Trends in the prevalence of disability and chronic conditions: implications for survey design and measurement of disability.

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This paper discusses recent trends in the reported prevalence of disability and long-term conditions and explores issues needing to be considered in working towards internationally comparable general measures of disability. The paper is partly based on some work-in-progress of the Institute's studies on measuring disability prevalence and trends.

1 Recent trends in the prevalence of disability and chronic conditions

Recently, a growing number of studies have reported a decline in disability prevalence among the older population in some developed countries (eg, Robine et al. 1998; Waidmann & Manton 1999; Schoeni et al. 2001; Jacobzone et al. 2000). However, mixed trends were reported across the OECD countries (Jacobzone et al. 2000). Decline in disability prevalence was reported for United States, Germany, France and Japan. Moderate decline in disability was reported for Sweden. Mixed patterns of prevalence were reported for Canada, with a clear decline for people aged 65–74, but an increase in most age groups over 75. No consistent decline in disability prevalence was reported in the United Kingdom and the Netherlands. In Australia, the latest population survey data indicated no decrease and in effect a possible increase in disability prevalence among people aged 75 or older (AIHW 2001; ABS: Davis et al. 2001; AIHW: Madden 2002).

The reported falling disability in some OECD countries was accompanied by an increase in the reported prevalence of chronic diseases or conditions. This increase was also reported in countries where no consistent decline in disability or a possible increase in disability was reported, such as Australia. Although changes in disease prevalence are not homogeneous and the literature is somewhat mixed in the picture of the disease trends, the bulk of evidence indicated an increase in the presence of chronic disease among the older population. For instance, in the US the reported prevalence of diseases increased in recent years, with the largest increases in heart disease and cancer. Increases were also reported in some chronic condition such as arthritis, osteoporosis and visual conditions. There has also been a decrease in the number of older Americans with no disease and an increase in the proportion of people with multiple conditions (Crimmins & Saito 2000).

In France, the reported prevalence rates increased between 1981 and 1991 in almost all the main groups of chronic diseases among older people, in particular the most frequent diseases—cardiovascular and osteoarticular diseases. The number of older people with at least one chronic disease also increased (Robine et al. 1998).

In Australia, the proportion of people reporting one or more long-term health condition increased from 66% in 1989–90 to 78% in 2001 (ABS 1991, 2002). For people aged 65 or more with a disability, the prevalence of most disabling conditions increased between 1988 and 1998.

2 Explanations for the recent trends in the prevalence of disability and chronic conditions

Many efforts were devoted to ascertaining whether there is a decline in disability prevalence within a particular country. A few studies aimed to explain the reasons for the reported falling disability. While some have suggested a number of factors that may be associated with this decline, little empirical evidence was presented. The proposed factors that might have contributed to the decline include: medical care improvements, increased use of aids and equipment, health related behaviour change, environmental supports, education and socioeconomic status, and disease and hazardous exposure (eg. Cutler 2001; Schoeni et al. 2001).

The most common explanations for the increase in the reported prevalence of chronic diseases are improvements in medical knowledge and diagnosis of those diseases (eg. Crimmins & Saito 2000; Robine et al. 1998). The propensity to report disease may also have increased due to the changes in community attitudes towards disease and illness. Decline in mortality from some major diseases, such as heart, stroke and vascular diseases and cancer, resulted in an increase in prevalence of those diseases (AIHW 2001b; AIHW: Dunn et al. 2002; Crimmins & Saito 2000).

A number of issues are crucial for measuring disability and monitoring trends in disability prevalence:

- Why has a decline in the reported disability prevalence been accompanied by an increase in the reported prevalence of chronic diseases in some developed countries?
- Why have different trends (increases and decreases) in disability prevalence been reported among the OECD countries?
- The cross-nation comparison of level of disability prevalence is limited by the differences in survey design and methods. However, could the trends in disability within each country be compared internationally on the basis of the existing survey data?

It has been suggested that the increases in chronic conditions are largely limited to conditions that are less severe or less debilitating (Freedman & Martin 2000). The advance in medicine and health care services contributed to a slowing down in the rate of progression of chronic diseases or less serious consequences via more supportive and effective treatments or rehabilitation. Therefore, even if the prevalence of chronic diseases increases, on average, the transition from those diseases into functional limitations and need for help with daily activities does not necessarily occur at the same high level as the prevalence of chronic diseases (eg. Manton et al. 1985; Moore et al. 1999).

