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Measuring Disability in India

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Disability status is often transitory or a matter of insidious change. A person's ability to function properly depends to a considerable extent on her/his social and physical environment. One area that slips through the large-scale studies like the census and National Sample Survey is the impact of the state and the market on the lives of people with disabilities. There is a case for a more fundamental re-envisioning of the nature of the disability estimates.

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A recent article on disability estimates from the 2001 Census and the 2002 58th round of the National Sample Survey (NSS) has concluded that "prevalence estimates in the census and the NSS are clearly not comparable...and it is unsure what aspects of disability are captured by the census and NSS current disability definitions" [Mitra and Sambamoorthi 2006: 4024]. Here we take this argument further: (1) to consider more reasons for caution in using either the census or the NSS for policy purposes; (2) to argue for more qualitative studies of disability; and (3) to consider the identification of disability not 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 say there is an impairment worthy of public attention).

NSS and Census Data

The census and NSS have radically different definitions of four of the five major kinds of impairment, which explains some, but not all, of the differences in their estimates.[1] 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 definitions provide a lower estimate of people with disabilities of 11.8 million; taking the wider definitions generates an estimate of 26.5 million.

Youth should be an important focus of policymakers. But the distributions of disability among youth (those aged 12-24, the focus of the 2007 *World Development Report*) suggest that these large-scale surveys provide only limited guidance. While the census finds 2.16 million youth with visual impairments, the NSS finds only 0.18 million (plus some of those with multiple impairments), as Mitra and Sambamoorthi would predict. But the figures for hearing impairments are much the same (0.21 million and 0.18 million, respectively). The census figures for speech impairments are twice those of the NSS (0.550 million compared with 0.255 million). Neither of these findings is in line with Mitra and Sambamoorthi's predictions for the differences between census and NSS results. Thus neither set of estimates can be relied upon with any degree of certainty when it comes to policymaking for youth with disabilities; and reports that rely heavily on a reanalysis of NSS data [such as World Bank 2007] seem to be grasping at straws.

There are no adequate ethnographies of how government sample surveys and census data collection are actually carried out in India and the likely impacts on what kinds of disabilities are recorded. Issues of stigma, the complexity of accurately diagnosing 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. But one in-depth small-scale study in India shows that house-to-house surveys and rapid rural appraisal methods identified essentially different populations of people with disabilities: a total of 334 people with disabilities were identified, but only 90 people appeared in both listings [Kuruvilla and Joseph 1999: 185]. Thus inferring simply that people with "real" disabilities are missed out by censuses and surveys [e g, Klasing 2007; World Bank 2007] is too facile: the micro-politics of how people are counted can lead to differential exclusion and inclusion.

The context of state programmes for people with disability in which investigations take place has changed quite dramatically because of the schemes introduced since the People with Disability Act of 1995 [Ministry of Law and Justice 1996]. In Madhya Pradesh (MP), for example, these include a 6 per cent reservation in Classes II, III and IV category of government jobs, for direct recruitment for persons with disabilities (allocated within the reservations by caste), divided equally amongst visual, orthopaedic and hearing and speech

impaired persons. Children aged six to 14 in households with "below the poverty line" certificates are entitled to Rs 150 per month as a "social security pension" while they are at school as well as being entitled to scholarships and exemptions from various charges [Disability India Network 2007].

These pensions and scholarships are neither generous nor adequate to meet the needs of the people receiving benefits. The procedures to obtain the benefits are often byzantine and costly. Not all those identified as having a significant impairment can register as disabled, which requires completing several forms and an assessment by a qualified medical practitioner that the person has at least a 40 per cent impairment. Assessments are not uniform: 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 without disabilities are now registered, using their influence with the enumerators to overcome the little detail of the absence of significant impairments. And people are less reluctant to identify themselves or others as having impairments. Two psychologists involved in community-based rehabilitation proposals identified people with disabilities in five villages near Ghaziabad, Uttar Pradesh (UP), with a total population of 16,000 [Pande and Dalal 2004] discovered 220 people with disabilities (1.37 per cent), and reported that despite repeated denials, "people in general and persons with disability in particular perceived the programme as a source that could fulfil their long-pending demands for financial help and assistance", and they eventually succumbed to accepting a number of such applications (ibid: 101).

