained one or more members with a disability were also counted in the new derived disability variable reported by individuals themselves. However, when the same examination was carried out with those reporting a limiting long-term illness, 68 per cent of those households which reported a member with a limiting longstanding illness were also counted in the new individual respondent disability variable.

The results demonstrate very considerable differences in the outcome produced by the alternative methods of asking for disability information via a household respondent as against asking individuals themselves. The results also reflect the differences between asking an entirely abstract disability question about the presence of disability as was the case with the household respondent question as against asking concrete questions about

the presence or absence of specific impairments and/or illnesses and whether these affect activities in customary daily life. Gannon and Nolan (2004) similarly examine the differences in counts of disability produced by differences in question wording and respondents in Irish population datasets.

The individual respondent disability variable resulted in a prevalence of 24 per cent of the population aged 16 and over classified as disabled, that is having one or more of the 20 difficulties listed in Annex A and experiencing quite or very severe restrictions on daily life in one or more of the domains identified.  Table 1 shows that 7 per cent reported severe or very severe restrictions in one domain.  A further 17 per cent however reported severe or very severe restrictions in more than one domain of daily life.

Table 1  Number of respondents who reported severe or very severe restrictions in one or more domains of daily life

|  | % | Cumulative % |
|---|---|---|
| **None** | 76 | 76 |
| **1 domain** | 7 | 83 |
| **More than 1 domain** | 17 | 100 |

In order to assess the validity of the disability measure, comparisons were made with rates of limiting long-term illness and poor health as captured by other variables in the survey. Trends in age and gender of the disability variable were analysed and compared to the results reported from other representative surveys in the case study society.

Table 2: Disability prevalence by measure

| Survey variables | *PSENI %* |
|---|---|
| Long term illness | 31 |
| Poor health over last 12 months | 15 |
| Disability in 1 or more domains | 24 |
| Household respondent report of disability | 3 |

The last large scale survey designed to specifically provide estimates of the prevalence of disability in Northern Ireland was the PPRU survey (McCoy & Smith, 1992).  This survey

reported an overall disability rate of 17 per cent compared with the 24 per cent identified here in the PSENI.  Figure 1 plots the PPRU measure of disability in Northern Ireland against the PSENI disability measure across eight age bands.

**Figure 1** Disability rates in Northern Ireland from two representative surveys by age.
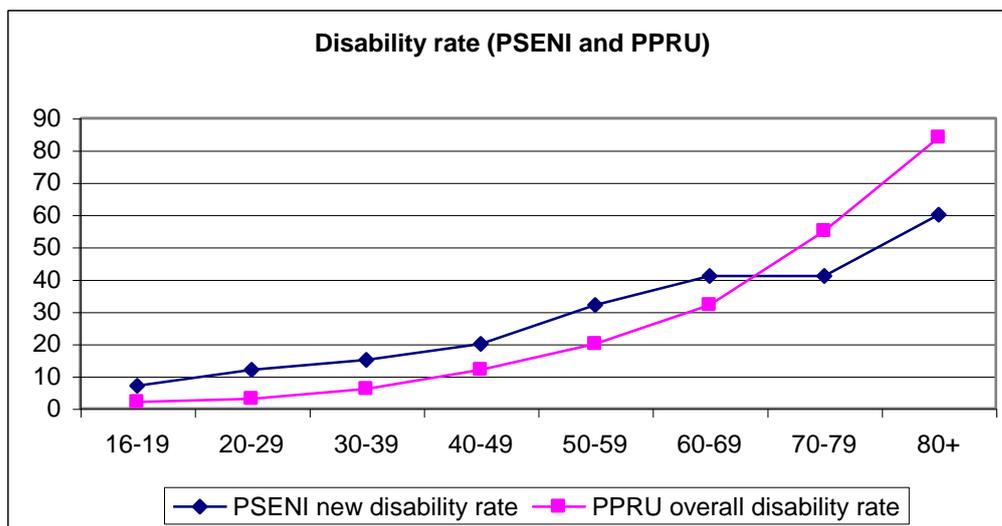


The disability prevalence measured in PSENI is consistently higher than the rates of disability reported in the PPRU survey. Although they follow the same pattern across age groups, until the age of 70 and over.  Does the higher prevalence rates of the PSENI individual report disabilities measure mean the measure was invalid or inexact?  The high level of overlap between the limiting longstanding health question, and the disability question, together with a high level of corroborating evidence in the form of receipt of disability benefit by those counted as disabled in the individual respondent PSENI disability variable and the expected distribution of the disabled subpopulation across gender and age all suggest that the PSENI individual disability variable is valid.

