PEOPLE WITH DISABILITIES IN INDIA: FROM COMMITMENTS TO OUTCOMES

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Abbreviations and Acronyms

ADL	Activities of Daily Living
ANM	Auxiliary Nurse-midwives
AP	Andhra Pradesh
CAPART	Council for the Advancement of People's Action in Rural Technology
CBR	Community Based Rehabilitation
CDC	Centers for Disease Control
CPWD	Commissioner for Persons with Disabilities
CSN	Children with Special Needs
CWD	Children with Disabilities
DALYs	Disability-adjusted Life Years
DC	Defined Contribution
DIET	District Institute for Education Training
DISE	District Information System for Education
DMHP	District Mental Health Programme
DPEP	District Primary Education Programme
DPO	Disabled Persons Organization
DRC	District Rehabilitation Center
EPFO	Employees' Provident Fund Organization
EPS	Employees' Pension Scheme
FICCI	Federation of Indian Chambers of Commerce and Industry
GOI	Government of India
IADL	Instrumental Activities of Daily Living
IAY	Indira Avaz Yogana
ICDS	Integrated Child Development Services
ICIDH	International Classification of Impairments, Disability and Handicaps
IDD	Iodine Deficiency Disorders
IED	Integrated Education of the Disabled
IEDC	Integrated Education of Disabled Children
J&K	Jammu and Kashmir
LIC	Life Insurance Corporation of India
MDG	Millennium Development Goal
MDT	Multi Drug Therapy
MHRD	Ministry of Human Resource Development
MI	Mental Illness
MP	Madhya Pradesh
MR	Mental Retardation
MSJE	Ministry of Social Justice and Empowerment
MSS	Mahila Swasthya Sanghas

MTA	Mother Teacher Association
NCPEDP	National Centre for Promotion of Employment for Disabled People
NFCP	National Filaria Control Program
NFHS	National Family Health Survey
NGO	Non Government Organization
NHFDC	National Handicapped Finance and Development Corporation
NIACL	New India Assurance Company Limited
NLEP	National Leprosy Eradication Programme
NPS	New Pension Scheme
NREGS	National Rural Employment Guarantee Scheme
NSS	National Sample Survey
NSSO	National Sample Survey Office
NTD	Neural Tube Defects
OBC	Other Backward Class
PC	Planning Commission
PHC	Primary Health Centers
POA	Plan of Action
PPI	Pulse Polio Immunization campaign
PRI	Panchayati Raj Institution
PTA	Parent Teacher Association
PWD	Persons with Disabilities
RCH	Reproductive and Child Health
RCI	Rehabilitation Council of India
RRTC	Regional Rehabilitation Training Centers
SC	Scheduled Caste
SCA	State Channelizing Agency
SCERT	State Council of Education Research and Training
SGRY	Sampoorna Grameen Rozgar Yojana
SGSY	Swaranjayanti Gram Swarozgar Yojana
SHG	Self Help Groups
SSA	Sarva Shiksha Abhiyan
ST	Scheduled Tribe
TBA	Traditional Birth Attendants
TN	Tamil Nadu
UP	Uttar Pradesh
VEC	Village Education Committee
VRC	Vocational Rehabilitation Centre
W&CD	Women and Child Development
WHO	World Health Organization
WWD	Women with Disabilities

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EXECUTIVE SUMMARY

"*The problem is not how to wipe out the differences but how to unite with the differences intact*".
– Rabindranath Tagore (quoted in Alur)

I. Introduction

1. While estimates vary, there is growing evidence that people with disabilities comprise between 4 and 8 percent of the Indian population (around 40-90 million individuals). This report, prepared at the request of Government of India, explores the social and economic situation of this sizeable group. It comes over a decade after landmark legislation promoting the rights of persons with disabilities to full participation in Indian society, and finds that progress is evident in some areas. However, the policy commitments of governments in a number of areas remain in large part unfulfilled. To some extent this was inevitable, given the ambition of commitments made, existing institutional capacity, and entrenched societal attitudes to disabled people in India. However, it also reflects a relative neglect of people with disabilities through weak institutions and poor accountability mechanisms, lack of awareness among providers, communities and PWD of their rights, and failure to involve the non-governmental sector more intensively. Most importantly, PWD themselves remain largely outside the policy and implementation framework, at best clients rather than active participants in development. There is also evidence in key areas like employment that disabled people are falling further behind the rest of the population, risking deepening their already significant poverty and social marginalization. The slow progress in expanding opportunities for disabled people in India results in substantial losses to people with disabilities themselves, and to society and the economy at large in terms of under-developed human capital, loss of output from productive disabled people, and impacts on households and communities.

2. The report explores primarily where and how it makes most sense for public sector interventions to improve the standard of living of disabled population, either directly or in partnership. To meet this objective, it first provides an overview of models of disability and the framework for the report. It then presents the socio-economic profile of people with disabilities, describes the societal attitudes faced by them, and identifies the main causes of disability in India. It then evaluates health policies and practice - both preventive and curative - and the education, employment, and social protection situation of people with disabilities. The report then has a discussion of the policies and institutions affecting disabled people, before concluding with a chapter on accessibility issues for people with disabilities. The report uses the so-called bio-psychosocial model of disability reflected in the ICIDH-2, which recognizes that personal, social and environmental factors are all at play in turning physical or mental impairments into disabilities. That is, the attitudes and institutions of society are seen to have significant impacts on the life opportunities of people with disabilities. This model, along with other approaches to disability, is outlined in the Introduction.

3. The main sources for the report are: (i) dedicated disability modules of the National Sample Survey (NSS) in 1991/92 and 2002 which allow for nationally representative analysis of persons with disabilities; (ii) the 2001 census; (iii) a dedicated survey and qualitative work on the lives of disabled people and their communities in rural UP and TN carried out for this report in late 2005; (iv) a series of background papers commissioned from Indian and international researchers on persons with disabilities and education, health, employment, policies and institutions, and access; and (v) a rich pool of secondary sources from Indian researchers and

NGOs, both quantitative and qualitative, and interactions with the Indian disability community and officials dealing with disability matters in various sectors.

4. **The report concludes that it will take a multi-faceted approach for disabled people to realize their full individual potential and to maximize their social and economic contribution to society**. Strengthening preventive and curative health care services, ensuring inclusion in education, and increasing the participation of disabled in the workplace will be essential. Also critical will be improvements in available information on disability and reducing stigma about disability. Efforts to minimize disability (e.g. immunization, early detection, better outreach for rehabilitation) will be critical, but more effective efforts to ensure inclusion of disabled in basic services (e.g. inclusive education, health, social protection programs) will also be required. In some areas, this will require more public resources, but the fiscal impacts of even significant proportional increases will be negligible and fiscally supportable.

5. **Although improvements are needed in a number of areas, interventions will need to be prioritized and sequenced if the agenda for promotion inclusion of people with disabilities is to be realized.** India's implementation capacity is generally weak in a number of areas of service delivery which are most critical to improving the situation of disabled people, and it is not realistic to expect that all the actions needed by many public and non-public actors can be taken all at once. It is important therefore to decide the most critical interventions and "get the basics right" first. Obvious priorities include: (i) preventive care, both for mothers through nutritional interventions, and infants through both nutrition and basic immunization coverage; (ii) identifying people with disabilities as soon as possible after onset. The system needs major improvements in this most basic function; (iii) major improvements in early intervention, which can cost effectively transform the lives of disabled people and their families, and their communities; and (iv) expanding the under-developed efforts to improve societal attitudes to people with disabilities, relying on public-private partnerships that build on successful models already operating in India.

6. **The study finds that it is neither possible nor desirable for the public sector to "do it all".** Operationalizing this insight will require stronger coordination of efforts within the public sector, greater engagement between public and non-public actors, and mobilization of actors in local governments and community institutions in order to address a variety of market, government and collective action failures.

7. **The report also brings out the heterogeneity of the situation of and policy options for different groups of disabled people in India.** There are substantial differences in socio-economic outcomes, social stigma, and access to services by disability type, with those with mental illness and mental retardation in a particularly poor position. As with the general population, there are also major urban/rural differences in outcomes, though the policy implications differ in some cases from those of the general population. Gender, class and regional variations are also significant in many cases. While the report therefore attempts an overview of the situation of people with disabilities in India, it is also important to stress such heterogeneity in order to explore implications for public policy. The main findings of the report and policy options for addressing disability are summarized below.

II. Socio-economic Profile of People with Disabilities (Chapter 1)

8. **While official estimates of disability are low (around 2 percent), alternative estimates using better methods and more inclusive definitions suggest a higher incidence of disability (4-8 percent).** The 2001 census found 21.91 million PWD (2.13 percent of the

population), while the 2002 NSS round's disability estimate is 1.8 percent of the population.[1] The share of *households* estimated by NSS to have a disabled member was 8.4 and 6.1 percent in rural and urban areas respectively (though this share seems high given the number of disabled individuals and survey results on their household size). Alternative estimates from a variety of sources suggest that the actual prevalence of disability in India could be easily around 40 million people, and as high as 80-90 million if more inclusive definitions of mental illness and mental retardation in particular were used.[2] Just as importantly, the bulk of disabled people in India have mild to moderate disabilities.

9. **The medical causes of impairments are rapidly changing in India - from communicable disease to non-communicable disease and accidents.** Between 1990 and 2020, there is predicted to be a halving of disability due to communicable diseases, a doubling of disability due to injuries/accidents, and a more than 40 percent increase in the share of disability due to non-communicable diseases. This reflects long term trends in fertility reduction and aging, increased road congestion, poor workplace safety practices, stubbornly poor nutritional outcomes, and progress in reduction of communicable diseases. In terms of age of onset, there is "double hump" of disability onset, first shortly after birth and then in the 50-60 year old cohort. In addition, the age profile of disability onset varies sharply by category of disability.

10. **For some impairments (e.g. speech and hearing), illness and disease remain major causes, while for others such as visual disability age is a major driver.** For mobility disabilities, the causes are shifting from a dominance of polio to a more mixed set of causes. For several disabilities, in particular mental illness and mental retardation, the causes of disability are often unknown, indicating the major knowledge gaps in current disability research.

11. **Physical and mental impairments are compounded by poor education outcomes, and children with disabilities (CWD) have very high out of school rates compared to other children.** As for any other group, education is critical to expanding the life prospects of people with disabilities. Disabled people have much lower educational attainment rates, with 52 percent illiteracy against a 35 percent average for the general population. Illiteracy is high across all categories of disability, and extremely so for children with visual, multiple and mental disabilities (and for severely disabled children of all categories). Equally, the share of disabled children who are out of school is around five and a half times the general rate and around four times even that of the ST population. In even the best performing major states, a significant share of out of school children are those with disabilities: (in Kerala, 27 percent; in TN over 33 percent). Indeed, evidence from more advanced states demonstrates that CWD remain perhaps the most difficult group to bring into the educational net even where overall enrollments are very high. Across all levels of severity, CWD very rarely progress beyond primary school. This underlines the importance of getting CWD into school if India is to achieve the education MDGs. [3]

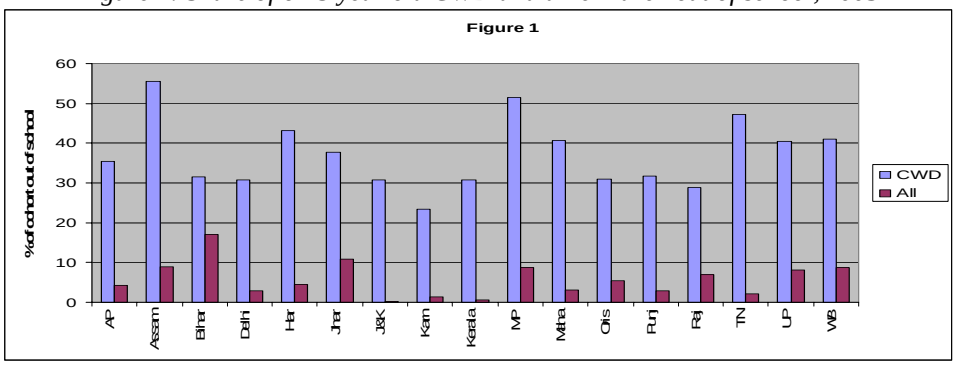
[1] Significantly, the two differ notably on the composition of the disabled population by type of disability. The differences are in part explained by different disability definitions in NSS and census.

[2] See GoI/WHO and Dandona et al (2004) on visual and Gururaj and Isaac (2005) on mental impairments.

[3] Around 90 percent of CWD who have ever attended school attend a regular rather than special school. This brings home that the choice facing most CWD is whether they are out of school or in regular school.

Out of school rates for CWD are high in all states and CWD account for a higher proportion of all out of school children as overall attendance rates increase

Figure 1: Share of 6-13 year old CWD and all children out of school, 2005



Source: SRI survey for MHRD, 2005.

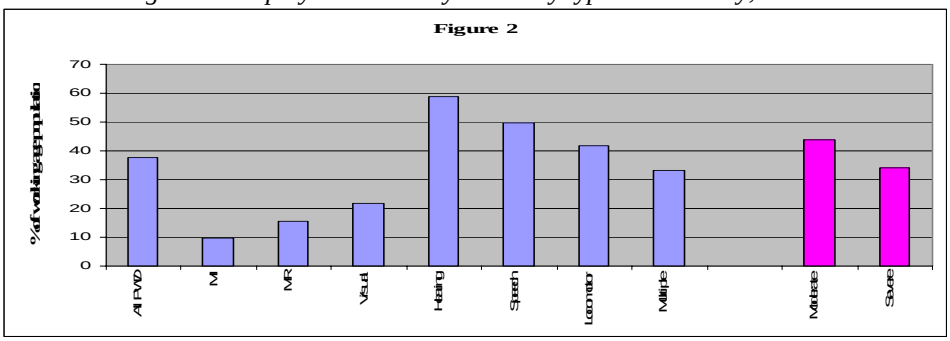
12. **Disabled people also have significantly lower employment rates than average, and this gap has been increasing over the past 15 years.** The large majority of PWD in India are capable of productive work. Despite this fact, the employment rate of disabled population is lower (about 60 percent on average) than the general population, with the gap widening in the 1990s.[4] Controlling for other factors, having a disability reduces the probability of being employed by over 30 percent for males in rural UP and TN, though the effect is lower for women. However, those in rural areas and the better educated (those with post graduate education or vocational training) have relatively better prospects of employment relative to other disabled people. People with certain types of disabilities, e.g. hearing, speech and locomotor disabilities, and those with disability since birth also have better chances of getting a job. Mental illness and particularly mental retardation have a strong negative impact on the probability of being employed**,** even in cases where such disabilities are not severe**.** The presence of a disabled member also has impacts on the labor supply of other adult household members. Around 45 percent of households in UP and TN with a PWD report an adult missing work to care for PWD member, the bulk of these every day and on average for 2.5 hours. However, other adult men are more likely to be working in households with disabled members, due to the need to compensate for lost income.

13. **A recent adverse development is the decline in the employment rate of working age disabled people, from 42.7 percent in 1991 to 37.6 percent in 2002.** The fall was almost universal across the country, but the extent varies greatly across states. The gap between the disabled and general population employment rates also widened for all education levels during the 1990s, and disabled people with lowest educational attainment have fared the worst. Improving job prospects for the disabled will be critical for improving their welfare, but also ensure that the economy can benefit from full labor potential. However, public sector initiatives to date in this regard have had only very marginal impact on employment outcomes for disabled people.

[4] It is important not to attribute these differentials entirely or automatically to discrimination, as many factors are at play, including lower than average educational levels and the nature of some disabilities. However, analysis in the report finds a significant unexplained element in employment participation probabilities (se Chapter 5).

Employment rates of PWD are low, but vary sharply by type of disability

Figure 2: Employment rates by disability type and severity, 2002



Source: Mitra and Sambamoorthi, based on NSS 58th round

14. **The attitudes of communities and families in which disabled people live, as well as of PWD themselves, contribute to converting impairments into disabilities** (see Chapter 2). Qualitative research into attitudes to PWD in India finds that households generally believe that disability is due to the "sins" of disabled people or their parents and hence deserved in large measure. Equally, communities have poor assessments of the capacities of disabled people to participate in key aspects of life, with negative opinions on the capacity of disabled children to participate in regular school and for disabled adults to be effective members of the workforce still dominant. While general opinions on participation of persons with disabilities in community life are more open, they often do not appear to be realized in practice. Negative attitudes towards some disabilities are much more pronounced than others, with those with mental illness and mental retardation the most marginalized. Most worrisome, both families of disabled people and people with disabilities themselves often share the low opinions of their communities of the capacities of disabled people to be independent and productive members of society. This internalization of negative attitudes reinforces social marginalization. Changing societal attitudes - in families, service providers, and disabled individuals, and the community at large - will be critical if disabled people are to realize their full social and economic potential.

15. **Low educational attainment, poor employment prospects and stigma mean that PWD and their households are notably worse off than average.** The UP and TN survey clearly finds higher rates of disability in poorer households, as well as lower frequency of three meals a day in PWD households. This is supported by national evidence from NSS, such as the 20 percent higher rural share among PWD households, and high rates of widowhood for disabled women (around 4 times that of non-disabled women). The quantitative findings are supported by unanimous findings from qualitative work in a number of Indian states (including Gujarat, AP, TN, UP, MP, and Orissa) that households with disabled members are poorer and more vulnerable than the general population. In addition to evidence of lower living standards of people with disabilities, it is important to stress what Amartya Sen has termed the "conversion handicap", whereby people with disabilities derive a lower level of welfare from a given level of income than the rest of the population, due to additional costs incurred in converting income into well-being.

III. Policies and Programs: Key Issues

Health (Chapter 3)

16. **India's progress on specific disabling diseases has been impressive in some cases.** The most dramatic is the reduction in polio, though the almost total elimination of new leprosy cases in official statistics is also an important achievement. However, considerable challenges in tackling the outstanding agenda in both preventive and curative care remain, and the health sector

needs to respond more proactively to disability. In a context of a health sector facing major challenges in achieving adequate coverage and quality of care for the entire population, it will be important to prioritize disability-related interventions.

17. **Success in reduction of some communicable diseases has not been matched by improvements in the general public health system in areas which have significant impacts on disability.** A large proportion of disabilities in India are preventable, including disabilities that arise from medical issues surrounding birth, from maternal conditions, from malnutrition, and from causes such as accidents and injuries**.** However, programs to address these are weak. One example is ineffective programs for addressing micronutrient deficiencies, where India maintains stubbornly poor nutritional outcomes (and where interventions such as expanding access to iodized salt or food fortification are highly cost effective). A second critical area of the general health system is reproductive, maternal and child health. Access to care during pregnancy and delivery is poor in India. In the three years preceding NFHS-2, 35 percent of pregnant women received no antenatal care: only a marginal improvement on the early 1990s, and with high-risk groups still with less access to care. The hard-won battle against some communicable diseases may also be in jeopardy. There appears to have been a worrying decline in immunization rates at the national level. On a national basis, full immunization coverage has declined from 54.2 to 48.5 percent in only 5 years.

18. **Policy and practice indicate that the bulk of both prevention and treatment of disability will continue to happen as part of the broader public and curative health delivery systems.** The challenges of Indian health systems have been discussed elsewhere and are outside the scope of this report, but are critical to prevention and to the lives of disabled people, who have generally greater needs for health system support. However, disability-specific interventions are important also, and have received less attention. Generally, the focus of PWD-specific public interventions has been rehabilitation. Technological support on rehabilitation is provided by the National Institutes on disability, though in recent years, India is increasing emphasis on community based approaches even in public interventions. Perhaps the most interesting services being offered to people with disabilities are Community Based Rehabilitation (CBR), which has been effective in rural areas in addressing the primary care and therapeutic needs of PWD. The concept is institutionally flexible and can be operationalized by communities, NGOs and government, separately or in partnerships.

19. **The likelihood of seeking health care differs across disabled groups**.[5] Firstly, evidence from NSS shows that those disabled from birth are much less likely to seek care. Secondly, women with disabilities were somewhat less likely to seek care, and even less likely to have assistive appliances. Regionally, access to care appears to be lowest in the North-East and eastern regions, while those in urban areas throughout India are much more likely to have sought care. As with the general population, higher levels of education substantially increase the access to health care, as does co-residence of the person with disabilities with their parents.

20. **Many factors drive low access to care among people with disabilities:** (a) current disability identification and certification system functions poorly, with poor skills among providers, awareness among PWD low, and rural outreach poor; (b) the available evidence indicates that provider attitudes remain a constraint on PWD access to health services; (c) community attitudes also continue to be a constraint on raising the profile of health services for PWD, particularly with mental illness; (d) physical accessibility of health facilities is a significant issue, and more acute at higher levels of the system; (e) as PWD households are poorer than

[5] Similar findings emerge for access to aids and appliances among PWD.

average, financial barriers to access are higher. In addition, PWD have higher than average *need* for health services, and incur higher expenditures; and (f) mental health is an area that continues to suffer particular neglect in both policy and implementation.

Education (Chapter 4)

21. While education policy in India has gradually increased the focus on children and adults with special needs, and inclusive education in regular schools has become a clear policy objective, there are several reasons for poor education outcomes for disabled people.

22. **Weak institutional coordination, poor expenditure performance, and a range of issues in delivery of education limit the inclusion of children with disabilities in education, though there has been marked progress in recent years**. Several institutional divisions hinder coordinated and inclusive education. They include split management of education of CWD between MHRD (responsible for education of CWD within the general system, which accounts for the large majority of CWD who are attending school) and MSJE (which is responsible for most special education facilities), weak coordination on teacher training between Rehabilitation Council of India and the general teacher training system with respect to special needs, lack of coordination in early identification of children with special needs, and belated (though growing) efforts towards convergence between government and NGOs/communities. The budget for inclusive education and its effectiveness is also limited. Overall, the spending share on inclusive education in SSA is low, at only 1 percent nationally, with major variation in spending share between states. Perhaps more important, expenditure execution on IE was until recently among the lowest of SSA heads (under 35 percent in 2004/05, though rising sharply to 66 percent in 2005/06) and also exhibits large variation across states. This is at one level not surprising, as IE is an inherently challenging area to develop models for effective public expenditure.

23. **Poor identification and access of disabled children to the education system**. First, the system for early identification of children with special needs is ineffective, though there have been noticeable improvements in outcomes in the most recent years (with the share of identified CWD in total children at elementary level doubling between 2003/04 and 2006/07 to 1.5 percent). There are significant discrepancies in the number of disabled children identified in census data, DISE, and SSA surveys, suggesting shortcomings in the SSA process for identifying children with special needs. Second, the physical accessibility of not only school premises and facilities but also accessibility from the child's home is limited. Official statistics on barrier free access indicate that basic education in India is not physically accessible for most children with disabilities. Third, financial incentives and aid/appliance support for CWD to facilitate participation in regular schooling are limited and survey data indicate that there is low awareness of these schemes. While assistive technologies are a right under SSA, they are in practice rationed, making them instead a privilege. Indeed, only around 15 percent of children nationally had access to aids and appliances, despite evidence of their positive association with school attendance. This is a challenge not only for SSA, as its model is one of convergence with other public programs such as ADIP under the MSJE, which are in some cases the funding source. However, it suggests that coordination mechanisms could be strengthened to promote better outcomes, whatever the source of financing and provision. Finally, while provider attitudes towards inclusion of children with disabilities are gradually improving, there appears to be less movement with respect to general community attitudes and those of parents of CWD, who still generally do not support inclusive education.

24. **The quality of the education available for students with special needs is also limited, but several states have made positive starts.** First and foremost, there is an absence of coherent

government strategies for promoting inclusive education in many states. However, the experience of states like TN and Gujarat offers cause for hope, with directed strategies for public/NGO partnerships to improve coverage and quality of IE. Second, curriculum and learning materials which are adapted to the learning needs of disabled children, both in content and format, are not readily available in most states. This applies both to adaptation of regular curricula and to differences in curriculum between special and regular schools. However, experience even in poor states such as Orissa shows that through collaborations between the government and NGO sectors gradual results are possible. In addition, there is under-coverage of teachers and administrators who are sensitized to the rights and needs of CWD in education, and are equipped with basic skills and access to resource personnel and materials. To date pre-service training of regular teachers includes no familiarization with education of special needs children. While the coverage of basic sensitization courses under SSA is growing, penetration of RCI training remains very limited. Finally, there was until recently an ineffective system for monitoring and evaluating the educational attendance and attainment of CWD that would help inform the development of inclusive education strategies and allow feedback on their performance. The new tools developed by NCERT in this respect, and training of states in their use, are a positive step, and evaluation of their use in due course will reveal how much improvement can be achieved in this area.

Employment (Chapter 5)

25. **There are a range of public programs to promote PWD employment, but their impact has been negligible and largely confined to urban areas.** This is in part due to weaknesses in design and implementation. Broader impacts on employment outcomes for people with disabilities will be dependent firstly on efforts to change perceptions on the productive contribution that disabled people can make, an effort that will require engagement of the public, private and NGO sectors.

26. **Public sector employment reservations exhibit poor outcomes due to design and implementation problems.** Despite a 3 percent reservation in public employment, as of 2003, only 10 percent of posts in public employment had been identified as "suitable" for PWD. As a result, the share of PWD in all posts thus remains negligible, at 0.44 percent. A second feature of the quota policy is that it applies only to three disability types – locomotor, visual and hearing - which limits many other disabled people from accessing jobs. A final and broader question on the policy is consistency with good international practice, which in the area of disability is moving away from quota-based approaches. Even if the quota system is retained, there is significant scope to improve it.

27. **Private sector employment incentives for hiring disabled people are few and piecemeal.** The PWD Act makes provision for a private sector incentives policy, with a target of 5 percent of the private sector workforce being people with disabilities. However, neither GoI nor states have introduced a general incentives policy (though there is a specific new incentive provided for formal sector workers in the 2007/08 budget). In the late 1990s, employment of PWD among large private firms was only 0.3 percent of their workforce. Among multinational companies, the situation was far worse, with only 0.05 percent being PWD. However, there are a number of private and public sector firms which have far better performance on PWD hiring, and offer good practice examples of more inclusive workplaces.

28. **A national network of special employment exchanges for disabled people exists, but plays a negligible role in promoting their employment.** Employment exchanges exist in state capitals, but overall, the link between employment exchanges and establishments in the private sector is weak. As a result, the job placement ratio is very low for both special and other

exchanges, 0.9 percent and 0.7 percent of registered PWD respectively in 2003, and has roughly halved over the past decade. The downward trend reflects shrinking job opportunities in the public sector, and a general failure of exchanges to reach out to private employers.

29. **A financial assistance program for entrepreneurs with disabilities exists, but few beneficiaries have been served**. The National Handicapped Finance and Development Corporation (NHFDC) was established in 1997 to provide financial assistance to disabled entrepreneurs. However, between 1997 and 2005, the number of NHFDC beneficiaries was negligible - only 19,643. Even among the small client base, there is a strong gender and disability bias. In addition, disbursements have been very low, in part due to long lags between receipt of funds and loan disbursement. If NHFDC is to reach more beneficiaries, the structure of the schemes needs to be revised so as to give channelling agencies, MFIs and banks better incentives to participate, together with improved accountability for channelling agencies. Equally, awareness of schemes among potential beneficiaries is very limited.

30. **GoI provides vocational services to disabled people, but coverage is low and its impact is not known.** Vocational Rehabilitation Centers (VRCs) have been established in state capitals to provide vocational training to disabled people based on a PPP model. The main tasks of VRCs are to make vocational assessments of PWD and to provide short term training. Some also provide job placement services. VRCs generally do not seem to make regular efforts to update the skills imparted along with shifts in labor demand. Like other active labor programs for people with disabilities, the size of the VRC program is very small, rehabilitating only about 10,500 persons a year. In addition, there seems to be a lack of focus on placement, with no evidence to date of net positive impacts on labor market outcomes for trainees.

31. **An expanding number of NGOs have become active in vocational training of PWD and direct employment generation, but the majority with no accreditation process**. The majority of NGOs are oriented towards skills for sheltered, group and self-employment rather than employment in the organized sector. There are a range of good practice examples like the WORTH Trust that can be built on in the future. At the same time, several common weaknesses of NGO programs can be observed. First, most have a strong urban bias, as well as under-representation of women trainees. Second, many NGOs acknowledge a lack of qualified trainers. Third, as in the public sector, NGOs frequently failed to undertake sufficient assessment of the local labor market conditions in determining courses for PWD. Monitoring of employment and wage outcomes for PWD trainees tends not to happen. Despite their challenges, NGO experience overall seems more positive than public sector interventions to date in promoting skill and employment for people with disabilities.

Social Protection (Chapter 6)

32. **The social protection system for PWD consists of social safety net and social insurance interventions, but these have had only small impacts on welfare levels of the disabled poor.** There are a range of social protection schemes targeted to PWD: These programs include (i) *Safety nets*: reservations under various centrally-sponsored anti-poverty programs, unemployment allowances for PWD, and "social pensions" for destitute PWD, i.e. monthly social assistance cash benefits and (ii) *Insurance*: different forms of insurance in cases of disability, including schemes for civil servants and the formal private sector, and schemes for informal sector workers.

Safety Net Schemes

33. **Safety nets for PWD offer low coverage and limited financial protection.** The PWD Act commits to reservations for PWD of not less than 3 percent in all poverty alleviation schemes, but it appears that PWD are well below 3 percent of beneficiaries in all schemes. For example, SGSY coverage rates between 1999 and 2004 were around 0.8 percent of total program beneficiaries, accounting for only 0.7 percent of the working PWD population. For IAY, the beneficiary share in recent years has been around the same. For SGRY, in the budget years 2002-04, the share of works for disabled was between 0.2 and 0.9 percent of total, and the new National Rural Employment Guarantee Act has dropped the provision for reservations for disabled people. India also has social assistance cash payments for destitute elderly, widows and PWD. All states/UTs for which data are available have disability social pension schemes, though coverage in different states exhibits wide variations. Nonetheless, it is estimated that around 14 percent of PWD receive a disability social pension, which makes it the most significant cash transfer program for this group. While the unemployment allowances for PWD are anticipated in the PWD Act, few states have such schemes.

34. **Several factors limit the effectiveness of safety net programs.** Low program impact is a product of low awareness among PWD of programs, weak channels for increasing demand (e.g. linking SHGs of disabled people to targeted credit), and in many states a lack of focus on the area of social protection for PWD (as absence of UA and low social pension coverage indicate). The disability social pension appears to date to have the most effective outreach in several states. In contrast, the system of reservations under poverty alleviation schemes has clearly failed to achieve the desired outcomes.

