

DISABILITY – GLOBAL TRENDS AND INTERNATIONAL PERSPECTIVES

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Abstract

Disability among populations is widespread and although many studies on disability exist worldwide there is a lack of comparability not only between countries and also between studies in the same country. Yet despite a lack of clarity disability is an increasingly major issue in public policy terms from the standpoints of equal opportunities, the increasing burden of age-related disability, work participation, social security benefits and so forth. One of the main problems is that disability is defined differently for different purposes so that there is no consistent overview of disability among populations, or the implications for disability policies. The first part of this paper addresses these deficiencies by reviewing and analysing global data on disability and relating it to ageing, health status, and functional measures of disability. It finds that a major cause of disability in future years will be ageing but that the prevalence of disability will depend on socio-economic factors and trends in healthy life expectancy. The second part of the paper considers policies for tackling disability particularly the financial aspects and the role of the public and private sectors and finds a multiplicity of institutional arrangements in place. The paper concludes by identifying five major issues for public policy-economic development, ageing and long term care, the importance of developing workpotential, and the need for international standards in the area of disability data.

Keywords: disability measurement, global trends, ageing, social security, disability policies, support systems

Background

The UK is currently experiencing what has been a relatively long period of economic success. The fruits of this success have been seen in the labour market, with unemployment currently standing at less than one million. However, there are some other labour market features that are worthy of note: unemployment has fallen faster than employment has risen, due to a rise in economic inactivity rates. The disabled is one group in society that the boom seems to have passed by. They are more likely to be unemployed or inactive than their able-bodied counterparts. Today, some 2.5 million of them find themselves on Incapacity Benefit alone.

Populations across the western world at least are ageing. This has a number of implications. It means that there will be an increasing number of people with disabilities. It also means that solving the problems of demography, sustainable growth and economic activity means understanding disability.

In this paper, Professor Mayhew discusses the problems and differences in the measurement of disability, and then goes on to discuss how different countries support the disabled. It is by understanding these issues that we can begin to understand the broader debate on disability and return to work.

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Introduction

It is everybody's fate, at some time in his or her life, to be disabled – either for a short duration through illness or permanently as a result of injury, or chronic illness. For a small percentage of the population disability is congenital and so begins at birth.

Levels of disability vary according to age, sex, level of economic development, access to health care, educational, environmental and other factors (WHO, 2000). A key finding of this paper is that levels of disability are probably far higher than most people imagine them to be. This is because disability is hidden from public view, as many disabled people are house or institution-bound and partly because much disability (e.g. cognitive disability) is itself 'invisible'. One reason for this belief is that in developed countries death and disability from infectious diseases has shown a remarkable and persistent decline as a result of better nutrition, prevention and cure and so their disabling consequences are less obvious to see.

At the same time and partly as a consequence of these improvements in nutrition and medical care there have been significant demographic shifts with large reductions in fertility and a gradual ageing of the population. Ageing however is accompanied by a significant increase in the likelihood of chronic disability as a result of natural ageing processes and the onset of chronic illness (ONS, 1997). Disability in these cases tends to be progressive, that is the chances are that disabilities will worsen over time rather than improve (Crimmins et al, 1994). It means that older people become increasingly dependent on others and for many dependency may be total especially in the period just prior to death (Seale and Cartwright, 1994). Indeed, as will be demonstrated, disability among the 65 and over age group, which is roughly on a par with disability among the under 65 age group today, is set to more than double relative to the under 65 age group over the next 20-30 years.

Without doubt disability is a 'growing industry' and yet how one quantifies it remains a subject of heated debate (Manton and Waidmann, 1998). Quantification is nevertheless a pre-requisite in order to develop appropriate public policy, deliver services, help disabled find work, planning for the future and so on. The problem is disability is a generic term for a wide range of physical and cognitive problems, which are hard to put into 'neat boxes'. We find that services for disabled are split into different facets of disability, according to age, gender, affiliation etc. with varied support networks and advocacy channels. There are specialists for almost everything: equipment, therapies, voluntary groups, and intermediaries concerned with transport, accommodation, social care and so forth.

With so many ways of categorising disability, as well as the potential to count people with multiple disabilities more than once, official and unofficial estimates of disability vary widely and can be rarely reconciled with one another. In practice we observe that the methods and means of measuring and comparing disability vary according to purpose. A policy driven approach for example needs to be able to identify beneficiaries of national policies (e.g. for financial support), and to identify those with rights under the law (e.g. anti-discrimination, or prejudice). It also needs to identify groups for policy interventions such as subsidies to hire disabled people, and to determine eligibility for particular services such as health care, rehabilitation, education and training or accommodation.

Many conventions are enshrined in national legal frameworks and sometimes determined locally. It is obvious therefore that using administrative statistics is unlikely to give a true and internationally comparable yardstick. It comes as no surprise therefore that literature on the subject of disability tends to fall into distinct categories, for example demographic,

medical, sociological, labour market, insurance, and social security. The purpose of this paper is to step back from some of this detail by comparing and synthesizing global trends, and reviewing the basic issues in disability policy as a whole. The juxtaposing demography with other facets of disability such as policy in one article is rare and plainly a tall order, given the diversity of the subject information and some of the limitations described.

A lot of the debate in the literature centres on objective measures of disability. If a consistent analysis of the nature and scale of disability were undertaken one might be able to provide insights despite flaws in the measurement instruments. Such insights could move the debate forward, by shifting the policy focus more on to ageing issues, drawing attention to the huge scale of disability in the poorest countries, or providing a better understanding of how disability maps on to social security systems. The aim of the first part of the paper is to analyse different approaches to disability measurement and to consider the ramifications in a global demographic context based on current knowledge. It finds that the 'medical' model of disability based on morbidity gives the best account of the causes of disability and is therefore valuable from a public health standpoint, whilst the functional 'model' is simpler to apply and has greater resonance within social security systems.

The second part focuses on the practical questions of principles, policies, institutions, and benefits. The analysis, drawing on examples from the European Union, shows that disability is a key dimension of social protection and follows hard on the heels of pensions and health care as major issues of public policy. It finds, however, that policies are more heterogeneous, that social provisions for disability are only partly driven by demographic needs and that institutional and other factors are as important. The issue for policy makers is to recognise that not only is disability a complex multi-faceted area of policy, it is also a shifting one with a diversity of approaches and fuzzy, often competing objectives.

WHO definition of disability

The World Health Organisation (WHO) has done much to raise the profile of disability by taking the lead in developing and promulgating measures of disability and introducing a system comparable to the International Classification of Diseases (ICD), known as the International Classification of Disability and Handicaps (ICDH). The ICDH framework, which was first published in 1980 and is currently being revised (Bickenbach et al, 1999²), provides a conceptual structure of the disability process. Despite criticisms of ICDH (e.g. see Kerrison and Macfarlane, 2000) it has provided an international basis for data collection and research, and so for practical reasons and without loss of generality we will use the existing ICDH definitions rather than the revised system. These define disability in terms of three aspects as follows:

- *Impairment*: any loss or abnormality of psychological, physiological or anatomical structure or function. This could include blindness or deafness, loss of limb and so forth.
- *Disability*: any functional restriction or lack (resulting from an impairment) of ability to perform an activity within the range considered normal for a human being. This could include walking, stretching, lifting, feeding and so on.
- *Handicap*: this is the relationship between impaired and/or disabled people and their surroundings affecting their ability to participate normally in a given activity and which puts them at a disadvantage.

²Among the proposed changes the new classification extends the dimensions to include environmental and personal factors. In addition the word handicap will be replaced by the less emotive term 'participation restriction'.

With certain definitional refinements models of disablement usually link these concepts in sequence. The starting point is a disease leading to impairment, then disability and so forth (e.g. see Verbrugge and Jette, 1994). National studies tend to focus on only one or two stages in the sequence, for example disease and impairment. Very few consider all stages especially 'handicap', which is necessarily contextual and which needs to take account of assistive devices such as hearing aids or spectacles in the cases of the deaf or partially sighted. In the following paragraphs we will exploit these concepts to produce estimates of disability in the world and identify key trends and differences. If we begin our investigation with impairments, however, we find that the trail to a better understanding of disability runs cold very quickly. For example in independent surveys of impairments Japan, India and China come to surprisingly similar conclusions that between 4%-6% of the population suffers from disability as defined in terms of impairments such as blindness (China details see: www.dinf.ne.jp/doc/prdl/othr/z00ap/003/z00ap00308.htm).

In 1990, the United Nations (UN, 1990) published a compendium of international statistics on disability that appeared to show that Egypt had the lowest disability rates and Austria the highest. In other countries such as Canada, the US and Australia published studies report even higher proportions of between 15% and 20% of the population. These counterintuitive findings are the result of using different concepts of disability with the impairment definition at one extreme. In the following sections we explore estimates using medical and functional approaches rather than the narrower impairment approach.

