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Jeffery, Roger; Singal, Nidhi

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Disability estimates: implications from a changing landscape of socio-political struggle

Roger Jeffery and Nidhi Singal

Abstract

National governments in the South, as well as international bodies such as the World Bank, are finally beginning to take the issues of the extent, causes and implications of disability seriously. There is, however, a danger that data on people with disabilities are not being collected in the most reliable manner, resulting in flawed policies and inefficient use of resources. In this policy brief we argue:

1. that the identification of disability must not be seen merely as a *technical* issue (does someone have or not have a particular impairment) but also as a *political* one (what claims are being made by or about someone if they define an impairment as worthy of public attention);
2. that in large scale surveys, questions concerning disability must move beyond primarily *medical definitions* and reconceptualise disability in a *functional and interactionist perspective*;
3. that there is a greater place for *qualitative* studies of the social meanings of disability to illuminate the effects of changes in policy and in wider society.

1. Problems in estimates of disability prevalence from large-scale data-sets

Universally acceptable definitions of disability are notoriously difficult to establish and large inconsistencies exist within national contexts. As an example, in India, disability prevalence estimates from the 2001 census (Registrar General of India, 2001) and the 2002 58th Round of the National Sample Survey (NSS) (NSSO, 2003) have radically different definitions of four of the five major kinds of impairment they consider. This explains some, but not all, of the differences in their estimates. The NSS definitions of hearing, speech and locomotor impairments are more inclusive, and produce larger estimates than does the census. But for visual impairments, the census includes people using spectacles or contact lenses, whereas the NSS ignores them. For mental impairment, the definitions used by the two agencies are very different, yet the estimated totals (2.3 million from the census and 2.1 million from the NSS) are very similar. Taking all disabilities together, the stricter census definitions provide a lower estimate of people with

disabilities of 11.8 million; taking the wider NSS definitions generates an estimate of 26.5 million.

Larger differences emerge if particular age categories are considered. Amongst youth (those aged 12–24) the census finds 2.16 million with visual impairments, but the NSS finds only 0.18 million (plus some of those with multiple impairments). The figures for hearing impairment are much the same (0.21 million and 0.18 million, respectively) despite the differences in definition used; and the census figures for speech impairments are twice those of the NSS (0.550 million compared with 0.255 million), the reverse of what would be expected from the definitional differences. Not surprisingly, a recent review notes that 'it is unsure what aspects of disability are captured' by these definitions (Mitra & Sambamoorthi, 2006: 4024). Thus neither set of estimates can be relied upon with any degree of certainty when it comes to policy-making for people with disabilities.

The Indian case is a particular example of a well-known problem: that there are major challenges in gathering reliable estimates of disability prevalence. Issues of stigma, the complexity of accurately identifying some types of impairments (such as mental retardation) and the overlooking of lesser degrees of impairments (such as needing spectacles or a hearing aid), especially in older age, are commonly reported as reasons for some surveys and censuses excluding some people with disabilities. Some of these problems may be exacerbated in the South, where enumerators may be less well-trained and survey managers may have fewer resources to work with. Other problems are inherent in the way that disability is understood (see further below). But, we argue, it would be wrong to assume that there is a 'correct' figure for disability prevalence that can be reached if only the right questions are asked and all those excluded because of stigma etc can be included. In practice, different methods produce different listings, suggesting the need to consider differential exclusion and inclusion (Kuruville & Joseph, 1999). We cannot infer simply that people with 'real' disabilities are missed out by censuses and surveys (e.g. Klasing, 2007; World Bank, 2006) and the task is to find them and include them. Rather, it is necessary to understand better the social context within which disability is socially produced.

2. Disability and entitlements

Since 1990, many countries in the South have introduced or extended programmes to provide benefits to people with disabilities. Again we take India as an example. Since the Persons

with Disabilities Act of 1995 (Ministry of Law and Justice, 1996), schemes have been introduced to provide reservations in Government jobs, 'social security pensions' for poor children with disabilities while they are at school, travel concessions and exemptions from various charges. These are neither generous nor adequate and the procedures to obtain the benefits are often byzantine and costly. Moreover, not all those identified as having a significant impairment are able to register as disabled, because of the complexity of application procedures, and disability certificates obtained from different states, and different hospitals within the same state can be widely discrepant (Ghai, 2003).