Disability Insurance Schemes

35. **Disability insurance schemes have low coverage, with financing mainly from the budget, but have considerable latent demand.** There are two main problems with the current arrangements for social insurance, including disability insurance. The first is related to the small share of the formal sector. Coverage is therefore low and concentrated in the top half of the income distribution. The second problem relates to financing. In the case of civil servants, the financing comes directly from the budget, with no reserves set aside. This is starting to change however, as a new defined contribution scheme is being phased in for new civil service hires. Demand for disability insurance among the unorganized sector is evidenced by the growing number of SHGs, welfare funds and micro-insurance offerings in this area, as well as public schemes like JBY which in 2006 covered around 3.6 million workers. However, membership in group schemes is limited (less than 5 per cent) and not all offer disability benefits. The prevalence of disability benefits in micro-insurance schemes appears to be even more limited, with only one quarter offered disability benefits (almost always lump sum payments). There is very little solid analysis available on how well these schemes function.

36. **As of 2006, two initiatives may lead to significant changes in the coverage and financing of disability insurance in India.** The *first initiative* is a bill for social security for the unorganized sector, submitted to GoI in May 2006 by the National Commission on Enterprises in the Unorganized Sector. The proposal includes benefits for old age, death, maternity, health and disability, and is proposed to be contributory. While the proposal is very ambitious, it is the first such national initiative which grapples with the core challenges of administration that social insurance for the unorganized sector implies. Draft legislation has subsequently been prepared by MoLE which seeks to realize the objectives of the NCEUS initiative in a manner consistent with fiscal and institutional capacities. As a precursor to this, GoI announced in the 2007/08 budget

the Aam Aadmi Bima Yogana, which is proposed to provide life and disability cover for up to 15 million rural landless households. The *second initiative* is a draft bill to introduce a New Pension Scheme (NPS). This would be available to any individual not already obligated to participate under the EPFO Act. When the NPS goes into effect, it will theoretically provide a platform for pension provision that would extend to both civil servants and informal sector workers. However, the NPS has yet to define a disability or survivors benefit. This will be necessary at some point. While in principle adding a group insurance policy for death and disability to a DC scheme of this kind is relatively simple, a number of implementation challenges remain. First, in India (and in most developing countries), relevant mortality statistics are not available. Second, the private insurance market is still at an early stage in development and does not have experience with annuity products.

Disability Policies and Institutions (Chapter 7)

37. India has one of the more developed disability policy frameworks of developing countries, but there remain a number of policy shortcomings in the PWD Act's design. The public implementation institutions are relatively weak and under-resourced, but NGOs have developed some promising approaches.

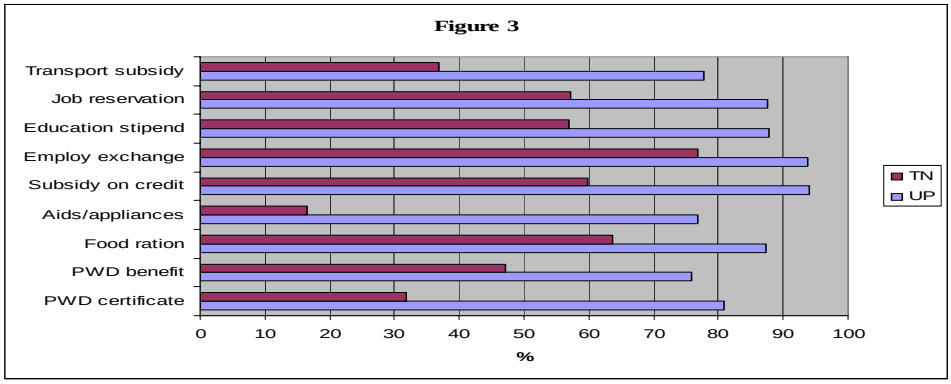
38. **The Persons of Disabilities Act, 1995 is a cornerstone of disability policy, while in many respects ground-breaking, has some weaknesses in design**. India has a long experience of policy and practice with respect to disability dating back to the 19th century, with the most recent approach embodied in the Persons with Disabilities Act, 1995 (PWD Act). The Act represents a major step forward in policy towards disabled people in India. Despite being ground-breaking in recognizing the multi-faceted nature of disability beyond mere medical intervention, there are some weaknesses its design. First, the Act covers only designated types of disability, which are not inclusive of several significant categories of disability (e.g. autism). This is in part driven by the linkage between the legal definition of disability and entitlements. Second, entitlements are often legally framed in a general manner which does not facilitate enforcement, and/or not linked to any sanctions for non-compliance. This is compounded by a rather weak enforcement mechanism, with no direct enforcement authority granted to the Act's watchdog – the central and state Commissioners for Persons with Disabilities (CPWD), which has quasi-judicial powers. Third, the approach of the Act has rather limited roles for actors outside the administrative framework, including NGOs/DPOs, PWD themselves and PRIs. Finally, commitments on health are particularly weak, with combination of the economic capacity proviso and general language making the provisions on prevention and early detection of disabilities little more than statements of intent.

39. **In the period 1998-2003, just under Rs. 1042 crore was spent by MSJE on the disability sector. This represents a negligible portion of total budgetary spending**. In recent years, this has ranged from 0.05 to 0.07 of total GoI spending, indicating the low priority placed by GoI on core programs for PWD. While spending under other ministries has risen in some cases (e.g. education under SSA, which ha seen a significant increased in spending on inclusive education initiatives), consolidated figures for spending on PWD are not available. Aside from level of spending, it is difficult to assess the effects of spending due to under-developed monitoring and evaluation systems. While recent initiatives such as AABY and the new employment incentive for PWD indicate an increased willingness on the part of GoI to increase resources to the disability sector, it remains to be seen what will be the effectiveness of program outreach and expenditure execution.

40. **In early 2006, a National Policy on Persons with Disabilities was approved by GoI. While a welcome measure, it could do significantly more to propose concrete strategies for realizing the entitlements of people with disabilities.** In addition, there continues to be very limited reference to the role of people with disabilities themselves as active participants in realizing the objectives of policy. However, despite the overall Policy, sectoral policy has progressed significantly in education, with inclusion of CWD into mainstream education increasingly accepted in recent years. At the state level, there remains a basic question in many states of limited political buy-in by many states to the commitments of the PWD Act. To date, the only states that have draft disability policies are Chhattisgarh and Karnataka. The latter largely mirrors the structure and major provisions of the PWD Act, without in most areas providing more specific commitments or implementation guidance. In contrast, the Chhattisgarh draft state disability policy can be considered "best practice" within India, and could provide a model for future national and state-level policy development (see Chapter 7).

41. **There is limited awareness of the entitlements of the Act—a key constraint in implementation.** [6] A key ingredient of effective implementation is awareness of entitlements. Evidence from various sources indicates that awareness of the PWD Act remains very low, and lower among households with PWDs than others. While awareness of specific entitlements is higher, it remains low for most benefits (see Figure 3). In addition, for those PWD who are aware of benefits/services, a substantial share of PWD report difficulties in accessing them. Very little empirical evidence exists of the interactions of PWD with the official institutional network, but this study confirms that around 43 percent of those eligible in UP and TN had not received any benefits or services. Three main challenges in receiving benefits and services include: (i) physical access problems; (ii) problems with procedures and officials; and (iii) communication difficulties for disabled people in approaching providers. In addition, the institutions from which PWD most often reported receiving services and benefits were at district level, though panchayats were growing in significance.

Awareness of entitlements under PWD Act is also low, though with strong state variation
Figure 3: Share of PWD HHs not aware of entitlements



Source: UP and TN Village Survey (2005).

42. **Implementation is made more challenging in part due to a nodal Ministry with limited resources and convening power, and weakly functioning coordinating institutions in much of the country.** Implementation is also constrained by a complex institutional framework for operation of the disability sector in India. The nodal agency for disability is the Ministry of Social Justice and Empowerment (MSJE). There are inherent challenges for any nodal ministry in a multi-sectoral field as disability. That said, there are areas where having MSJE as lead agency seems questionable. Two examples are special education and early identification of

[6] CAG (2004).

disability, where the MHRD and Ministry of Health together with Women and Child Development Ministry respectively are the appropriate lead agencies. In addition, there is a broader challenge of "convening power" of MSJE relative to ministries which it must coordinate. What this points towards is the unusual importance in disability of inter-sectoral institutional coordinating mechanisms. To address this, the PWD Act mandates central and state-level Coordination and Executive Committees, which are intended to be key institutions in development of disability policy. Unfortunately, according to GoI's own assessment, the track record of these coordinating institutions is poor, with few exceptions. Finally, in addition to no direct enforcement authority (noted above), the CPWDs have limited capacity to perform their 'watchdog' function effectively, in many states having skeletal staff levels. Despite this, Karnataka has managed to develop one of the more active commissioners' offices, introducing a range of initiatives such as multi-sectoral district disability management reviews and lok adalats (peoples' courts) specifically on the rights of disabled people. Finally, PRIs are largely absent in public sector disability policy and practice, making the institutional framework for disability increasingly out of line with broader developments in decentralization of service delivery.

43. **The disability NGO movement has contributed greatly to promoting the interests of PWD.** In light of the major challenges facing public sector institutions for PWD, non-governmental institutions assume unusual significance. There are acknowledged shortcomings in the capacity of the disability NGO sector to grow into an expanded role, both in its own right and as a partner of government. Many NGOs have links with public agencies, predominantly for contracting out of services, technical assistance and training. While results have in many cases been positive, there remain concerns about weak monitoring of NGO performance and accountability for use of public funds. Consultation between the public and NGO sectors on disability policy issues also remains under-developed, both at the centre and in most states. In addition, the monitoring and evaluation role for NGOs seems one that could be developed within public interventions.

44. **While both public and NGO institutions are important, informal institutions – primarily the family – remain the most important factor in the lives of PWD**. Families– particularly the women in families – play a critical role in providing support to PWD. The family is not however an unambiguous source of support for PWD in several ways: (i) it may be over-protective; (ii) it may – consciously or not – favour non-disabled household members; and (iii) it may be a direct source of harm to the PWD member (as evidence on physical and sexual abuse of disabled women indicates). Previous research and that for this report indicates quite clearly that there is a major awareness raising agenda on disability among family members of PWD, and even among people with disabilities themselves.

Accessibility for People with Disabilities (Chapter 8)

45. **Many of the rights provided for people with disabilities in India can not be realized without ensuring that the services to which they are entitled are accessible, and that barriers to access in the broader environment are reduced.** Overall, while India has standards on promoting access to the built environment and basic services, it faces major challenges in implementation due to a combination of institutional coordination challenges, poor enforcement mechanisms, and lack of awareness of the needs of people with disabilities.

46. **The provisions on access for people with disabilities in the PWD Act are framed as contingent entitlements**, but the nature of the legal obligations is somewhat vague. Indeed, there are no specific enforcement provisions or sanctions for failure of authorities to be proactive in undertaking their obligations under the Act. Nor is a mechanism spelt out for how authorities

should move to implement the Act's provisions, e.g. amendment of bye-laws etc. While the PWD Act can be considered a starting point in promoting accessibility, there is clearly a significant need to build on it. There has been progress on the policy side in promoting accessibility since the Act. The Ministry of Urban Affairs and Employment issued Guidelines and Space Standards for Barrier Free Built Environment for Disabled and Elderly Persons in 1998 (with a similar document from the Chief CPWD Office). This is a guiding document to central and state authorities in modifying their bye-laws, and applies to most construction other than domestic buildings. In addition, the latest 2005 revision of the National Building Code (NBC) includes provisions for buildings, services, and facilities for people with disabilities. The NBC acts as a model code for construction by Public Works Departments, other public agencies and private construction companies. The documents do not have direct force, though are of course important standards and sources. In order to make them legally binding, they need to be adopted into local building bye-laws for construction and systems for approvals. To date, around 16 states have modified their bye-laws or adopted new ones, with others in the process of doing so.

47. **There is much evidence, both quantitative and anecdotal to indicate that accessibility for PWD remains a largely unrealized goal in India to date.** One of the major issues in promoting access for people with disabilities is that of institutional coordination. Particularly for the built environment, there are in most cases a range of line agencies and other local authorities responsible for infrastructure. This frequently results in no single agency considering itself responsible for making the built environment accessible, and/or problems with very partial accessibility in the face of uncoordinated action. The institutional issues in promoting access reflect deeper challenges of accountability. In this respect, the PWD Act itself is not of great use in terms of establishing clear lines of accountability for ensuring that accessibility standards are adhered to. A further important weakness in improving accountability has been the general lack of consultation with people with disabilities themselves in prioritizing investments to promote access, and in monitoring access outcomes.

48. **Despite the constraints, various channels have proved useful in promoting accessibility.** The courts have played a role in promoting the access commitments of the Act, both directly in relation to physical access provisions (e.g. to transport), and in broader areas of civil participation such as access to polling stations. Another simple but more powerful tool in promoting accessibility has been the growing practice of access audits, generally by NGOs, though in a number of cases supported by Commissioners' office.

IV. Policy Options for Improving the Lives of People with Disabilities

49. The issues identified above suggest that it will take a multi-faceted approach to improve the welfare of disabled people and maximize their contribution to the economic and social life of the communities in which they reside. There is a clear need in several sectors to do a better job in "getting the basics right", i.e. minimizing the incidence of disability; identifying and certifying disabled people as early as possible; getting far more disabled children into school and making it a worthwhile experience for them; increasing efforts to raise awareness among PWD and service providers of their rights; and developing creative approaches to minimizing the social stigma of disability. As noted, it is neither possible nor desirable for the public sector to "do it all", particularly in an environment of major challenges in general service delivery. The specific areas of improvements are highlighted below:

Addressing Prevention and Treatment of Disability

50. Improvements in access to care and outcomes for PWD are needed in several areas, some of which are in the general public health and health delivery systems and other specific to services for disabled people:

51. **Improving identification and certification of disability**: A thorough review of the existing early identification system for disability - with strong coordination between the ICDS system, local health care providers (both public and private) and communities - is needed to improve early identification of disability. This effort needs to be accompanied by improved outreach and possibly simpler procedures for disability certification, including raising awareness that such a system exists and exploring new approaches to disability certification that exploit private sector medical capacity in the face of serious public sector supply constraints on certifying doctors.

52. **Minimizing the incidence and severity of disability**: Cost effective interventions to minimize disability need to be strengthened, including iodization of salt (recently made mandatory once more), and micronutrient supplementation for children and pregnant women. This would include a reversal of declining immunization coverage (polio excepted), which contributes to both disability and mortality rates. Current efforts such as provision of simple aids such as glasses or crutches also need to be expanded – in partnership with the private sector – to prevent mild impairments becoming serious disabilities which compromise learning, work, and other activities of daily life. The importance of simple interventions such as cataract surgery and hearing devices will also increase with an ageing population. However, other efforts will be needed beyond the health sector. Efforts to promote road safety are an important case, with the rapid expansion in accident-related disability (estimated by the Planning Commission to cost India around Rs. 55,000 crore annually at 2000 prices). While the draft National Road Safety Policy is one step, greater efforts at the state level such as those being pioneered in Kerala are needed to stem the major increase in traffic injuries and death. The draft National Road Safety and Traffic Management Bill soon expected to be introduced is another important effort to address the institutional and other challenges to improving road safety,

53. **Improving quality of care for disabled people:** Key actions to be taken include: (i) better integrating disability management in existing health delivery systems. Departments of social welfare, health and W&CD have to work together and in tandem with early intervention through the education system, NGOs and communities. This would include joint disability training for local level service providers and communities based on common mandates, combined with incentives and identification of influential champions. Improving training of PWD as health advocates and field facilitators is needed if they are to become active agents and not passive beneficiaries; (ii) improved referral systems for the existing rehabilitation network, followed by increased funding and personnel (whose levels are currently at less than 10 percent of WHO standards for developing country rehabilitation services); (iii) a stronger distribution network for Government programs of aids and appliances, including awareness raising of among PWD; (iv) improved centers and resources devoted to disability management, including assessment, rehabilitative services and medical intervention Indian organizations have capacity to develop low cost technology for PWD, but need adequate funding and incentives, and finally, (iv) more aggressive efforts to develop government and NGO partnerships in all areas of disability services will be needed to strengthen service delivery (in particular with respect to community-based rehabilitation); and finally (v) continued efforts to ensure that prevention of disabilities through immunization and other preventive measures is strengthened.

54. **Addressing current and future provision and information gaps.** New legislation and its enforcement are needed**,** particularly in the areas of mental health and road safety (including emergency and trauma care), both of which are assuming increasing importance as causes of disability. The aging of the population and attendant disability needs of the elderly will need to be addressed in the future. Finally, data and statistics on disability need to be more reliably and regularly collected, in particular through strengthened NFHS and general health surveys, which have neglected disability.

55. **Given capacity constraints, improving the health sector's response to disability may most feasibly happen in two phases. The first phase could concentrate on accelerated response closest to the community level.** This would include an improved certification system, promotion of CBR (including awareness raising and stigma reduction elements), and enhancing micronutrient supplementation (including options for food fortification) and immunization. The supply side interventions would need to include training of general duty medical officers in disability certification, and of community volunteers. **The second phase could focus on improved referral systems between levels of the health system,** including increased supply of therapists and support for establishment of therapy centers in rural areas. It would also likely involve networking of hospitals and specialized centres, possibly with support form the private corporate sector.

Improving the quality and access to education

56. **More than most sectors with regard to people with disabilities, the education sector has been relatively progressive in policy terms, and has also committed to a progressive menu of options for delivering education to children with special needs.** However, there are a range of challenges in turning policy into effective practice for a variety of reasons, and India will not achieve its MDG goals without substantial improvements in outcomes for disabled children. Some of the elements in executing this agenda include:

57. **Improving access to education**: Identifying childrens' impairments and learning capacities early and getting them into some form of education is a critical first step, which remains an incomplete agenda to date. It will be important to review the SSA systems for identifying children with disabilities entering the education system, and explore their convergence with early identification systems prior to school age. In most states, these systems are struggling to identify many children with disabilities, and by operating parallel systems, may be overburdening anganwadi workers and others with reporting demands. Improved initial identification needs to be complemented with development of simple systems for ongoing school-based assessment of emerging (and often easily reversible) disabilities. All new school construction should also be physically accessible and current efforts of retrofitting accelerated.

58. **Improving the quality of education services:** GOI should require all states to develop a strategy for delivering education to children with special needs, in order that SSA and other central funds can be allocated in a less mechanical manner. This strategy would assist in improving the currently poor expenditure performance, and more importantly move the system towards a genuinely child-centered allocation which can provide parents and local authorities with more options and greater accountability for resource use. Secondly, a key element of strategy execution must be making the special needs resource centre model operational. In many states, this will require piloting of different models with good evaluation. Thirdly, current efforts to make the curriculum accessible and adapted to the learning needs of children with disabilities need to be accelerated. This is recognized in the National Curriculum Framework of 2005. For special education curricula, greater efforts to assess the needs of children in activities of daily

living and focus learning materials on acquisition of these skills is required. Under SSA, states such as Assam, AP, and TN have initiatives with "plus" curriculum and development of TLM which will be worth monitoring closely for lessons. Fourth, as part of this strategy, the Government could also ensure that special education knowledge is imparted to all teachers in pre-service training. In this regard, it would be important to review the performance of Rehabilitation Council of India in its training provision and regulation role.

59. **Strengthening education institutions.** This reform would first involve a more direct institutional relationship with MHRD rather than MSJE. It would seem desirable to shift all special education under MHRD, so that planning, financing and monitoring of the education of all children with special needs in the public and aided systems can be done in a coherent manner. Ensuring VECs, CBR groups, womens' groups, and other community organizations are actively engaged in the importance of educating children with special needs, and familiarized with the benefits for all children educationally and socially will also be important. IE exposure is now included in the training for community leaders, and states such as Bihar have included IE exposure in VEC training. Finally, as in the case of health service delivery, overcoming weaknesses in public sector implementation by developing public/private partnerships, learning from NGO sector innovations in education of children with special needs, and deepening public/NGO partnerships in those states where they are lagging will be important. There is a promising base, with around 530 NGOs involved in 26 states, but clearly scope for widening and deepening this engagement consistent with SSA's commitment to PPP in IE.

Enhancing Employment Prospects

60. Improving employment outcomes for people with disabilities starts with the education system and community attitudes. However, a range of more specific reforms and program reorientation is needed, including:

61. **Improving public sector employment practices.** First, the reservation for disabled workers needs to be reviewed and reformed. If a quota approach is retained, it should be based on a share of all posts in public agencies and discontinue the practice of "identified posts" for disabled people. The Government should also review whether special employment exchanges should be integrated into the regular exchange network. In either event, there must be a systematic engagement with the private sector to assess labor market demand and move away from the current focus on public sector employment. TN and Gujarat provide promising models in this regard. Vocational Rehabilitation Centers and their implementing NGOs need like many areas of training in India to drive curricula from the market, including diversifying the range of skills from traditional handicraft activities more typical of "sheltered workshops". Awareness campaigns for public programs are also needed, as knowledge about available programs remains very low.

62. **Improving quality of private sector initiatives, and strengthening public-private partnerships.** GoI and the NGO and private sectors should jointly review the draft private sector incentives policy for people with disabilities developed by NCPEDP and FIICI to assess its financial and administrative feasibility and adopt those measures deemed workable into policy. There should be dissemination by the Commissioners' offices of good practice in public and private sector enterprises in hiring and promotion of inclusive workplaces for people with disabilities. In particular, a review of the impact and viability of NHFDC should be carried out. At a minimum, the structure of NHFDC schemes needs to be revised so as to give SCAs, MFIs and banks better incentives to participate, and accountability mechanisms for channelling agencies improved. There should also be more experimentation with group-based lending to

disability SHGs, which has been shown in states like AP (and in mainstream targeted credit programs) to be more effective than individual lending in expanding credit coverage.

63. **Increasing outreach to marginalized groups and regions.** Both public and NGO training for disabled people needs to make greater efforts to include women with disabilities and a broader range of disabilities. They also need to develop simple processes for regular assessment of labor market demand. Pilot interventions for rural outreach of both public and NGO active labor programs are needed, and public funds from existing programs should be dedicated to this purpose. This will require much stronger engagement with communities and SHGs of disabled people.

Providing Effective Social Protection

64. Policies and programs should help improve awareness and targeting of safety net benefits to the poor and develop innovative approaches to extend coverage of disability insurance.

65. **Improving the safety net.** A first step in improving the poor performance of safety net programs for disabled people is familiarizing implementing officials and PRI representatives of the commitments under the PWD Act. Once such familiarization is done, the next step is for implementers to make efforts to raise awareness of schemes and PWD entitlements. In parallel, efforts need to be made in the public and non-governmental sectors to mobilize PWD themselves, so that there is more bottom-up demand on the delivery system. Formation and capacity building of PWD SHGs could be an important part of both strategies. Developing more focused efforts are also needed for specific programs, including: (i) for SGSY, targeted efforts to mobilize formation of SHGs of disabled people; (ii) for NREGS, adjustment of the national guidelines to include disabled people and efforts to identify categories of works well suited to disabled people and processes for ensuring their adequate inclusion; and (iii) for social pensions, review of states with poor coverage, relaxing the eligibility criteria for disability social pensions, and considering central funding of a base benefit as is done already under the National Old Age Pension Scheme.

66. **Expanding disability insurance.** In order to address the demand that clearly exists for disability insurance, a low cost platform with standardized products and uniform regulations is likely to be the only approach that can be scaled up at the national level. Such a platform has recently been proposed under the New Pension System to deal with old age pensions for both the informal sector workers and civil servants. However, it will be necessary to have far more coordinated efforts across different arms and levels of government to link various social insurance initiatives to such a platform. Equally, the role of intermediary organizations such as MFIs, NGOs, and perhaps PRIs will be critical in improving program outreach and playing a role in contribution mobilization and claims processing if transactions costs are to be kept manageable.

Strengthening Disability Policies and Institutions

67. At this point, a focus on outcomes for people with disabilities would suggest that the priority should be on institutional reform in order to improve implementation capacity. Nonetheless, several policy reforms remain important, and are outlined below.

68. **Policy Reforms.** Disability policy reforms are needed in several areas: First, there should be serious consideration given to broadening the categories of disabled people included in the PWD Act, which may in any event be necessary in light of the new UN Convention to which India is a signatory. This may also require a de-linking of definitional inclusion of different groups with specific entitlements under the Act. While fiscal and other capacity issues suggest

that not all disabled people may be supported through public interventions, this does not seem a good reason to exclude them from inclusion as PWD under the Act. Legislation and policy should ensure that clear obligations for involvement of persons with disabilities themselves at all stages of policy development, implementation and monitoring. Second, MSJE and central and state Commissioners' offices should develop programs in collaboration with DPOs and NGOs for awareness raising of officials, service providers, PRI representatives and communities on programs for people with disabilities. A periodic monitoring of awareness, with particular focus on lagging states and remote regions, should be put in place to assess impact. States should be strongly encouraged to develop their own disability policies which elaborate a credible strategy for meeting their commitments under the PWD and other acts. The example of Chhattisgarh offers a useful example of such a policy. Finally, there should be a process for basic benchmarking of feasible policies and programs for people with disabilities in the areas which are currently subject to the economic capacity proviso.

69. **Institutional reforms** would seem desirable in several directions: First, the institutional framework at all levels needs to have a substantially strengthened direct role for persons with disabilities themselves. Second, responsibility for specific programs for PWD should be brought clearly under relevant line Ministries in some cases, e.g. bringing all education policies under MHRD as noted above. Third, GoI may like to consider overhauling the current coordinating mechanism into a National Commission for PWD, which would have the status and convening power which is currently under-developed in the sector. It is important that such a body be a coordination and oversight agency, and not be viewed as a separate "silo" for disability. Such an initiative would only make sense if the structural problems of coordination within and between levels of government, and between the public and non-governmental sectors are addressed. It would also require a transition strategy if the current Commissioners' Offices are to be merged into a future Commission, so that there is not simply duplication of responsibilities. In this light, any move towards a Commission should not forestall the urgent need to strengthen the capacity of Commissioners' Offices to perform their current functions, in particular on grievance redressal. Fourth, the enforcement mechanisms for the Act need to be clarified and strengthened. One option would be a Disability Tribunal with direct enforcement powers. This has pros and cons, as there is a risk of "over-judicializing" the grievance mechanisms for PWD and thus reducing their access. An alternative is obviously strengthening of both central and state Commissioners' offices to play their grievance redressal function more effectively. A review of human resource and financial capacity of central and state Commissioners' offices is also needed, and guidelines on minimum staffing levels introduced. The national policy and legislation needs to reflect the growing role of PRIs and use it as an opportunity to extend institutional reach to the village level, and more importantly to increase the local channels for accountability of public and other disability service providers. NGOs should also be brought more actively into both policy and implementation, but with strengthened financial accountability and monitoring of program outcomes. Finally, there needs to be more direct engagement between both public and NGO sectors with PWD themselves and their families, with SHGs being a logical vehicle.

Changing Attitudes

70. Changing societal attitudes to people with disabilities, even among people with disabilities themselves, presents many challenges. Changing attitudes to disability is likely to area where it is particularly important for governments to work with people with disabilities, NGO/DPOs, and communities to raise awareness about disabilities in order to help address a number of the demand side challenges in improving outcomes for disabled people. A second important step where media, persons with disabilities, social activists, and NGOs are likely to

have comparative advantage is putting the experience and success stories of persons with disabilities into the public arena. An important step in this regard is following the guidance offered by people with disabilities in India on interactions with disabled people, as outlined in Chapter 2.

Improving accessibility

71. Improvement in accessibility for disabled people is a long run agenda, but several recommendations emerge. Firstly, both national and sub-national policies on promoting access for people with disabilities should be required to include consultation with disabled people in setting priorities, and in monitoring outcomes through access audits and other channels. Secondly, states and/or municipal authorities which have yet to amend their building bye-laws to comply with the 1998 guidelines should be encouraged to do so in the nearest future. These should allow for clear sanctions in case of failure to comply with accessibility standards, and administrative clarity on official accountability in cases of failure to comply. MoSJE in collaboration with Commissioner's offices, the Ministry of Urban Development and Employment, and the states should also work towards benchmarking minimum national standards of accessibility to which authorities could be held accountable. This will be a necessity under the new UN convention. Thirdly, public funds for the welfare of disabled people should also be used to support research on their access priorities, development of assistive devices for improving mobility of disabled people, implementing cost-effective universal design, and analysis of the impacts and costs of failure to provide accessible environments. Finally, university and in-service training courses for architects, engineers and planners should include exposure to principles and practices of universal design and accessibility as a standard course element. Financing for designated centres of excellence in this area should be made available.

Strengthening Measurement and Surveys

72. Improving measurement of disability is critical for understanding the magnitude and scope of the disability issue in India, raising awareness of disability, and helping address disability issues. This is a large agenda, but initial recommendations are: there is a need to harmonize definitions of disability categories across NSS and census. In this process, there is also a need to improve and harmonize the approaches across disability types within each survey (detailed recommendations are in Chapter 1). Revising the NSS disability module for the next dedicated round, in particular improving PWD household consumption information and other welfare indicators, and including other disabilities more explicitly in the survey would help improve measurement. It will also be necessary to incorporate disability questions into mainstream health, education and other surveys to an extent not done to date. This includes the main schedules of NSS, so that more reliable comparisons between the disabled and non-disabled populations on critical indicators like educational attainment and living standards can be made.

INTRODUCTION AND FRAMEWORK

1. This section addresses two overarching themes which recur in the report. A brief discussion of each is useful by way of framing the main body of the report. The themes are (i) models of disability; and (ii) a framework for thinking about public policy and disability.

2. ***(a) Models of Disability:*** [7] Virtually all the literature on disability outlines the ***shift in disability policy thinking from the charity and medical models of disability towards social model of disability.*** The various models can be described briefly as follows:

- the ***medical model of disability*** relies on a purely medical definition of disability. It thus equates the physical or mental impairment from a disease or disorder with the disability that the person experiences. From a policy viewpoint, the person with disability is viewed as the "problem", and in need of cure and treatment. In terms of services, the general approach within this model is towards special institutions for people with disabilities, e.g. special schools, sheltered workshops, special transport etc. The limitations of the pure medical model are evident, though it till underlies some current analysis such as that based on disability-adjusted life years (DALYs).