Various summary indicators of disability have been proposed and literature on the subject is extensive. A review and critique of available measures is contained in 'The Global Burden of Disease' (Murray and Lopez, 1996) but we shall initially confine our attention here to the concept of years lost to disability (YLDs). This builds on the incidence of diseases, including trauma and the stream of 'disabilities' arising from them, measured from the age of onset for the duration of the disability. Each type of disability is weighted for severity but is given a higher weight if it is medically untreated rather than treated. By multiplying the incidence, duration and severity weight together, an estimate is derived of the years lost to disability. So, adapting one of their examples, a condition like asthma carries a weight of 0.1 if untreated and 0.06 if treated. If the incidence of asthma in males age 15-44 is 1.3 million, the untreated portion is 35% and the average duration is 7 years, then this condition is estimated to result in about 670,000 YLDs in a given year. Murray and Lopez present a table, reproduced below, showing the leading causes of disability in the world. Several key observations follow:

- The number of years of disability per annum totals almost 500m worldwide spread over a large number of conditions which implies a prevalence of just over 8%.
- Disability plays a central role in the health and well being of the population, but the problem is hidden from view in public health terms because the leading causes of disability differ from the leading causes of death.
- There is a significant burden of mental illness. Of the ten leading causes five are psychiatric conditions. All together these conditions account for about 28% of YLDs but only 1.4% of deaths.

| | | Total (millions) | Per cent of the total |
|----|---------------------------------------|------------------|-----------------------|
| | <i>All causes</i> | 472.7 | |
| 1 | Unipolar major depression | 50.8 | 10.7 |
| 2 | Iron – deficiency anaemia | 22 | 4.7 |
| 3 | Falls | 22 | 4.6 |
| 4 | Alcohol use | 15.8 | 3.3 |
| 5 | Chronic obstructive pulmonary disease | 14.7 | 3.1 |
| 6 | Bipolar disorder | 14.1 | 3 |
| 7 | Congenital anomalies | 13.5 | 2.9 |
| 8 | Osteoarthritis | 13.3 | 2.8 |
| 9 | Schizophrenia | 12.1 | 2.6 |
| 10 | Obsessive compulsive disorders | 10.2 | 2.2 |

Table 1: Worldwide medical causes of disability. This table is posted on the WHO web site via www.who.int/whosis. A full description of the methodology can be found in Murray and Lopez (1996).

What does the Global Burden of Disease say about the prevalence of disability in different populations? Another useful concept is so-called disability adjusted life expectancy or DALE, which in turn is a development of work by Sullivan (1971) and others, and is one of several attempts to produce summary indices of health expectancy (Robine et al, 1993). WHO publishes data on life expectancy at birth and also disability adjusted life expectancy. We compared data from 191 countries to ascertain on average what proportion of life is spent in disability.

Figure 1 shows each country's normal life expectancy (thin line) and DALE against its life expectancy at birth (thick line). On the left are countries with low life expectancies including many in Africa and on the right countries with high life expectancies. Each point on the graph represents the DALE for a given country with the thicker solid line being a statistical or best-fit average. The vertical gap between the thin and thick lines therefore represents the average years of disability for any given normal life expectancy. To give an example in a country where life expectancy at birth is say 60 years (point A), the expected years of disability would be given by length PQ (9.5 years).

Several important conclusions emerge using this approach. For example, it can be verified that:

- In more developed countries with life expectancies over 70 years around 8 years are spent on average in disability or around 11.5% of normal life span (and thus is higher than Murray and Lopez's percentage).
- In least developed countries with low life expectancy years spent in disability increase to 11 years or roughly 25% of normal life span. Countries with the most serious problems in this regard include Uganda, Malawi, Zambia and Sierra Leone.
- An improvement of one year in life expectancy equates roughly to a reduction of 1 calendar month of disability throughout life.

A key issue is that medical causes of disability and consequent premature death are substantially different in less developed countries compared with more developed countries. In the former acute illness and infectious diseases, such as AIDS³, are more likely causes of disability whereas in the more developed world it is more the consequence of chronic illness. This means that the gearing between disability and life expectancy shown in Figure 1 is due more to the elimination of disabling infectious diseases in richer countries. Thus, it does not necessarily imply that living longer means living healthier, once infectious diseases have been eliminated from the spectrum of disabling medical conditions.

What does this mean in terms of the prevalence of disability in the population (i.e. numbers per unit of population)? The answer depends on the underlying age distribution of the population; however, for typical population distributions the percentage ranges from around 28.5% in certain parts of Africa to around 12.2% in more developed countries using this methodology. Note that whilst we cannot easily verify these percentages at least we have established a benchmark that can be tested on the ground.

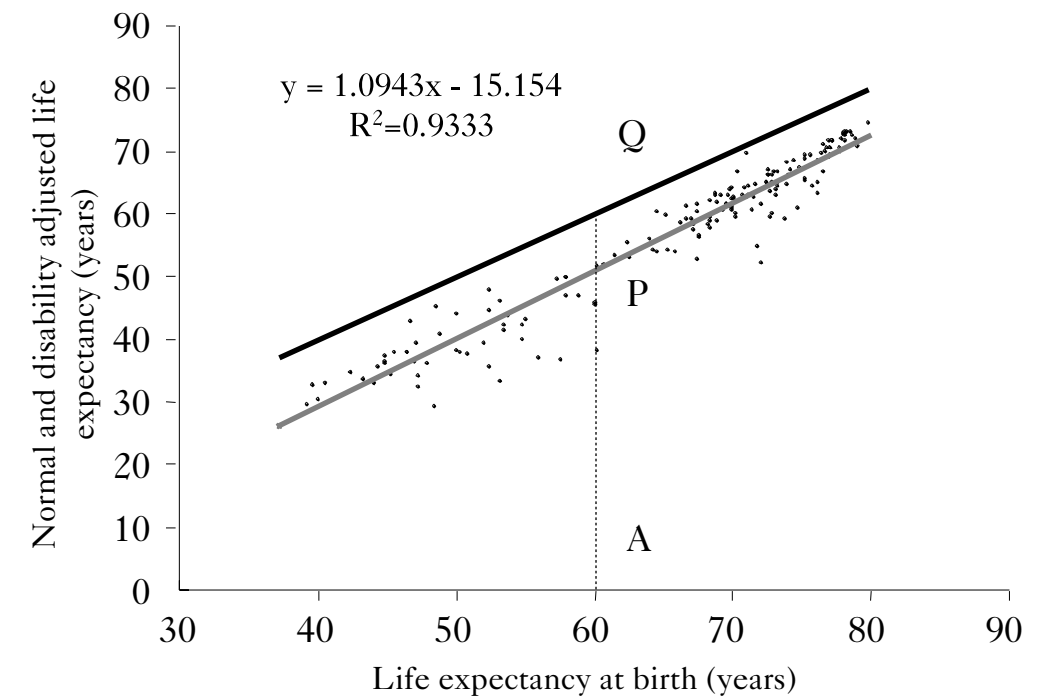


Figure 1: Plot for different countries showing normal and disability adjusted life expectancy as a function of life expectancy. The vertical gap between the thin and thick line shows the average years of disability for any given value of life expectancy. The best-fit equation is shown at top.

³As part of its research work programme, the United Nations Population Division studied the demographic impact of AIDS in the world. In the 29 hardest-hit African countries it found that life expectancy at birth is estimated to be 47 years, 7 years less than what could have been expected in the absence of AIDS (www.popin.org/pop1998/6.htm).

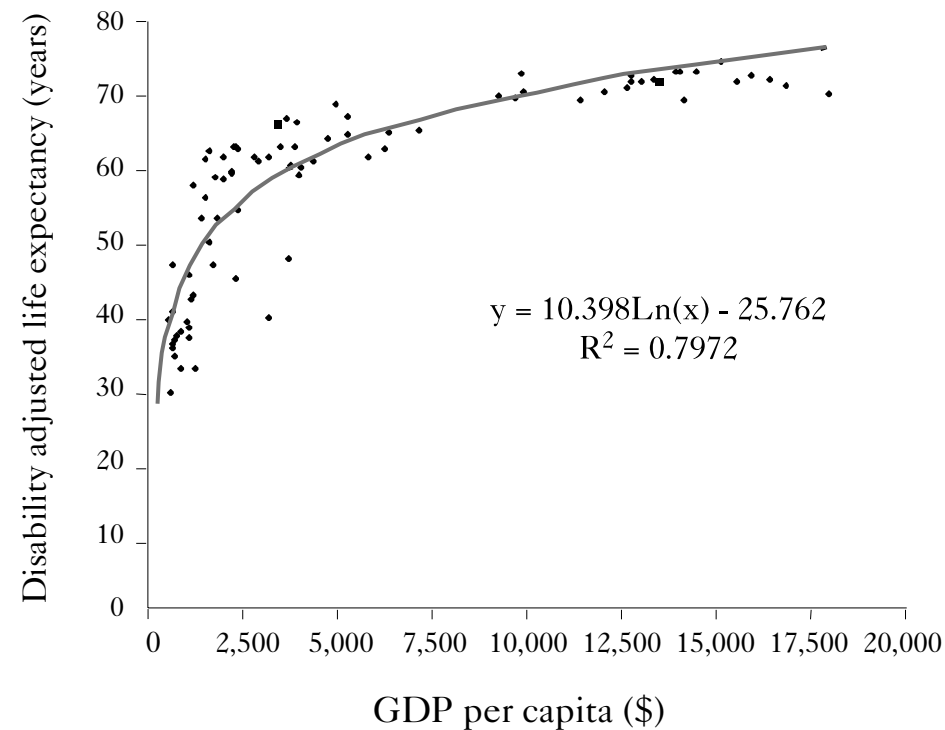


Figure 2: relationship between disability adjusted life expectancy and income per capita in different countries (data source: WHO, 2000). Best-fit equation is also shown.