Multiple disability is counted as self-report of quite severe difficulties in more than one of the five domains of daily life.  Table 3 shows that of the 24 per cent of people disabled, 49 per cent are in receipt of Disability Living Allowance/Attendance Allowance (DLA/AA).  Of those with severe restrictions in one domain of daily life, 30 per cent were in receipt of these benefits. However, for the 17 per cent of people with multiple disabilities, 56 per cent were receiving DLA/AA.  This suggests that the first disability variable differentiated well between those with minor disablement resulting from chronic ill health or impairment in

their context but was also able to identify those for whom disability was a more pervasive and difficult experience.

Table 3

|  | Overall Disability % | Disability in 1 domain % | Disability in more than 1 domain % |
|---|---|---|---|
| Individual disability variable | 24 | 7 | 14 |
| Receipt of DLA/AA | 49 | 30 | 56 |
| Self reported health 'fair' | 28 | 34 | 25 |
| Self reported health 'poor' or 'very poor' | 51 | 30 | 59 |
| Employment status:<br><br>Working:<br>Unemployed:<br>Economically inactive: | <br><br>21<br>4<br>75 | <br><br>30<br>4<br>66 | <br><br>18<br>3<br>79 |

In the next part of the paper we further assess the validity of the PSENI disability measures by comparisons between them and other datasets of the case study society. The analysis suggests the reported rate of disability from the derived disability variable in PSENI (24%) is a more realistic measure than that reported in the PPRU (17%).

***Prevalence of disability in other population datasets***

Table 4 below shows the percentage of individuals reporting a limiting long-standing illness or disability in the Continuous Household Survey (CHS), the Health and Social Wellbeing Survey (HSWS), the Census and the PSENI individual disability rate. All rates are higher than the 1990 PPRU disability rate with the PSENI figures for disability and poor health consistent with rates in the other surveys.

**Table 4**: Rates of limiting long-term illness or disability and self-reported health status

| Survey | Limiting long-term illness or disability % | Self-reported poor health % |
|---|---|---|
| PPRU Disability survey | 17 | n/a |
| CHS | 26 | 18 |
| HSWS | 28 | 17 |
| CENSUS | 24 | 13 |
| PSENI | 24 | 15 |

The CHS, HSWS, Census and PSENI all used a common definition of disability, a limiting long term illness (more than 12 months).  The PPRU as explained before had used a narrower definition of disability.  There were also some differences in the population coverage between the datasets which would have affected the disability prevalence rates found.

The PPRU Disability Surveys covered adults and children in private households and places where the disabled live communally.  The Census covered people in private households, residential/nursing accommodation and the prison population.  The CHS and PSENI included people in private households only.  The HSWS coverage is of both private and communal establishments.

Percentage prevalence rates can also be affected by the nature of the achieved sample in other ways.  The overall prevalence rate of disability found for example is sensitive to the proportions of males and females in each survey's sample.  All surveys show a similar trend of more females than males reporting a limiting long-term illness or disability.

Figure 2 below compares rates of limiting long-term illness and disability from the various surveys plotted across eight age bands.

**Figure 2**  Rates of limiting long-term illness and disability

**Rates of limiting long-term illness and disability in Northern Ireland by age band**
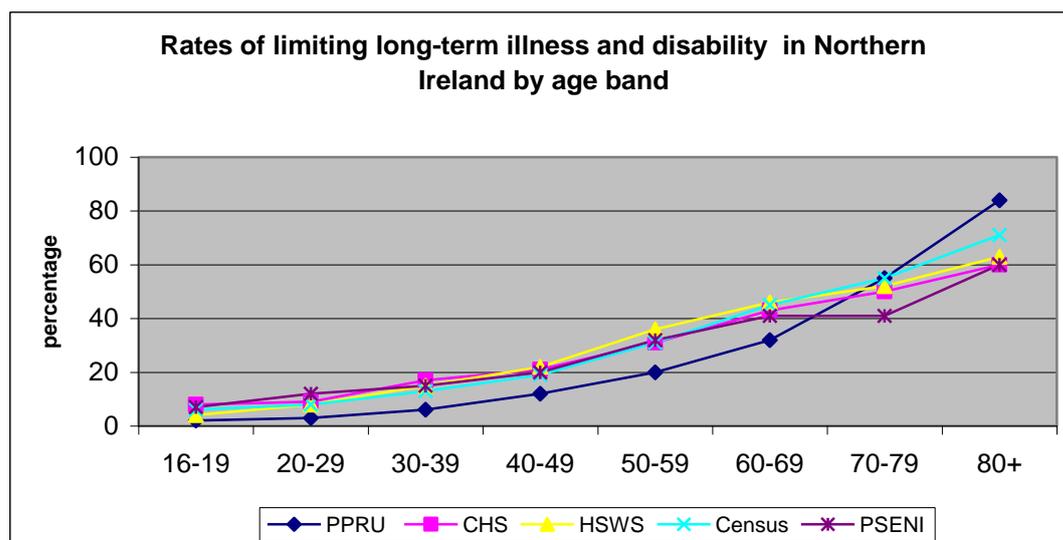