- the ***charity model of disability*** also view the person with disabilities as the problem and dependent on the sympathy of others to provide assistance in a charity or welfare mode.

- the ***social model of disability*** "places the emphasis on promoting social change that empowers and incorporates the experiences of PWD, asking society itself to adapt". [8] The social model emphasizes institutional, environmental and attitudinal discriminations as the real basis for disability. Thus it is the society at large which disables the person with disabilities through discrimination, denial of rights, and creation of economic dependency.

- the ***rights-based model of disability*** builds on the insights of the social model to promote creation of communities which accept diversities and differences, and have a non-discriminating environment in terms of inclusion in all aspects of the life of society.

3. It took time to build consensus on a conceptual framework which reflected dimensions of disability beyond the medical. The International Classification of Impairments, Disability and Handicaps (ICIDH) from WHO in 1980 was a breakthrough in this evolution. It recognized that personal, social and environmental factors are all at play in "creating" disability. This acknowledged that not only physical or mental impairments but the attitudes and institutions of society had significant impacts on the opportunities of PWD.

4. The ICIDH-2 from 1997 represents a further step in this process. It defines disability as:

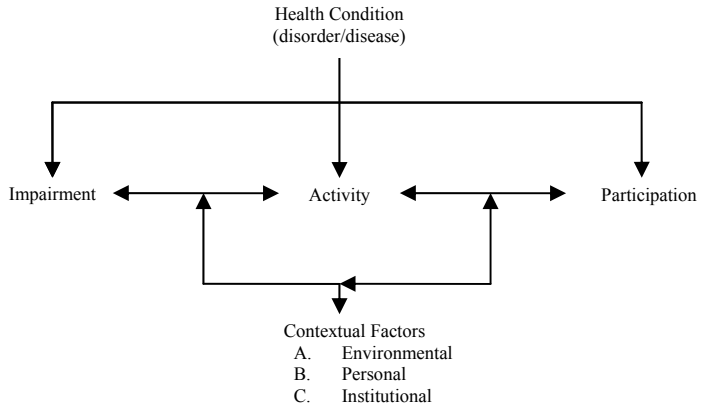
"..an umbrella term covering three dimensions: (i) body structures and function; (ii) personal activities; and (iii) participation in society. These dimensions of health-related experience are termed "impairments of function and impairments of structure", "activities" [i.e. nature and

[7] This section draws from Metts (2000), and inputs from Alana Officer.
[8] See DFID (1997).

extent of individual functioning due to impairments], and "participation" [the nature and extent of a person's involvement with life situations] respectively".

5. While the language of ICIDH-2 is dense, the intuition is simple. Limitations on PWD participation in the life of their society are created by the interaction of general environmental factors (e.g. the built environment; societal attitudes), individual-specific factors (e.g. gender, age or education), and the impairment(s) that the individual has. The ICIDH-2 is sometimes termed a ***biopsychosocial model of disability***. The model is presented in diagrammatic form in Figure 4.

Figure 4: The ICIDH-2 Framework for Understanding Disability



Source: WHO.

6. Metts provides a useful explication of the ICIDH-2 approach, noting that "people may…:

- have impairments without having activity limitations (e.g. disfigurement but no activity limitation)
- have activity limitations without evident impairments (e.g. experience poor performance in activities due to disease)
- have limited participation without impairments or activity limitations (e.g. discrimination due to past mental illness or HIV)
- experience a degree of influence in the reverse direction (e.g. experience muscular atrophy due to inactivity or loss of social skills due to institutionalization)."

7. The ICIDH-2 was followed by the International Classification of Functioning (ICF), which skips the linkage between health conditions and functioning, and classifies functioning directly, using the same domains as ICIDH-2: body functions, activities and participation). The ICF has developed more detailed classifications of functioning with respect to products and technology, natural and man-made environments, support and relationships, attitudes, and services, systems and policies. [9]

8. ***In broad terms, this report adopts the ICIDH-2 approach to disability***, though the practical differences to the ICF approach are not significant. The combination of medically-based and socially determined definitions of disability that it offers seems particularly appropriate to a poor developing country. It is also useful in terms of public policy, where determinations of

[9] See WHO website.

disability need to be made (e.g. for access to benefits or services) which have simple decision-making rules consistent with limited institutional capacity, and thus avoid high levels of observation and/or discretion.

9. ***(c) Public Policy and Disability:*** Disability has public policy implications in several main areas:

- prevention of disability
- risk management and amelioration by either monetary or in-kind means (when disability can not be prevented)
- the interaction of poverty and disability in a context of widespread poverty and vulnerability
- the interaction of disability with delivery of public services such as education or health in a context where the general systems of service delivery face many challenges.
- the role of public policy in areas like employment and attitudes where the market or social institutions play a dominant role.

10. ***Much of this report focuses on the question "Should – and if so, how should – public policy intervene in the area of disability ?"***. The question must be addressed in the context of constrained public resources, which presents hard questions for India in terms of focusing marginal resources on the most effective channels for promoting opportunities for people with disabilities. It must also be asked with some sense of how current market and community-based or household arrangements succeed or fail in creating opportunities for PWD to participate fully in society.

11. ***Standard analyses would look to justify public intervention in the area of disability on the basis of market failures*** – either those that interfere with efficiency of the economy or those that are inspired by a desire for equity or social justice. That is, it may be that some problems associated with disability cannot be solved by people acting individually via ordinary market transactions. A somewhat more sophisticated analysis would balance the identification of such problems with explicit consideration of constraints on governments' ability to address them. For example, some things, such as comprehensive disability insurance, are not available on the market for systemic reasons. However, they may be just as difficult to provide publicly for the same reasons. The following paragraphs discuss characteristics peculiar to disability that influence the ability of both private transactions and public policy to ameliorate the problems faced by PWD. They contrast both market and public action with social action – the informal support systems that people rely on – and ask when is there something public policy can do to strengthen market and/or social action outcomes for PWD, or when it might inadvertently weaken these systems.

12. ***(i) Analyzing the well-being of people with disabilities:*** Amartya Sen has persuasively pointed to the shortcomings of the dominant western theories of justice in analyzing the well-being of PWD relative to others in society. [10] ***An important distinction that he makes is between the "earnings handicap" which PWD typically face and the "conversion handicap".*** While noting that PWD are typically poorer than average throughout the world (the earnings handicap), he also notes that they are doubly deprived in that they have greater difficulty in

[10] Sen (2004) outlines the failures of utilitarianism, the Rawlsian theory of justice and the income/wealth-approach underlying welfare economics to accommodate disability, concluding that "none of the dominant theories of ethics and justice can really pay serious attention to the issue of fairness to the disabled".

converting income into well-being or good living (the conversion handicap). For example, a PWD may need to spend money to achieve the mobility that non-PWD achieve without cost (e.g. due to need for prosthesis or additional expenditures on transport). ***The conversion handicap which PWD face thus makes a given level of income yield a lower level of well-being relative to the non-disabled population.*** Calculations of the relative importance of the earnings and conversion handicaps from the UK indicate that around three quarters of the differences in poverty rates between PWD households and non-PWD households can be accounted for by the conversion handicap and only around one quarter from the earnings handicap. [11]

13. The above insight is important to keep in mind in assessing the empirical evidence in this report on the relative position of PWD. Several elements of the socio-economic profile are only able to capture the earnings handicap or equivalent in terms of access to services or other indicators. ***It is important to keep in mind that the conversion handicap makes the direct deficits that PWD typically face (e.g. in income of access to services) very much lower bound estimates of the total welfare loss that disability imposes on them.***

14. ***(ii) Disability and risk management: A core challenge that disability poses for public policy is mitigation of risk,*** both the risk of being born with an impairment and the risk of acquiring one later in life. It is problematic since both private markets and public provision are subject to severe constraints. Ideally, insurance would make it possible for someone to buy a policy that would "make good" any losses – monetary or psychic – caused by a chance event that results in impairment. Not only would one be able to buy health insurance in the case of an injury (to pay for medical care costs), but also disability insurance to replace the loss of earnings the injury might lead to. Similarly, it would be ideal if parents could buy an insurance policy that would pay compensation for any congenital impairments in their new-born. For various reasons, both markets and governments are unable to provide such comprehensive coverage.

15. ***Mitigating the risk of disability is subject to two major challenges. The first is observability.*** Correctly observing the existence of a disabling impairment presents many challenges for both public and private systems. The situation is complicated by the fact that many impairments occur on a continuous spectrum (e.g. percentage loss in eyesight or reduction in IQ). This raises the question of at what point an impairment can be considered a disability, justifying public intervention or private insurance payout. For some kinds of impairments, there may be a clear threshold effect, but for many there may not. If there is a slow decline in earning capacity (or ability to enjoy life as in depression) as an impairment worsens, it takes considerable knowledge, time or resources to be able to tell at what point a person should become eligible for a public program or insurance payout. It is this need for substantial discretion on the part of an official or insurance agent that makes verification of disability prone to misuse either by the client or by the officer who can demand payment for a favorable decision.

16. ***The second challenge in disability is that of valuation.*** Once it is successfully observed that a person has a given level of impairment, there are major challenges in defining what would "make good" the well-being of the person. Even if in principle one could define the appropriate average compensation for a given type and level of impairment, it would be almost impossible to prove how much - in the individual's specific context - the impairment has reduced well-being. Some elements of the estimation are possible (e.g. direct costs of medical treatment already undertaken or income lost). Others are possible to define but it is much more difficult to cost them (e.g. future lifetime medical costs or loss of earnings). Still others are not possible in

[11] Kuklys, cited in Sen, op.cit.

practice to value (e.g. loss of pleasure from life due to severe depression, or sense of isolation due to mobility impairment).

17. ***(iii) Social services and people with disabilities: There are also likely to be challenges for both the market and governments in direct service provision to PWD,*** at least where service provision is disability-specific and not simply a factor in a PWD accessing general services. This is driven by the characteristics of the group of disabled people. First, while by no means negligible, they are a relatively small share of the population. With respect to service provision, the (still smaller) size of particular sub-groups of PWD also matters, e.g. where disability-specific aids and appliances are needed. As a result, PWD are likely to be a dispersed group for providing services. Second, PWD and the households in which they live are poorer than average, so that their appeal for the commercial sector is relatively limited (though may be higher for some segments of the market such as NGOs). Third, even where supply-side issues can be overcome (e.g. cities), there may be significant demand side issues. These could include lack of interest in services for disabled people (e.g. lower demand for schooling relative to other children), greater problems in physical access to goods and services for PWD, or simply the poverty constraints already noted.

18. ***When both "arms-length" relationships (market and government) fail, then people as groups may be able to take care of some types of market failures***. In the case of disability, local communities may provide a service that is too difficult or expensive for the market or government to provide (e.g. this may explain some of the success of community-based rehabilitation for PWD in India and elsewhere). They can be more precise in their appraisal of the extent and consequences of a person's impairment. Care of a PWD will not be over-provided by family or community, and is not prone to exploitation in the same way as a public program. The "insurance" in this case is implicit in the expectations of reciprocity among family members and of the community at large – both of which are very different in different cultural environments.

19. ***If effective household and/or community support is dependent a sense of reciprocity with the PWD, the most vulnerable PWD are those who do not have a sufficient support system within their community.*** This may be either because their connections to those with resources are few or weak (which may be driven by reasons such as social stigma, caste, age or gender), or because the people they can depend on (typically their family) are very poor themselves. There can thus be two weaknesses of social action – one that is driven by the absence or thinness of networks of reciprocity, and one that is driven by the limited capacity of social networks to provide support. There are reasons to expect that the lives of PWD are characterized by both these weaknesses more than average. Empirically, a typical feature of disability in all countries appears to be more limited social networks (in particular due to stigma) and higher household poverty. ***The effectiveness of social action in both promoting opportunities and providing basic social protection for PWD is thus likely to be unusually constrained.***

20. ***What is the role of government in the context of community-provided care (either by informal community institutions or the family?*** The direction of help may be two-way. Firstly, governments may choose to help the disabled for the sake of alleviating poverty – not only for the PWD but for the entire support system if care-takers are themselves poor. Secondly, government programs for PWD may be able to use the greater and more detailed information available in the community in the identification of beneficiaries and, possibly, the extent of entitlement.

21. ***In light of the challenges that face market, government and social action in the field of disability, what combination of interventions seem sensible for trying to address different forms of failure?*** There is not is simple answer to this question. Different combinations appear more appropriate for different aspects of PWD lives (e.g. employment versus education), for PWD in different settings (e.g. urban/rural), and also for people with differing types of degrees of disability. For example, government and market action may be easier in urban areas with concentrated populations of disabled people, while collective action may be more readily mobilized in rural settings among groups where social cohesion is strong. The approach also needs to take account of binding commitments of the state to PWD – e.g. where legal rights have been guaranteed to PWD. The rest of the report deals with the issues outlined above in turn.

CHAPTER 1: SOCIO-ECONOMIC PROFILE OF PERSONS WITH DISABILITIES

1.1. This chapter presents a socio-economic profile of persons with disabilities in India. It is based primarily on data from the 47th and 58th NSS rounds and the 2001 census, but is supplemented by analysis from a dedicated survey in rural UP and TN carried out in 2005.

A. Socio-economic profile of PWD

1.2. ***(a) Disability Prevalence:*** The starting point is an estimation of the total number of PWD in India. ***On this point, the two major official sources of data on disability differ, with the census estimate around 18 percent higher than NSS estimates***. The 2001 census found 21.91 million PWD (2.13 percent of the population), while the 2002 NSS round's disability estimate is 1.8 percent of the population, which would come to around 18.5 million (Table 1.1). The difference in aggregate estimates is in part explainable on the basis of different definitions used in the NSS and census for disabilities (see Annex 1). Both sources find disability rates to be higher among men and higher in rural than urban areas. In fact, the 58 percent share of males in total PWD estimates is worthy of further exploration.

1.3. Just as importantly in terms both of the impact of disability in the population and in terms of political economy and voice among people with disabilities, is the share of households estimated to have a member with a disability. ***The NSS for 2002 estimates that 8.4 percent of rural households and 6.1 percent of urban households had a member with a disability.*** These higher figures are important for several reasons. Firstly, the direct impacts of a disabled household member will clearly go beyond the individual with the impairment (as, for example, the chapter in impacts on non-disabled family member work participation in Chapter * indicates). Secondly, 7.8 percent of households nationally represents a significant "vote bank" which suggests that there may be more political mileage in policies to promote inclusion of disabled people than is commonly thought.

Table 1.1: Disability rates from census and survey sources, early 2000s.

PWD as share of…	Census	NSS 58th
All individuals	2.13	1.8
All urban individuals	NA	1.50
All urban households	NA	6.1
All rural individuals	NA	1.85
All rural households	NA	8.4
All males	2.37	2.12
All females	1.87	1.67

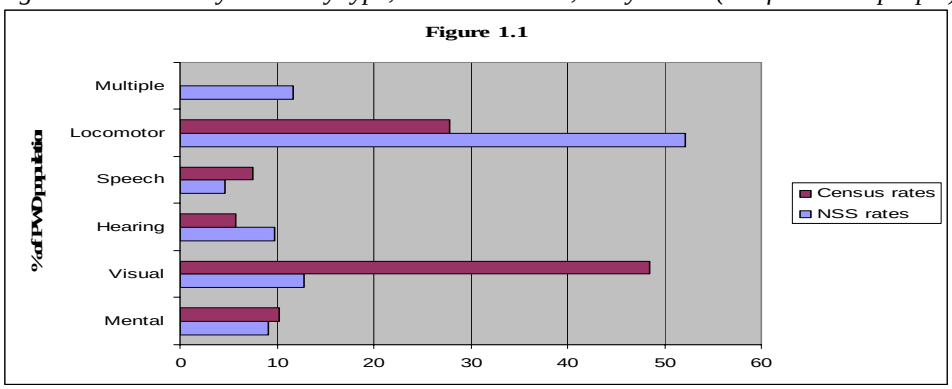
Sources: Census 2001 and NSS 2002.

1.4. ***Looking at the prevalence of specific disability types, the divergence between census and NSS estimates are very pronounced for locomotor and visual disabilities*** (see Figure 1.1). While they also differ significantly for both hearing and speech disabilities, the inclusion in NSS of multiple disabilities is a factor, as speech and hearing disabilities may be more likely to combine. The locomotor and visual disability differences are however much more sharp and can

not be explained by this. The major driver of the differences appears to be definitional, with the census defining visual disabilities more broadly and vice versa for movement disabilities.[12]

Census and NSS sources give a divergent picture of the composition of disability

Figure 1.1: Disability shares by type, census and NSS, early 2000s (% of disabled people)



Source: NSS, 58th round and census, 2001.

1.5. ***The aggregate number of PWD in India is keenly disputed, with alternative estimates invariably higher than official ones.*** [13] Higher estimates are based on several arguments:

- ***exclusion of disability categories in both NSS and census***. The reliance on PWD Act categories is a limiting factor. There are numerous examples of excluded disability categories, including autism, thalassemia, haemophilia, and many learning disabilities.
- ***the method of questioning on disability in both census and NSS which relies on a traditional "diagnostic" identification of disability by untrained interviewers, which recent work coming out of a UN expert group suggests is the method which yields the lowest disability estimates.*** Box 1.1 notes the various methods and issues involved. Simply asking whether or not people have a disability (and what type) has been found worldwide to yield lower bound estimates of prevalence, with a strong bias towards more serious disabilities.
- ***disability-specific surveys which have found often substantially higher rates of disability in cases where interviewers have been far better trained on detection and probing.*** Examples include: a meta-analysis of mental illness incidence gives an estimated prevalence of 5.8 percent of the population based on dedicated surveys. [14] A GoI/WHO survey in the 1980s estimated visual disabilities at 1.5 percent of the population, a share that may have grown based on a national estimate of blind persons in 2000 of 18.7 million, of which 9.5 million were cataract-related and 3 million refractive error-related. [15] Naturally, different studies are subject to differences in approach and definition, but careful work by well-trained interviewers using better instruments and with reasonable definitions of disability have produced substantially higher estimates of disability prevalence than official statistics. The

[12] Bhanushali (2005). GoI has recognized a number of these issues, as summarized in the 2006 Technical Advisory Committee report on Disability Statistics.

[13] See Puri (2005) prepared as background material for this report, which provides a comprehensive summary of micro-studies on prevalence of different forms of disability in India.

[14] Khandelwal et al. (2004).

[15] Dandona et al (2001). If there is no change in the current trend of blindness, the study estimates that the number of blind persons in India would increase to 24.1 million in 2010, and to 31.6 million in 2020.

higher estimates are also more consistent with comparable international estimates of disability from WHO and individual countries.

- ***it is clear from primary field research from this report (and previous work) that significant categories of people who are functionally disabled will not typically be identified by households as being disabled.*** The primary example of this is elderly people with significant functional impairments who were not disabled before they became old. In field work, the standard answer on probing was that even seriously functionally impaired elderly people were "just old" or "like many other old people" rather than disabled. The main exception was elderly disabled people who were disabled before becoming old. Given the relatively higher rates of functional disability among elderly populations worldwide, such cultural factors are likely to be a significant source of under-estimation of disability prevalence.
- ***the social stigma attached to disability is also likely to contribute to under-estimation.***[16] Chapter 2 provides insights on the strong stigma often attached to disability in India. Stigma – as in many countries – seems to be particularly pronounced for mental illness and mental retardation. Stigma is a factor in many countries, but Indian notions of karma seem likely to make the problem of lack of identification by households more pronounced in India.

1.6. ***Due the above and other factors, official disability estimates in India can therefore be considered a more reliable estimate of serious disabilities, particularly for mental retardation and mental illness.*** A more inclusive definition would appear to include around80-90 million people. It is stressed that the total figure of over 90 million (or around 8 percent of the population) is not intended to be "the" estimate of disability prevalence, but simply to indicate that reasonable alternative definitions and reliable sources find a possible prevalence rate of disability which is considerably higher than the official NSS and census estimates. It also points to be great importance of mental illness in overall prevalence, an area of particular difficulty in measurement. This points to the complex issues of both definitions for measurement and of conducting interviews with non-specialist interviewers.

1.7. ***International evidence from developing and developed countries provides useful insights for interpreting both official disability estimates for India and those from reliable alternative sources.*** Several pertinent findings on international experience in estimating disability prevalence are:

- ***how disability questions are asked matters, and India's methods of asking in both NSS and census tend to generate the lowest disability estimates worldwide.*** This can be seen in Table 1.2, where prevalence rates are seen to vary sharply according to how the disability questions are asked. Interestingly, many countries find a prevalence range of 1-3 percent using India's current method of asking disability questions, while activity-based questioning yields higher rates. More detail on the different approaches is provided in Box 1.1.

[16] See Harriss-White (1995).

Table 1.2: Disability Prevalence rates by country and disability question method, various years

Country and question type	Disability prevalence rate (% of population)
Do you have a disability ? Yes/No	
Nigeria	0.5
Jordan	1.2
Philippines	1.3
Turkey	1.4
Mauritania	1.5
Ethiopia	3.8
Jamaica	6.3
List of Conditions	
Colombia	1.8
Mexico	1.8
Palestine	1.8
Chile	2.2
Uganda	3.5
Hungary	5.7
Activity-based questions	
Poland	10.0
United Kingdom	12.2
Brazil	14.5
Canada	18.5
United States	19.4

Source: Mont (2007)

- ***it is not unusual for different official surveys from the same country to yield different estimates of disability, even where interviewer capacity is high.*** An extreme case is provided by Canada, which has estimates from various official sources ranging from 13.7 to 31.3 percent. In the region, there are also significant variations across source in disability estimates, e.g. in Sri Lanka, the census-based estimate is 1.6 percent, while a UNICEF survey estimated around 4 percent prevalence.
- ***official disability prevalence rates tend to rise with country income levels.*** This is a product of various factors, but would appear to be less about the "true" rates of disability (though older age structures are a factor in that respect) as other factors. These include more inclusive definitions of disability, better measurement and identification, social security systems which provide incentives to self-declare as disabled etc. [17]
- ***despite the general pattern of rising disability rates with higher country income, developing countries which have implemented more advanced survey and census-based measurement have found notably higher prevalence rates of 10-15 percent of the population.*** Three notable examples are Brazil, Zambia and Nicaragua, which also demonstrate that new forms of measurement can be achieved even in very low income and capacity settings. Brazil for example moved from around a 1 percent prevalence rate to 14.5 percent with a change in the method of asking questions in its census. Using other household surveys with improved methodology, Nicaragua's rate is just over 10 percent, while Zambia has a rate of around 13 percent. The example of the change in questions for Brazil is given in Annex 2.

[17] There may also be strong political incentives to increase disability rolls, e.g. prior to elections, when political incentives drive recategorizing of "unemployed" people to "disabled". Another example is during periods of economic restructuring (as for example, in transition countries during the 1990s) when putting laid-off older workers onto disability benefits may provide more sustained post-layoff social protection and dilute public perceptions of the unemployment impacts of enterprise restructuring.

Box 1.1: Different approaches to asking about disability in census and surveys

The UN Statistics Division has formed the Washington City Group on Disability Statistics, which is focused on measurement of disability in national censuses and surveys (website is http://www.cdc.gov/nchs/citygroup.htm). There are broadly four methods of trying to identify disability in surveys, which are:

- **Diagnostic:** An example of this approach would be "Is anyone in house deaf ?". This method tends to generate the lowest prevalence estimates among those now available and is the one used in India for both NSS and census.
- **Activities of daily living (ADL):** This method relies on a functional approach based on common activities of individuals. An example of this approach would be "Do you have trouble bathing or dressing yourself ?". This yields higher prevalence estimates than the diagnostic approach, but can be very culturally sensitive for purposes of cross-country comparison (e.g. putting on a sari is a more demanding task than putting on a skirt).
- **Instrumental ADL (IADL)**: This asks about more complex functionings, e.g. "Do you have trouble maintaining the household ?". This tends to yield the highest rates of disability, but can more often include those with chronic illness who may not otherwise be classified as disabled.
- **Participatory/social roles** – This method is underpinned by a social model of disability. An example would be "Do you have a mental or physical impairment that limits the type/amount of work you can do ?". This would tend to yield prevalence estimates between diagnostic and ADL/IADL approaches.

Source: UN Washington City Group

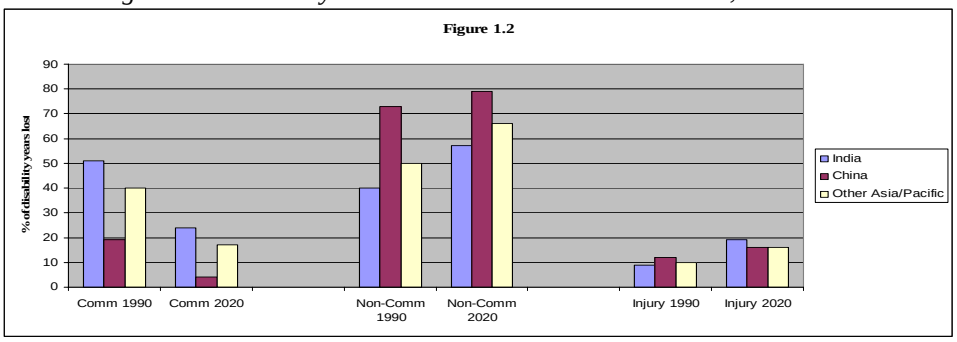
1.8. ***Such methods have recently been piloted in India by WHO/UNESCAP and lead to notably higher disability prevalence rates (of over 20 percent), pointing to the importance of not having a single prevalence rate for multiple purposes.*** While the surveys were not sampled to be nationally representative, they point to both the very different results that are obtained using different approach to investigation of disability.[18]

1.9. The above estimates rely on national census and survey work. An alternative approach to estimating disability prevalence and trends by cause is to estimate the total years lost due to disability using the DALY methodology. This method is open to a number of criticisms [19], but is nonetheless of interest in comparative terms. An interesting insight the method provides is comparative estimates of the shift in the main drivers of years lost to disability between 1990s and 2020. This is presented below for India, China and other Asia/Pacific countries.[20] ***All are in the midst of a disability transition, but the pace of that transition in India is predicted to be most rapid. Between 1990 and 2020, there is predicted to be a halving of disability due to communicable diseases, a doubling of disability years due to injuries/accidents, and a more than 40 percent increase in the share of disability years due to non-communicable diseases (e.g. cardiovascular and stroke).*** An additional point of note is that around half the disability from non-communicable disease for South Asia is estimated to be due to neuropsychiatric disorders (mainly mental illness and mental retardation), suggesting that 30 percent of total years lost to disability in India by 2020 could be due to these causes. This is of interest in that it appears to confirm that mental illness and retardation are significantly under-estimated in official statistics (as the national research referred to above also strongly suggests).

[18] See Mont, op.cit, for detailed results, including comparative information from 4 other developing countries.
[19] See Mont (2006) for a persuasive criticism of the DALY approach from a disability perspective.
[20] Murray and Lopez (1997).

The share of disability impact due to communicable causes is falling sharply in India and much of Asia, with the share due to non-communicable diseases and injuries rising

Figure 1.2: Disability transition in various Asian countries, 1990-2020



Source: Murray and Lopez, 1997.

1.10. Numbers from a variety of reliable sources suggest that ***the real prevalence of disability in India could be easily around 40 million people, and perhaps as high as 80-90 million if more inclusive definitions of both mental illness and mental retardation in particular were used.*** The focus of this report is not on precise prevalence estimates of disability in India. However, the large range in estimates both of the number of disabled people and what is the composition of their impairments points to the need for improvements in public data collection efforts.

1.11. **(b) <u>Socio-economic characteristics of households with disabled members</u>:** Despite the above concerns, it is useful to examine the socio-economic profile of PWD in India that emerges from NSS and census. With respect to education, health and employment, more detail is provided in Chapters 3-5. The socio-economic characteristics of households with PWD and others can be done using the 58th and 47th rounds of NSS. The PWD schedule and main schedule are not the same sample, but are representative of the PWD and general populations respectively. Key points are in Table 1.3. [21]

- ***one notable difference between the characteristics presented is the urban share of the PWD and general household populations,*** with the urban share of the general population over 20 percent higher than for the PWD household population, pointing to issues with access to health care, the nature of work, and other factors. In terms of the relative poverty rates of PWD households, this is likely to have significant implications, as national estimates from 1999-00 find rural poverty rates more than double those in urban areas. [22]

- the share of illiterate or basic education HH heads in PWD households is only marginally higher than for the general population. However, the share of heads in PWD households with secondary or higher education is around 15 percent lower than the general population. These rates are of interest in terms of poverty correlates of PWD households, and would suggest slightly higher poverty rates among PWD households.

[21] Unfortunately, direct comparison of per capita consumption is not possible between PWD and non-PWD households from NSS, as the disability module has a different consumption aggregate.
[22] See Deaton and Dreze (200*).

Table 1.3: PWD and general population social characteristics, 2002

Household characteristic	General population	HHs with PWD
ST	8.1%	6.9%
SC	20.2%	21.1%
OBC	39.9%	42.0%
Female headed	7.7%	7.2%
Urban	26.1%	21.6%
Land owned (hectares)	0.83	0.95
HH head illiterate or primary/less education	65.8%	66.7%
HH head with secondary/higher education	20.3%	17.2%
Household size	7.23	6.05
Age of HH head	45.98 years	50.04 years

Source: NSS, 58th round, Bank staff estimates.

- ***a finding that runs contrary to the above findings of higher of poverty in several indicators is that PWD households have higher than average land holdings.*** This is not simply an artifact of the higher rural population share among PWD households, as the rural-only sub-samples indicate around 10 percent larger average land holding than for general population. Another is that ***the differences by SC/ST status are not dramatic between PWD and non-PWD households, with PWD having only a slightly higher aggregate share of SC/ST/OBC.*** The share of SC/ST households among PWD is of significance in terms of likely poverty rates, both have higher than average poverty rates. [23]

1.12. The rural UP and TN survey provides insights into a wider range of comparable welfare measures between PWD and non-PWD households. The results are presented in Figures 1.3 and 1.4 below. Figure 1.3 presents the incidence of a disabled or severely disabled household member by quintile, using an asset index to rank household welfare. The incidence of disability was estimated based on an ADL approach. Figure 1.4 presents findings again by quintile for two measures – first a per capita consumption ranking and secondly an asset ranking. The difference is that presence of disability is in this figure based on community identification of households with a disabled member. A few points emerge:

- ***there is a clear decline in the proportion of people with disabilities of all severity (using an ADL measure) as the wealth of households rises.*** There are more PWD in poorer households in rural UP and TN.