The other important point to emerge from this brief global analysis is that disability and life expectancy are correlated with the level of economic development. This is not the place to go into detail but as Figure 2 clearly shows there is a rapid improvement up to \$4,000 and then diminishing returns to GDP per capita after that.

Functional measures of disability

The above findings are based on a morbidity-driven model of disability; however, there are many problems with the approach. For example one obvious limitation is that the weights Murray and Lopez use to measure severity are determined by panels of experts rather than by primary medical sources, although it is evident great care is taken to maximise objectivity. Another problem is the non-specificity of the general medical conditions of the elderly, and so their methodology is likely to lack precision in this critical regard, whilst a third problem is how to distinguish between multiple pathologies or co-morbidity.

An entirely different approach to measurement, and one which WHO also promotes, is based on a 'functional' rather than medical approach and uses concepts contained in ICDH. Its use is perhaps best illustrated by the excellent and still used survey of adult disability carried out in Britain in the 1980s (OPCS, 1988). The central hypothesis turns on people's ability to carry out activities of daily living (ADLs) in terms of mobility, dexterity, seeing, hearing, personal care, continence and so forth. Based on the survey, OPCS were able to

produce a disability scale ranging from 1 (least disabled) to 10 (most disabled). For example someone who is deaf in one ear but who is otherwise able would score 1. On the other hand a person who had suffered a serious stroke who cannot walk, feed himself, or exercise any personal care would score 10.

For our purposes we bracket OPCS's scores into 3 severity groups – scores 1 to 4 (least severe), 5-7 (intermediate severity), and 8-10 (most severe). Using OPCS's findings Figure 3 shows the prevalence of disability in Britain at that time expressed in rates per thousand in the relevant age and severity group⁴. Clearly disability occurs throughout the age spectrum but there is an exponential increase in disability rates beyond 50 years of age such that by age 80 there is over a 70 percent chance of being in one of the three disability categories described. Note that the scale is not a measure of the economic cost of disability: a disability score of 4 does not mean someone is twice as dependent as someone who has a score of 2, so the scale cannot be directly converted into a needs assessment.

Applying these rates to the UK adult population we obtain an average prevalence of around 14%. This is roughly equivalent, but still below, values obtained in household and census based surveys, which use self-reporting methods rather than detailed interviews, as per the OPCS study. As already noted, comparable studies in the US (e.g. see Kaye et al, 1997), Australia and Canada also report values in the range 14% to 20%, although in Italy the rates are considerably lower (Golini and Calvani, 2001). Clearly, OPCS's estimates are at the lower end of this range but there are sound reasons for the differences observed. One is the bias typically found using self-reporting techniques (ONS, 1998a), whilst another is the sampling framework and response rate. In a controlled field study of the OPCS kind it is clearly possible to achieve greater accuracy and consistency than is the case with simply asking people if they suffer from a limiting illness. A third reason is the definitional threshold for disability so that if were lower more 'disability' would be captured as a result. This occurs in certain alternative scales such as Instrumental Activities of Daily Living (IADL), which are based around typical household activities such as cooking and washing (Lawton and Brody, 1969).

It is noticeable that these percentages are also higher than those produced by Murray and Lopez's methodology and far higher than the impairment based methodologies previously reported above for Japan, India and China. This suggests ADL techniques are likely to produce a lower disability threshold of the methods described. The problem is no two countries using ADL techniques survey disability in exactly the same way as the recent survey of techniques used in EU countries demonstrates (Ramussen et al, 1999). Thus it is impossible to obtain consistent and comparable disability estimates around the world using without harmonized standards of measurement.

⁴Prevalence is accurately described by an exponential equation, $d_x = 7.92 \exp(0.052x)$, where x is age. OPCS did not survey disability in children in this study, although the figure 7.92 per thousand is taken to be a reasonable but difficult to verify approximation for congenital disability.

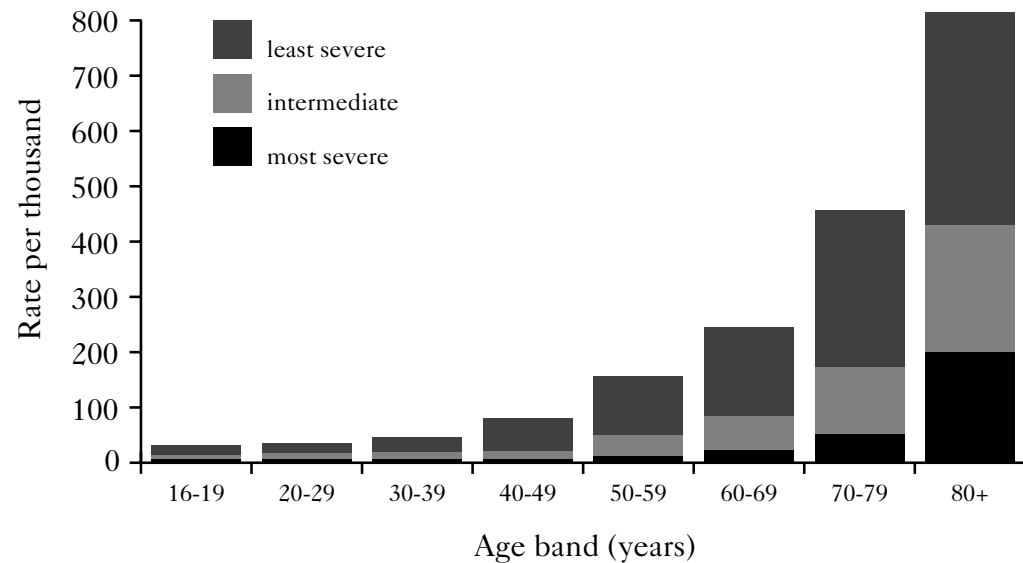


Figure 3: Prevalence of disability by age and severity category in Great Britain. Adapted from OPCS (1988).

Such surveys ignore the fact that age-specific disability prevalence in a population may change. Large-scale longitudinal databases following individuals through time are rare but experience from the United States using the National Long-Term Care Survey (NHLTCS) consistently shows small but accelerating downward trend in disability prevalence among the elderly (Manton and Gu, 2001). This has been linked to improved health care, healthier life-styles, assistive devices preventing falls etc and also educational and ethnic factors (Cutler, 2001). Whether US experience is repeated elsewhere will depend on many factors including the stage of economic development, access to health care, health behaviours and so forth. There is a need for example to disentangle time spent in disability from premature death, a point we return to below.

Let us stay with the OPCS prevalence figures for the moment and ask the simple question what they would imply in terms of the scale and incidence of disability if such rates were to apply worldwide. Let us also make a distinction, which is often made in a policy context between disabled people of working age (under 65, say) versus disabled people who are 65 and over. We know from a whole range of studies that world population growth is slowing down but at the same time becoming older – even in less developed countries (e.g. see Lutz, 1996; Mayhew 2000). Such age shifts would indicate probable increases in the number of disabled if current prevalence rates, that is those observed in Britain, were to continue. We took the most recent UN global population projections to 2050 in order to understand how disability might evolve in different regions and age groups. Our results are shown in Figures 4 a-c.

It is noteworthy that the pattern of evolution is different in all three cases even allowing for imperfections in the estimation procedure. In more developed countries disability in older age, at present on a par with disability in working age, will increase substantially whereas working age disability will level off or even decline. For example, by 2025 60% of disabled people will be 65 or over and by 2050 this will increase to 70%.