Nonetheless, awareness of the benefits of having an identified and certificated disability is spreading. Some people have been able to acquire disability certificates despite not having significant impairments, and people are increasingly keen to identify themselves or others as having impairments. One study found that 'people in general and persons with disability in particular perceived the [research] programme as a source that could fulfil their long-pending demands for financial help and assistance' (Pande & Dalal, 2004: 101). This was our own experience in a small-scale inquiry in Madhya Pradesh, central India. Many villagers are now familiar with enquiries about people with disability, and may ask them to write the names of people with disabilities, usually in the hope of benefits. But others make moral points: the Government (or others) *should* be informed about these people. Not all those with a disability may be identified in this way, however. Poorer households, those with fewer literate members, but also smaller households and those headed by women are less likely to apply for benefits, or to come to the attention of census staff. Rural women with disabilities may be the most likely to be overlooked (Mehrotra, 2004). Stigma may be a factor, but other more practical and tangible reasons may also explain why some households escape the 'survey' net, and others push themselves into it.

Nonetheless, disability issues are no longer simply marginalised. People with disabilities may well find themselves enmeshed in a kind of 'surveillance society', unlike the situation in the mid-1990s when virtually nothing was known (Harriss-White, 2003: 1). District disability officers may annually up-date listings of schoolchildren, in order to distribute scholarships for children with disabilities. Similarly, regular surveys by school-teachers or others on a three-year cycle identify adults (with their age, type of impairments and father's name). Whether these listings correspond to the situation 'on the ground' is another matter.

Some Government officers in India claim that most people with disabilities are now receiving the benefits to which they are entitled. Certainly, a great majority of people now know of the benefits available to people with disabilities. But many of those with disabilities report difficulties in accessing the programmes, and casual enquiry turns up people unable to get a disability certificate despite having obvious and major impairments. The main problems reflect the need for determined and knowledgeable intermediaries to pursue one's case with the relevant officials. For example, many

people remain unaware of medical camps, and are therefore unable to get themselves assessed by a doctor for a disability certificate.

What this example shows is that disability cannot be seen as a morally and politically neutral condition. Rather, people with disabilities constitute a contentious and emergent category, in which social status, socio-economic position, human and social capital (both of the person with an impairment and her/his significant others) are inevitably intertwined with the process of identification. Data collection methods that do not take account of these processes will inevitably be fundamentally flawed.

3. Research Design and Underlying Models of Disability

As Harriss-White notes, 'disability is a relative term because cultures define differently their norms of being and doing' (Harriss-White, 2003: 3). While this point has been accepted for international purposes, it is also valid (to an unknown extent) when considering variations within a country, by region, language or ethnicity, for example. Factors such as gender, age, types of impairments and local perceptions also play significant roles in defining someone as disabled (Kuruville & Joseph, 1999). When framing survey or census questions, then, the actual words used may be crucial: for instance, in his research on chronic poverty and disability in Uganda, Lwanga-Ntale noted that the commonly used word for disability was 'rather problematic', as it primarily referred to those with physical impairment, mostly of upper and lower limbs. Hence there was a strong likelihood of ignoring those with learning difficulties, visual, hearing, or locomotor impairments. (Lwanga-Ntale, 2003). This is a general point, not limited to Uganda: in most languages, there is no single word that can be safely and simply translated into the English word 'disability'.

Evolving understandings of disability have been marked by models that have been either purely medical or have argued for a purely social construction of disability. However, it has now become clear that attempts to understand disability need to focus both on bodily issues and also on the impact that these have on an individual's activity and participation. Questions of disability should not be exclusively anchored in an 'impairment based' or an 'activity limitation' approach. Since an individual's functioning and disability occurs in a context, it is useful to operationalise the bio-psycho-social approach proposed in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). (See, as an example, the sample questionnaire item on page 4 of this Brief.) Herein disability is conceptualised in terms of the interaction between the impairments of body structures and functions, limitations of activities, and restrictions of participation.