- ***a similar pattern can be seen where the measure of disability is community identification of whether or not a household has a disabled member.***

- a further finding of interest is that consumption measure captured only a very weak disability and poverty correlation when the ADL measure was used to identify PWDs, while the link between poverty and disability is quite pronounced using the consumption measure when community identification of PWDs is used. This is an interesting finding for research on disability survey methodology.

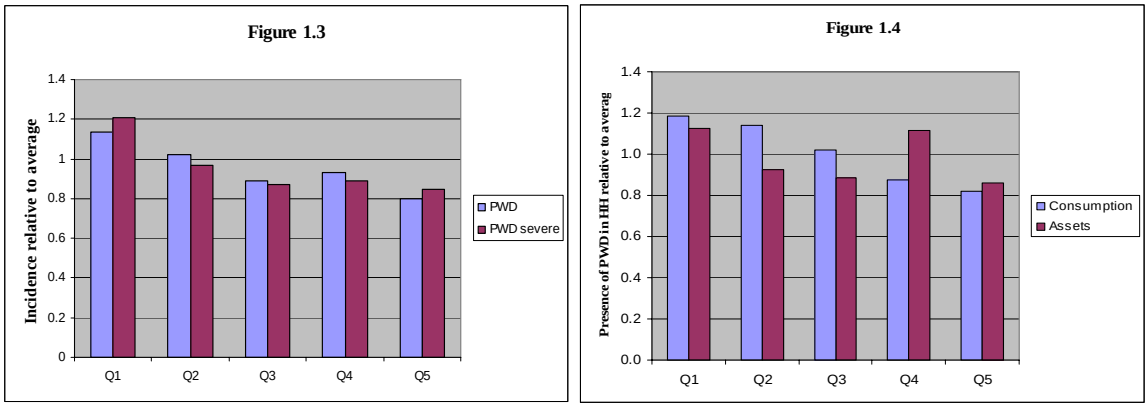
[23] See Sundaram and Tendulkar, in Deaton and Kozel (2005) on SC/ST poverty rates.

- It is also important to recall Sen's "conversion handicap" for disabled people, i.e. that equivalent levels of income are less easily converted into individual welfare by PWD. Taking account of this factor would further widen the gap between PWD and non-PWD households.

In rural UP and TN, disability is clearly associated with lower economic status

Figure 1.3: Relative share of PWD and severe PWD by asset quintile, UP and TN, 2005

Figure 1.4: Relative HH share with PWD by consumption and asset quintiles (community identification), UP and TN, 2005



Source: UP and TN village survey, 2005, Bank staff estimates. Q1=poorest and Q5 richest quintiles.

1.13. ***There are several other non-income indicators at the household level from the village survey which are of interest, and most of which also point in the direction of households with PWD being worse off than average.*** Those which were statistically significant are presented in Table 1.4. While the differences are not in most cases dramatic, several points are worth noting:

- ***the key welfare indicator of three meals a day year-round shows a clear difference, with PWD households almost one quarter less likely to report a positive answer.***
- there are also significantly lower rates of ownership of key assets for PWD households.
- interestingly, the share of SC households with disabled members was substantially lower than the households without disabilities.

Table 1.4: Non-income indicators for households with and without PWD, UP and TN, 2005

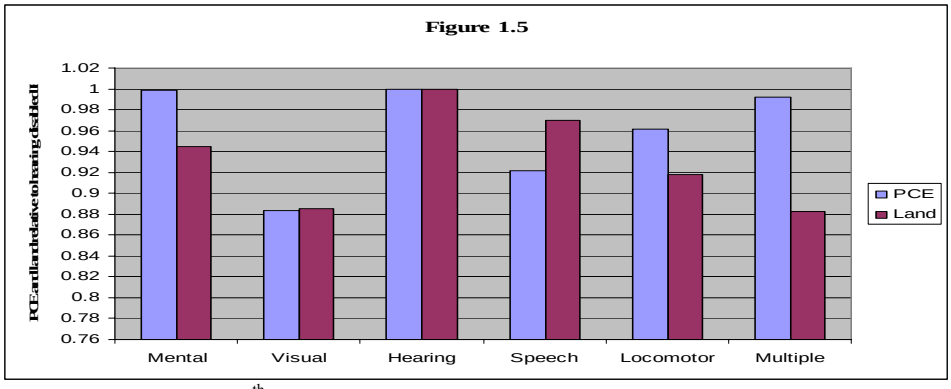
Indicator	HH without PWD	HH with PWD	HH with severe PWD
Three meals per day year round	47.9%	36.7%**	37.4%**
Pucca floor	39.9%	34.1%**	34.9%
Good light source	48.3%	42.2%**	42.8%
Good toilet	6.9%	4.1%**	4.0%*
Making some savings	35.9%	32.7%	30.1%**
Scooter/motorbike	16.9%	12.5%**	12.1%**
SC household	28.2%	20.4%**	20.9%*

Source: UP and TN village survey, 2005, Bank staff estimates. ** = significant at 5%; * = significant at 10%.

1.14. A final point which the NSS allows to explore is the relative welfare *among* households with a disabled member by disability type. This is not subject to the same problems of a different consumption measure as with comparisons to households without a PWD. Results for both per capita household consumption and land holdings are presented in Figure 1.5. ***Overall,***

households with a hearing disabled member are the relatively best off among households with disabled members whether measured by consumption or land. Equally, households with a visually disabled member seem to be the worst off across both measures, around 12 percent lower PC expenditure and 12 percent smaller average land holding. What is harder to interpret are the differences in relative situation of other disability types across the expenditure and land measures. Equally, the relatively good position of households with a person with mental disability is unexpected.

Figure 1.5: Relative per capita HH consumption and land holdings by disability type, 2002 (hearing disabled as reference)

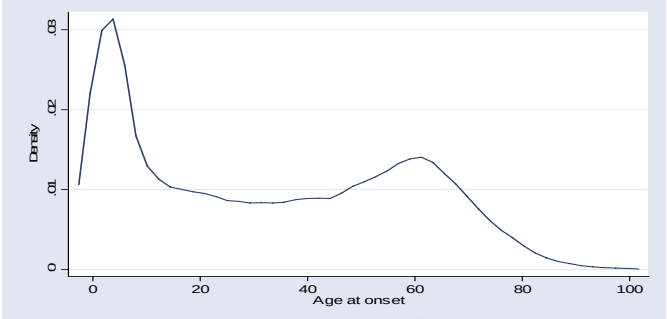


Source: NSS, 58th round, Bank staff estimates.

1.15. **(c) <u>Socio-economic profile of people with disabilities</u>:** The above characteristics relate to households within which PWD live. Of even greater importance is the socio-economic profile of PWD themselves. This is dealt with in greater detail in chapters on health, education and employment. However, some details are presented in the following section, above and beyond the incidence data already discussed.

1.16. An important issue for policy and planning purposes is age at onset of disability. In all countries, this will shift over time, generally towards later onset as maternal-child health systems improve, infectious diseases are superseded by age and lifestyle related conditions, and the share of accidents in total disability causes shifts. ***For India, 2002 data on age at onset of disability are in Figure 1.6, and show an expected double peak, with the highest rate of disability occurring at or shortly after birth, though with a second noticeable hump in onset from the 50s to early 60s. Just as important is that the disability-specific patterns of onset vary considerably.*** This is discussed in detail in Chapter 3, but show the critical importance of early childhood identification of disability and intervention.

Figure 1.6: Kernel Density of Age at Onset of All Disability - 2002



Source: Das (2005), based on NSS 58th Round

1.17. A second issue with obvious implications for policy is how severe are the disabilities of people with disabilities in India? Table 1.5 presents the NSS indicator, which is extent of reliance on aids and appliances and other people for self-care. ***The key point is that the bulk of PWD are only mildly/moderately impaired by the NSS measure.*** In addition, a further sixth of PWD are capable of self-care with the necessary aids and appliances. This is an important point to stress, and has significant implications for education policy and implications for the employment capacities of PWD.

Table 1.5: Reported extent of disability among PWD, 2002

Extent of disability	Share of all PWD
Can not take care of self even with aid-appliance	13.6%
Can take care of self only with aid-appliance	17.2%
Can take care of self without aid-appliance	60.2%
Aid-appliance not tried/available	9.0%

Source: NSS, 58th round. Bank staff estimates.

1.18. A second key social indicator that the NSS reports is education enrollment and attainment. Educational indicators were also captured for PWD in the 2001 census. The summary results are reported below, with more detailed analysis and econometric findings presented in the education chapter. Figure 1.7 presents educational attainment levels for PWD and the general population averaged across all age groups, using 2001 census data for both groups. ***It shows substantially higher rates of illiteracy among the PWD population relative to general, and conversely lower shares of PWD with higher levels of educational attainment.*** Across all PWD, illiteracy is 52 percent, versus only 35 percent in the general population. For specific disability categories, the illiteracy rates are higher again: with almost two thirds of both speech and mentally disabled people being illiterate. Conversely, those with locomotor disabilities have 44 percent illiteracy rate, significantly lower than the PWD average but still one quarter higher than the general population rate.[24]

1.19. ***As with the general population, there are strong gender differences in educational attainment among PWD, with PWD female illiteracy rates on average 64 percent (against a male PWD average of 43 percent), and as high as 73 percent for the visually disabled.*** There are also strong locational differences as one would expect, with the total PWD illiteracy rate for rural areas as high as 57 percent, against a rate of 37 percent in urban areas.

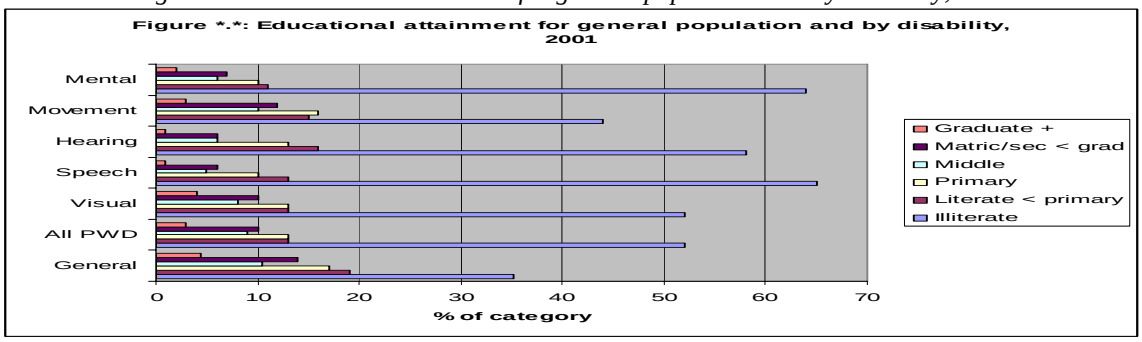
1.20. While Figure 1.7 is important, of most immediate relevance is school attendance of the current batch of children in general education, as this is a group for whom improvements could occur in time to affect their lifetime attainment. Nationally representative figures from survey conducted in 2005 are presented in Figure 1.8 which show the proportion of children out of school along various social indicators, including disability.[25] ***The share of disabled children who are out of school is dramatically higher than other major social categories, with the average out-of-school rate for CWD five and a half times the rate for all children, and around four times even that of the ST population (generally considered to have poor educational outcomes).***

[24] NSS data from 2002 show even higher rates of illiteracy among most PWD categories, most notably visually disabled.

[25] These can be considered very much lower bound estimates, as school attendance for the purposes of the survey was not required every day. Other national attendance data from Pratham from 2005 suggest that regular attendance rates for all children may be around 70 percent.

PWD have high rates of illiteracy relative to the general population, for some disabilities close to double national averages

Figure 1.7: Educational attainment for general population and by disability, 2001

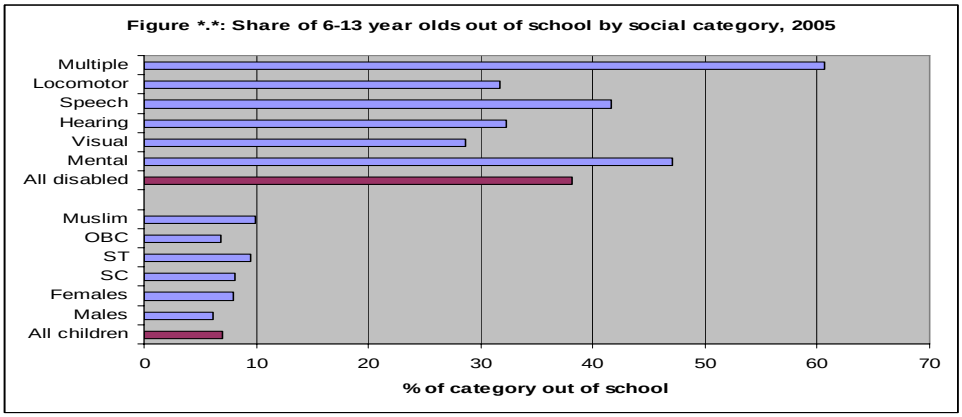


Source: Census, 2001.

1.21. ***In addition to the very high average rates of out-of-school children among disabled children, the rates among some disability categories are extremely high, with more than 60 percent of multiple disability and almost half of mentally disabled 6-13 year olds out of school.*** Even the lowest disability group (surprisingly, visual) have almost 30 percent of children in the general education group out of school. It is very clear from these numbers that India's hopes of reaching the educational MDGs are highly unlikely to be realized unless there is major improvement in getting CWD into school.

The proportions of children with disabilities out of basic education is dramatically higher than national averages for non-disabled children

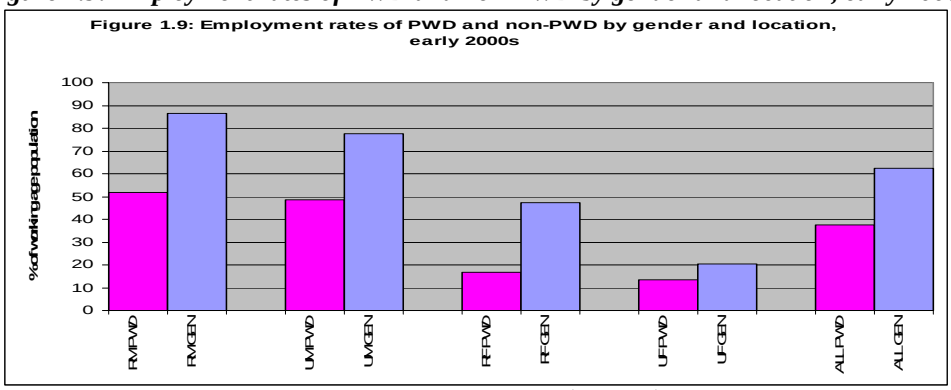
Figure 1.8: Share of 6-13 year olds out of school by social category, 2005



Source: SRI (2005)

1.22. In terms of individual and household welfare, employment is a key variable for analysis among disabled adults. This is discussed in detail in Chapter 5, but summary statistics are presented in Figure 1.9, which indicates that ***PWD employment rates were substantially below those of the general population in both urban and rural areas and for both genders.*** Chapter 5 also shows that the relative employment situation of people with disabilities has deteriorated during the 1990s, with those with the lowest educational levels doing the worst.

Figure 1.9: Employment rates of PWD and non-PWD by gender and location, early 2000s

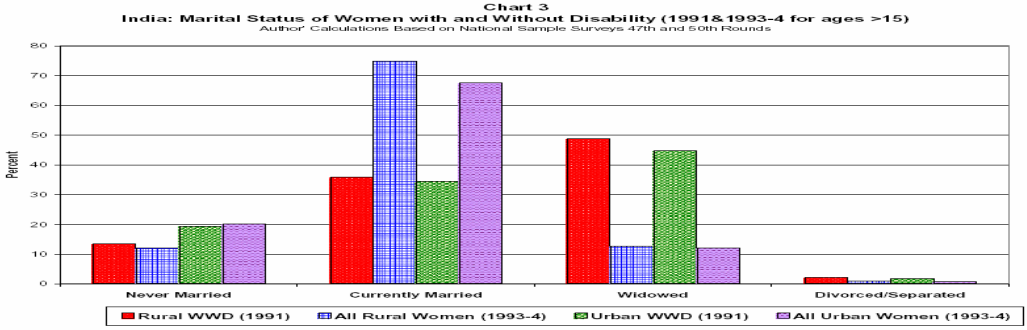


Source: Mitra and Sambamoorthi, based on NSS 58th and 47th rounds in 2002 and 1991 (PWD) and 55th and 50th rounds in 1993/94 and 1999/00 (non-PWD).

1.23. A final key individual welfare indicator for women is marriage and widowhood rates. It has been clearly shown that widows in India have much lower average living standards, and much sociological literature attests also to their low social standing and high levels of vulnerability. [26] ***NSS data indicate that women with disabilities have much higher rates of widowhood than women without disabilities in both urban and rural areas – in both cases around four times the non-WWD rate.*** Conversely, the proportion of women with disabilities who are currently married is much lower than non-disabled women. This can be seen for the first half of the 1990s in Figure 1.10. The explanation for such differential rates can most likely be found in the common practice of marrying of women with disabilities to men much older than themselves – men who are unable to find more "marketable" brides.[27]

Rates of widowhood for women with disabilities are around four times those of women without disability, and the share of women with disabilities who are married is around half

Figure 1.10: Marital Status of Women with and without Disability (1991&1993-4 for ages >15)



Source: Das (2006).

B. Conclusions and recommendations

1.24. ***A range of non-income indicators, together with the asset and consumption findings from the UP and TN survey, cumulatively suggest that PWD households and individuals are notably worse off than average***. These include:

[26] Dreze (200*).

[27] See Unnati and Handicap International (2004) for more detailed marriage data and qualitative insights on the marriage practices of men and women with disabilities in Gujarat.

- much lower educational attainment rates, associated in India with lower living standards.
- substantially lower employment rates. This is not definitively an indicator of lower living standards in India, due to cultural preferences with respect to womens' work outside the home and features such as higher unemployment rates among the educated. However, taken together with the much lower education rates of PWD, it is probably a good indication of lower living standards.
- clear evidence from the UP and TN survey of declining rates of disability in households as they become richer.
- non-income indicators from UP and TN like frequency of three meals a day.
- the higher than average rural share in the PWD household population, with considerably higher than average poverty rates in rural areas nationally.
- the very high rates of widowhood for women, implying higher probabilities of being poor.
- consistent findings from qualitative work (both in the UP/TN study and in other studies in India on disability) of community perceptions that households with disabled members tend to be poorer and more vulnerable.[28]

1.25. Clearly much remains to be done in getting a clearer picture of the scale and composition of PWD in India. This is a large agenda, but some initial recommendations are:

- ***there is a need to harmonize definitions of disability categories across NSS and census. In this process, there is also a need to improve and harmonize the approaches across disability types within each survey.*** This has been recognized by GoI in the work of its Technical Advisory Group on Disability Statistics. Specifically [29]: (i) in the census, there are inconsistencies across disability types as to whether the functional limitation applies to a situation where an assistive device is used, an overly wide definition of visual disability, and an overly subjective definition of some elements of mental illness; and (ii) in the NSS, the current definitions of disability and disability types are a mix of activity limitation (general definition, visual and mental disability), functional limitations (e.g., speech) and impairments (e.g. locomotor) which result in inconsistent approaches across disability type.

- ***in both census and NSS, piloting new methods of asking disability questions which are more in line with good international practice as exemplified by the UN's Washington Group and by WHO.*** Box 1.2 below gives examples from the Washington Group census questions, which have already been field tested in 7 developing countries including India. [30] While these questions also have their challenges (e.g. dressing may be more difficult in some countries than others, or for women than men), and are still not well-tuned to capturing a number of mental disabilities, the general approach to look at activities of daily life is instructive.

- ***either adding additional specific categories of disability to such investigations or at least allowing for a broad "other category".***

[28] See ORG-MARG (2006) for UP and TN; Unnati and Handicap International, op.cit., for Gujarat; Erb and Harriss-White, op.cit., for TN; Lang (2000) for Karnataka; ActionAid (200*) for AP and (200*) for Rajasthan.
[29] See Mitra and Sambamoorthi (2006).
[30] The countries are Vietnam, India, South Africa, Philippines, Fiji, Indonesia and Mongolia. See Mont, op.cit.

Box 1.2: Census questions on disability designed by UN Washington Group on Disability Statistics

The Washington Group has developed some model census questions on disability, as follows:

Because of a physical, mental or emotional health condition….

72.1. Do you have difficulty seeing even if wearing glasses ?
72.2. Do you have difficulty hearing even if using hearing aid/s or are you deaf ?
72.3. Do you have difficulty walking or climbing stairs "
72.4. Do you have difficulty remembering or concentrating ?
72.5. Do you have difficulty (with self-care such as) washing all over or dressing ?
72.6. Do you have difficulties communicating (for example, understanding or being understood by others) ?

Question response options are No, Some, a Lot, and Unable.

Source: UN Washington group, cited in Mont, 2007.

- ***revising the NSS disability module for the next dedicated round, in particular*** improving how questions about disability are asked, PWD household consumption information and other welfare indicators. GoI, state governments and the non-government sector should also facilitate more detailed analysis of existing data than has been typical to date, and consider financing future analysis more systematically to address the large knowledge gaps on the socio-economic situation of people with disabilities.

- ***incorporating disability questions into mainstream health, education and other surveys to an extent not done to date.*** This includes the main schedules of NSS, so that more reliable comparisons between the disabled and non-disabled populations on critical indicators like educational attainment can be made.

CHAPTER 2: ATTITUDES TOWARDS DISABILITY AND PEOPLE WITH DISABILITIES

2.1. This chapter explores evidence on attitudes to disability in India, and their implications for public policy. Attitudes of society, families and PWD themselves contribute to converting impairments into disabilities. ***Research in India has consistently found substantial social marginalization of people with disabilities***. The attitudes of specific societies are critical in assessing both the intensity of disability (i.e. how disabling a given type or level of impairment becomes for the individual disabled person) and in assessing areas where collective action is likely to fail the disabled community, and hence public action be desirable. In addition to the attitudes of the general society, the attitudes of persons with disabilities and their families are important, in some ways even more important. At the same time, the different sets of attitudes clearly interact, so that negative views about disabled people in the broader community are likely to be internalized in many cases by people with disabilities and their household members.

2.2. ***Much of the literature on disability in India has pointed to the importance of the concept of karma in attitudes to disability,*** with disability perceived either as punishment for misdeeds in the past lives of the PWD, or the wrongdoings of their parents. As two Indian authors have put it, "At a profoundly serious and spiritual level, disability represents divine justice". [31] At a more mundane level, people with disabilities are traditionally perceived as somehow inauspicious. Much qualitative research has found considerable social marginalization of people with disabilities in India, though most also acknowledge that the social status of the PWD's family has an impact on their potential acceptance in society. Box 2.1 discusses images of PWD in Hindu mythology and Bollywood cinema by way of illustrating popular culture perceptions of people with disabilities.

2.3. Research from urban and rural Andhra Pradesh in the early 2000s asked people about whether disability was a punishment or curse of God.[32] The researchers found around 40 percent of respondents agreeing that it was, with the share of people holding such views increasing with age, being higher among women, higher for lower socio-economic groups, and higher for those who were illiterate. Interestingly, there was not a major difference in such views between urban and rural respondents, though urban people were slightly less likely to hold such views. This is in contrast to earlier qualitative research in Karnataka, which had found higher belief in medical causes of disability in urban populations.[33]

2.4. The present study asked a similar question for a much larger sample of households in rural UP and TN, and the results are presented in Figure 2.1. ***For both households with and without a disabled member, around half the respondents believed that disability was always or almost always a curse of God.*** The variations in this belief between the two states were not dramatic. An additional interesting result was that in UP respondents in households with a PWD had a 15 percent higher share with this belief than households without a PWD member.

[31] Bacquer and Sharma (1997); Coleridge (1993), Miles (1995), and Erb and Harriss-White (2002).
[32] Rao et al (2003). Such insights are supported by qualitative work in rural AP by ActionAid (200*).
[33] Lang (2000).

Box 2.1: Disability in Indian mythology and Bollywood movies

An interesting perspective on Indian attitudes to disability is two forms of mythology: the traditional Hindu myths which still play an important role in shaping social norms and values, and the "modern myth machine" of Bollywood, which has impacts on popular culture and society.

In Hindu mythology, the portrayal of people with disabilities is overwhelmingly negative, but also exhibits a strong gender bias in terms of the perceived capacities of disabled men and women. Disabled men in the Hindu myths are in some cases powerful and capable people. However, the visually impaired king Dritarashtra and the orthopedically impaired Shakuni side with the forces of evil in the Mahabharata war. Such images of powerful but evil and cruel disabled men have been reinforced by historical figures such as Taimur Lang. In contrast, women with disabilities in Hindu mythology are simply irrelevant. A prime example comes in a story from the *Karthik Poornima*, where Lord Vishnu refuses to marry the disfigured elder sister of Lakshmi, saying that there is no place for disabled people in heaven. The sister is instead married to a peepul tree.

In Bollywood films in which PWD feature, several common images of disabled men and women emerge. Firstly, the disabilities of hero(ine)s are typically acquired after birth rather than congenital, "normalizing" the actor somewhat. Equally, the disability is quite often cured during the course of the film. In addition, the stars are often from better-off socio-economic strata, with resources to promote their integration, though they remain often dependent on others. Apart from these similarities, ***there are also gender differences in perceptions of disabled people in Bollywood movies.*** First, men with disabilities feature far more often than women with disabilities. Second, men with disabilities are often loved by a devoted woman without disabilities (as in *Saajan*), whereas women with disabilities are rarely loved by men without disabilities (and in cases where they are such as *Mann*, the men loved them before the onset of disability). Third, women with disabilities almost never attain economic self-sufficiency. While male stars with disabilities may not be very wealthy, they can attain such independence. Finally, the disabilities that women are portrayed with are very rarely ones that impact their physical appearance, so that they largely remain beautiful. Overall, women with disabilities in India cinema are doubly weak – women and women with disabilities. This contrasts to more frequent portrayals in Hollywood cinema of women with disabilities who have strength and discover independence.

However, it is important also to note films that have sought to enhance the sensitivity of society towards the needs, rights, sensibilities and potential of people with disabilities - *Sparsh, Black, Koshish* (both old and new), *Jagriti, Dosti, Main Aisa hi hun and Koi Mil Gaya* to name a few. *Lagaan* is an excellent example of a mainstream film that has highlighted the process of inclusion of a dalit disabled person. In the absence of opportunities for interaction between people with disabilities and society at large, such films have played an important role in highlighting aspects of the lives of people with disabilities that are not clearly understood and in dispelling myths and biases that society holds about them. Films such as those noted have also demonstrated the attempt of non-disabled people to understand people with disabilities.

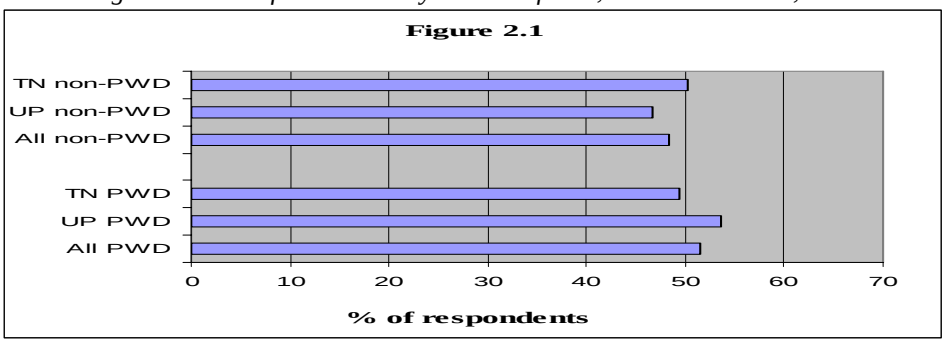
At a different level, there are initial but interesting initiatives in the NGO sector on the issues of media and people with disabilities. There have been already two national film festivals on disability issues, and a third focusing on mentally challenged people was held in November 2006. Related to this, NGOs have also tried more directly to stimulate film and media material by PWD themselves, and to engage the Indian film and television industry on disability issues. For example, Brotherhood, a Delhi-based NGO, has organized training workshops for people with disabilities on film making, and conducted sensitization sessions with Indian scriptwriters and film-makers. As a result, short films by disabled people have been made. Brotherhood is currently seeking financial support to establish a national disability film and communication centre which would conduct research on portrayal of disabled people in film and media, develop an archive of films on disability issues, sensitize film makers, journalists and other media people, and directly support film makers, in particular disabled film-makers, through availability of basic equipment and studio facilities.

Sources: Bhambani (2003) and (2005). Sharma (2006); Materials from Brotherhood.

2.5. The results in Figure 2.1 are aggregated across different disability types. The survey also asked the same question by major disability categories, and results are presented in Figure 2.2. which show significant differences in the perception of disability as a curse according to type of disability, with both visual and mental disabilities viewed as more likely to be due to a curse of God, and non-polio locomotor disability (in most cases from injuries/accidents) significantly lower than average (though still substantial).

Half rural respondents in rural UP and TN believe that disability is always a curse of God

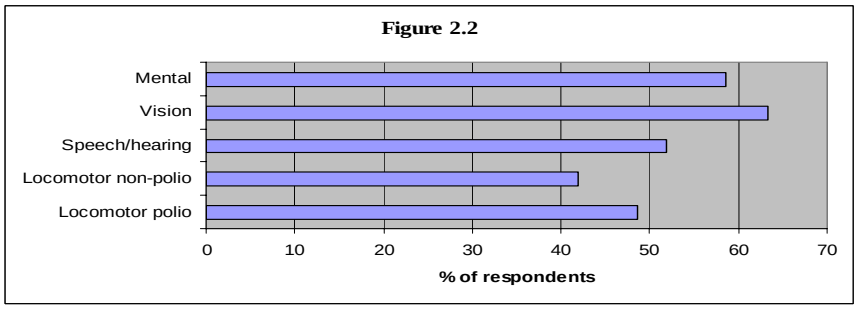
Figure 2.1: Belief that disability a curse of God, rural UP and TN, 2005



Source: UP and TN survey, 2005. % of respondents replying that disability was always/almost always a curse of God

2.6. The UP and TN study surveyed just over 1400 households with and without disabled members about their attitudes to participation of PWD in some key social and economic activities. The three major activities assessed as critical to "normal" social participation of PWD were education, employment and marriage/family life. The survey also asked about participation in local community and political life.