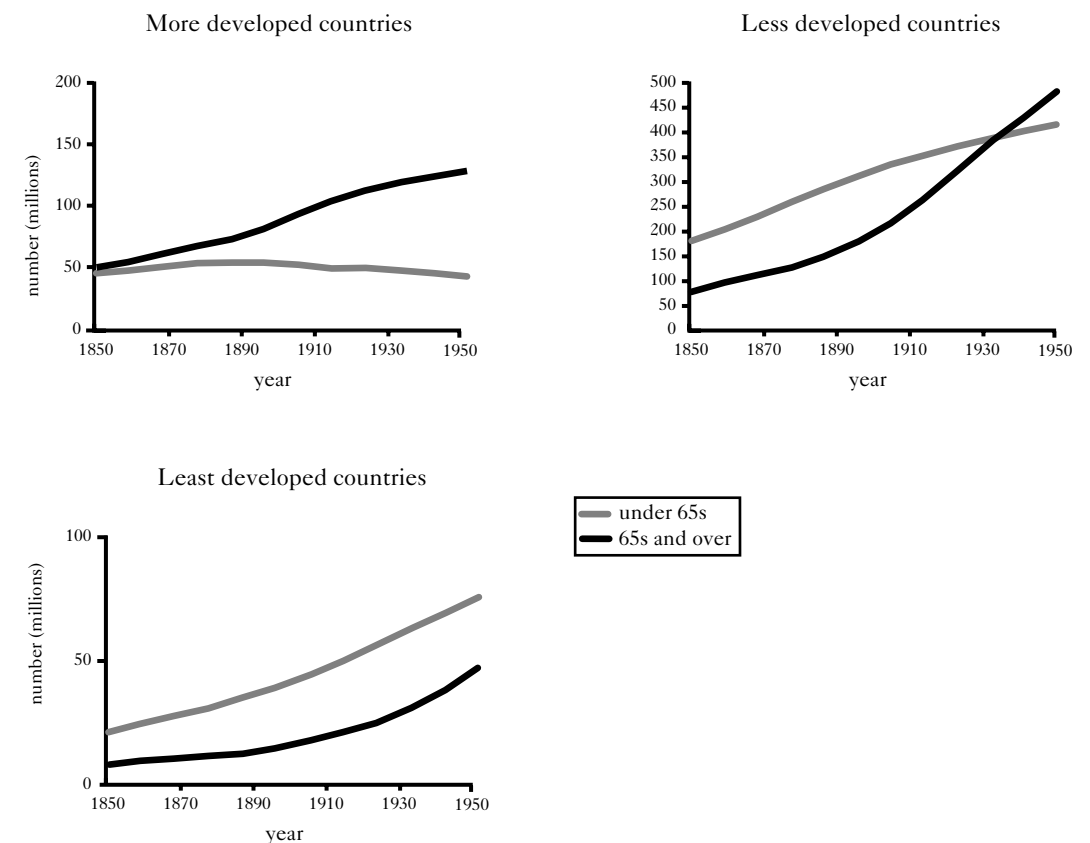


Figure 4: Projecting the number of disabled in different country groupings using OPCS disability prevalence rates: 1995-2050.

In less developed countries both age groups increase throughout the period, with old age disability overtaking working age disability after 2045 (effectively there is a 50-year lag compared with more developed countries). In least developed countries the expected pattern is for increases at comparable rates in both age groups. Demographers are predicting a high probability that global population will stop growing before 2100 peaking at around 9 billion (Lutz et al, 2001). Stable population theory predicts increases in life expectancy will be cancelled out by falling birth rates and thus global population will continue to age with the proportion of disabled doubling. Life expectancy in 2100 for example will be 83 years – currently the only population reaching that level is Japanese females.

The total level of disability using OPCS prevalence rates is not dissimilar to but slightly less than the global figure reported by Murray and Lopez of 472m. worldwide or around 8% of the population today. Any similarity must be regarded as a co-incidence and not proof the methods are consistent. In fact the prevalence method seriously underestimates disability in least-developed countries in younger age groups as we saw from earlier estimates. As Seale (2000) notes, AIDs and tuberculosis, both typical causes of death cause considerable long-term debilitation, dependency and symptoms, regardless of environment.

Disability among the very old

Age related chronic disability has become an important public policy issue in more developed countries especially in the area of long-term nursing care for people close to death. The main issue is one of cost, in particular who pays? The fact that debate is happening at all is a commentary on rapid ageing trends, changing family structures as well as on costs. Is it possible to estimate from the methodology of previous sections what the period of most intensive care and high dependency is and how that might be affected by various different factors?

We consider this issue with reference to two countries – England and Japan. The primary reason for selecting England is partly our familiarity with the quality and extent of the data. The argument for Japan is that there are currently demographic and ageing trends underway which could alter our earlier projections. These coupled with other changes in Japanese society may have profound implications in terms of care of the elderly.

Figure 5 is a survival curve for males and females based on English Life Table 15 produced by the Office for National Statistics in conjunction with the Government Actuary. A life table does not represent the actual population but what the population would look like if age specific mortality were to apply to a synthetic population, usually 100,000 people, hence the values on the vertical scale. Let us assume on average that disability tends to be both progressive as well as permanent and is concentrated in the period leading up to death. The shaded area of Figure 5 represents the portion of the surviving population that is disabled – that which falls into OPCS severity categories 1-10 and extrapolated back to birth.

Diagrams like this are a useful tool for illustrating the compression of morbidity and mortality (Fries, 1980; see also similar examples in Manton and Stallard, 1996; Crimmins et al, 1997). It is fairly obvious that the horizontal width of the shaded area gives an indication of the expected duration of disability at a given age whereas the vertical height gives an estimate of the number of disabled of a given age. It turns out that the average width or duration is similar to our previous global analysis, although it is apparently much longer for those disabled at a younger age, perhaps through accident or congenitally. Disability prevalence using this method is 12.9%, which is slightly lower than when we used the actual population distribution.

The average 'stock' of disabled of a given age is given by measuring A-C and the duration by A-B. In fact it is striking how very nearly the duration tends to be constant in older age but is longer if disability begins at a younger age, say between 40 and 50 years. The overall average is 9.91 years. If we were to construct the same diagram but only represent on it the most severely disabled group (categories 8-10) our shaded strip would be much narrower. This group is the most severely disabled and contain those likely to be in need of intensive nursing or palliative care. It turns out that for this group the duration of severe disability averages 1.48 years.

This result provides a convenient if somewhat crude yardstick for evaluating nursing care needs among the very old (in fact there is considerable dispersion around the average). As the number of deaths each year rises or falls depending on fertility patterns decades earlier so one can predict approximately the numbers in need of nursing care.

However, more detailed estimates need to take account of gender differences, financial, household and family circumstances. Females on average outlive male partners but spend a longer period in disability and thus it is females who are in the majority in long-term care.

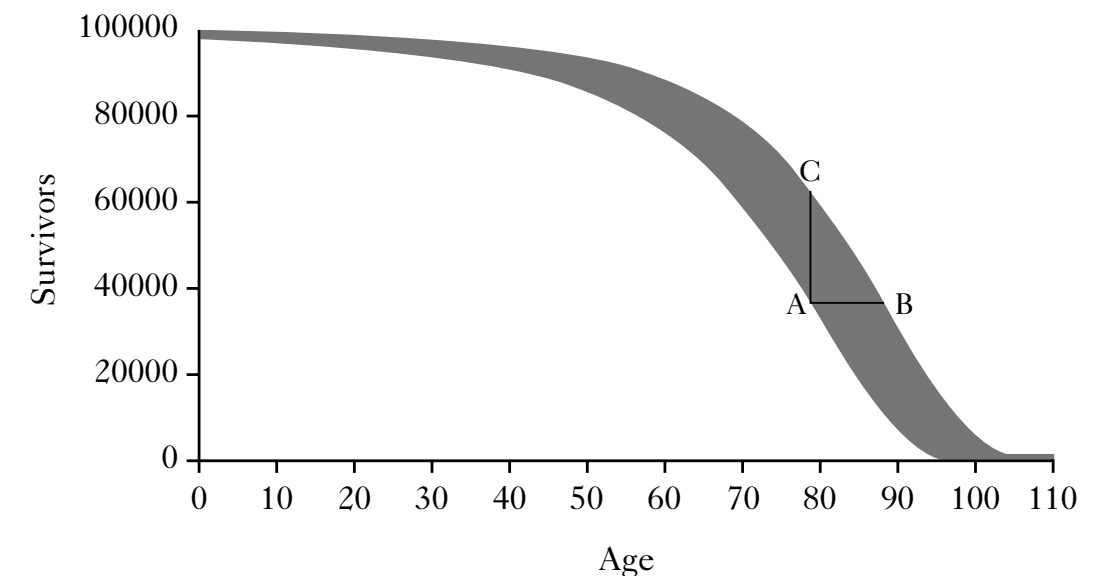


Figure 5: Survival curve based on English Life Table 15. Grey area shows population with disabilities. AB denotes duration and CA denotes stock at given age.

Japan is the fastest ageing country in the world with the longest life expectancy (Mayhew, 2001b; Wilmoth, 1996). Due to the 1950s baby boom, it means that the number of annual deaths is set to double over the next decades, a pattern that will be repeated in many other countries due to the post-war baby boom (see Figure 6). If these trends are translated directly into nursing beds then Japan would need something like 2.5 million beds by 2025. In fact not all people will die in a nursing home environment but societal changes in family structures means that nursing home places will continue their fast rate of expansion since the early 1990s from almost nothing to an estimated 250,000 today (Mayhew, 2001a).