4. The potential of qualitative studies of disability

Ideally, social research designs use methods of data collection that are appropriate to the questions being investigated. 'Mixed' methods (quantitative and qualitative) are often the right choice. In disability research, additional concerns prompt such an approach. For example, when there are low prevalence rates (as in the case of some impairment groups) and the groups are heterogeneous, it is

Sample Questionnaire Item on Impairments.

Seeing					
Yes = 1 No = 2	Degree 1 = mild 2 = moderate 3 = severe	Since what age?	Does this reduce the amount or kind of activity --- can do		
			At home?	At work or at school?	In other areas, for example, transport or leisure?
			Yes sometimes Yes, often No	Yes sometimes Yes, often No	Yes sometimes Yes, often No

Note: similar questions should be asked of other impairments, for example in hearing, speaking, walking, learning, and personal care. In addition, questions should be added to collect data on any aids and appliances the person may have access to.

hard to control for variance and come to sound statistical conclusions (Hartley & Muhit, 2003: 108). In disability research, qualitative approaches can help go beyond a quest for an unattainable precision (Fujiura, 2001). Disability status is too complex to be captured easily just through better survey questions. Impairments can be substantial or minor, and a result of critical events, or they may be transitory or a matter of insidious changes. A person's ability to function properly depends to a considerable extent on her/his social and physical environment.

Alongside large-scale surveys and attention to disability in population censuses, therefore, we need additional small-scale, qualitative studies of the impact and meaning of impairments to those most affected by them. Gaining a picture of demographic and social characteristics must be complemented by better understandings of the cultural perceptions of impairments, the social and environmental barriers to inclusion, and social provisions (including care arrangements) for different kinds of people with disabilities. Correlations that emerge from large-scale enquiries (such as between kinds of impairment and access to employment) should prompt a closer enquiry – using qualitative methods – into the social processes of definition and negotiation that generate them.

In other words, present (primarily large scale quantitative) methods of identification result in errors of omission and of commission. Subsidies, where offered, are therefore likely to miss some eligible people with disabilities, yet also to be given to some who should not be eligible. These errors of targeting result in resource misallocation, which might be much greater in the area of disability

than in many other areas of social targeting. Integrating quantitative and qualitative studies is a powerful way to inform policy-makers on the extent of targeting errors, and how to avoid them.

One major area that slips through large-scale quantitative studies is how the state, the market, civil society organisations and the family impact on the lives of people with disabilities. With changing social arrangements, the long-held assumption that people with disabilities would be supported by other family members, especially in rural areas, does not necessarily hold true. At the same time as market forces may be undermining family solidarities, some social needs may increasingly be met by market provisions (for those able to pay). As family arrangements change, civil society organisations sometimes arise to fill in gaps or make new claims for social inclusion. On the other hand, as discussed above, state interventions may begin to offer new opportunities, while imposing different kinds of costs. Understanding how people with disabilities are affected by such changes requires integrating quantitative and qualitative research, sometimes in innovative ways.

5. Conclusion

We have argued in this Policy Brief that disability is not merely a *technical* issue but also inevitably a *political* one. In large scale surveys – the main vehicle currently acknowledged for providing policy-relevant evidence – the questions concerning disability are currently too restrictive and are primarily informed by medical definitions of impairments. Purely quantitative information systems are seriously misleading, lead to waste and confusion, and should be replaced by data collection techniques that improve recognition of impairments in particular contexts and more efficient targeting of

benefits. We argue that governments should draw on best practice in quantitative studies and integrate qualitative research methods to help illuminate the social meanings of disability. Such an approach will allow for an improved understanding of those features of local social settings that affect who is and is not identified as 'disabled', and provide crucial insights into changes in wider society and how social policy can become more efficient and effective.

Address for correspondence: r.jeffery@ed.ac.uk

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