Figure 2.2: Belief that disability a curse of God by disability type, rural UP and TN, 2005



Source: UP and TN survey, 2005. % of respondents replying that disability was always/almost always a curse of God

2.7. With respect to education, people were asked under what circumstances children with specified disabilities could participate in regular school, and/or in special schools. Table 2.1 presents the findings on regular and special schooling. The table reports the share of respondents reporting that children with the indicated disabilities should always or almost always attend each type of school. Several interesting findings emerge:

- ***overall, there is low acceptance of children with disabilities attending regular schools.*** [34] ***At the same time, there are major differences by disability type in the acceptability of CWD attending regular schools.*** Acceptance that children with locomotor disabilities can always attend regular school is high (though acceptance that they could attend a special school is even higher). For those with vision and speech/hearing disabilities, only between a fifth and a quarter of respondents thought that they could always/almost always attend regular schools. However, for children with mental illness or retardation, there was very high agreement that they should never attend regular schools.

Table 2.1: Acceptance that children with disabilities should always attend special (top) and regular (bottom) schools, by disability type, UP and TN, 2005

Special School	Non-PWD	PWD	Severe PWD
Locomotor	96.7	95.3	96.2
Vision	91.1	87.2	88.3
Speech/hearing	86.5	82.5	83.4
Mental Ill	61.4	50.1	52.9
MR	60.8	51.9	54.0

Regular School	Non-PWD	PWD	Severe PWD
Locomotor	81.8	80.6	80.4
Vision	25.7	27.8	25
Speech/hearing	21.3	19.9	19.9
Mental ill	2	1.9	2
MR	1.1	1.3	1.3

Source: UP and TN survey, 2005. Bank staff estimates.

- ***for children with mental illness and mental retardation, almost half of respondents (including in PWD households) did not think that they could always attend either regular or special school.*** This confirms the much more serious attitudinal issues with respect to children with these disabilities.
- perhaps the most interesting overarching result is that ***households with disabled or severely disabled members exhibit very similar attitudes to those of households without disabled members.*** The small differences indicate slightly less willingness of households with disabled members to accept attendance of disabled children in regular schools.

2.8. ***Previous research has pointed to significant challenges for persons with disability in getting married and having families***.[35] Even where marriage can be arranged, disabled women in particular are frequently married to much older men, and rates of divorce and abandonment have been found to be high, as the NSS data on widowhood among disability would seem to support. Attitudes to marriage and family life were also asked in the current study and the findings are presented in Figures 2.3 and 2.4. A few observations emerge:

[34] The results receive some support from the AP survey, where 42 percent of respondents disagreed that children with disabilities could be educated in regular schools. It is also worth noting that there is a school of thought particularly for hearing and visually impaired children that supports separate education in primary school, with integration later. In India, the fact is that only around 5 percent of children with disabilities who attend school at all are in general schools, so that for the majority such options are not a practical reality

[35] See for example, Unnati and Handicap International (2004); ActionAid (200*) for AP; and Bhambani (2005) for a general discussion of attitudes to marriage of women with disabilities.

- ***overall, unconditional acceptance of a PWD marrying a non-PWD was found in only around half of households.*** This did not show much state variation. Qualitative work undertaken in parallel with the survey revealed that there was wider acceptance of PWD men marrying non-PWD women than the reverse, particularly if the men were well-off. [36] The insight is supported by survey findings from Gujarat of women with disabilities having more than double the rate of spouses with disabilities. [37] In addition, communities indicated that it would generally be easier for people with the same disabilities to marry.
- ***at the same time, more than a quarter of households in TN felt that a PWD should never marry a non-PWD.*** On this issue, the difference with UP were very pronounced.
- ***despite the majority acceptance of the possibility of PWD/non-PWD marriage, around half respondents felt that dowry would always need to be adjusted in such cases***.

Figure 2.3: Acceptance of PWD marrying non-PWD

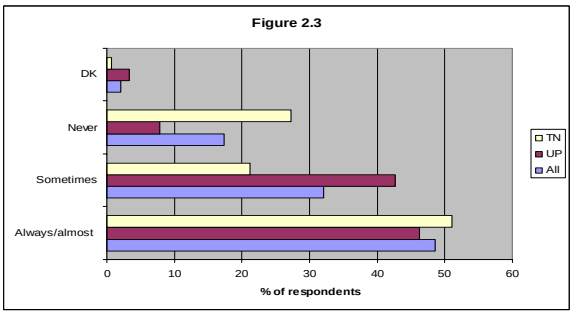
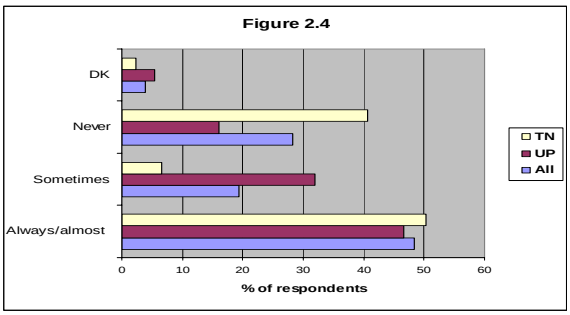


Figure 2.4: Opinion on need for dowry adjustment if PWD marries non-PWD



Source: UP and TN village survey, 2005. DK = don't know/can't say.

2.9. An important associated question was the perceived capacity of women with different disabilities to have children and care for them. Much sociological literature from India notes the fundamental importance of these roles in defining womanhood. [38] Exclusion from marriage and child rearing results in "social obscurity and annulment of femininity".[39] The results from the UP and TN survey are presented in Table 2.2 below by disability type on the proportion of households agreeing with the statement that women with specific disabilities can always/almost always have and care for children. The main points to note are:

- ***overall, positive perceptions on the ability of disabled women to have and care for children are minority views.***

- ***there is strong variation by disability type in positive perceptions, with again mental illness and mental retardation attracting the strongest negative attitudes.***

- ***there are sharp variations by state in the perceptions with respect to different disabilities.*** [40]

[36] ORG-MARG (2006). This is consistent with research on disability and marriage by Bhambani (2005), and from Erb and Harriss-White, op.cit.
[37] Unnati and Handicap International, op.cit.
[38] See Desai and Krishnaraj (199*); Coleridge (1992); Ghai (2003).
[39] Ghai. Op.cit.
[40] Research from AP found that around two thirds of respondents agreed that PWD could have happy family lives, further suggesting the possibility of inter-state variations in attitudes. Rao et al, op.cit.

Table 2.2: Positive perceptions of capacity of women with disabilities to have and care for children, UP and TN, 2005 (%)

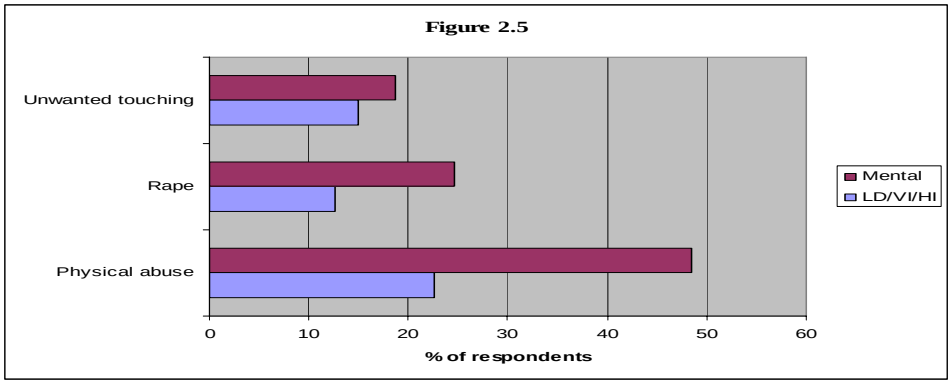
Disability	All	UP	TN
Locomotor	53.7	65.8	41.4
Vision	34.8	58.6	10.6
Hearing/speech	65	57.7	72.5
Mental illness	6.9	13.4	0.3
MR	3.6	7.2	0

Source: UP and TN village survey, 2005. % of respondents answering "always/almost always" to statement "Women with [specified] disabilities are capable of having and caring for children".

2.10. A final important element of intra-household attitudes and community views relates to violence against women with disabilities. This is a subject on which little quantitative research has been done to date in India. However, a recent study from Orissa indicates that ***women with disabilities were subject to significant domestic abuse and sexual abuse, and that the situation was sharply worse for women with mental impairments relative to women with other types of disabilities.*** [41] Results are presented in Figure 2.5 below. The results for rape are the most shocking, with fully one quarter of women with mental disabilities reporting having been raped (with the large majority carried out by family members), and almost 13 percent of women with locomotor, visual and hearing disabilities. In only a small share of cases did the women report the abuse to her family, and in the vast majority of those cases the reaction of the family was either not to listen or to pretend nothing had happened.

Women with disabilities in Orissa report high rates of physical and sexual abuse, particularly for women with mental disabilities

Figure 2.5: Women with disabilities reporting physical and sexual abuse, Orissa, 2005



Source: Swabhiman (2005). Physical abuse = "being beaten at home". Unwanted touching = "touching, pinching etc".

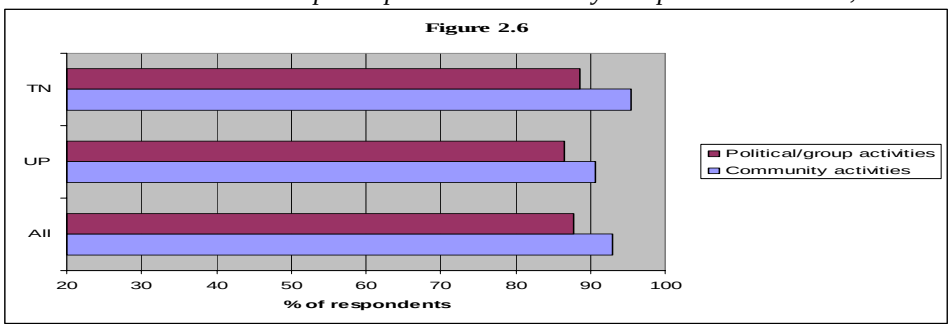
2.11. In the UP and TN survey, households were also asked about participation of PWD in community activities like festival and religious celebrations, and on participation in local political and group activities such as gram sabhas and farmers' associations. The results, presented in Figure 2.6, are far more positive than several of the attitudes presented above. ***Overall, there was high agreement with the proposition that PWD should always be allowed to participate in community activities, and almost as strong agreement that they should be included in local political and group activities.*** In both cases, the share of respondents indicating that PWD should never be allowed to participate was only around 1 percent.

[41] The results on higher levels of abuse are supported by research such as that of ActionAid in AP.

2.12. Interestingly however, ***with respect to participation in community activities, qualitative work with the same communities found that the initially positive responses weakened during deeper discussion,*** with concerns for certain celebrations such as weddings that the presence of PWD may be inauspicious. This more nuanced situation is supported by research from Orissa finding low rates of participation by disabled women in religious and social life, with the situation much worse for women with mental impairments. [42] Research in Gujarat has also found that people with disabilities attended only around half of social and religious functions and were often discouraged from attending marriages. [43] With respect to local political participation, households with PWD had similar (high) voting rates to non-PWD households in gram sabha elections, though somewhat lower attendance rates as meetings.

Attitudes to participation in community and political life of PWD are much more positive

Figure 2.6: Positive attitudes to PWD participation in community and political activities, UP and TN, 2006



Source: UP and TN village survey, 2005. % of respondents answering always/almost always to participation of PWD.

2.13. The final attitudinal questions were about whether PWD can be successfully employed and the results are presented in Figure 2.7. A few points emerge:

- ***overall, the assessment of PWD capacity for successful employment is low.*** Even in the best case (locomotor disability) only half of respondents felt that PWD could be always/ almost always successfully employed. This share fell to less than 30 percent for vision impairments, and was less than 2 percent for both mental illness and mental retardation. In contrast, respondents felt that people with mental illness could never be successfully employed in 86 percent of cases, and for mental retardation the share was 78 percent

- ***there is major variation in attitudes to the possibility of successful employment by disability type,*** with mental disabilities experiencing the most negative attitudes. For the other three categories, the shares are higher. In addition, around a further third of respondents felt that those with locomotor, vision and hearing/speech disabilities could be successfully employed sometimes. The variation by disability type is consistent with previous research in rural south India, though the relative impact of different disabilities varied, with for example a strong premium placed on visual acuity but notably less on hearing capacity (reflecting the demands of agricultural work).[44]

- while the above findings are perhaps not surprising, the major variation between UP and TN on attitudes to non-mental disabilities was less expected. More research is needed on the drivers of such differences. Part of the explanation may lie in commonness of disabilities in

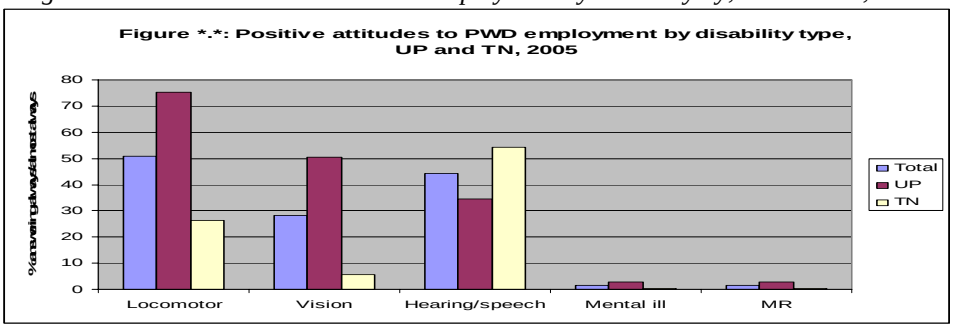
[42] Swabhiman (2004).
[43] Unnati and Handicap International, op.cit.
[44] Erb and Harriss-White, op.cit.

different areas, as for example the incidence of locomotor disabilities from polio is higher in UP and may be associated with more accepting attitudes.

2.14. ***An additional interesting finding on employment is that responses by PWD themselves to the same question revealed surprisingly similar results*** in terms both of low share of respondents answering positively on PWD employment capacity and in terms of the variation in positive response shares across disability types. In all cases, the share of PWD answering positively was slightly lower than for household heads, indicating that there is a major self-esteem agenda among PWD to be addressed in order to improve their labor market outcomes.

Strong positive attitudes to PWD employment capacity are low, and there is major variation in attitudes to PWD employment, both by disability type and location

Figure 2.7: Positive attitudes to PWD employment by disability by, UP and TN, 2005



Source: UP and TN Village Survey. Proportion of HH head respondents answering always/almost always to statement: "People with a disability can be successfully employed".

2.15. All the above results are from households. In qualitative work, similar questions were addressed to key service providers and officials, including ANM/anganwadis, teachers, doctors, and panchayat representatives. Overall, the opinions of service providers were somewhat more inclusive with respect to participation of PWD in their services. The same did not appear to be the case with panchayat representatives, who largely reflected the views of their communities.

2.16. With respect to education, there has been more research on the attitudes of teachers and education administrators to CWD and their inclusion in regular school settings. This is discussed in Chapter 5. ***More broadly, much research remains to be done on assessing, and developing strategies to improve, the attitudes of public officials and service providers to PWD.*** Despite the PWD Act, some evidence suggests that these key groups – at least in some states - may continue to have negative attitudes towards PWD, as data from Orissa on attitudes to PWD presented in Table 2.3 demonstrates. The attitudes of corporates and workers in community institutions were more accepting than those of government officials, education and health workers.

Table 2.3 Government officials and education and health workers had the highest rates of negative attitudes towards PWD in Orissa

Organization	% regarding PWD as burden
Government officials	37
Education providers	38
Police and court officials	23
Financial sector workers	32
Corporate workers	19
Community places	10
Transport workers	12
Hospital workers	36

Source: Swabhiman (2005).

2.17. While providing empirical insights is useful, how to work on changing long held and sometimes culturally-grounded attitudes is of course much more challenging. It appears that the challenges will be particularly acute in the areas of mental illness and mental retardation. However, there are positive examples of NGOs working towards attitudinal change on disability, in some cases with quantifiable impacts. Some efforts have been broad-based, others focus on service provides in specific areas, while others work at a very localized level through CBR and other channels. One of the more ambitious, well-documented and high impact efforts at attitudinal change is outlined in Box 2.3. which demonstrates the potential impact of effective public/private partnership in spreading awareness and reducing stigma for disabilities. There are also many examples of NGOs working with educators and other community figures to change attitudes and outcomes, as illustrated by the example of Vikas Jyot Trust in Vadodara in Box 2.2.

Box 2.2: Development organisations successfully taking up disability issues at community level - Vikas Jyot Trust, Vadodara

VJT has been working for the past 30 years in the slums of Vadodara on the rights of women and children. It has been implementing several community based programmes and activities for street children, adolescent girls, women in distress, commercial sex workers and their children. After participating in an awareness and skill development workshop on inclusion of people with disabilities in development programmes the staff of VJT have now assumed a significant role in including them in their programmes. "It was only after we participated in this initiative that we became aware of the services available in the district for people with disabilities. Earlier we had very limited information and no idea of the possibility of including people with disabilities in development processes", says Jyoti. Today VJT, without any additional resources, has assumed new roles in the community as far as people with disabilities are concerned. They identify people with disabilities; link them with the service providers; establish personal contact with people with disabilities and their families and enable them to work out individual plans; involve community to enhance acceptance of people with disabilities; orienting civil society (police, railway protection force, anganwadi and health workers, staff of remand and observation homes for children etc.) to the rights and needs of people with disabilities.

One area where they have concentrated efforts is in getting children into schools. Using films, games, experience sharing and informal discussions, they facilitated interactions between children with disabilities and non-disabled children; teachers from mainstream schools that had admitted children with disabilities and those that had not done so; and parents of children with disabilities and parents of non-disabled children. This series of one-day interactions helped both the groups in each case to share their experiences, feelings, and hopes, barriers that they were facing and what they would like to and could do. It helped in highlighting the need for inclusion of children with disabilities, the support available from the government or otherwise for children with special needs, and the positive experiences as well as challenges of those who had attempted to be inclusive. Vikas Jyoti Trust has supported the enrolment of children with disabilities in mainstream schools and special schools.

Source: Officer (2005)

Conclusions and recommendations

2.18. ***Changing societal attitudes to people with disabilities, even among people with disabilities themselves at times, presents many challenges. However, a basic starting point is facts.*** The leprosy campaign and its impact are clear demonstration that part of the stigma attaching to disability is driven by ignorance (see Box 2.4). It will thus be critical that various public health, educational, and other general awareness campaigns of government and non-

governmental sectors drive home the causes of disability, and that disability is not a pre-ordained event.

2.19. ***Changing attitudes to disability is likely to area where it is particularly important for governments to work with people with disabilities, NGO/DPOs, and communities.*** However, governments at all levels can work to identify effective change agents in their communities, and allocate explicit funding to support their activities. They can also contribute to raising the profile of people with disabilities through awards and other forms of recognition such as the national Awards for Persons with Disabilities, which are given to outstanding employers and persons with disabilities each year in International Day of Disabled Persons. [45] Finally, the potential of cultural performance and the arts for both transformation of self-perceptions among PWD and of the general community of their capacities is significant, as the experience of Ability Unlimited, a dance troupe of people with disabilities, demonstrates (see Box 2.3).

Box 2.3: Changing attitudes of young people through dance

Ability Unlimited is a professional dance troupe of disabled people which provides training and employment opportunities for its members and also seeks to expose non-disabled people to the artistic capacities of people with disabilities. Founded in 1989 in Bangalore, it moved in the early 2000s to Delhi, where the group has performed to around 50,000 school children, and as well performances for the general population. It has also performed abroad in Malaysia, Finland, and in 2007 the USA. The troupe currently has a pool of around 150 performers of different socio-economic and caste backgrounds, who perform a dance repertoire including traditional Indian folk tales, "martial arts on wheels" performances of Thang (a Manipuri martial art with swords), stories of the life of Buddha and other material. In its own words, Ability Unlimited "is committed to changing apathy, negativity and fear that surrounds education, employment and inclusion of persons with disabilities in arts by providing equal access to arts for them". School students pay to view the performances, as well as being exposed to issues such a lack of accessibility of school premises by assisting the disabled performers in set-up. It also acts as an important form of dance therapy for the performers. Feedback from children seeing performances indicates positive impacts on their perceptions of people with disabilities and their capacities, including among parents of the performers themselves. Media reactions also attest to the impacts on audience of all ages:

"It is for the first time that we have seen a holistic mega therapeutic theatre project of this magnitude…where all the participants are physically and mentally challenges…Movement with wheelchairs and crutches was immaculately timed to different choreographic patterns". *The Hindu.*

"Therapeutic ballet by special kids steals show". *The Asian Age.*

"Though they are our children, we never knew that they had so much in-built power within them, now we feel proud to be called their parents, and will definitely encourage them to pursue their dreams which are possible now". *Parent reaction quoted in New Straits Times, Malaysia*

For more information, go to www.abilityunlimited.com

2.20. A second important step where media, persons with disabilities, social activists, and NGOs are likely to have comparative advantage is ***putting the experience and success stories of persons with disabilities into the public arena.*** This is increasingly being done, but at times in ways that characterize disabled people as objects of pity or "superhuman" in dealing with their

[45] Similar awards schemes exist in the NGO sector, e.g. the NCPEDP Helen Keller Awards, and the Cavinkare Ability Awards for Achievers with Disability, sponsored by the Cavinkare consumer products company and the Ability Foundation.

disabilities. However, this is not always the case, as the powerful work of activists such as Harsh Mander demonstrates. [46] Equally, the disability movement is becoming more effective in disseminating insights into the lives of persons with disabilities through vehicles such as the Success and Ability quarterly of the Ability Foundation in Chennai.

2.21. The most powerful impacts, however, are likely to be felt at the individual level. An important step in this regard is following the guidance offered by people with disabilities in India on interactions with disabled people. Their "simple tips" are as follows: [47]

- listen to the person with the disability. Do not make assumptions about what the person can or cannot do.
- when speaking with a person with a disability, talk directly to that person, not through her companion.
- extend common courtesies to people with disabilities as you would to anyone else. Shake hands or hand over business cards. If the person can not shake your hand or grasp your card, they will tell you. Do not be ashamed of the attempt however.
- offer assistance to a person with a disability, but wait until your offer is accepted before you help.
- it is okay to feel nervous or uncomfortable around people with disabilities, and it is okay to admit that. When you encounter these situations, think "person" first instead of disability and you will eventually relax.
- when meeting a person who is visually impaired, always identify yourself and others who may be with you.
- speak naturally to a hearing impaired person and do not exaggerate or over-emphasize your speech, as this will be easier for the person to "see" the word.
- when speaking with a person who uses a wheelchair or crutches, place yourself at eye level in front of the person.
- treat adults as adults. Address people with disabilities by their first names only when extending the same familiarity to others.
- never pretend to understand the speech of a person with a disability if you are having difficulty doing so.

[46] Mander (2001) and regular newspaper pieces.
[47] This taken from Swabhiman (2004) and Success and Ability, Oct-Dec. 2005.

Box 2.4: Raising awareness and changing attitudes to leprosy

Since 1983, leprosy has been easily curable with Multi-Drug Therapy. The biggest remaining barrier to eliminating the disease is ignorance and stigma. The BBC World Service Trust developed a campaign in India to address this, in partnership with Doordarshan TV and All-India Radio. The campaign underlined the fact that leprosy is totally curable and that drugs are available free throughout India. It also stressed that leprosy is not spread by touch and that people with leprosy should not be excluded from society. The various methods and details included:

- **TV** - A total of 25 advertising spots and 12 campaign dramas were produced and broadcast almost 1,500 times. With repetition, they accounted for more than 45 hours of TV. Among the formats used were Hindi film romances, rural folk operas, famous Hindu fables, domestic dramas and comedies.
- **Radio** - A total of 213 radio programmes were broadcast more than 6,000 times. Thirty-six radio advertising spots were made. They were then "transcreated" into 18 local dialects, making 136 spots. There were also 12 musical dramas and an eight-part radio serial, and 41 radio call-in shows.
- **Community** - 1,700 live theatre performances in villages, small towns and urban slums to widen the reach with approximately 500,000 people attending. Performances were based on popular-entertainment forms, including folksongs, magic shows and drama.
- **Poster** - offered basic information about leprosy symptoms and treatment and stressed the importance of community care and support for people with leprosy. 85,000 produced and displayed.
- **Videos** - 2,700 'video van' screenings featuring the most popular TV spots and dramas produced under the BBC-Doordarshan partnership.
- **Press Relations** - More than 95 articles appeared in the regional English and vernacular press. Two-day press workshops on leprosy were held.
- **Film** - A 10-minute feature film on a leprosy theme screened in cinemas in Hindi-speaking states

Impact: Independent market surveys were conducted at the start of the campaign, after the first round of campaigning and again after the second round. The findings were:

- **Media Reach** – the campaign reached 59 percent of respondents, equivalent to 283 million people.
- **Misconceptions** – the equivalent of 178 million people were persuaded to reject belief that leprosy is hereditary and the equivalent of 120 million people corrected their understanding that leprosy is communicable by touch.
- **Curability & Communicability** - The total population who believe leprosy is transmitted by touch fell from 52 to 37 to 27 percent. The share believing that leprosy patients on treatment are infectious fell from 25 to 20 to 12 percent. The share who regard leprosy as curable rose from 84 to 88 to 91 percent of the population.
- **Symptoms** - awareness of loss of sensation as a possible symptom rose from 65 to 72 then 80 percent. Awareness of pale reddish patches as a possible symptom remained level at 86%. Awareness of non-itchy patches as a possible symptom rose from 37 to 53 to 55 percent.
- **Awareness** - Awareness of the modern cure for leprosy in control villages was only 56 percent, while in villages with live drama shows was 82 percent. Rural Awareness of a modern leprosy cure free of cost was 89 percent among those exposed to the poster, against 20 percent among those not exposed.
- **Stigma** - Percentage of people claiming they would be willing to sit by the side of a leprosy patient, was 10 percentage points higher in drama show villages than control, and the share of people claiming they would be willing to eat food served by a leprosy patient rose from 32 to 50 percent.

Source: Officer

CHAPTER 3: HEALTH AND PEOPLE WITH DISABILITIES

3.1. ***Disability is both a "lens" through which broader health policy issues can be viewed, as well as a specific set of needs of people with disabilities that health policy and systems need to address:*** Both prevention and management of disability are core issues in general in access to health. It is difficult to separate the interventions that are disability-specific from those that are related to health of the population in general. In this sense, disability is a lens through which health policy issues can be viewed. However, when it comes to diagnostic, screening and rehabilitative services for PWD, a disability-specific dimension enters health policy, particularly when institutional structures need to be reformed to improve access and outcomes for PWD.

3.2. ***In much of the world, the literature on health and disability is typically framed within a medical model***: India is no exception. Thus, much of the literature on disability and health in India sees disability within a disease framework. Hence, PWD are viewed as "patients" in need of "treatment". Empirical evidence also comes predominantly from the medical discipline, focusing on causes of disability and clinical trials; although some recent studies have focused on poverty correlates and social stigma issues that affect PWD. There is little information on access to health for PWD or their general and disability-specific health needs - except whether "treatment" was sought for the disability. Moreover, data do not allow an analysis of supply and quality of services available to PWD, and the extent to which this affects demand.

3.3. This chapter explores health issues for PWD.[48] The structure is as follows: Section A focuses on the causes of disability in India and implications of these for public policy. It includes a brief discussion of the institutional issues with respect to heath services for both prevention and treatment of disability. This is followed by a section on the preventive aspects of disability policy, and public programs which have aimed to reduced the incidence of disability in India. This is followed by a review of evidence on health seeking behaviour of PWD. A section on the health care system and both public and non-governmental interventions for treatment of PWD follows, before conclusions and recommendations.

A. Causes of Disability in India

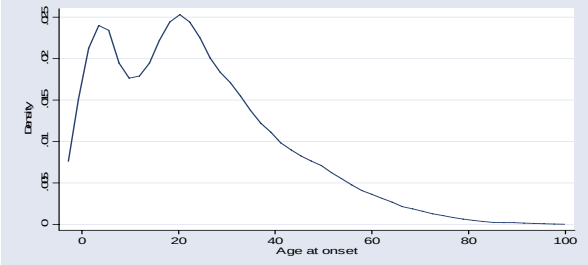
3.4. Chapter 1 reviewed evidence on the incidence of disability in India by disability type. It was seen that there remains considerable uncertainty on the relative shares of different disability types in the overall composition of the disabled population. This section focuses in more detail on the causes of different types of disability, using primarily NSS sources. While NSS data are subject to the caveats noted in Chapter 1, this remains a useful source of insight.

3.5. ***(a) Age of onset of disability:*** Chapter 1 provided cross-disability data on average age of onset of disabilities, noting the "double hump" of disability onset, first at our shortly after birth and then in the 50-60 year old cohort. However, cross-disability averages conceal as much as they reveal. The figures below provide disability-specific data on age at onset by major disability categories. ***The age profile of disability onset varies sharply by category of disability.*** Some notable patterns stand out:

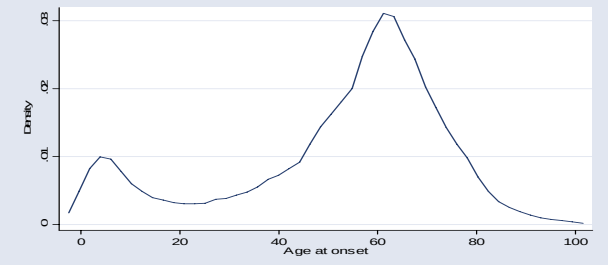
[48] The chapter draws on background papers by Das (2006) and Puri (2005).

- ***onset of mental disabilities is concentrated in childhood and 20-30, resulting in the lowest average age of onset.*** While more analysis is needed, it is assumed that MR is more focused on the earliest years and mental illness becomes more pronounced in young adulthood.
- ***in contrast, visual disabilities are much more associated with ageing, with easily the oldest mean age of onset.*** While ***hearing disabilities exhibit a more pronounced dual peak***, they are also on average subject to later average onset.
- ***both locomotor and speech disabilities are more concentrated in younger ages also***, with the highest onset in the early years of life in both cases, and a more noticeable second wave of onset for speech disabilities around age 60.