Comparison by age shows higher rates of limiting long-term illness and disability across age bands than rates of disability in the PPRU up to the age of 70 and over. The rate of disability in the PPRU in the 80 plus age group (84 per cent) is the highest of all the other surveys.

**'Good enough' measurement – a comment**

Hutchinson and Gordon (2005) recently concluded that if policymakers wish to have robust statistics on the prevalence of disability among child populations then they will obtain a 'good enough' level of accuracy and measurement validity by asking parents the simple question: does your child have a disability? The findings here on the advantages of more concrete questions about the presence or absence of disability concur with Hutchinson and Gordon insofar as they suggest that the excessive technicism present in the last national survey of disability (OPCS 1990; NISRA 1995) is not warranted in terms of gains in statistical robustness. The findings here indicate robust self report severity and presence of disability data especially when respondents are prompted to consider the effects of impairments and illness on concrete aspects of lived experience.

The objective of measurement should be to achieve a level of statistical precision and robustness which is ethical and fit for purpose - that is robust in creating knowledge which is sufficiently truthful and precise to inform decision making on such issues of public interest as the allocation of public expenditure between public services and between territories in line with need but which is also value for money and not excessively or unnecessarily intrusive in terms of citizens' privacy and time. 'Good enough measurement' is thus measurement

which is fit for purpose, ethically sound and scientific. The purpose being good enough policy and policy making (Williams, 1999, see also Zola, 1993). Emperor's new clothes of spurious precision and excessive technicalism can be used and abused by researchers, decision-makers and others to disempower, delay and obscure rather than inform the public (McLaughlin, forthcoming 2006). Where and if such abuses occur, the science of social science has been abused for anti-democratic purposes – the possibility of such abuse is something the social science and scientific academies should always be alert to and resistant of see also Fujiura and Kutkowski-Kilta 2001. Decisions about the new UK Disability Survey are already well advanced and it seems likely that the excessive technicalism and spurious precision of the 1990 and 1995 Surveys will be repeated at significant public cost.

Whether the social model informed measurement of disability, impairment and chronic ill health we carried out in the PSENI was successful in shaking off 'the shackles of methodological individualism' which Oliver (2003) argued underpinned the WHO classification of disability and almost all medical and social research, we leave now for others to judge

**References**

Abberley, P. (1992) 'Counting Us Out: a discussion of the OPCS disability studies'. *Disability, Handicap and Society*, Vol 7, (2).

Berthoud, R. (2003) Multiple Disadvantage in Employment: a quantitative analysis. York: Joseph Rowntree Foundation.

Bickenback, JE, Challerji, S., Bradley, EM, Ustun, T. (1999) Models of Disablement, Universaliam and the international classification of impairments, disabilities and handicaps. Social Science and Medicine, 48: 1173 -1187.

Burchardt, T. (2000) *Enduring Economic Exclusion: disabled people, work and income*. York: Joseph Rowntree Foundation.

Bury, M. (1996) 'Defining and Researching Disability: challenges and responses' in C. Barnes and G. Mercer (eds) *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press.

Byrne and McLaughlin (2005) *Disability and Equality – the challenges for equality theorising and practice, equality and social inclusion*, Project working paper number x.

Drake, R.F. (1999) *Understanding Disability Policies*. London: McMillan Press Ltd.

Fujiura, G.T. & Rutkowski-Kmitta, V. (2001), 'Counting Disability' in Gary Albrecht, Katherine Sealman and Michael Bury (2001), *Handbook of Disability Studies*. London: Sage.