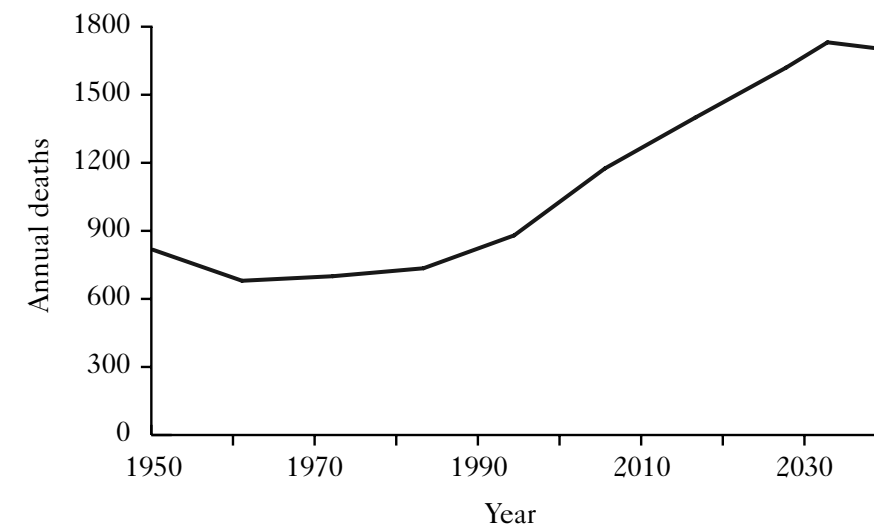


Figure 6: Past and projected annual deaths in Japan (source: United Nations)

This analysis depends of course on current estimates of mortality but we know that life expectancy is increasing and that mortality gains have a tendency to be under-predicted (e.g. see Olshansky, 1988). A crucial question is whether added years are spent in reasonable health or in extreme dependency. It seems clear that death and the cost associated with death cannot be eliminated, only postponed but what effects might this be expected to have?

Life expectancy in Japan, especially among females has shown remarkable acceleration since the 1950s. For females aged 50 it has been increasing at around 1 year every 4 years as compared with 1 year every 18 years up to 1950 when it reached 24 years (source: Nanjo and Kobayashi, 1985). According latest figures from the Japanese Ministry of Health and Welfare, female life expectancy at 50 is now 35.5 years, representing a continuation of this trend almost exactly. The reasons for the change are not entirely clear but must undoubtedly be related to Japan's increasing prosperity as well as to Japanese life styles (in fact similar patterns have been observed in other developed countries).

A mathematical model was developed to investigate the implications of this trend, assuming the rate of improvement in life expectancy will continue as it has been (Mayhew, 2001a). The results, shown in Figure 7, are remarkable. Notice for example the increasing steepness in the mortality curve with time, an effect sometimes known as the 'rectangularisation' of the mortality curve or the 'compression of mortality' (Fries, 1980), although the effect is less evident in English, US or Swedish data where gradients, whilst right-shifting tend to be constant (Mayhew, 2001b; Wilmoth and Horiuchi, 1999). The results indicate that by 2018 there will be a 20% probability of being alive at age 97 as compared with age 84 in 1950, a 13-year increase over the period. Note finally, the results also suggest a 'spur' of very old Japanese women, which appears to have developed from 1982 onwards and which itself would be an interesting subject for research.

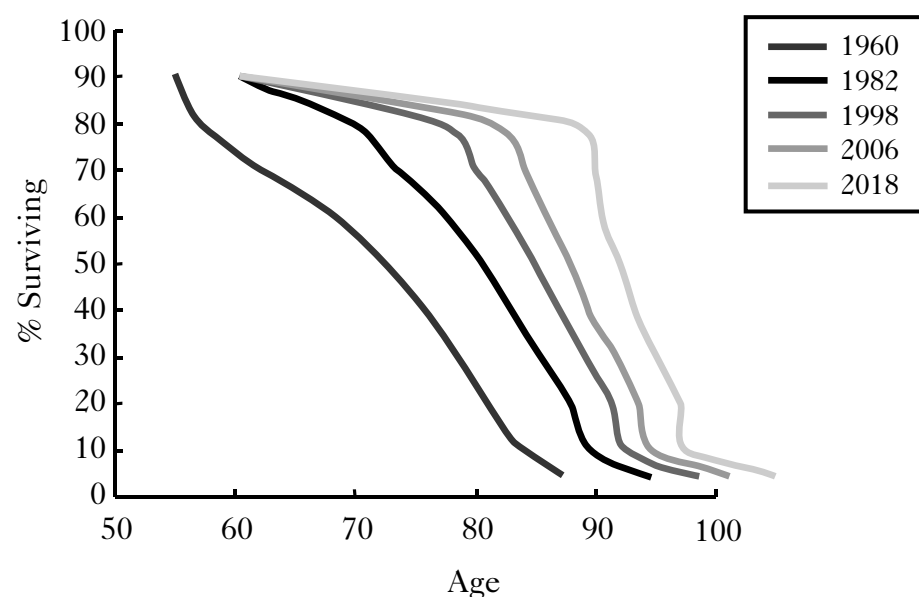


Figure 7: Percentage of Japanese females surviving beyond 50. 1960 and 1998 (actual); 1998, 2006, 2018 (projected). Model based on data provided in Nanjo and Kobayashi (1985).

The impact on society of these ageing processes will depend crucially as we have said on whether added years of life are spent healthily or in disability and dependency (Liu et al., 1990; Bebbington, 1991; Manton and Stallard, 1994; Manton et al, 1997; Freedman and Martin, 1998). Consider the following mathematical formula:

It shows the relationship between the prevalence of chronically ill people above age x , the period of chronic disability, a , and e_x life expectancy at x . This relationship, which should hold at least approximately in the real world (Mayhew, 2000), encapsulates the healthy versus unhealthy life-years issue in the longevity debate. If the duration of disability prior to death is fixed and longevity is increasing, one would expect the prevalence rate to fall. This would correspond to a situation in which a population was living longer, disability-free lives; in other words, increments to life expectancy consisted of disability-free life years. If, in contrast, increments to life expectancy consist of chronically disabled life years, then the prevalence rate would rise over time.

Say, for example, life expectancy at age x was 10 years and the duration of chronic illness prior to death was 2 years. Then, if life expectancy and the number of years spent in this state rose in lockstep, we might observe prevalence rising as $2/10, 3/11, 4/12, \dots$. Using a different example, if the duration of disability remains in constant proportion to life expectancy, then prevalence is constant (e.g. $2/4, 4/8, 8/16, \dots$). Plainly, if the duration of chronic illness before death remained constant, prevalence would decline.

We therefore conclude that any projections of prevalence rates depend on whether the longevity revolution is producing healthy or chronically ill life years. We have not been able to find specific evidence either way for Japan, although it would not be too difficult to study. Evidence from other countries, where ageing processes have not advanced as far, is mixed. In the UK, for example, healthy life expectancy is progressing at a slower rate than total life expectancy with consequent increases in disability (Bebbington, 1991; Dannel and Dix, 2000; ONS, 1998b; Grundy et al 1999), and so the reverse of US evidence. This raises intriguing questions: for example whether differences in health care systems are a factor and if long waiting times for elective surgery increase disability prevalence and dependence.

In the case of Japan, where this demographic revolution is farthest advanced there will be increases in a range of services aimed at elderly people for example in the area of residential and long-term care. The demand for these services is being accentuated by parallel changes in family structures and dependency ratios with the likelihood of shortages of carers (Horlacher, 2001a and 2001b). However, because fertility is falling total dependency rates will continue to be lower than they were in the 1950s but the public expenditure implications of a higher elderly population are greater. As other countries follow in Japan's wake it is likely similar pressures will build up.

International perspectives on policies towards the disabled

Attitudes towards disability

We now turn our attention to the second part of paper which considers disability from a policy perspective and draws on international experiences. It is evident from the above that measurement of disability implicitly starts from the proposition that disability is capable of objective measurement. How society deals with the disability issue usually starts from a different basis and the relationship for example between disability support systems and levels of disability may be tenuous indeed, both for economic and social reasons. Our aim in the second part of the paper is to review the impact of these trends in society and their effects on institutional arrangements and benefits systems. The conclusion that emerges is that there is a multiplicity of 'models' with no single model that suits all needs.

The United Nations and other international organisations have been active in raising awareness of disability over a long period of time. The most important outcome of the International Year of Disabled Persons, 1981, was the World Programme of Action concerning Disabled Persons, which was adopted by the General Assembly the following year. Out of this emerged the notion that persons with disabilities had a right to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development. There also, for the first time, handicap was defined as a function of the relationship between persons with disabilities and their environment.

As a result of experience gained during the United Nations Decade of Disabled Persons (1983-1992), the United National General Assembly adopted a resolution in 1993 entitled "Standard Rules for the Equalisation of Opportunities for Persons with Disability" (www.un.org). The main thrust might be summarised as a general shift in approach from disability as a medical issue to one of disability as human rights issue in which an "ethos of compensation for perceived abnormalities is replaced by one based on the removal by society of barriers to inclusion of all its members.....the new approach is based on the notion of right rather than charity and an accommodation for differences rather than a compulsory adjustment to an artificial norm" (see *'The New Disability Policy'* European Commission: <http://europa.eu.int>).

Whilst the rules do not have international legal force they offer a strong moral and political impetus to take specific actions, and indeed it is clear that many countries have adopted this approach in their own national policies. This has partly been achieved through the device of 'mainstreaming' (e.g. the inclusion of anti disability discrimination in legislation only indirectly connected with disability) and partly through the development of new institutions and strategies. As an example, the European Union adopted a new strategy in 1996 entitled "Equality of Opportunity for People with Disabilities – A New Community Disability Strategy", variants of which have been taken up at national level.