Many villagers are now familiar with visitors with clipboards asking about people with disability. Such visitors may be asked 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. Our experience in a small-scale inquiry in MP is that people with disabilities or their significant others talk readily about impairments and associated problems. Even after clearly stating that we had no connection with the government or with any NGO programme, we could not always deter requests, and sometimes finally wrote a name to avoid hurting sentiments. Not all those with a disability may emerge 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 households escape the "survey" net.

Nonetheless, disability issues are no longer simply marginalised: now people with disabilities may well find themselves enmeshed in a kind of "surveillance society". In MP, district coordinators for disability have thick files with an annually updated listing of schoolchildren, with columns for the school attended, class, and the father's and mother's names and address. Under the Sarva Shiksha Abhiyan (SSA), children with disabilities are listed in order to distribute scholarships. Similarly, adults (with their age, type of impairments and father's name) are identified through regular surveys on a three-year cycle, by teachers or others.

Charity Approach

More people now know of benefits available to people with disabilities, but many of those with disabilities are still unable to access the programmes. Government staff say that such criticisms are unfounded, either because the 40 per cent minimum was not reached, or because all available benefits had in fact been received. But casual enquiry amongst people with obvious and major disabilities turns up people unable to get a disability certificate, and of the need for determined and knowledgeable intermediaries to pursue one's case. Even when official records indicated that a large number of medical camps had been organised, many people remained unaware of them and were unable to get themselves assessed by a doctor for a disability certificate.

These "top-down" programmes can be evaluated in their own right, or seen as a particular aspect of the transformation of the Indian state. The post-1991 refashioning of states worldwide has seen the death of the developmental state and its replacement by one supposedly responsive to civil society [Veron et al 2003: 2-3]. Disability policy is an example of governance as a form of "biopower", centrally concerned (at least formally) with the welfare, care and security of the population living in a particular territory. In India, the rolling back of the state (e g, in industry and finance) has been accompanied by ambiguous and uncertain moves in social policy. In health and education the public sector is increasingly dominated by the private sector. Yet under panchayati raj some functions have been decentralised and new programmes (like SSA and the National Rural Health Mission) may extend the state into new spheres. Some initiatives, like the Mahila Samakhya, are premised on ideas of empowerment [Sharma 2006]; others, such as the Employment Assurance Scheme in West Bengal, may offer opportunities for participatory development that can be negotiated, contested, and offer unexpected outcomes [Veron et al 2003].

A major worldwide shift in how people with disabilities engage with the programmes set up in their name has taken place: people with disabilities now expect "nothing about us, without us". Yet in its approach to disability, the government has kept people with disabilities marginal to the programmes and policies aimed at them. In India, the vibrant civil society working for (rather than ideally "of") people with disabilities tends to be either delivering services, such as hostels for young people with certain impairments attending schools or vocational training, and/or involved in awareness raising of government programmes.

Moreover, the official discourse continues to perceive disability as purely a medical condition (with 40 per cent a magic number known even in villages), to be certified and provided for through aids, appliances and concessions in education and employment. Framing the individual on her/his own, without engaging with the wider social and physical context, is common in medicalised approaches. Dominant cultural beliefs and perceptions about disability reinforce this perception

of the person with disability as "suffering", resulting in a charity framework. Thus, while the discourse of "empowerment" is present in the government's approach to the issues of gender, its orientation to disability remains one of "charity", towards bettering the life chances of the "deserving" poor, rather than striving for fundamental shifts and meeting demands for human rights and entitlements.

Conclusions

The claim that the census and NSS help us "understand the lives of persons with disabilities" [Mitra and Sambamoorthi 2006: 4022] must be qualified: without additional small-scale, qualitative studies of the kind we have cited (and are now involved in ourselves), many implications of the census and NSS data remain obscure and partial. One major area that slips through such large-scale studies, for example, is the impact of the state and the market on the lives of people with disabilities: both are as often part of the problem as of the solution. We need more fundamental re-envisioning of the nature of disability estimates [Fujiura and Rutkowski-Kmitta 2001]. Disability status is often transitory or a matter of insidious change, and a person's ability to function properly depends to a considerable extent on her/his social and physical environment. Political issues tend to make disability an issue closely bound up with citizenship, and the changing nature of the state with respect to its subjects. Disability enquiries must become increasingly participative in nature, focusing on greater engagement with lived realities, rather than being fixated with numbers.

NOTE

1 Census figures are mostly to be found in Tables C 20-24 (Registrar General of India 2001); NSS figures come from NSSO (2003).

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