Nevertheless, the explanations of the above issues are far from adequate. As studies on disability trends among older Americans indicated, the reported decline only occurred in less severe disabilities and there is no consistent evidence suggesting a decline in more severe disabilities. Little attention was paid to the variations in survey measures and their impact on cross-nation comparison of trends in disability prevalence. The measurement issues are critical in identifying causes differently affecting the reported disability trends in different countries.

3. A comparison of the United States and Australia

Since a number of recent studies on trends in disability are concentrated on older Americans we may take the US as an example of a reported decline in disability with an increase in the reported prevalence of chronic conditions. Australia may be an example of those countries with no consistent decline in disability prevalence but with an increasing trend in chronic conditions.

The evidence of decline in disability among older Americans is based on various US survey data that differ in concepts, definitions, collections, coverage and methods of estimation. Most surveys either measure disability in a limited number of time points or they cover a relatively short time span. The exception is the US National Health Interview Survey (NHIS), which has collected disability information annually since 1982, with a comparable period of 15 years, 1982–1996 (Schoeni et al. 2001).

A study analysed the most recent data from the NHIS and integrated its results with evidence from other US national surveys (Schoeni et al.). The weight of the evidence showed that the reported decline in disability prevalence did not persist throughout the entire 1982–1996 period. There were clear declines in disability prevalence between 1982 and 1986, but no improvements during 1986–1992. Disability began to decline again more modestly around 1992, falling through to 1996 (the last year of available data). The estimates of prevalence also indicate that the decline occurring throughout the period was for people who only need help with routine care activities, such as household chores, doing necessary business, shopping, and getting around. There was no change in the prevalence in this period for people with a more severe disability, i.e. those who need help with personal care activities. The evidence was fairly consistent across five US national surveys (Schoeni et al. 2001:S217).

The Australian Bureau of Statistics (ABS) disability surveys provided cross-sectional data collected at four points in time (1981, 1988, 1993 and 1998) over a period of 17 years. For Australians aged 65 or more, the age-standardised rate for people with any specific activity restriction[1] increased markedly between 1981 (32.9%) and 1988 (45.1%). The rate increased slightly between 1993 (44.6%) and 1998 (45.5%), while the 1998 rate (45.5%) is similar to that reported in 1988 (45.1%). The rate of people reporting a profound or severe core activity restriction[2] increased from 16.2% in 1981 to 17.9% in 1988. The rate then declined marginally to 17.1% in 1993, but increased to 19.6% in 1998. The increase was mainly in the 75 years and over group, in particular very old people.

It may be useful to look at some differences in the operational definition of disability and survey design between the United States and Australia to examine the possible impact on reported trends in disability prevalence. In the US surveys, screening questions are mainly about Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). People enter the survey via questions about activity limitations; information about diseases and conditions are often collected later in the survey. In the ABS surveys, respondents enter the survey via screening questions largely about impairments and long-term diseases or

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[1] A 'specific restriction' is defined in the ABS disability survey as a restriction in core activities (self-care, mobility and communication), schooling or employment (ABS 1999).

[2] Profound core activity restriction refers to a person who is unable to do, or always needs help with, a core activity. Severe core activity restriction refers to a person who sometimes needs help with a core activity, or has difficulty understanding or being understood by family or friends, or, who can communicate more easily using sign language or other non-spoken forms of communication (ABS 1999).

conditions restricting every day activities, or 'difficulty gripping or holding things' and 'whether is restricted in physical activities or in doing physical work'. In effect, the screening questions are the criteria for defining disability in the Australian disability surveys and the gateway to subsequent questions on activity limitations. This difference may have partly contributed to the difference in the trends in the reported disability prevalence between the US and Australia.

It appears that increase in the prevalence of chronic conditions restricting everyday activity are less likely to be captured in surveys using activity limitations as the sole screen to define disability. In contrast, increases in the prevalence of chronic conditions could have more impact on the estimates of disability from surveys that include impairments and long-term conditions affecting everyday activity as part of the operational definition of disability.

In the US there has been a reported decline in the prevalence of dementia (Manton et al. 1995), while in Australia the number of people with a main disabling condition of dementia increased. This raises the question of whether the US survey screening questions, that are largely ADLs and IADLs, are adequate to pick up disabilities associated with these types of conditions. In the ABS survey, although classification of severity of disability is based on difficulty and assistance with core activities (self-care, mobility and communication), people with a disability associated with dementia are identified by the survey screening questions. Most of them are still picked up as having severe or profound disability by subsequent questions on needs for assistance with core activities.