The standard rules themselves are intended to cover children and adults but interestingly there is no explicit mention of older adults or disability in old age. This, one suspects, is partly due to the administrative distinction between working and retirement age disability. Explicit policies for older people, in other words the same sort of equality agenda, have not been developed at the same speed as policies for disability although plainly there are

overlaps. For example, the aim is to help working age disabled into work, whereas with older people it is arguably to take them out of institutional care and back into the community. Its fair to say that disability among the elderly has received less priority in policy terms, but with a rapidly ageing population and increasing medical costs this seems set to change.

On 6-7 October 1999 an EU sponsored conference was held in Helsinki on the subject of "Independent Living of Older Persons and Persons with Disabilities" organised by the Finnish Presidency. The conference – designed in part as a tribute to the UN International Year of Older Persons – set out to discuss the challenges of ageing and disability policy in the new millennium and to work towards a more inclusive and non-discriminatory society. At the conference there was some recognition that the boundary between work and retirement was becoming blurred and that the low labour participation rates of elderly workers was detrimental to the long-term needs of the European economy. This suggests that policies aimed at improving health and reducing disability will assume far greater significance, especially in the 50-70 age group.

In general, labour markets are difficult to analyse partly because of administrative and behavioural effects such as changes in retirement age and pension rules, which are known to encourage take-up of disability benefits and pensions. Benefit expenditure has increased substantially almost everywhere, and the suspicion has grown that the benefit system is being used as a 'shelter' by certain groups of workers (Aarts and De Jong, 1992) or as an alternative to unemployment. In many ways developed economies are favourably poised to absorb more disabled and older people back into the workforce but experiences to date have been mixed and the evidence contrary. In labour markets generally participation rates among men have fallen with declines in manufacturing and risen among women as services have increased.

Another trend in labour markets is the tendency towards part-time work and less secure terms of employment. Research in the US suggests that disability groups have suffered disproportionately from these changes, and the IT revolution which in theory should benefit the disabled by allowing them to work from home has not had the impact expected (see University of California – San Francisco, Institute for Health and Ageing: <http://dsc.ucsf.edu/>). The pattern is repeated in the UK where disabled people are nearly seven times more likely to be out of work and claiming benefits as non-disabled people (Disability Rights Commission: www.drc-gb.org).

To add to the confusion, there are now many examples and much anecdotal evidence how individuals, through imaginative employment support schemes, have been able continue to work and in some cases achieve high office. In general, the success of back-to-work or retention strategies for disabled people need to be viewed in a more limited context and evaluated against the target groups the strategies are intended to assist (see for example, Duckworth et al 1998 for an analysis of strategies used in the UK). A lot depends on the institutional support structures involved, a subject to which we now turn.

Pillars of support

Disability policy is complex because it impinges on so many aspects of society and on all age groups. One major distinction to be drawn from the outset is that disability support systems in developing countries are concentrated within the family or the community rather than in institutions. In more developed countries the classic model of welfare consists either of the institutionalised type or the residual type in which the state only assumes responsibility when the family or the market fails (Titmuss, 1958). More recent thinking draws a distinction between systems with links to the work place, those based on 'needs' or means tests, and those based on universality (Esping-Andersen, 1990). Increasingly welfare systems are becoming 'hybrids' of these different types and the following paragraphs we attempt to put these differences into a logical framework as far as disability is concerned. We then illustrate this by reviewing benefit arrangements for disability in the European Union (EU).

One way favoured by public policy analysts and economists is to split areas of social protection (such health care, pensions etc) into three pillars distinguishing between the roles of the state (or other public and international bodies), the role of employers and the roles of individuals themselves. The state for example is involved primarily with regulation and enforcement (e.g. in areas such as health and safety legislation, employment terms and conditions, equal opportunities) but it also a provider in the form of financial benefits and allied services.

In its provider role the state does not necessarily assume full risk, and that risk may be divided between state and employer in some way. In the area of industrial injuries for example the boundary line tends to depend on whether the employer or employee is at fault. There is also a wider public sector role with some aspects of public administration being devolved locally (for example in respect of building regulations containing provisions for the disabled, or community care services). On the other hand the role of enforcing, say, equal opportunities and human rights legislation might be given to independent bodies such as the recently created Disability Rights Commission in the UK.

Compared with the state, individual employers have more discretion over benefits they offer workers above any prevailing minima, and will use 'benefit packages' to attract and retain the best workers. Individuals, the third pillar of support in this schema, have a range of responsibilities towards their own health and safety and to their families. They may decide to take out additional insurance against contingencies such as ill health and disability if they believe the state or employer will not provide adequately for them. Additionally they may provide money or support in kind to voluntary sector bodies whose aims include providing help to disabled people. A summary of these different roles is set out in Table 2.

| State | Individual | Employer |
|---|--|---|
| <ul style="list-style-type: none"> • Policy (e.g. equal rights) • Provision of benefits • Prevention (e.g. health and safety legislation) • Regulation and legislation (e.g. national insurance) • Employment policy | <ul style="list-style-type: none"> • Personal health and well-being • Health and well-being of family • Charitable donations • Community support • Wider involvement in voluntary organizations and initiatives | <ul style="list-style-type: none"> • Employee and family benefits • Policies on long term sick leave • Severance policies • Early retirement • Charitable donations • Support for community initiatives |

Table 2: The three principal actors and examples of the different roles and responsibilities.

If comparisons are made between the split of responsibilities and activities of these three pillars it is clear that different countries draw the boundary in different places. Visualise to begin with the three pillars as a triangle with the apexes labelled state, employer and individual. A society that elevates the role of the state will tend to erect systems that place obligations on the roles and responsibilities on the employer whereas societies with more libertarian approaches to social protection will reduce the role of the state to a minimum and elevate individual responsibility (i.e. Titmuss's residual model).

In many European countries for example employers are obliged under legislation to provide for certain benefits and entitlements whereas in the UK and US employer benefits are seen more as a perquisite or a duty rather than an obligation as such. In these cases the state adopts an 'exhortation' or best practice role in which it, its agents or employee representatives, lean on employers to effect changes in policy. However, a few generalisations are possible. A country with a very high state 'pillar', for example Austria, would not be expected to have as well-developed a market for private disability insurance as the US where the balance of risk lies more with the individual than with the federal government or employer. Conversely, state disability schemes whilst perhaps not being as generous as some private schemes have the significant advantage of at least covering the whole population, whereas employer based systems are not much use to the self-employed and the non-employed.

In reviewing each area of social protection it is clear the balance between pillars is altering some areas more than others. Figure 8 for example shows where pensioners in the UK are deriving their income. As is seen the mix of sources of income has shifted away from the state towards the employer in the form of occupational pensions. However, with the introduction of private pensions from 1988 and the maturity of occupational pension schemes (which itself is a reflection of changes in the job market) the balance is expected to shift in the direction of private pensions and the individual. This simple way of looking at things can, in principle, be extended to other areas of social protection including disability.

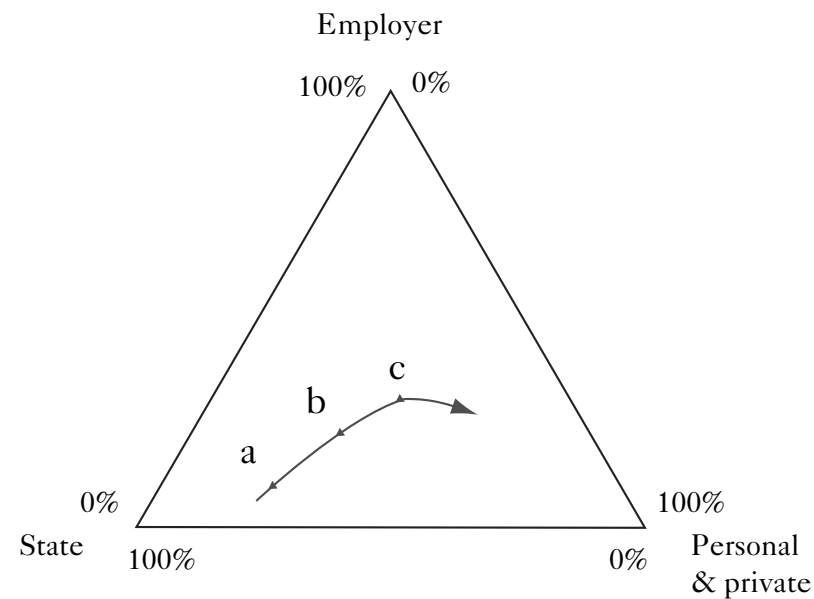


Figure 8: Sources of income of UK pensioners: a) pensioners in 1979, b) pensioners in 1996, c) pensioners just retiring in 1996 (based on DSS 2000). The chart shows how the mix of pensioner income is changing towards private means such as personal pensions and savings.