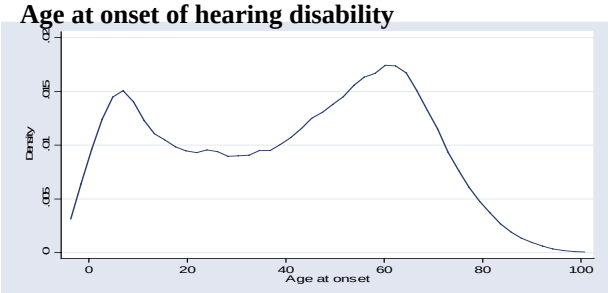
Age at onset of mental disability



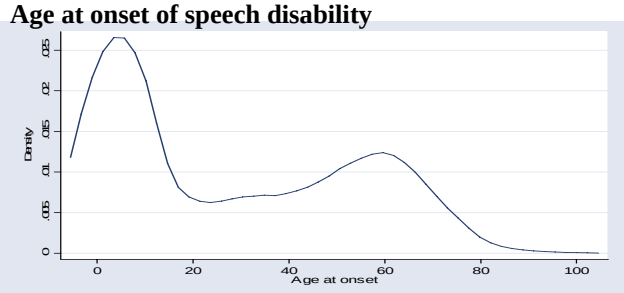
Age at onset of visual disability



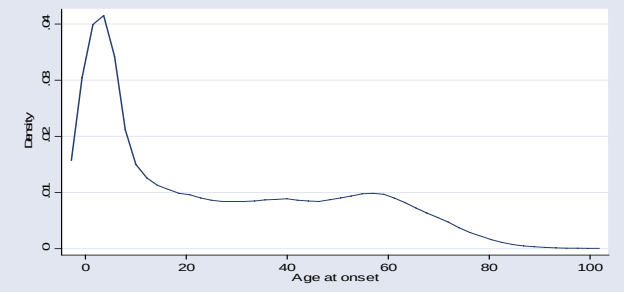
Age at onset of hearing disability



Age at onset of speech disability



Age at onset of locomotor disability



Based on Das (2006), using NSS 58th round

3.6. ***The age profile of onset reflects the differing structure of causes by disability category***. While aggregate trends in disability cause discussed in Chapter 1 (i.e. transition from communicable to non-communicable causes, and increasing importance of injuries/accidents) are important, design of appropriate interventions also needs to focus on disability-specific profiles of causes. Critical periods for intervention for locomotor and speech disabilities are particularly in early childhood. For mental disabilities, the critical period for MR is also early childhood, while for mental illness, adolescence and early adulthood are key. For hearing impairments, screening throughout life seems important, but especially as people age, and for visual disabilities, the focus

period is during a person's 50s and early 60s. Overall, the importance of early identification and intervention can not be stressed enough. The specific conditions are discussed in turn below.

3.7. The main causes of ***visual disabilities*** are presented in Table 3.1, and are primarily age-related, with cataract and other age-related issues being the chief causes. The major share of visual disability is thus preventable and occurs due to lack of treatment. In a national estimate, Dandona et al estimate that almost two-thirds of blindness is preventable or treatable. If there is no change in the current trend of blindness, the study estimates that the number of blind persons in India would increase to 24.1 million in 2010, and to 31.6 million in 2020. If effective strategies are put in place to eliminate cataract, blindness in 15.6 million persons would be prevented by 2020, and 78 million blind person-years. Similarly, if effective strategies are implemented to eliminate refractive error blindness and corneal disease/glaucoma, another 7.8 million persons would be prevented from being blind in 2020, and 111 million blind person-years.

Table 3.1: Causes of Visual Disabilities (for Individuals with Single Disability (i.e Visual Only)

Cause	Percent
Cataract	23.4
Old age	23.0
Corneal opacity/other eye errors	20.0
Not Known	9.8
Other	5.6
Glaucoma	5.3
Burns or injury	4.7
Small pox	4.1
Medical/surgical intervention	2.6
Childhood diarrhea	0.7
Sore eyes after first month	0.9

Source: Das (2006), based on NSS 58th round.

3.8. ***The major cause for both speech and hearing disabilities is illness and disease, or in the case of speech disability, is not known. In addition, over 21 percent of all hearing disabilities are due to old age.*** The importance of non-specific causes in these categories (other illness, other, not known in the case of speech disabilities) highlights that disability is intrinsically related to other public health issues, and that increasing access to better quality care is an important step towards reducing disabilities. This has implications not only for prevention but for diagnostic facilities and technology, and referral and rehabilitation services.

Table 3.2: Causes of Hearing and Speech Disabilities - 2002

Percent	Cause - Hearing Disability	Cause - Speech Disability	Percent
21.3	Old age	Voice disorder	12.6
18.6	Discharge	Paralysis	11.9
8.7	Other	Other	8.3
5.3	Burns and injury	Burns and injury	0.9
2.1	Noise	Cleft palate	4.5
1.6	Medical/surgical intervention	Medical/surgical intervention	3.8
0.7	Rubella	Mental illness	2.8
0.01	Not Known	Hearing Impairment	1.6
23.0	Other illness	Old age	1.1
		Other illness	25.2
		Not Known	21.7

Source: Das (2006), based on NSS 58th round.

3.9. ***Locomotor disability is the category which is undergoing the most rapid change in causal profile***. As Table 3.4 shows, for the current group of locomotor disabled people, polio remains the highest single cause, accounting for almost a third of all locomotor disability. However, burns and injuries are also a major share, and once more non-specific causes account for over 20 percent of total. As will be seen, progress in reduction of new polio cases has been a public health success stories in India in recent years, so that the causes of locomotor disability are shifting significantly.

Table 3.4: Causes of Locomotor Disability - 2002

Cause	Percent
Polio	30.9
Burns and Injury	28.5
Other illness and disease	12.7
Stroke	6.3
Not Known	4.5
Other	4.5
Arthritis	3.0
Old age	2.8
Leprosy	2.2
Medical/surgical intervention	2.2
Cerebral Palsy	2.1
TB	0.4

Source: Das (2006), using NSS 58th round

3.10. As noted in Chapter 1, estimates of mental disabilities in India remain particularly problematic. This is driven by various challenges, including identification skills of health providers, families and surveyors, and stronger social stigma attached to such conditions. With such a caveat, ***the NSS-identified causes of mental disabilities are presented in Table 3.4, and more than any other category highlight that causes of mental disabilities remain little understood in India.*** [49] As noted, research by mental health organizations has found much higher rates of mental disabilities, with for example a meta-analysis estimated the prevalence of mental illness at 5.8 percent of the population. [50] Equally, suicide rates in India have risen significantly since the 1980s, from 7.5 to 10.3 per 100,000 population between 1987 and 1997. [51] Suicide rates also have notable state variations, with pockets of high prevalence for suicide, for example, in Kerala, West Bengal and Tamil Nadu. [52] Addressing mental health issues during and after disasters has also come into focus after the Bhopal gas leak, earthquakes in Marathwada and Gujarat, and more recently the tsunami for 2004.

Table 3.5: Causes of Mental Disability - 2002

Other	41.65
Not known	36.31
Serious illness in childhood	11.97
Head injury in childhood	3.83
Heredity	3.17
Pregnancy/birth related	3.01

Source: Das (2006), using NSS 58th round

3.11. A further cross-disability issue that is likely to assume greater importance over time is the prevalence of accidents and injuries as a cause of disability. Table 3.5 provides insights by gender from 2002 on where such accidents occur. ***Overall, using NSS sources, accidents and injuries have some role in around 18 percent of all disabilities. There are, however, major gender differences in the source of such injuries.*** For males, over 35 percent of these injuries are at the place of work, while for women, the overwhelming proportion – 60 percent - are in the home.

3.12. ***In addition, around 27 percent of male and 14 percent of female burns and injuries happen in transport accidents***, confirming data from other sources of a major impact of road

[49] As Gururaj and Isaac point out, psychiatric epidemiology suffers from particular methodological and definitional problems not only in India, making comparability of research more challenging.
[50] Reddy and Chandrashekar (1998).
[51] World Mental Health Report (2001).
[52] Puri (2005).

traffic accidents on disability in India. A recent study estimated that 1.2 million people are seriously injured and around 300,000 permanently disabled in road traffic accidents each year in India, often through failure to take simple precautions such a wearing seatbelts or wearing motorcycle helmets.[53] In terms of economic impact, a 2002 Planning Commission report estimated that road accidents cost India around Rs. 55,000 crore in 2000 prices. Just as importantly, the trends are discouraging. A recent WHO/World Bank international report found an almost 80 percent increase in road traffic fatalities in India between 1980 and 1998.[54] The largest group of such fatalities are pedestrians, among whom the poor are likely to be over-represented. This can be seen in Table 3.6 for Delhi, Mumbai and on highways from 11 Indian locations. Micro-studies confirm that the poor are at higher risk of pedestrian injuries, and that a high share of injuries of pedestrians are due to buses.[55]

Table 3.6: Proportion of road deaths by types of user and location

Location	**Type of road user (%)**								
	Lorry	Bus	Car	TSR	MTW	HAPV	Bicycle	Pedestrian	Total
Mumbai	2	1	2	4	7	0	6	78	100
Delhi	2	5	3	3	21	3	10	53	100
Highways	14	3	15	-	24	1	11	32	100

Source: Mohan (2002), cited in WHO/World Bank (2004). TSR = three wheel scooter taxi; MTW = motorized two wheelers; HAPV = human and animal powered vehicles. Highways from 11 locations (not including tractor fatalities)

3.13. No credible data are available to ascertain the outcome of accident survivors; it is generally perceived that outcomes in patients with single system injury (e.g. musculoskeletal trauma) have improved, but not for polytrauma. There is a high mortality rate amongst those with multi-system injuries, due to the primitive state of trauma-care systems, lack of pre-hospital care and inadequate critical care, especially in rural and small urban areas.[56]

3.14. While the above analysis provides some insights into the medical, environmental and social causes of disability, it is equally important to understand what weaknesses in health delivery (and other) systems contribute to disability outcomes in India. It is clear that effective interventions need to be across sectors beyond health, including nutrition programs for children and mothers, workplace and home safety, traffic management, water and sanitation, and other environmental areas. Sections B and C explore this in more detail for both preventive and treatment/rehabilitation services. These are preceded by a discussion of some elements of health seeking behaviour among PWD.

Table 3.7: Place of Incident for Burns and Injuries by Sex for PWD – 2002

	Male	Female
Agricultural field	18.4	9.4
Mines	0.6	0.4
Factory	3.6	0.9
Other work site	12.8	4.8
Transport accident	26.9	13.8
Home	24.4	59.3
Other	13.2	11.1

Source: Das (2006), using NSS 58th round

[53] Ganveer et al (2005). Such estimates are supported by regional studies indicating that traffic accidents as a share of all accidents almost tripled between 1986 and 1998. See also Chacko et al (1986) and Annamali and Chinnathambi (1998).

[54] See WHO/World Bank (2004). The report also estimates the economic costs of road traffic accidents in Asia as a whole at around 1 percent of GNP, with regional data indicating that this economic impact rises with country income levels to around 2 percent of GNP in highly motorized countries.

[55] Persaud et al (2005), which documents an unmatched case control study from Delhi.

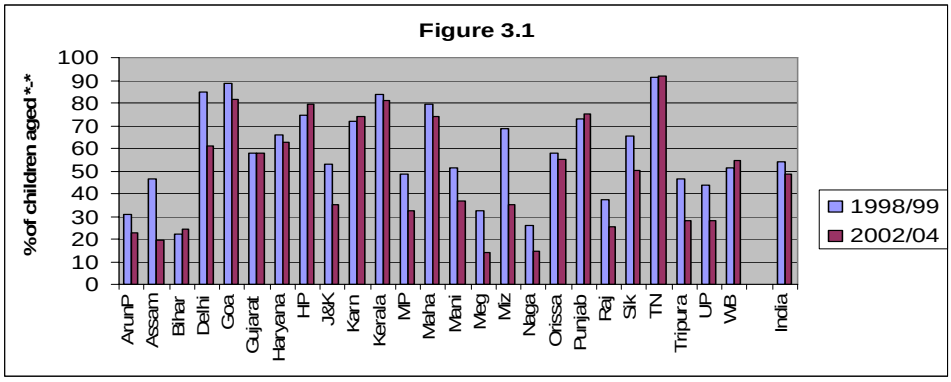
56 Joshipura (2004).

B. Prevention of Disability

3.15. ***A large proportion of disabilities in India are preventable, including disabilities that arise in the circumstances surrounding birth, including maternal conditions, from malnutrition, and from causes such as traffic accidents or workplace injuries***. The many causes of disability, and the unclear genesis of some disabilities, make it difficult to define comprehensively the scope of interventions and public policies that impact the level and nature of disability in India. This section therefore focuses selectively on a sub-set of public interventions. Some of them, such as India's campaign against polio, can be considered success stories of the public health system. Others, such as comprehensive immunization, display trends which are worrying both in terms of disability and mortality. A common issue with many preventive public health initiatives is the mode of national campaigns and how these work in a context of increasingly devolved responsibility for various aspects of the health delivery system.

3.16. ***(a) Immunization Programs***: India has long had vertical programs that address comprehensive immunization according to international norms of the Universal Programme for Immunization. Immunization affects mortality, morbidity and disability. Measles in particular is associated with blindness, and other vaccine preventable illnesses predispose infants and children to other diseases which may in turn cause long-term disability. Recent data from the Reproductive and Child Health (RCH) surveys show what may be a disturbing trend (Figure 3.1). ***While coverage of polio has progressed remarkably (see below), there appears to have been an overall decline in immunization rates at the national level,*** with the most serious decline evidenced in the north eastern states.[57] ***On a national basis, full immunization coverage has declined from 54.2 to 48.5 percent in only around 5 years, a fall from an already low base.*** While a number of states have sustained or slightly increased high coverage rates (e.g. TN, Punjab, Karnataka), there are worrying declines in coverage rates in both the NE and some larger states (e.g. MP, UP, J&K, Rajasthan). However, a caveat is in order. NFHS data from 1998/99 for a number of states – including several poor states - give dramatically different coverage rates to RCH-1 data (e.g. UP, Orissa, MP, Rajasthan, Assam and AP), suggesting that issues of sampling need careful examination in assessing trends. Nonetheless, it seems reasonable to say that India's immunization performance has at best stagnated in recent years and most probably declined in a sizeable portion of the country.

Figure 3.1: Full Immunization coverage rates by state, 1998/99 and 2002/04



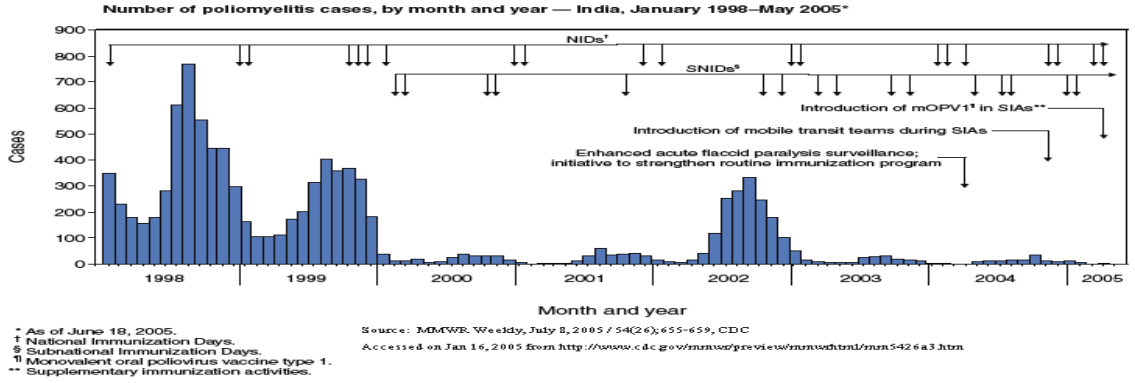
Source: RCH surveys.

3.17. ***(b) Polio eradication:*** The above data relate to full coverage immunization. However, with respect to disability, the story of recent years has positive elements as well,

[57] Both the scale of declines in the NE and comparisons to NFHS rates for 1998-99 suggest that issues of sampling in RCH data seem worthy of further exploration.

perhaps the most high profile being progress against polio through the Pulse Polio Immunization campaign (PPI). In order to reach the global goal of zero incidence of polio, a strategy to intensify PPI was adopted in 1999-2000. It consisted of four nation-wide PPI rounds in late 2000-early 2001; followed by two sub-national rounds in Assam, Bihar, Gujarat, MP, Orissa, Rajasthan, UP and West Bengal, plus routine immunization, especially in poor performing States.

Figure 3.2: Number of poliomyelitis cases, by month and year – India, January 1998- May 2005



3.18. ***Results of PPI in the last decade have been dramatic, though the nature of the virus also results in cycles of new cases.*** The Centers for Disease Control (CDC) report that in India there were 135 polio cases with onset of paralysis in 2004, and for 2005, India reported only 66 polio cases with onset of paralysis for the year: mostly in Bihar and UP. This compares to several thousand cases per year as recently as 1998, and much higher rates previously (Figure 3.2). At the same time, numbers went up again in 2006, in part due to the cyclical nature of the disease, which tends to peak in 3-4 year cycles (and within each year in the earlier months of the year). From only 66 cases in 2005, there were 674 cases in 2006, mostly in UP (546 cases) and Bihar (61 cases), though date for the first quarter of 2007 indicates better outcomes, with only 44 cases to end March. [58] The polio laboratory network remains one of the strongest components of India's polio eradication program, providing significant support to vaccine and surveillance efforts. The laboratories provided rapid results in 2004, even though more than twice as many specimens were tested as in 2003. The authorities are optimistic that polio can be eradicated in India, though the fact that it is endemic raises major challenges in sustaining recent efforts. [59] The continued commitment to polio eradication is clear in the FM's 2007/08 budget speech, which outlines a targeted strategy in high risk districts of UP and Bihar, and use of monovalent vaccine which is more effective in combating the strain of polio which continues to cause most new cases. A second question raised by some public health players is the sense that other immunization and public health initiatives may have suffered as a result of the intense focus on polio eradication.

3.19. ***National Blindness Control Programme (NBCP):*** The NBCP was started in 1982 and is one of the largest disability prevention programs. It undertakes activities like general eye care, cataract surgery, correction of refractive errors etc. However, cataract surgery is the main indicator used to evaluate success, and annual outcomes in terms of surgeries have expanded impressively since the mid-1980s (Table 3.8). At the same time, unit costs have risen steeply, not only due to general price inflation, but also due to use of more costly technology such as intra-ocular lenses and more advanced eye theatres.

[58] An excellent monitoring site is the National Polio Surveillance Project, a collaboration of GoI and WHO started in 1997. See www.npspindia.org.

[59] A further debate relates to the vaccination strategy of GoI, which relies on oral polio vaccine (OPV) rather than the more costly alternative inactivated polio vaccine (IPV). See Paul (2006) for a discussion.

3.20. The NBCP, like other vertical programs functions at the apex through a National Programme Management Cell in MoH, State Ophthalmic Cells, tertiary Regional Institutes of Ophthalmology and Eye Hospitals, and at the district level through District Blindness Control Society and District/Sub-District Hospitals. In order to address problems of outreach in rural areas, the Programme has tried to expand accessibility of ophthalmic services. It sponsors central and district mobile units which conduct mobile eye camps and performance of cataract surgery. Most cataract operations in rural areas are conducted through mobile camps. Primary health centers have also been equipped with ophthalmic equipment and by posting para medical ophthalmic assistants. However, by its own admission, the Program's main challenges is to expand activities beyond cataract surgeries to focus on other causes of blindness, improve quality of services and post-surgical follow-up, strengthen human resource development and outreach/public awareness.

Table 3.8: Cataract Surgeries under the National Blindness Control Programme

Year	Cataract Surgeries (lakhs)	Expenditure (Rs. in crores)
1985/86-1989/90	58.78	28.91
1990-91-1994/95	83.9	93.27
1995-96-1999/00	114.52	333.32
2000-'01	36.7	109.7

Source: Ministry of Health 2005

3.21. ***National Leprosy Eradication Programme:*** Started initially in 1954-55 as the National Leprosy Control Programme, the increased focus led to its renaming as the National Leprosy Eradication Programme (NLEP) in 1983 with the objective of eliminating leprosy (i.e., reducing the caseload to less than one case per 10,000 population). In 1993-94, the first National Leprosy Elimination Project was started on a national scale, using multi-drug therapy (MDT), strengthening existing services, intensive health education, trained manpower development, disability prevention and care including reconstructive surgery. The second phase of the project decentralized implementation to States/UTs and districts, and integration into the overall health system. Recently there have been nationwide Modified Leprosy Elimination Campaigns with intensified community IEC and better outreach.

3.22. ***Progress in leprosy reduction has been impressive***. In 1981, India had a prevalence of 57.6 leprosy cases per 10,000 population. As of early 2004, this had fallen to 2.44 cases, though with strong statewise concentration in UP, Bihar, Maharashtra and West Bengal. Seventeen States/UTs have eliminated leprosy, including large states such as Rajasthan. Another seven States/UTs are close to this goal of leprosy elimination (with current prevalence of 1-2/10000), including MP, Karnataka, Gujarat, AP and Tamil Nadu. As of early 2006, GoI reports that leprosy has been almost eliminated nationally.

3.23. ***In other preventive programs however, the authorities have struggled to find effective modes of intervention.*** An example is the National Filaria Control Program (NFCP) [60]. Launched in 1955, official reviews revealed very limited impact. The program was then withdrawn from rural areas. A revised strategy for control in endemic states was launched in 1996-97. Four main areas were targeted under the revised strategy: (i) single day mass drug administration; (ii) referral services at selected centres; (iii) Information-Education-Communication (IEC) in the community; and (iv) anti vector measures in all urban areas.

3.24. Despite these efforts, only about 11 percent of those living in endemic areas of India fall within an active control program, with particular shortfall in rural areas. The major constraints of the program are: (i) detection of carriers by night blood surveys which is costly and poorly

[60] India is said to contribute about 40 percent of the total global burden of filariasis and account for about 50 percent of those at the risk of infection.

accepted by the community; (ii) poor perception of the disease and the benefits of the control program; and (iii) drug compliance was not at a level to interrupt transmission in many states.

3.25. ***(e) Prevention in the general health care system:*** The above experiences indicate some success in India is reducing the incidence of disabling communicable diseases. ***However, successes in reduction of some communicable diseases have not been matched by progress in the broader public health system in several key areas which have significant impacts on disability.*** One example is in programmes addressing micronutrient deficiencies, where India maintains the "South Asian curse" of stubbornly poor nutritional outcomes for its population. Irreversible debilities can arise from both mother's anemia and in nutritional deficiencies in childhood, and children from poor families are at particular risk (e.g. vitamin A deficiency is a cause of blindness; iodine deficiency disorders (IDD) are preventable causes of mental retardation). National programs to deal with iodine, iron and Vitamin A deficiency have been in existence for some time. Despite this, UNICEF reports that approximately only 45 percent children from 6-59 months were covered by Vitamin A supplementation in 2003 and only half of all households consumed iodized salt in the period 1998-2004.[61] However, IDD is a problem in every part of India. Of 286 districts in the endemic states surveyed by the Ministry of Health and Family Welfare in 1998, IDD was endemic in 242. [62] Coverage of these programs is intrinsically related to coverage of other maternal and child health programs and draws attention to the links between overall health goals and prevention of disability. In this regard, a positive development in 2005 was the re-banning of non-iodized salt by GoI

3.26. Children from poor households are at greater risk of malnutrition-induced disabilities. In addition, CWD may also be at greater risk of malnutrition if their there is relative neglect of their feeding, and/or their disability contributes to problems with feeding. Findings of a study exploring the impacts of malnutrition among children in the Dharavi slum of Mumbai show: [63]

- mean weight for age of children with disabilities was significantly lower compared to their siblings.
- CWD had significantly lower mean hemoglobin levels compared with siblings.
- CWD with feeding difficulties were significantly more likely to be malnourished using all indicators, compared to disabled children without feeding difficulties.

3.27. A second critical area of the general health system that has major impacts on minimization of disability is reproductive, maternal and child health. This relates not only to young children themselves but also to mothers. There is a large body of literature that underscores the importance of maternal factors such as education, nutrition and health care for child health outcomes. However, ***access to care during pregnancy and delivery is poor in India***. In the three years preceding India's National Family Health Survey 1998-99 (NFHS-2), only 35 percent of pregnant women received no antenatal care: a marginal improvement on the 36 percent in the 1992-93 NFHS.[64] The survey showed that the women who failed to seek care tended to be older (ages 35 to 49), with a high number of previous pregnancies, and were illiterate and socio-economically disadvantaged. Other micro-studies confirm these patterns. [65] Such maternal characteristics tend also to be associated with higher risks of disability in children. The UP and TN survey also provides support for the importance of ante-natal care. Mothers of CWD were

[61] UNICEF (2006).
62 Tiwari et al (1998).
63 Yousafzai et al (2000)
64 International Institute for Population Sciences (IIPS) and ORC Macro, National Family Health Survey (NFHS-2) 1998-99
65 RamaRao et al (2001)

almost three times more likely to have had difficulties during pregnancy, indicating a much higher than average need for ante-natal care. They were also significantly less likely to have accessed government allopathic ante-natal care when they did (and more likely to have used public traditional or private providers).

3.28. Disability arising from maternal causes is difficult to assess and estimate, but it is well-known that low-birth weight, prematurity, maternal anemia, and malnutrition increase the risk of disability among babies. For example, neural tube defects (NTD) a condition that leads to considerable and irreversible disabilities in newborns can be prevented by including folic acid supplements in pregnant women's diet. [66] The prevalence of NTD is reported to be 3.63 per 1000 live births and the highest being in the northern states of Punjab, Haryana, Rajasthan and Bihar. [67]

3.29. ***Apart from impacts on the child, poor access to quality services can result in a range of disabling conditions for mothers themselves***, some of which are easily treatable conditions such as fistula which can become disabling if not attended to. [68] Information on women with disabilities (WWD) and their reproductive health needs in India is limited. [69] Among the most severe of these disabilities are the conditions resulting from obstructed labour, conditions virtually unknown in countries where Caesarean sections are easily available. Other lingering problems may include anaemia, incontinence and sterility. Obstetric fistulae disproportionately affect very young and very poor women. Internationally, girls under 15 are 25 times more likely to have critical complications related to pregnancy than women in their 20s. [70]

3.30. ***(f) Prevention outside the health care system: road traffic initiatives:*** As noted, accidents are a major cause of disability, and traffic accidents account for a significant share of all accidents. While this is increasingly acknowledged in India, efforts to address the epidemic of traffic accidents have been more limited. Recently, GoI has produced a draft National Road Safety Policy which sets a number of positive directions for action. However, execution of policy is largely a matter for the states, and concrete action has been lacking in many cases. Kerala provides a positive example of state-level action which addresses a range of factors in road safety, with a state-level Road Safety Action Plan developed, and initial implementation begun through initiatives such as a Good Practice Manual of Public Education in Road Safety. Pilots are under discussion in the Cochin/Ernakulam area for model road safety programs including promotion of seat belt and helmet use. There has also been focus on police accident reporting practices, vehicle fitness initiatives, and emergency medical response to accidents. Tamil Nadu is also taking action such as mapping of "accident black spots", with planned investments in both improving road safety and in medical response capacity in high-risk areas.

C. Curative and rehabilitative health interventions and PWD

3.31. As noted in Chapter 7, ***the health sector is the one where the PWD Act makes the weakest incremental commitments in public policy.*** This is for two main reasons. Firstly, it focuses mainly on prevention and early detection of disabilities, and raising of public awareness

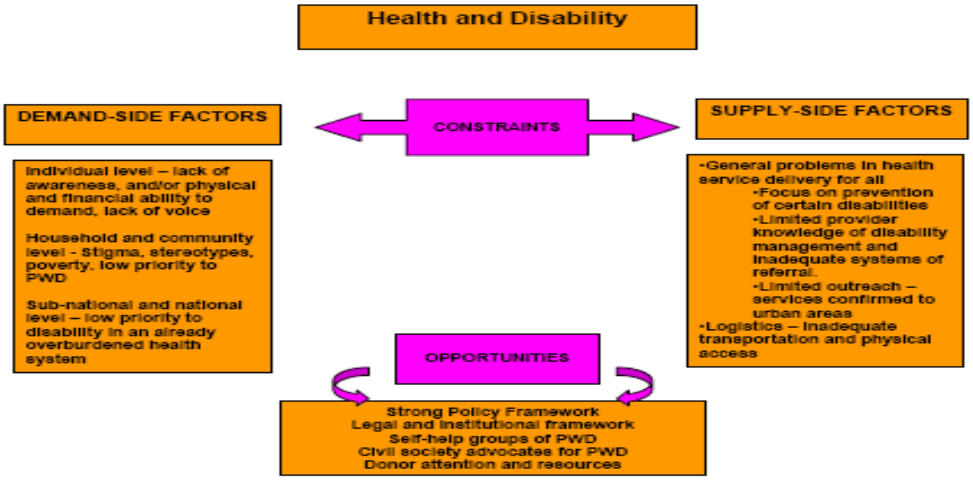
66 Luneley et al (2000).
67 Verma (2000).
68 Every minute worldwide, more than 30 women are seriously injured or disabled during labor, thus rendering vast numbers of women in the developing world physically and socially disabled. For every woman who dies from complications of pregnancy, between 30 and 100 more live with painful and debilitating consequences. UNFPA.
69 On links between reproductive health and disability and its application to India, see Das (2004).
70 See Das (2006).

on these issues. It does not make specific additional commitments on treatment and rehabilitation of PWD. Secondly – in contrast to areas such as education and employment – the Act's provisions on health are in the form of unenforceable commitments due to the rider "within the limits of [governments'] economic capacity and development". As a result, respect to health issues and PWD, the Act remains largely aspirational even in principle with, mainly outlining the type of prevention and early detection initiatives that states should seek to implement.

3.32. ***Both policy and practice therefore indicate that the bulk of both prevention and treatment of disability will continue to happen as part of the broader public and curative health delivery systems.*** Equally, access to health for PWD will be characterized by a combination of elements common to all people (e.g. the effects of household income on access to care), as well as disability-specific needs and issues of access. There is thus a complex interaction of supply and demand side factors that come into play. Figure 3.3 sets out some of the linkages.

3.33. This section explores specific elements of the health delivery system which are of particular relevance to PWD. This includes initiatives that are specific to PWD in both the public and non-governmental/community sectors (e.g. disability certification), and some where interactions of PWD with the general health delivery system may raise issues above and beyond those of the general population.