Gannon, B. & Nolan, B. (2004) *Disability and Labour Market Participation*. Dublin: The Equality Authority.

Gordon, D., Adelman, L., Ashworth, K., Bradshaw, J., Levitas, R., Middleton, S., Pantazis, C., Patsios, D., Payne, S., Townsend, P. & Williams, J. (2000)  Poverty and Social Exclusion in Britain.  Joseph Rowntree Foundation.

Hillyard, P., Kelly, G., McLaughlin, E., Patsios, D. & Tomlinson, M. (2003) *Bare necessities: poverty and social exclusion in Northern Ireland – key findings*. Belfast: Democratic Dialogue 16.

Hutchinson, T., & Gordon, D. (2005) 'Ascertaining the prevalence of childhood disability'. *Child*, 31 (1) pp 99 – 107.

Kind, P., Dolan, P., Gudex, C. and Williams, A. (1998) 'Variations in population health status: results from a United Kingdom national questionnaire survey'. *British Medical Journal*, Vol 316, 7 March 1998.

McAuley, C., Hillyard, P., McLaughlin, E., Tomlinson, M., Kelly, G. and Patsios, E. (2003) Working Paper No 1, *The Necessities of Life in Northern Ireland*. Belfast: School of Sociology and Social Policy, Queen's University Belfast.

McCoy, D. & Smith, M. (1992) *The Prevalence of Disability Among Adults in Northern Ireland*, Policy Planning and Research Unit, Report 1. Belfast: PPRU.

McLaughlin, E. forthcoming (2006) 'Pseudodemocracy and Spurious Precision' Paper presented at The Cash and Care Symposium, University of York, April 2005 in Kemp, P. & Glendinning, C. (eds), *Cash and Care*. Bristol: The Policy Press.

McLaughlin, E., & Montieth, M. (2005)

Morris, J. (2000) *Reclaiming the Social Model of Disability*.  Conference Report available at leeds.ac.uk/disability-studies.

Oliver (1990) *The Politics of Disablement*, Basingstoke Macmillian.

Oliver, M. (2003)  *Using Emancipatory Methodology in Disability Research,* available at www.leeds.ac.uk/disability-studies/archiveuk/index.html.

Priestly, M. (2003) *Disability: A lifecourse approach*. Milton Keynes: Open University Press.

Rieser, R. (2002) *The social model of disability*, *Disability Equality in Education*, available at http//inclusion.uwe.ac.uk, see also www.diseed.org.uk.

Scambler, S. (2005)

Shakespeare, T. & Watson, N. (2001) 'Making the Difference: Disability, Politics and Recognition' in Gary Albrecht, Katherine Sealman and Michael Bury (2001), *Handbook of Disability Studies*, London: Sage.
UPIAS (1976) *Fundamental Principles of Disability*. London: Union of the Physically Impaired Against Segregation.

Silvers, (1992)

Stone, D. (1985) *The Disabled State*. London: MacMillan Publishers Ltd.

White, S. & Pettit, J. (2004) 'Participatory Approaches and the Measurement of Human Wellbeing', WeD Working Paper 08.  Bath: University of Bath.

Williams, F (1999) 'Good-Enough Principles for Welfare', *Journal of Social Policy*, 1999, Vol. 28, part 4, pp.667-687

World Health Organisation (1980) International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease. Geneva: WHO.

Zola, I.K. (1993) 'Disability Statistics, What We Count and What It Tells Us: A personal and political analysis', in Fujiura, G.T. & Rutkowski-Kmitta, V. (2001), 'Counting Disability' in Gary Albrecht, Katherine Sealman and Michael Bury (2001) (eds), *Handbook of Disability Studies*. London: Sage.

ANNEX A

1. Difficulty in seeing

2. Difficulty in hearing

3. Difficulty in speaking

4. Arthritis and rheumatism

5. ME

6. CFS (Chronic Fatigue Syndrome)

7. MS (Multiple Sclerosis)

8. Heart problems

9. Diabetes

10. Asthma or other breathing problems

11. Blood pressure problems

12. Cancer

13. Stroke

14. Back pain

15. Anxiety, depression or other mental health problems

16. Alcohol or drug abuse

17. Epilepsy

18. Autism

19. Memory loss

20. Dyslexia, or other learning disabilities