If we were to do this however, we would find that the trend towards personal responsibility has not progressed as far for various reasons. Firstly, disability is more complex than a retirement policy, which is invariably triggered by the simple device of reaching the age of retirement. For the prospective insurer it means there are several risks involved. Moral hazard, for example, refers to the existence of an explicit or implicit insurance contract that leads the consumer to change his or her behaviour in order to be eligible for benefits. Adverse selection occurs when only certain people who are predisposed to disability take out insurance and thus increase the likelihood of disability occurring with the insured group, which could have the effect of increasing premiums to unaffordable levels. Information asymmetry becomes a problem when a disability claim is made and benefits are paid on the basis of medical and other check-ups and where there are in-built incentives to bias decisions in favour of either party.

Partly for these reasons, private disability insurance is a relatively specialised, niche market, especially in those countries with high state thresholds and low benefits. In the US and UK there is what is termed a group insurance sector, insurance taken out by some companies on behalf of their employees as an extra benefit. In insurance terms the risks are more confinable and the policies therefore cheaper per capita than those available on the open market. The attraction for employees is that the benefits are likely to be more generous if their disability occurs at a young age than an actuarially reduced early pension package. However, overall compared with pensions, which have the added attraction of significant tax relief on contributions, the willingness for individuals to buy disability insurance is much reduced.

With people of working age who are in employer-based schemes the scope for support is wider than for retired people who only have themselves or the state to fall back on. For example it would be very rare but not completely impossible for an employer to provide for long-term care after retirement. Another important distinction is that old age disability is

anticipated but working age disability is unanticipated, arguably suggesting individuals should expect to provide more for themselves in old age. Shifts in retirement patterns and related societal changes challenge previously held assumptions in various ways. At present effective retirement ages are going down (DSS, 1997), but state retirement age is going up, loading more costs and risks onto the state disability benefit system and on to the individual.

Categorization of disability benefits and EU comparisons

Disability benefits may be divided into two broad categories – either benefits in cash or benefits in kind. To this may be added a range of what might be termed 'generic' benefits, for example building or transport adaptations that benefit not only people of all ages with different disabilities but also, for example, mothers with young children. As far as cash benefits are concerned these may be insurance based in which eligibility is dependent on payment of contributions, universal as in Sweden where it depends on citizenship, or means tested in which case they depend on income. As we shall see later the UK system of disability benefits exhibits variants of all three types.

Cash benefits are provided by the state, employer, and insurance company or from other private means. Examples of benefits in kind include accommodation, assistance in carrying out daily tasks operated for example through social services or private operators, and rehabilitation. Table 3 sets out the range of benefits as described, but importantly draws a distinction between benefits for people of working age and benefits for those above retirement age. As is seen they are broadly similar with the principal exception that benefits for retired people do not, at least in this typology include any benefits related to work or training.

As described this typology bears close correspondence with ESSPROS, the European System of Social Protection Statistics (Eurostat, 1996 and 1998), which maintains the usual distinction between people below and above retirement age. For working ages it defines disabilities as: "...the full or partial inability of people to engage in economic activity or to lead a normal life due a physical or mental impairment that is likely to be permanent or persist beyond a minimum prescribed period" (Eurostat, 1996, p55).

It excludes all medical care specific to a disability and payments for short-term sickness, which is included in ESSPROS under sickness and health care. It also excludes the range of generic benefits in column three of Table 3 so the picture we are able to draw, whilst useful, is still only partial. Put another way if one were to transfer from old age benefits related to assistance in carrying out daily tasks, carer allowances, and so forth, and if one were to transfer from the health and sickness benefits periodic payments for sickness but not medical care the picture would change considerably. Let us, however, stay with the more limited ESSPROS classification, what does it tell us about disability benefits in general?

| | Periodic payments | Benefits in kind | Wider benefits | Generic benefits |
|----------------|---|--|--|---|
| Retirement age | <ul style="list-style-type: none"> • Care allowances • Income support | <ul style="list-style-type: none"> • Rehabilitation • Accommodation • Home help • Transport • Equipment • Health and long-term care • Home adaptations • Family support | <ul style="list-style-type: none"> • Travel concessions • Leisure • Entertainment | <ul style="list-style-type: none"> • Building adaptations • Transport adaptations • Public space adaptations |
| Working age | <ul style="list-style-type: none"> • Paid sick leave • Disability pension • Early retirement on ill health • Care allowance • Disability Working allowance • Income support | <ul style="list-style-type: none"> • Rehabilitation • Vocational training • Job place subsidies • Job support • Accommodation • Home help • Transport • Equipment • Health and long term care • Home adaptations • Family support | | |

Table 3. Table showing categories of disability benefits in common use for people above and below retirement age.

According to ESSPROS disability accounts for 8.4% of all social protection expenditure⁵ in the EU. It lies in equal third position behind pensions and health care, which account for 38.9% and 27.6% respectively. The next categories are unemployment benefits (also 8.4%) and benefits for families and children (7.6%). Figure 9 shows social protection expenditure as a percentage of GDP for different EU countries in 1995 ranked from lowest (Ireland) to highest (Sweden). On the same chart we have included expenditure on disability as a percentage of total social protection expenditure and as a percentage of GDP (the smallest columns).

⁵Categories of social protection considered by ESSPROS include beside disability the old age function (pensions, old age care), sickness and health care, survivors benefits, benefits for families and children, benefits for the unemployed, housing benefits, and social exclusion (i.e. income support).

The chart tells us that there is no obvious relationship between expenditure on social protection overall and that on disability. This differs from old age benefits for which, as relative social protection expenditure declines, a greater percentage of what is spent goes on old age. We see too that in countries in northern Europe disability takes a large share of the social protection 'cake' where eligibility thresholds are lower. Countries like the UK, Portugal and Luxembourg, spend a smaller amount on social protection but give relatively high priority to disability within the total spend. On a spend per capita basis, not shown in the chart, there are three clear groupings: countries in the highest group are Netherlands and Scandinavia, in the middle group are countries like the UK, Germany and France, and at the low end are Portugal, Spain and Ireland.

The result is a typically diverse picture of how individual countries support people with disabilities. Notice for example the major contrasts between Sweden and the UK shown in Figure 10. In Sweden there is very little means testing but significant emphasis on benefits in kind. In the UK there are no benefits in kind and a significant degree of means testing, although as much proportionately as in France and Germany. There is also wide diversity in terms of eligibility for disability benefits between countries. Within countries there may also be separate schemes for different categories of worker – for example the self-employed, agricultural workers or railway employees.

Insurance contributions vary from between 6% and 12% of relevant earnings with eligibility for benefits depending mainly, as one would expect, on loss of earnings capacity. There is a threshold for receipt of disability benefit between 50% and 66% incapacity, although in the Netherlands a partial pension is possible on the basis of as little as 15% incapacity. Working capacity is normally defined in relation to the income an individual could earn if he or she were in good health. In most countries it is necessary to have paid contributions the qualifying period for which could range from a few months up to several years, emphasising the diversity of entitlement conditions. Unlike the UK where there is no linkage, disability benefit is often termed a disability pension because, in effect, it is an early pension received because of disability.

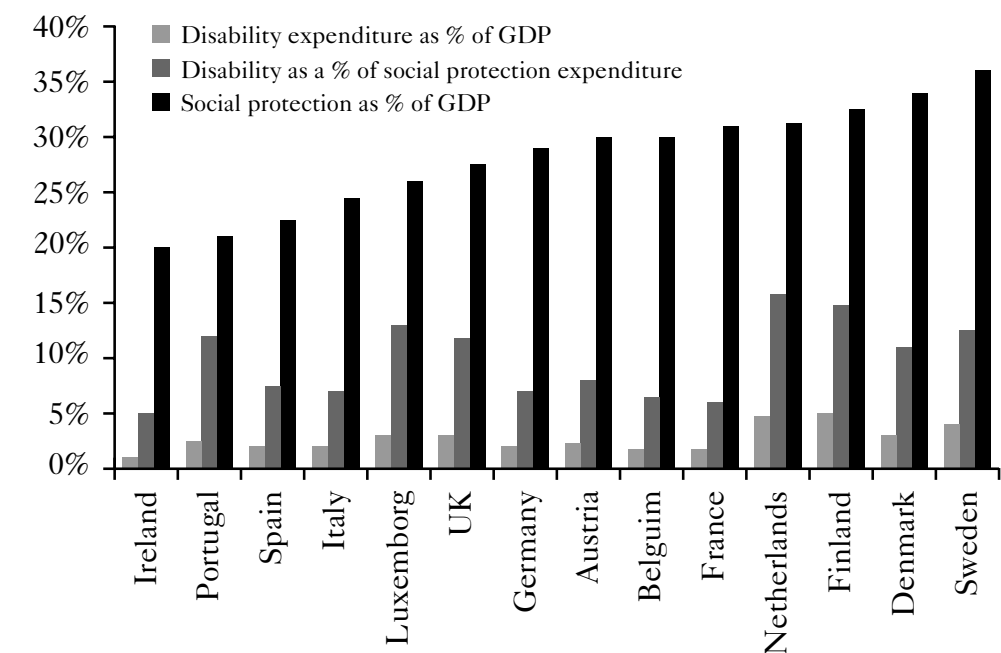


Figure 9: Chart showing relative expenditure on disability among different EU countries