Analysis of the US population survey data indicated the effects of using aids and equipment on the reported disability prevalence. There were individuals using aids and appliances who did not report activity limitations and, therefore, were not captured by surveys defining disability only based on activity limitations (Madans et al. 2002). The ABS disability survey screens 'captured' people who reported at least one restricting impairment or long-term condition and were using any aids or equipment, even though they reported 'no difficulty' in response to subsequent survey questions about whether having a difficulty with core activities. An increase in the number of people in this group would be less likely to result in underestimates of disability by the ABS surveys. But this may not be the case in surveys using activity limitations as the sole screen to define disability without considering the effect of using aids.

Like the effects of using aids and equipment, there might be people receiving assistance with activities who did not report activity limitation and therefore, would not be captured by surveys using activity limitations as the sole screens to define disability.

The ABS disability surveys contain a limit of 6 months or more for inclusion of any disease, disorder, impairment, activity limitation or participation restriction. Most US surveys do not contain a requirement of duration limitation for disabilities except for the National Long-term Care Survey (NLTCS) that limits disability to that of three months or more (Waidmann & Manton 1999). Without a duration limitation in survey definitions of disability, the estimated disabilities may include a large number of people with short-term difficulties or limitations, and thus, may result in great variations in the estimated disabilities over time.

The ABS disability surveys are specifically designed to collect comprehensive information about disability in the Australian population, while in the United States the collections of disability information are largely components of health and social surveys. Australian data showed that information collected in the national disability surveys tended to be more comprehensive and resulted in higher prevalence of disabilities then those collected in other national health and social surveys.

4 Suggestions on working towards internationally comparable general measures of disability

This section discusses issues that need to be considered when working on internationally comparable general disability measures, drawing implications from the recent trends in the reported prevalence of disability and chronic conditions.

Focusing on activity/participation but also including functioning dimension of the ICF

For strategic planning, it is important not only to measure the level of disability but also to monitor and understand tends in disability prevalence. Given that there is a trend of increase in the prevalence of chronic conditions, changes in morbidity may impact on disability prevalence. The examples of the United States and Australia appear to indicate that the reported disability prevalence might be affected by whether presence of any impairments and chronic conditions restricting everyday activity are included as part of the survey definition of disability. Increases in the reported prevalence of chronic conditions could have more impact on the estimates of disability from the surveys that included limiting impairments and chronic conditions in the operational definition of disability. This may further affect the reported trends in disability prevalence. Hence, to assist in collecting internationally comparable data and monitoring the trends in disability prevalence, at least two general measures of disability need to be considered.

One measure may consist of questions focusing on the activity/participation dimension(s) of the ICF and perhaps in addition an open-ended question on any long-term health conditions limiting everyday activities.

Another measure may focus on the body function dimension of the ICF. This measure will enable collections of data on impairment that result in restrictions in participation but no difficulty in any activities (For instance, if a person is HIV positive, the person may be out of a job because of discrimination). People who use aids or equipment due to functional problems can be 'captured' by this measure even though they do not have difficulties in activities when using the assistive devices. Similarly, this measure can 'capture' people who do not have difficulties in activity when receiving assistance. The measure also allows countries with a need for data on impairment or health conditions to get information about disabilities associated with specific type of conditions or impairments.

It is also worth noting that most US studies measured disability by focusing on dependence in ADLs and IADLs. About half of the recent OECD disability or health surveys include IADL items (Gudex & Laforture 2000). It has been suggested that such measures, particularly IADLs, are highly influenced by socially defined roles and social, cultural and physical environment. Decline or increase in the reported disability prevalence could reflect the changes in people's expectations about their ability to function independently or environmental modifications instead of improvements in underlying physiological capacity (Freedman & Martin 1998). This may be particularly true when comparisons are made between developing countries and developed countries. Therefore, one general measure may need to focus on functional impairments such as problems in seeing, hearing, speaking and walking.

Focusing on long-term disabilities

There is a need to include a duration qualifier with a focus on long-term disability in general measures of disability. Without a duration qualifier in the operational definitions of disability, the estimated disabilities may include a large number of people with short-term difficulties or limitations, and thus, may result in great variations in the estimated disabilities over time. This will in turn generate difficulties in international comparisons.

Focusing on severe disability in the general measures

Australian disability data show that the reported prevalence of severe or profound disability (need for assistance with self-care, mobility or communication) is more stable and less likely to be affected by changes in perceptions and attitudes towards disability than less severe disability (AIHW 1997). Analysis of US data also found that there is no change in prevalence for people with more severe disability—need for help with personal care activities. The evidence is fairly consistent across five US national surveys (Schoeni et al. 2001). Focus on severe disability in the general measure of disability may increase the comparability of data from different countries, including time series data.

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