Figure 3.3: Demand and supply side linkages in health and disability



Source: Das (2006)

3.34. ***(i) Dedicated PWD health services: Generally, the focus of PWD-specific public interventions has been on rehabilitation.*** Technological support on rehabilitation is provided by the five National Institutes on disability, set up in the 1970s and 1980s. [71] The mix and PWD coverage of services by the Institutes is presented in Table 3.9, which have serviced just over 1.8 mln. PWD in their existence. In recent years, India is placing an increased emphasis on social and community based approach. In early 1995, the Government launched the District Rehabilitation Center (DRC) Scheme as a model of comprehensive rehabilitation services to rural

[71] The National Institute for the Visually Handicapped, Dehradun (1979); the National Institute for the Orthopaedically Handicapped, Kolkata (1978); National Institute for the Hearing Handicapped, Mumbai (1983); National Institute for the Mentally Handicapped, Secunderabad (1984) and National Institute for Multiple Disabilities (being set up in Chennai). The two apex level Institutes are the National Institute of Rehabilitation, Training & Research, Cuttack (1984) and the Institute for the Physically Handicapped, New Delhi (1976).

PWDs. The scheme operates in 11 centers in 10 States. The objectives of the DRC include surveying the disabled population, prevention, early detection and medical intervention and surgical correction, fitting of artificial aids and appliances, therapeutic services - physiotherapy, occupational therapy and speech therapy, provision of educational services in special and integrated schools, provision of vocational training, job placement in local industries and trades, self-employment opportunities, awareness generation for the involvement of community and family to create a cadre of multi-disciplinary professionals to take care of major categories of disabled in the district.

3.35. There are 4 Regional Rehabilitation Training Centers (RRTC) that function under the DRC scheme which provide training to village level functionaries, DRC professionals, and State Government officials. They also conduct research in service delivery and low cost aids production. Apart from developing training material and manuals for field use, RRTCs also produce material for creating community awareness. A National Information Center on Disability and Rehabilitation was also established in 1987 to provide a database for comprehensive information on all facilities and welfare services for the disabled within the country. It acts as an agency for awareness creation, preparation/collection and dissemination of materials/information on disability relief and rehabilitation.

Table 3.9: Coverage of National Institutes for PWD by Type of Services

Institution	Special Educators Trained	Rehabilitation Services	Extension Services	Clinical Services	Total PWD served
National Institute of Hearing Handicapped	2,536	23,452	11,077	175,893	212,958
National Institute of Mentally Handicapped	31,804	14,445	54,071	18,923	119,243
National Institute of Orthopedically Handicapped	–	23,487	65,083	221,804	310,374
National Institute of Visually Handicapped	5,972	325,771	83,463	24,128	439,514
Institute for the Physically Handicapped	619	22,090	47,201	65,652	135,562
National Institute of Rehabilitation Training and Research	415	26,369	1,863	330,437	359,089
District Rehabilitation Centre/Regional Rehabilitation Training Centers	–	26,614	149,583	204,286	380,483
Total	41,346	462,228	412,526	1,041,123	1,957,223

Source: Asia Pacific Development Center on Disability India Country Profile.

3.36. State governments have their own policies and schemes for PWD as well. These include institutes that are run by state governments and grants to NGOs that access schemes of the state governments. The issue of access to health services that are not rehabilitative in nature has been addressed only obliquely. For instance, the RCI has a program for the training of medical officers in Primary Health Centers.

3.37. Perhaps the most interesting set of services being offered to PWD in India are ***Community Based Rehabilitation (CBR),*** which has been effective in rural areas in addressing

the primary care and therapeutic needs of people with PWD. Surprisingly, this mode of service delivery is missing from the PWD Act. CBR has been promoted with particular strength in south India, often with initial international funding through NGOs. At the same time, CBR strategies have constantly been evolving in response to changing needs, times and criticisms. Despite this, CBR has to date been implemented in only around 100 (of around 600 total) districts, and only 6 percent of villages have coverage of rehabilitation services within 10 kilometres.

3.38. ***While there is no single CBR model, most CBR initiatives share a range of common objectives and features***, i.e. to: (i) deinstitutionalize medical care, working with PWD in their communities; (ii) expand PWD access to rehabilitation services; (iii) demedicalize social responses to disability and thereby help reduce social stigma; and (iv) shift investments away from curative to preventive measures. The concept is institutionally flexible and can be operationalized by communities, NGOs and government, separately or in partnerships. Local level identification, training and technology development is encouraged, involving not only disabled people and their families but teachers, healers and religious leaders.

3.39. ***There is also significant community outreach by hospitals and community institutions for the disabled:*** Medical colleges, hospitals, schools of social work, and institutes of higher education often have a community outreach programs for PWD. For instance, the renowned cerebral palsy institutes started rural and slum outreach programs in the 1970s, where their staff provided community-based services to children with CP and multiple disabilities. Several of these outreach units developed into independent centers of community based rehabilitation. Vidyasagar – an institute for children with multiple disabilities in Chennai, also has an ongoing partnership with local hospitals and assessment centers to which it refers its clients. Its outreach has also included links with specialized centers for specific disabilities.

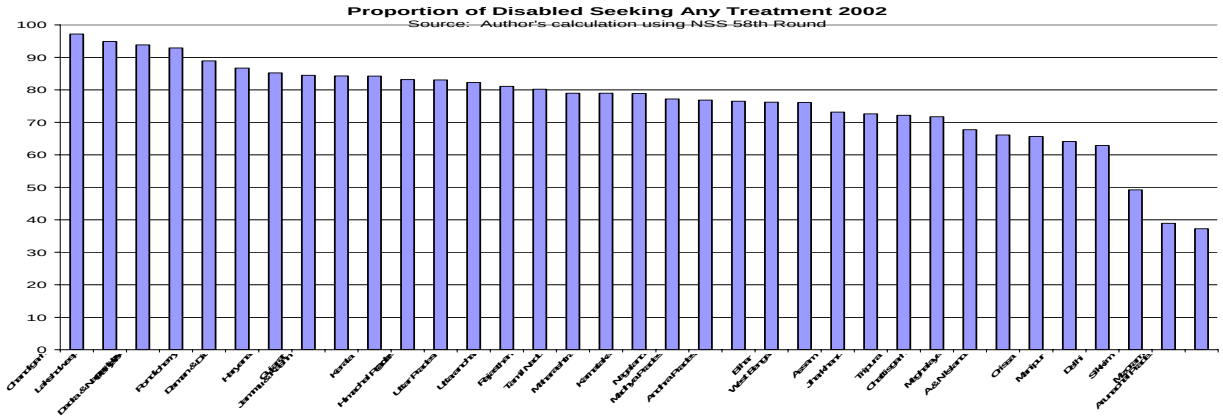
C. Use of Health Services by PWD

3.40. ***As noted, there is relatively limited research on use of health services by PWD in India, and the drivers of usage patterns.*** This section reports NSS data on overall use of health services by PWD and more specifically access to aids and appliances. It also includes evidence from the UP and TN village survey. Figure 3.4 outlines self-reported seeking of health treatment by PWD in the previous [year] for 2002. [72] Overall, a large proportion of PWD – almost 80 percent – sought some treatment in the previous [year]. Disaggregating by state, a few points emerge:

- overall, PWD in north-eastern states tended to have low use of health services, with Mizoram and Arunachal Pradesh less than half the national average usage among PWD.
- broadly, states that are lagging in overall supply of health services also lag with respect to use of services by PWD.
- the exception is Delhi, which has good services overall, but less than fifty percent of PWD who sought any treatment.

[72] The word "treatment" in the NSS 58th round used to describe any assessment, diagnosis or rehabilitation that PWD have sought.

Figure 3.4: Proportion of disabled seeking any treatment 2002



3.41. NSS also allows examination of factors that affect the probability of PWD seeking treatment. The results are reported in Table 3.10, which reports the regression results on the probability of seeking treatment among specified categories of PWD relative to a series of reference category PWDs. [73] A number of interesting findings emerge:

- ***being disabled from birth has a major impact on likelihood of having sought treatment***, with those disabled from birth more than 70 percent less likely than those who acquired their disability later in life to have sought treatment.
- ***women are around 13 percent less likely than PWD men to seek treatment***.
- ***higher levels of PWD education substantially increase the likelihood of seeking treatment***.
- ***PWD with locomotor conditions are the most likely to have sought treatment, while the other extreme is those with hearing and speech disabilities***, who are less than half as likely as locomotor PWD to have sought treatment.
- ***predictably, ST/SC/OB status has a negative effect on likelihood of seeking treatment***, with ST in particular only half as likely to have sought treatment. This can be considered to be picking up broader income/welfare features which are not well captured in the data.
- ***the north-east and eastern regions have easily the lowest likelihood of having sought treatment by PWD***. The northern region in contrast has the highest likelihood of having sought treatment.
- ***those in urban areas are 55 percent more likely to have sought treatment***, reflecting not only the generally better access to health services, but also the disproportionately worse situation with respect to disability-specific rehabilitation and treatment services offered in rural areas.
- ***PWD living with their parents are much more likely to have sought treatment***.
- several indicators had either statistically insignificant impacts on likelihood of seeking treatment, or significant but marginal impacts. These include the age of the PWD, whether or not they are married, household size, and amount of land possessed by the household.

[73] Given the sampling of NSS disability module, such an exercise can not be performed relative to the general population, but only among the PWD sample.

Table 3.10: Probability of PWD seeking health treatment, 2002

Variable	Odds ratio of the probability of ever seeking treatment
Individual Characteristics	
Female	0.87
Age	0.99
Any education up to primary	1.32
Post Primary	1.64
Disabled from Birth	0.28
Disability Dummy (Locomotor as reference)	
Mental	0.75
Visual	0.61
Hearing	0.43
Speech	0.43
Household Characteristics	
ST	0.53
SC	0.74
OBC	0.89
Household Size	1.02
Residence	
Urban	1.55
North	1.40
South	1.16
East	0.78
West	1.14
NE	0.78
Living Arrangements (Living w/ Parents as reference)	
live_alone	0.59
live_spouse	0.77
live_kids	0.62
live_other	0.66

Notes: (a) all coefficients significant at the .001 level except NS=not significant; (b) Reference categories for dummy variables are upper caste, no education, central region (UP/Uttarnachal, Bihar, Jharkhand), rural, currently not married or never married, and male. Source: Das (2006), using logistic regression.

3.42. The NSS does not provide information on what types of health services PWD accessed, nor information on why PWD did not access services. Some information is available on these questions from the UP and TN survey, from which results are presented in Table.[74] In terms of type of service received, easily the dominant one was medication (in 86 percent of cases), with physical therapy the only other significant service (in 44 percent of cases). In terms of type of provider accessed, the results in Table 3.11 for PWD are not noticeably different from non-PWD population in terms of public/private and allopathic/traditional service providers. With respect to reasons for not accessing services, the dominant reasons are economic, and others are probably common to the non-PWD population. However, around 16 percent of PWD report negative attitudes of providers as a reason for not seeking treatment. Finally, the failure to note inaccessibility has to be interpreted with caution, as these are local facilities which may be accessible by default (e.g. entire facility at ground level; no facilities like toilets).

[74] The findings are supported by evidence from the Unnati and HI study of Gujarat on health-seeking behaviour of people with disabilities.

Table 3.11: Type of Service Accessed and Reasons for Not Using Services by PWD, UP & TN	
Type of facility used if healthcare facility accessed in the last 3 months (multiple responses possible)	
Public health facility – Allopathic	31.6%
Private health facility – Allopathic	61.4%
Private health facility – Traditional	17.5%
Faith healer, tantric, or astrologer or other facility	7.1%
Reasons for not using health facilities even if needed (multiple responses possible)	
No services in area	52.3%
Transportation	20.5%
Could not afford services	70.5%
Building inaccessible	0.0%
Waiting time too long	13.6%
Providers don't treat people like me	15.9%
Other	2.3%

Source: UP and TN village survey, 2005.

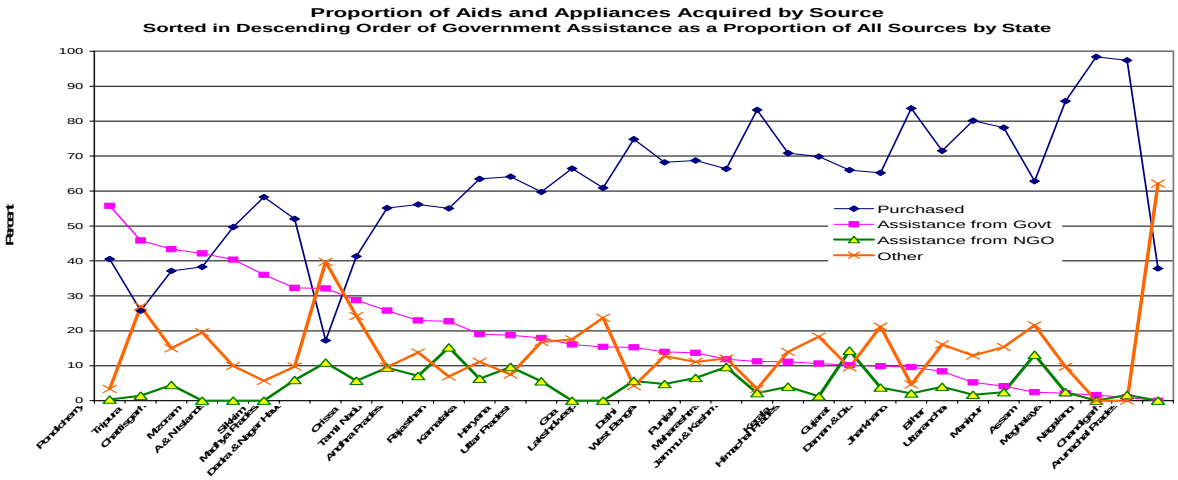
3.43. Clearly more work is needed on both the health-seeking behaviour of PWD and the extent to which their problems in accessing decent services are similar to those of the general population, or have specific features above and beyond that such as attitudinal or physical access problems. One specific service that is important for many PWD is access to aids, appliances and assistive devices. Evidence on this is presented in Table 3.12. ***Only just over 20 percent of PWD in the NSS 58th Round had ever been advised on aids and appliances and less than 16 percent had acquired any such aids or appliances.***[75] Of those who had acquired them, less than one fifth nationally had got them through a government scheme, with almost two thirds purchasing themselves. This is shown in Figure 3.5, which also shows the cross-state variation in Government assistance, with some states such as Chattisgarh having well over 40 percent of aids and appliances provided by Government, while in much richer states such as Gujarat that share was only around 10 percent. The generally low awareness of government schemes for free aids and appliances that the numbers suggest is supported by results from the TN and UP survey, which found that close to half of PWD respondents were not aware of such schemes (and that only 4 percent of all PWD had benefited from them).

Table 3.12: Disabled Individuals' Access to Aids and Appliances	
	Percent
Acquired	15.95
Not acquired	6.0
Not advised	78.0
Source: Das (2006), using NSS 58th round	

3.40. Access to free aids and appliances is currently within the ambit of a social security system that functions very inadequately, not in small part due the manner in which it is designed. Thus, assistance to buy aids and appliances fall within a range of individual beneficiary schemes that often have serious implementation problems and low coverage. Due to this and other demand and supply side issues, coverage of rehabilitative services and aids is very limited. In addition, systems for support and maintenance of assistive devices remain under-developed.

[75] This excludes people with mental disabilities, who were excluded from the question.

Figure 3.5: Proportion of Aids and Appliances Acquired by Source



Source: Das (2006), using NSS 58th round.

3.41. Table 3.13 also presents results on probabilities of accessing aids and appliances according to various characteristics. While many of the results are similar to probabilities of seeking treatment, there are a few interesting differences:

- female PWD are even less likely relative to male PWD to receive aids and appliances than they are to seek treatment (this may also be a factor of the low number of women technicians)
- while those disabled from birth still have lower rates of access (around two thirds the level of other PWD), the situation is considerably better than for seeking treatment relative to PWD who acquired their disabilities later in life.
- the disability-specific probabilities are quite different to those for seeking treatment, with visually impaired people substantially more likely to receive aids and appliances, and those with speech impairments having insignificant probability.

Table 3.13: Results on Probabilities of Accessing Aids and Appliances

Variable	Odds ratio of the probability of acquiring aids & appliances
Individual Characteristics	
Female	0.71
Age	1.02
Any education up to primary	1.23
Post Primary	1.56
Currently Married	1.06NS
Disabled from Birth	0.64
Disability Type (Locomotor as reference)	
Mental	
Visual	1.56
Hearing	0.55
Speech	0.04
Household Characteristics	
ST	0.63
SC	0.81
OBC	0.87
Household Size	0.99
Residence	

Urban	1.46
North	1.40
South	1.10
East	0.95NS
West	1.36
NE	1.38
Living Arrangements (Living w/ Parents as reference)	
live_alone	0.72
live_spouse	0.69
live_kids	0.63
live_other	0.74

Notes: (a) all coefficients significant at .001 level except NS=not significant; (b) upper caste, no education, central region (UP/Uttaranchal, Bihar, Jharkhand), rural, currently not married or never married, male are reference categories for dummy variables. Source: Das (2006), using NSS 58th round logistic regression.

D. Factors affecting PWD access to health care

3.42. This section outlines some of the more specific challenges faced by PWD in accessing decent health services, some on the supply side of the system and others on the demand side.

3.43. ***(a) Disability identification and certification:*** A critical element of accessing treatment and rehabilitation services for PWD is identification and certification of disability. The challenges in institutional coordination of disability identification are discussed in Chapter 4. With respect to certification, the standard model is to rely on assessment and certification by teams at district hospitals. The obvious shortcoming of the system is that rural populations will often have low knowledge of and access to such teams (in addition to the costs associated with accessing district headquarters). In addition, evidence from Orissa indicates that arrangements for disability certification do not always function well, with only just over 10 percent of hospitals having disability certification schedules in place. [76] This is supported by research from Rajasthan which found vacancies for essential medical posts at districts facilities led to major problems with certification. [77] Faced with such challenges, disability NGOs have in some areas assumed a more assertive role vis-à-vis their district hospitals, e.g. in Rajasthan, the disability group Viklang Sangharsh Samiti attends the district hospital every week on the day designated for certification and monitors doctors' attendance and completion of certification of all PWD who present. [78]

3.44. To address the problems with district level certification, the authorities have also relied on a camp-based approach to disability identification and certification. This is a more accessible form, but still faces major challenges in both scale of outreach and human resource capacity to go to scale. ***The shortcomings of the current identification and certification process are brought out by results from the UP and TN survey, which found that 56 percent of PWD were not aware of the disability certification process***, and that only around 21 percent were in possession of a PWD card.

3.45. ***There is clearly a major challenge in developing mixed models of early identification of disabilities which are feasible in the face of supply side constraints on qualified assessors.*** In this regard, many potential actors will be involved, from health care providers to anganwadis

[76] Swabhiman (2004).
[77] Bhambani (2005).
[78] Bhambani, op.cit.

to the new asha workers under the National Rural Health Mission to schools and communities themselves. A key need will be simple tools which allow for screening and referral of at-risk infants and children. Pilot exercises underway in a number of developing countries provide a model which is worthy of more systematic use in India, and has already been effective on a localized basis in India through initiatives such as Samadhan's community worker model of early screening in poor areas of Delhi. The Ten Question Screening Instrument developed by WHO based on extensive developing country pilots is outlined in Box 3.1.

3.46. ***(b) Attitudes and knowledge of health service providers:*** As with education, provider attitudes to PWD can have significant impacts on their access to health services. This is an area that to date has received less attention than attitudes among education professionals. However, the limited available evidence indicates that provider attitudes seem to be a constraint on PWD access to health services. Research from hospitals throughout Orissa found that less than 40 percent of providers were aware of entitlements under the PWD Act, and that close to 40 percent of them considered PWD as a burden. In Gujarat, many village health workers did not know that mental illness and retardation were disabilities. The existence of attitudinal barriers receives support from the UP and TN survey also, which found that 16 percent of PWD did not seek health services due to provider attitudes. In addition, field research from Karnataka and Rajasthan indicates a generally low level medical awareness among health care providers of disability issues, in particular with respect to mental health. [79] Finally, articulation of demand by district and sub-national governments for health services for PWD is poor. This is partly due to the fact that - in a system that is struggling to respond to overall health issues - disability has little priority, and partly because disability is subsumed within the preventive programs.

3.47. ***(b) Attitudes and knowledge of health service providers:*** As with education, provider attitudes to PWD can have significant impacts on their access to health services. This is an area that to date has received less attention than attitudes among education professionals. However, the limited available evidence indicates that provider attitudes seem to be a constraint on PWD access to health services. Research from hospitals throughout Orissa found that less than 40 percent of providers were aware of entitlements under the PWD Act, and that close to 40 percent of them considered PWD as a burden. In Gujarat, many village health workers did not know that mental illness and retardation were disabilities. The existence of attitudinal barriers receives support from the UP and TN survey also, which found that 16 percent of PWD did not seek health services due to provider attitudes. In addition, field research from Karnataka and Rajasthan indicates a generally low level medical awareness among health care providers of disability issues, in particular with respect to mental health. [80] Finally, articulation of demand by district and sub-national governments for health services for PWD is poor. This is partly due to the fact that - in a system that is struggling to respond to overall health issues - disability has little priority, and partly because disability is subsumed within the preventive programs.

[79] Bhambani, op.cit. Low levels of knowledge among health care providers is not of course restricted to disability, as recent studies even from urban centres such as Delhi have shown (Hammer and Das, 2005), but the lack of knowledge on disability-specific issues appears particularly pronounced.

[80] Bhambani, op.cit. Low levels of knowledge among health care providers is not of course restricted to disability, as recent studies even from urban centres such as Delhi have shown (Hammer and Das, 2005), but the lack of knowledge on disability-specific issues appears particularly pronounced.

Box 3.1: WHO's "Ten Question Plus" Screening Instrument

WHO has over the past 25 years been developing a simple methodology for identification of children at risk of disability, and subsequent screening. It relies on the two-phase Ten Question Screening Instrument (TQSI), recently adjusted to include an eleventh question in the so-called TQSI plus. The first stage is carried out by community workers, and seeks to identify children whose mothers answer positively to one of the eleven questions below. A short questionnaire in the Yes/No format was developed to identify 3-9 year old children with disabilities in community-based setting. Of the ten questions, four were concerned with child's vision, hearing, movement and seizures, and six concerning the child's cognitive competence.

House to house survey on approximately 1000 children was carried out by community workers. It was followed by professional assessment of children who were screened positive. A small proportion of randomly selected presumed non-disabled children (screened negative) was also assessed. The original instrument was modified to test whether the instrument could be used on children as young as 2 years of age. For this purpose an alternative version of question 9 on speech was used on children younger than 3 years old. TQ has been validated to be used for screening disabilities in 2-9 year old children.

1. Compared with other children, did the child have any serious delay in sitting, standing or walking?

2. Compared with other children does child have difficulty seeing, either in daytime or at night?

3. Does the child appear to have difficulty hearing?

4. When you tell the child to do something, does he/she seem to understand what you are saying?

5. Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?

6. Does the child sometimes have fits, become rigid, or lose consciousness?

7. Does the child learn to do things like other children his/her age?

8. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognisable words?

9. *For 3- to 9-year-olds ask:*
Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family?

For 2-year-olds ask:
Can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?

10. Compared with other children of his/her age, does the child appear in any way mentally backward, dull or slow?

11. Does your child show any behavioural problem, such a frequent tantrums, aggressive behaviour, or difficulty relating to people ?

Children who are identified as possibly disabled according to the above questions are referred to a second phase, where screening is carried out by a team of medical professionals and psychologists. The epidemiological data from Stage 2 are then used also to generate prevalence estimates of disability in children (requiring a sample size of around 10,000 children in stage 1). To date, more than 70 countries rely on a stage-1 only version of TQSI. While useful, this is more helpful for direct intervention and less for prevalence estimates. A number of developing countries (e.g. Bangladesh) use the two stage TQSI.

To validate the TQSI, an international pilot study of severe childhood disabilities was conducted in 9 developing countries (Bangladesh, Brazil, India, Malaysia, Nepal, Pakistan, Philippines, Sri Lanka and Zambia) in 1980-1981 by WHO and partners. It has proven to be a non gender biased screening instrument that identifies high risk groups and is sensitive for sensory, cognitive, motor, and seizure disabilities. It has proven to be a reliable, efficient and low-cost instrument for undertaking surveillance and monitoring the prevalence of developmental disabilities where professional resources and technology are limited.

TQ probe is a modified version of the Ten Questions used in the original pilot study. As before, it is a short questionnaire, in a Yes/No format consisting of 11 questions with probes concerning the child's vision, hearing, movement, and seizure, and six concerning cognitive competence, and one extra question regarding any other serious health problems. Each question was supplemented with additional one or more questions to further probe into the problem detected. The probe questions were only asked if a problem was reported in response to the main question. For each 2-9 year old child listed and still living in a household, one TQ probe was completed. The two stage methodology is now being piloted in seven countries across four regions in the OECD/World Bank Disability Screening Initiative.

- Vietnam and Indonesia in East Asia
- Bangladesh in South Asia
- Ethiopia and Kenya in Africa
- Panama and Mexico in Latin America and Caribbean

On obvious question on such a method relates to cost. Experience in pilot countries (e.g. in recently completed pilot in Ethiopia) with TQ probe indicates a need for training and capacity building of community workers in the pilot phase, but also that local teams have became rapidly self-sufficient.

Source: OECD and World Bank staff

3.48. ***(c) Physical access to health facilities:*** Again, this remains an under-researched area, though there is an increasing number of NGO access audits on facilities which confirm significant issues in physical access for PWD. The courts have also been active in certain cases in promoting access of PWD to basic services. [81] As noted, problems of immediate physical access to PHCs were not identified by PWD in the UP and TN survey as an issue. However, around on fifth of respondents identified accessible transport as a major issue, indicating that "door to door" access remains an issue for health services. In addition, results from other states indicate that physical access is indeed a significant problem at higher levels of the system. In addition, evidence from Orissa for example suggests that more complex facilities like district hospitals have serious access issues for PWD, with for example the main entrance in around half the hospitals and toilets in around 90 percent of hospitals not being accessible. [82]

3.49. ***(d)*** The number of ***rehabilitation staff*** available is inadequate. According to WHO's guidelines at least one trained P&O (prosthetics and orthotic) personnel is required to meet the needs of 1000 people in need. In India, there are estimated to be less than 700 in total, against a need of over 10, 000. The number of P&O facilities is also low. In India there are approximately 500 workshops, and 80 percent of these services are located in the major cities.

3.50. ***(e)*** A poor ***referral system*** which doesn't fully utilize the expertise at the higher levels of the system. At present there are a collection of disparate services between health and rehabilitation and there is a need to develop a supply chain from PHCs with community participation to national level medical and rehabilitation services. There are however, promising initiatives such as that in 9 districts of Gujarat, which aims to: (i) enhance knowledge and skills of primary health professionals in disability identification and prevention so that they are able to identify persons with disabilities and persons at risk of developing a disability and refer them for intervention; and (ii) improve coordination between government health providers at different levels through developing mechanisms for referral, treatment and follow-up ensuring improved access and continuity of service.

[81] Disability Law Network (2005).
[82] Swabhiman (2004).

3.51. ***(f) Financial barriers to access:*** As for the general population, the bulk of health services for PWD in India are provided by the private sector, both qualified and unqualified. As such, to the extent that PWD households are poorer than average (as evidence in Chapter * indicates is the case), financial barriers to access will be higher than average. In addition, it could be assumed that PWD may have higher than average *need* for health services due to their disabilities, and hence potentially incur higher expenditures and financial constraints. This is an area where limited evidence is available. The UP and TN survey results are, however, consistent with such a hypothesis, with per capita spending on health care by PWD households around 26 percent higher than that of non-PWD households. The household level spending trade-offs this necessitates can be seen in the lower average spending on education and lower average savings rates of PWD relative to non-PWD households in the same survey.

3.52. ***(g) Weakness in mental health policy and services***: ***Mental health is an area that continues to suffer particular neglect in both policy and implementation.*** The National Mental Health policy was originally articulated in 1982. The fulcrum of the policy was the District Mental Health program (DMHP), which barely reached 25 districts in the country. The government recognizes the gaps in access to mental health and its growing role in the community. The policy is in the process of being re-envisioned with an emphasis on institutional reorientation, improved community awareness, strengthening of community mental health initiatives, improved research and informational resources, and improved priority setting and inter-sectoral collaboration.

3.53. ***(f) Community attitudes: As in many areas of disability, community attitudes continue to be a constraint on raising the profile of health services for PWD.*** This is particularly the case with mental illness, but also a more general product of community attitudes to causes of disability which place insufficient emphasis on health-related causes of disability. Such attitudes are in part driven by the lack of voice of PWD, which may limit their capacity to articulate their need for health services. For some PWD, communication may itself be an issue, and so they may be additionally constrained by the nature of their disability. In sum, the status of the PWD within the household, age, type of disability, and time of its onset, can all affect the demand at the individual level.

E. Conclusions and Recommendations

3.54. ***It is clear that much remains to be done to improve the response of health systems to disability, both in terms of prevention and in terms of access to treatment and rehabilitation services.*** While specific interventions and services for prevention and treatment of disability are needed, ***improvements in the general public health and health delivery systems will have the most significant benefits in the area of disability:*** The analysis points to one overwhelming conclusion: the major share of disability is caused by poor access to health services, malnutrition and diseases that are peculiar to developing countries. Thus, prevention of disability is intrinsically related to reform of the public health system. ***It is also clear that prevention of disability is also dependent on policies and actions outside the health system***, including in the areas of road and workplace safety, water and sanitation, and nutritional interventions.

3.55. Improvements in access to care and outcomes for PWD are needed in several areas, some of which are in the general public health and health delivery systems and other specific to services for disabled people:

3.56. **Improving identification and certification of disability**: A thorough review of the existing early identification system for disability, with strong coordination between the ICDS

system and local health care providers (both public and private), is needed to improve early identification of disability and ensure more cost effective prevention and treatment. The TQSI probe methodology seems worth experimenting with in this respect. This effort needs to be accompanied by improved outreach and possibly simpler procedures for disability certification, including raising awareness that such a system exists. Given the serious supply side constraints, it also seems sensible to explore accreditation of qualified private health care practitioners for disability certification. While this is not without risks and would require a basic oversight mechanism, it seems a feasible way to address the major outreach problems of the public sector with respect to certification.