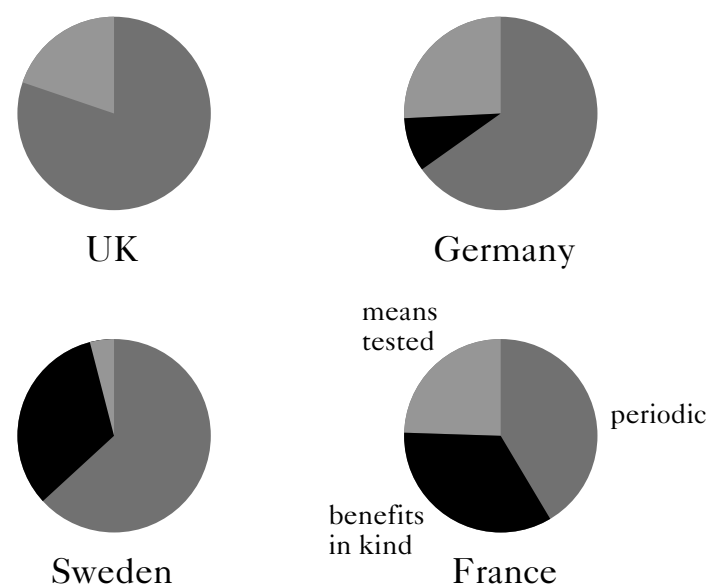


Figure 10: Relative disability expenditure on benefits in cash or kind for four EU countries – UK, Germany, Sweden, and France (Source: tables C2.15.2, C2.3.2, C2.6.2, C2.14.2, Eurostat, 1998).

The value of benefits is usually set at a percentage of earnings and tends to lie between 50% and 80%. Benefits are thus an economic evaluation based on loss of income but they do not compensate for the additional costs of being disabled, for example in terms of support needs, which are dealt with separately. In Austria the maximum disability pension is 80% of covered earnings, and it was quite common for Austrians to retire early on disability grounds, once they had attained maximum pensionable years. In Belgium the rate is 65% if there are no dependants otherwise 40%, whereas in France it is either 50% or 30% of best earnings in last ten years depending on incapacity. In the Netherlands full disability pension is worth up to 70% of earnings or 50% for partial pension (source: International Social Security Association).

The UK system of disability benefits is possibly unique in that each type of benefit – universal, contributory and means tested – is represented. The reasons are historical but the system has the advantage of flexibility and adaptability in terms of policy levers available. The balance between all three tends to shift with successive Governments and changes of philosophy. In 1998 the Labour Government published a green paper setting out its proposals, which, some would argue, suggest a weakening in the contribution principle. Generally, however, these could be described reasonably as incremental rather than revolutionary and therefore quite in keeping with the tradition of previous reforms (DSS, 1998).

A key difference between the UK and other EU countries is that none of the current disability benefits is earnings related – that is related to an individual's former salary or pension entitlement. A resulting implication, some would argue an advantage, of the UK system is that it can be adapted and targeted at particular groups more readily and be used, for example, to provide work incentives. Yet another by product of the UK approach is that it opens the way for second tier private disability insurance for those wishing to maintain a comparable standard of living were they to become disabled although this market remains

small. There are no special public provisions for the elderly over and above their pension, except for help for example to pay for carer costs and means tested disability premiums. This is one reason why disability surveys and disability beneficiaries do not reconcile although there are several others such as lack of 'take-up'.

In a few countries the costs of residential long-term care are fully met by the state, whereas in the UK it depends on the severity of medical condition and personal financial circumstances. There is, as yet, no compulsory long-term care insurance as has been introduced in for example Germany or Japan. Benefits in kind, such as personal and social care in the home, fall outside the ESSPROS definition because they are subject to means testing. In practice local authorities delivering these services operate a wide degree of latitude in the way they apply the means test.

Key issues arising from this paper

Let us try to draw the threads together from both parts of this analysis concentrating on strategic issues rather than detail. Thinking about disability in the broadest sense, we saw that the level of economic development was a major determinant not only of life expectancy but also the level of ill health and disability present in poor countries. In poor countries disability and consequent premature death is far more likely to be caused by health conditions that would not have arisen had adequate health services been available or there had been better nutrition or a more stable economy. Disability in this category, including disability resulting from hostilities, may thus be fairly described as 'avoidable'.

In richer countries disability splits into two broad types. First there is congenital disability and disability caused by accident or trauma and affecting mainly younger age groups (although accidents are also common in old age). Some disability in this category, for example arising from road accidents, could fairly be described as partly preventable. The other category is disability associated with aging. This is variable in onset, severity and progression and is much more likely to be age and life-style related and includes a higher incidence of conditions related to cognitive illness and mental health as well as physical disability. Old age disability may thus be fairly described as essentially inescapable, although potentially deferrable if individuals take appropriate precautions with their health.

A lower bound world estimate for the level of disability in all categories is 500m people rising to over 1 billion by 2050 with the proportion of disabled rising from around 8% to 14% over the period with further increases thereafter. A reason for the rise in prevalence was the fact that populations are set to age significantly over the next 20 or so years and have already started to do so in more developed countries. Because disability rates are much higher in older populations it is therefore certain to lead to a switch in both the demography and nature of disability. It will mean for example that whereas today roughly half of all disabled people in more developed countries are of working age by 2025 this proportion will reduce to less than 30%.

The policy environment for disabled people has also undergone transformation partly at the behest of disabled people themselves, especially those of working age. Today disabled people tend to be bracketed with other minority groups and their cause is seen more in the context of an equal opportunities and human rights issue. This switch has in turn spawned

a whole variety of initiatives to help disabled people find work and develop their potential. Their effectiveness however is hard to evaluate beyond the groups they are meant to target, and trends in information technology, which were expected to benefit disabled workers have still to make an impact.

There are complex issues to be addressed regarding the equal treatment of disabled persons whose disability has arisen from different causes, and this complexity is reflected in disability policies. Broadly a distinction can be drawn between anticipated disability that results from ageing compared with unanticipated disability resulting from congenital defects, critical illness or accident. Should each category be dealt with similarly within the system or should for example anticipated disability be the responsibility of the individual (Jackson, 1998)? Without the informal support systems provided in family settings it is calculated for example that the cost of social care would approach the scale of health service expenditure. What are the implications of this distinction for areas such as personal and long term care and will changing family structures accentuate the shortage of carers?

Institutional arrangements for handling disability are varied with a variety of financial and other support systems available in different countries. Governments are inevitably key players as regulators and providers, although in the US arrangements vary from state to state. Because of the relative generosity of European financial benefits and obligations of employers it is arguable the private sector has not had the same impact as in the US. In the UK disability insurance, like medical care insurance, has developed into a niche market and disability insurance is now an employment benefit in some organizations, although tax advantages are not on the scale of pensions. Will the private sector develop further and how will it adjust to an ageing population and will the pressure be on individuals to take greater personal responsibility?

As our final 'strategic' theme we take the issue of data collection and availability. It is obvious from the first part of this synopsis that comparability and objectivity are major issues. Such information as exists tends to be based on different measurement scales, even if the surveys on which they are based use generally accepted concepts. For example one survey might ask whether an individual can climb stairs unaided whilst another may ask whether an individual can walk 500 metres unaided (e.g. see Ramussen et al, 1999). Where accepted scales are available their use is restricted in the absence of contextual data such as income, household structure and so forth. Thus, they might be useful for home carer needs assessment, but not for establishing eligibility to cash benefits if the test is based on capacity for work.

Is there such a thing as an 'ideal data set' and what would it look like? It is easy to underestimate the scale, statistical complexity and cost of what would be required. As well as providing consistent measures of disability, its designers might decide that would need to meet several inter-related user needs. Potential users would comprise primarily health care providers, social services and social security, insurers and actuaries as well as academic and policy communities. It would need to capture the progression of disability through time, and include medical diagnosis, as well as functional measures. Information on capacity to work, income and expenditure including benefit income would also be desirable in order to map outputs onto benefit entitlement – currently a significant gap in

policy analysis terms. It would contain details about living arrangements, and cover the institutionalized as well as non-institutionalized population. Finally, the survey sample would be sufficient to obtain meaningful estimates of disability by age, sex, education, marital status, occupation, and so forth.

The history of data collection, however, is against comprehensive surveys on this scale on grounds of cost and competing priorities unless they are part of ongoing household, or income and expenditure surveys where there are other competing data needs. Major progress appears possible in the area of harmonizing concepts and questions in such surveys and in those of a one-off or longitudinal variety. ESSPROS shows that it is possible to harmonize data in the area for social protection purposes so why not for disability measurement scales? Partly the reason for this is the fragmented research and user community and a lack of focus for any capacity building. The conclusion of this paper is that these are major challenges, but with their track record in building internationally comparable statistical systems national statistical agencies are probably best placed to co-ordinate this work.

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