3.57. **Minimizing the incidence and severity of disability**: Cost effective interventions to minimize disability need to be strengthened, including iodization of salt (recently made mandatory once more), and micronutrient supplementation for children and pregnant women. This would include a reversal of declining immunization coverage (polio excepted), which is contributes to both disability and mortality rates. Current efforts such as provision of simple aids such as glasses or crutches also need to be expanded – in partnership with the private sector – to prevent mild impairments becoming serious disabilities which compromise learning, work, and other activities of daily life. The importance of simple interventions such as cataract surgery and hearing devices will also increase with an ageing population. However, other efforts will be needed beyond the health sector. Efforts to promote road safety are an important case, with the rapid expansion in accident-related disability. While the draft National Road Safety Policy is one step, greater efforts at the state level such as those being pioneered in Kerala and Tamil Nadu are needed to stem the major increase in traffic injuries and death.

3.58. **Improving quality of care for disabled people:** Key actions to be taken include (i) better integrating disability management in existing health delivery systems. Departments of social welfare, health and W&CD have to work together and in tandem with early intervention through the education system, NGOs and communities. This would include joint disability training for local level service providers and communities based on common mandates, combined with incentives and identification of influential champions. Improving training of PWD as health advocates and field facilitators is needed if they are to become active agents and not passive beneficiaries are also important; (ii) improved referral systems for the existing rehabilitation network, followed by increased funding and personnel (whose levels are currently at less than 10 percent of WHO standards for developing country rehabilitation services); (iii) a stronger distribution network for Government programs of aids and appliances, including awareness raising of among PWD and incentives schemes for producers; (iv) improved centers and resources devoted to disability management, including assessment, rehabilitative services and medical intervention Indian organizations have capacity to develop low cost technology for PWD, but need adequate funding and incentives, and finally, (iv) more aggressive efforts to develop government and NGO partnerships in all areas of disability services will be needed to strengthen service delivery; and finally (v) continued efforts to ensure that prevention of disabilities through immunization and other preventive measures is strengthened.

3.59. **Addressing current and future provision and information gaps.** New legislation and its enforcement are needed**,** particularly in the areas of mental health and road safety (including emergency care), both of which are increasingly important causes of disability. The aging of the population and attendant disability needs of the elderly will need to be addressed. Finally, data and statistics on disability need to be more reliably and regularly collected, in particular through strengthened NFHS and general health surveys, which have neglected disability. More specifically, India has some way to go in developing a robust injury surveillance system,

including for road accidents, and examples such as Thailand's National Injury Surveillance System introduced in 2003 provide useful lessons in this respect.[83]

3.60. **Given capacity constraints, improving the health sector's response to disability may most feasibly happen in two phases. The first phase** would concentrate on accelerated response closest to the community. This would include an improved certification system, promotion of CBR (including awareness raising and stigma reduction), and enhancing micronutrient supplementation (including food fortification) and immunization. The supply side interventions would need to include training of general duty medical officers in disability certification, and of community volunteers. **The second phase** would focus on improved referral systems between levels of the health system, including increased supply of therapists and support for establishment of therapy centers in rural areas. It would also likely involve networking of hospitals and specialized centres, possibly with support from the private corporate sector.

[83] See WHO/World Bank, op.cit.

CHAPTER 4: EDUCATION FOR PEOPLE WITH DISABILITIES

4.1. As for any other group, education is critical to expanding the life prospects of people with disabilities. In addition, the socialization of children with disabilities (CWD) through education assumes an unusually important role in societies such as India where social exclusion of PWD is significant. ***Despite its importance, educational outcomes for children and adults with disabilities remain very poor***. ***Illiteracy rates both for all PWD and for school-age disabled children remain much higher than the general population, and school attendance among school age CWD massively lags that of non-disabled children.*** This chapter discusses first the policy developments in India and internationally on education of CWD. It then presents an educational profile of CWD and PWD, and finds that India's MDG goals in education will not be met with current performance with respect to children with disabilities. A review of the current performance of public initiatives in the general education system to get CWD into school and improve their learning outcomes follows. An overview of non-government initiatives in PWD education then follows, before conclusions and recommendations.[84]

4.2. As in other areas of service delivery, many of the issues discussed in the chapter reflect broader challenges in an education system which is grappling with issues of quality and drop out for children without specific needs even at the primary level. ***Many of the issues discussed with respect to CWD are thus more acute manifestations of broader challenges.*** The chapter seeks to identify key constraints on improving participation and learning outcomes for CWD, but equally acknowledges that the agenda is a medium term – in some cases long term – one, which requires prioritization and sequencing in the face of limited institutional capacity, and often constrained resources. Equally, it raises difficult trade-offs for those responsible for allocation of public resources for education. While Indian law and policy are clear in the commitment to the right of all children to basic education, in practice difficult issues arise. For example, if a given fiscal allocation aims to maximize enrollment, minimize drop-out and improve quality of education for all children, there may be tough choices in cases where the resource requirements for CWD are higher than for other children and bringing CWD into the system implies that greater numbers of non-disabled children do not enroll or drop out as a result. This is an area where a rights-based approach and that of economists and utilitarians can conflict.

4.3. However, they need not. ***International evidence suggests that the educational outcomes of non-disabled students can also be improved by inclusion of CWD in integrated classes.*** While more evidence from developing countries is needed, evidence from Canada and the USA at both pre-school and basic education levels found improved outcomes for non-disabled students from integrated learning. [85] Studies in India on the issue are to date lacking, but evidence from a pre-school study in the slums of Mumbai found that a range of developmental indicators for non-disabled children also improved significantly following the inclusion of disabled children. [86]

[84] The background papers for this chapter are by Sundararaman (2005) and Chadhha on Orissa (2005), and also benefited from field visit notes from Jangira.
[85] Freund (1995) re pre-school, and Cook (1995), which points also to differential impacts on non-disabled students according to the disability severity of classmates. On the latter, the impacts on general students of having more severely disabled children in the class were more clearly positive than where children with more mild disabilities were included.
[86] Alur and Rioux (2004).

A. Indian and International Policy Developments on Education of CWD

4.4. The education of children with disabilities and special needs in India was initiated in the late 1800s, with the establishment of special schools for the Deaf in Bombay in 1883, and for the Blind in Amritsar in 1887. By 1900 numerous special schools for the visually and hearing impaired children were set up across the country. ***This initiated the tradition of special schools in the country and till the 1970s, this was the dominant mode of service delivery for children with special needs (CSN).*** [87] It was only in 1974 that the scheme on Integrated Education of Disabled Children (IEDC) broke new ground by stressing the need for educating children with mild to moderate disabilities in regular school settings. However, the tensions between the role of special and general schools for CSN continues today, even after the widespread recognition that inclusion is seen as a more effective educational and social strategy in most cases.

4.5. ***The National Policy on Education (1986) brought the fundamental issue of equality for CSN to the forefront.*** [88] It stated that the "objective should be to integrate physically and mentally disabled people with the general community as equal partners, to prepare them for normal growth and to enable them to face life with courage and confidence". ***While the NPE helped set the stage for further integration and inclusion, only in 1990 did the government provide teeth to the policy through the adoption of the Plan of Action (POA).*** The POA ambitiously committed to universal enrolment by 2000 for both children with and without disabilities. It also strengthened the NPE by demanding that CSN be educated *only* in regularly schools and not in special schools as had been allowed earlier. The placement principle for CSN in effect relegated special schools to the status of bridge schools. Children in these schools were expected to obtain training in non-curriculum areas, to help them prepare for general curricula, after which it was expected that they would be transferred to general schools.

4.6. By the mid-1990s, GoI initiated the District Primary Education Programme (DPEP) and its subcomponent known as the Integrated Education of the Disabled (IED). The main aim of DPEP has been to universalize primary education, including ensuring that CSN do not get sidelined in the process of expansion. Given that micro-planning has been a key element of DPEP, the Center offered states assistance to help plan execution of the IED. At present, DPEP is implemented in 23 districts of 3 states (Rajasthan, Orissa and West Bengal). Over 600,000 children with special needs have been enrolled in regular schools under the program.

4.7. The PWD Act itself was an important intervening policy development in education. As discussed in Chapter 7, its position on a rights-based entitlement to basic education was clear, and consistent with India's international commitments on education of CWD (see Box 4.1). At the same time, its guidance on modalities for ensuring realization of the right was less so, with all options for delivery of education for CWD allowed for and not as much specific guidance on which was the priority mode anticipated and in what circumstances other modes would be appropriate. Just as importantly, it gave no guidance on who should take the decisions on the most appropriate form of education delivery for a specific child with a disability: administrative channels, more locally representative bodies such as PRIs or VECs, parents of the CWD, or the role of the CWD themselves in taking such decisions.

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[87] There are currently estimated to be over 2,500 special schools in India. RCI (2000).

[88] The NPE was predated by the National Education Policy of 1968. While the NEP also contained the essentials of an integrated schooling system for children with and without disabilities, it did not get translated into a detailed set of strategies for implementation. The NEP followed the recommendations of India's first education commission (Kothari Commission in 1966). Its recommendations included expansion of education facilities for physically and mentally handicapped children and also the development of integrated programs enabling children with disabilities to study in general schools.

Box 4.1: International policy development on education of children with disabilities

There has been a gradual – though by no means linear – strengthening of international commitment to inclusive education of CWD over the past 2 decades. India has been an important participant in these developments, and its own policy development in large part tries to incorporate its international commitments into domestic policy on IE. Some of the major milestones have been:

The 1989 ***Convention on Rights of the Child*** noted that "Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardians' race, color, sex, language, religion, political or other opinion, national, ethnic or social origin, property, *disability*, birth or other status." While a general base, it was an important step in reaffirming the right to education of CWD. However, unfortunately, the EFA declaration in Jontien in 1990 failed to mention explicitly the right of CWD to education.

The failure explicitly to mention CWD in Jontien led to the ***Salamanca Declaration of 1994***, which had an exclusive focus on children with special needs in the context of EFA. The Salamanca Statement and Framework for Action has the most definitive statement on education of children with special needs. Ninety-two countries (including India) endorsed the Salamanca statement requiring that "ordinary schools should be equipped to accept all children, regardless of their physical, intellectual, emotional, social, linguistic or other conditions". The declaration also states that "Educational policies at all levels,. . should stipulate that children with disabilities should attend their neighborhood school, that is, the school that would be attended if the child did not have the disability". The Declaration also commits that children with disabilities and special needs must have access to regular schools which should accommodate them within a child-centered pedagogy capable of meeting these needs.

Unfortunately, despite the Salamanca Declaration, the EFA declaration in Dakar in 2000 again failed to mention CWD. Girls, ethnic minorities, and the poor are explicitly mentioned in the Declaration, and there remains a commitment to education for all, but Dakar represents a missed opportunity on IE. Hopefully, such stop-start initiative on IE will end with the recently-approved ***UN Convention on the Rights of Persons with Disabilities.*** Article 24 of the Convention very clearly recognizes the rights of CWD to inclusive education. The key provisions are as follows:

"States Parties shall ensure that:

a. persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
b. persons with disabilities can access and inclusive, quality and free primary education and second education on an equal basis with others in the communities in which they live;
c. reasonable accommodation of the individual's requirements is provided;
d. persons with disabilities receive the support required with the general education system to facilitate their effective education;
e. effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

4.8. SSA was launched in 2001, and it aims to provide eight years of uninterrupted, good quality education to children between the ages of 6-14 years, and to have all children in school, learning and completing primary and upper primary cycles by 2010. ***The framers of SSA came to an early realization that their objectives could only be met if the education of CSN was an important part of the program.*** The key provisions under the SSA for integrating and including children with special needs is through: (i) a cash grant of up to 1200 Rupees per CSN per year; (ii) district plans for CSN that will be formulated within the above prescribed norm and (iii) the involvement of key resource institutions to be encouraged.

4.9. ***A specific feature of SSA is a zero-rejection policy.*** This suggests that no child having special needs can be neglected, nor denied enrolment on the basis of such concerns. The PWD Act provides, however, a loophole in how this is defined in practical terms. It states that children will be educated in an *"environment, which is best suited to his or her learning needs"* and that it is possible that the special needs of a child compel him or her to be educated in special schools. Where possible, the decision on the appropriate form of education is taken jointly by resource teachers, parents, medical teams and regular teachers. SSA itself provides useful flexibility to the local levels in making this determination, with an emphasis on AIE/EGS schools and home-based support, all intended to bridge CSN into mainstream education. While SSA offers each district to plan for its own future and for that of its inhabitants, the centre is playing play a useful role in disseminating good practice to help districts make appropriate choices.[89]

4.10. ***The year 2005 saw the most recent and comprehensive policy push from GoI on education of both children and adults with disabilities, in the form of the Minister of HRD's Policy Statement in March 2005,[90] followed by a year long development of a national Action Plan for Inclusion in Education of Children and Youth with Disabilities.*** [91] The main objectives of the Action Plan are set out in Box 4.2. The Plan should – if effectively implemented – provide major impetus to improving educational outcomes of CWD. At the same time, the draft Plan and consultations around it suggest that there will remain major challenges in promoting institutional coordination within and between levels of government and administration, and in developing genuine partnerships with NGOs and civil society. This is part due to an absence of a comprehensive diagnostic of existing initiatives during the Plan's development.

Box 4.2: National Action Plan for Inclusion in Education of Children and Youth with Disabilities

The main objectives of the Action Plan will be to:

- Ensure that no child is denied admission in mainstream education.
- Ensure that every child would have the right to access an anganwadi and school and no child would be turned back on the ground of disability
- Ensure that mainstream and specialist training institutions serving persons with disabilities, in the government or in the non-government sector, facilitate the growth of a cadre of teachers trained to work within the principles of inclusion
- Facilitate access of girls with disabilities and disabled students from rural and remote areas to government hostels
- Provide for home based learning for persons with severe, multiple and intellectual disability
- Promote distance education for those who require an individualised pace of learning
- Emphasize job-training and job-oriented vocational training
- Promote an understanding of the paradigm shift from charity to development through a massive awareness, motivation and sensitization campaign.

Source: Minister of HRD Statement (2005).

4.11. ***It is clear that education policy in India has gradually increased the focus on children and adults with special needs, and that inclusive education in regular schools has become a primary policy objective.*** The following section examines the extent to which these policy commitments are being met in practice in the educational attendance and attainment of CSN.

[89] Some of the resource materials from SSA authorities include a manual for planning and implementation of inclusive education under SSA, documentation of good NGO practice under SSA, documentation of good home-based practice in special needs education, and a regular newsletter on inclusion.

[90] Statement made in the Rajya Sabha on 21.3.2005 by the Minister for Human Resource Development on the subject of the Inclusive Education of Children with Disabilities (Office Memorandum dated 22.3.2005 of Department of Secondary and Higher Education, MHRD)

[91] Available on MHRD website.

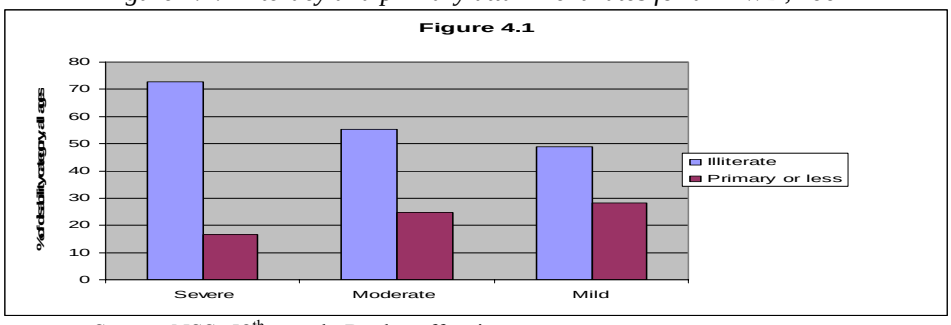
B. Educational profile of PWD

4.12. While policies are important, it is educational outcomes that matter. This section describes current data on educational outcomes of CSN and PWD. Overview statistics on both the educational attainment of PWD and the current school attendance rates of CWD in basic education were presented in Chapter 1. ***It is very clear that both educational attainment of all PWD and current attendance of CWD are very poor and far below national averages.*** This section develops the picture from Chapter 1 with more detail on CWD educational performance, mainly relying on NSS sources. The focus is primarily on children in general education.[92]

4.13. ***(i) Literacy rates of all PWD:*** Chapter 1 showed the high illiteracy rates of PWD across disability categories. It is also possible to analyze illiteracy rates of all PWD by the self-declared extent of their disability. This is presented in Figure 4.1 from NSS. The findings run in the expected direction. ***Almost three quarters of those with severe disabilities are illiterate, and even for those with mild disabilities, the illiteracy rate is around half.*** [93] For the severely disabled, just over 10 percent have achieved middle school or higher education, while even for moderately disabled people the share is only 20 percent. Table 4.1 examines the same data for children currently of school going age, and show that the situation has not improved at all for children in the current generation with severe disabilities.

Illiteracy rates are very high for all PWD, but extreme for those with severe disabilities

Figure 4.1: Illiteracy and primary attainment rates for all PWD, 2002



Source: NSS, 58th round. Bank staff estimates.

4.14. ***(ii) Literacy and attendance for children with disabilities:*** Figure 4.1 presents attainment data for the entire PWD population. For policy purposes, the more immediate focus has tended to be on current school age children and improving their educational attendance. Chapter 1 showed that around 38 percent of CWD aged 6-13 are out of school, with the rates much higher for certain disabilities. Figures 4.2 and 4.3 below track the school attendance of CWD between the ages of 5 and 18 by rural/urban and gender from 2002 NSS. Several points emerge:

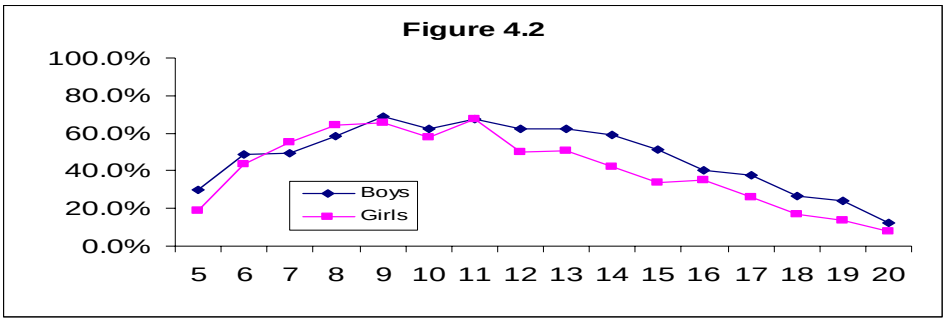
- ***across all CWD, attendance at school never rises above 70 percent for boys and around two thirds for girls***, confirming the SRI data on non-attendance from Chapter 1. These rates also compare very unfavourably with the age-specific rates for all children, which for boys peak at over 90 percent (at around the same age), and for girls at close to 90 percent.[94]

[92] Vocational education for young adult PWD is discussed in the employment chapter.
[93] Literates in the NSS 58th round were defined as persons who could read and write a simple message with comprehension, and those unable to do so, were deemed illiterates. Such findings are consistent also with a number of micro-studies, including Unnati and Handicap International form Gujarat.
[94] World Bank (2006, forthcoming), using the same NSS 2002 round for calculation of general rates.

- ***significant gender differentials among CWD do not emerge till around age 12.*** This shows a marked difference to the general school age population, for which boys' attendance rates remain 8-10 percentage points higher than girls' throughout the basic education cycle. [95] The conclusion would seem to be that the negative attendance impacts of disability are diluting the gender discrimination in basic education which one sees for non-disabled children.

School attendance of both boys and girls with disabilities is low, but gender differentials less than for non-disabled children

Figure 4.2: School attendance of PWDs, 5-20, by age and gender

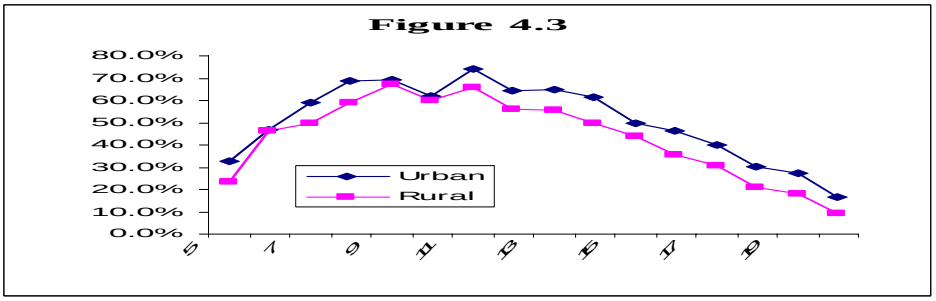


Source: NSS, 58th round. Bank staff estimates.

- ***as expected, attendance rates in urban areas for CWD are higher than rural, but even at peak attendance never exceed 74 percent in urban and two thirds in rural areas.*** This can be compared to figures from the same NSS round for all children in Figure 4.4, which indicate much higher age specific enrollment rates for both rural (close to 90 percent) and urban (over 90 percent) children without disabilities.

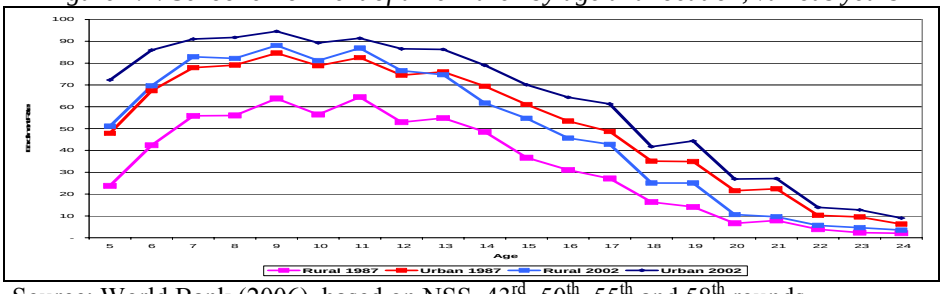
School attendance for CWD in rural and urban areas is far lower than for other children throughout school age

Figure 4.3: School attendance for PWD, 5-20, by age and area



Source: NSS, 58th round.

Figure 4.4: School enrollment of all children by age and location, various years



Source: World Bank (2006), based on NSS, 43rd, 50th, 55th and 58th rounds

[95] Op.cit.

4.15. As for the entire PWD population, it is also possible with NSS to look at both school attendance and current levels of educational attainment by severity of disability for those currently in school age. This is presented in Table 4.1 below for children 5-14 (the broad target age for basic education in India). Several points emerge:

- ***almost three quarters of children with severe disabilities are illiterate and the same share do not attend school.*** [96]
- ***at the other end, close to one third of children with only mild disabilities are not in school.*** These are children who need no aids/appliances to participate, and should in principle not be significantly more difficult than other children to bring into the school system.
- ***across all levels of severity, CWD very rarely progress beyond primary school.***

Children with disabilities have very high illiteracy rates, in part because so many are out of school

Table 4.1: CWD education attendance and attainment by severity, 2002

Educational indicator	Severe PWD	Moderate PWD	Mild PWD
Goes to school	25.7%	56.3%	67.9%
Illiterate	72.2%	42.6%	34.9%
Primary or less	26.4%	52.0%	58.2%
Middle	1.5%	5.3%	6.8%
Secondary	0.0%	0.1%	0.0%
Higher	0.0%	0.0%	0.0%

Source: NSS, 58th round. Bank staff estimates.

4.16. The above figures focus on national averages. Differences in CWD attendance can also be seen. This is shown in Figure 4.5 for CWD 6-13 years old. ***In even the best performing major state (Karnataka), almost a quarter of CWD are out of school, while more than half are out of school in states such as Madhya Pradesh and Assam.*** [97] There does not appear to be any correlation between the state-specific general out of school rate and that of children with disabilities, nor any clear pattern in CWD rates between state income levels and outcomes. ***Perhaps the most obvious point is that even states with excellent outcomes on their general child population such as Kerala and TN have stubbornly high out of school rates for CWD.*** Thus in Kerala, CWD account already for 27 percent of out of school children, and in TN for over 34 percent of all out of school children. This underlines the increasing importance of getting CWD into school if even well-performing Indian states are to achieve the education MDGs. [98]

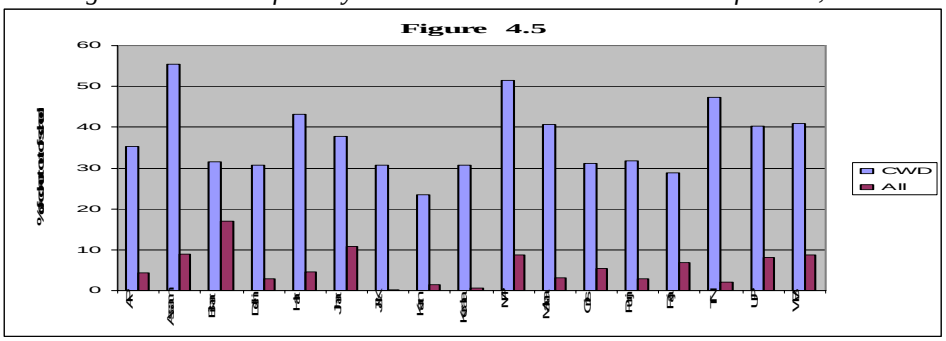
[96] As in many parts of the world, attendance at pre-school education is an important contributor to better educational outcomes later in life. Multivariate analysis of the NSS reveals that CWD who attended pre-schooling are significantly more likely to be attending school. However, available evidence suggests that until recently CWD have been largely ignored in ICDS, the national ECD program of GoI. Alur (2000).

[97] The administrative data (DISE) at the aggregate level broadly confirm these insights, though there is by no means a close match on a statewise basis.

[98] The point for India is consistent with international estimates that 33-40 percent of out of school children worldwide have disabilities (UNESCO, 2004).

Out of school rates for CWD are high in all states and CWD account for a higher proportion of all out of school children as overall attendance rates increase

Figure 4.5: Share of 6-13 year old CWD and all children out of school, 2005

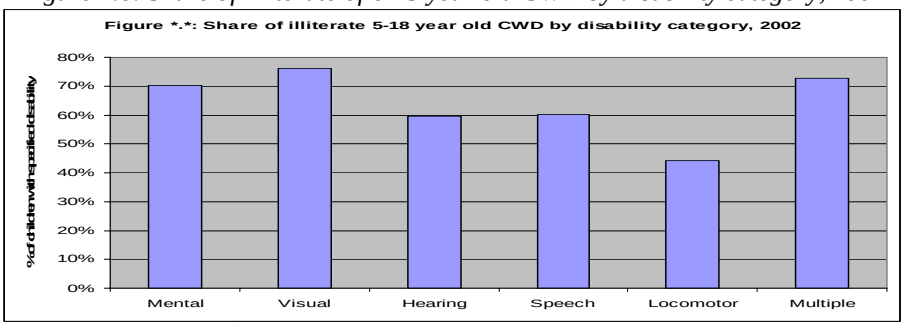


Source: SRI survey, 2005.

4.17. The other obvious aspect of educational attainment is to look at specific categories of CWD. This is shown in Figure 4.6. ***It is clear that illiteracy is high among all categories of disability, and extremely so for children with visual, multiple and mental disabilities.*** The numbers also rebut a common assumption that poor educational outcomes of CWD are a function of low intellectual capacities among children with mental impairments. ***At the same time, locomotor disabled children stand out as having substantially lower illiteracy rates than other CWD.*** This is explainable in part by the fact that less curricular or learning material adaptations are needed to promote inclusive education for locomotor disabled compared other categories of disabled children are required, but are also driven by family and community attitudes.

Illiteracy rates are very high among all CSN, though lower for children with locomotor disabilities

Figure 4.6: Share of Illiterate of 6-13 year old CWD by disability category, 2002



Source: NSS, 58th round. Bank staff estimates.

4.18. ***(iii) Where are CWD going to school ?*** This has several elements – whether CWD are attending regular or special schools, whether they are attending public or non-government schools, and for those in the government system what proportion of CWD are receiving alternative forms of education. This can be pieced together from several sources. ***On the issue of regular or special school, the NSS indicates that the overwhelming majority of CWD attend regular rather than special schools.*** Around 70 percent of disabled children and young adults aged 5-20 have *ever* attended school in their lives. Of these, fully 90 percent have attended a regular school. The figures for those currently attending school are very similar and are shown in Table 4.2, with nearly all 5-18 year old CWD who are in school attending regular schools. ***This brings home clearly that the choice facing most CWD is whether they are out of school or in regular school, and hence the necessity of promoting inclusive regular schools.*** The NSS also provides insight into why CWD are not enrolling in special schools. The picture is somewhat ambiguous, with a fairly even split between clear supply side factors such as lack of any or accessible special schools, clear demand side factors such as lack of parental interest and economic reasons, and factors related to the child's disability which are hard to interpret.

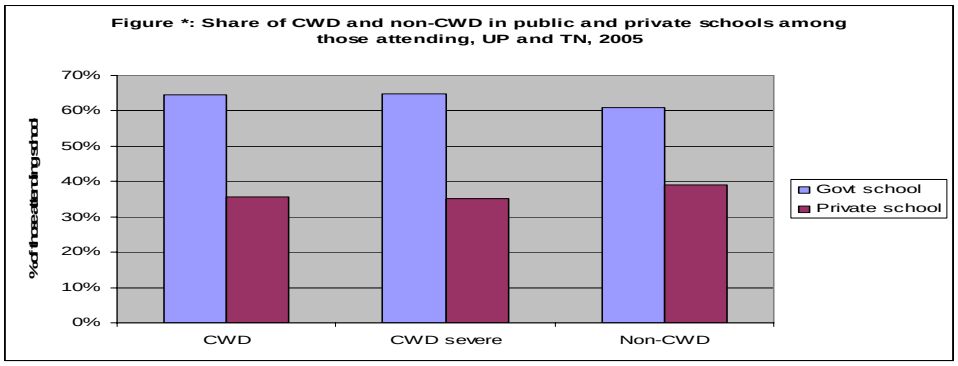
Table 4.2: Share of CWD attending regular and special schools, 2002

	Currently attending regular school	Currently attending special school
5-14 years	94.3%	5.7%
5-18 years	94.8%	5.2%

Source: NSS, 58th round. Bank staff estimates.

4.19. ***A second important element of the educational attendance of CWD is whether they are in private or public schools and how that compares to children without disabilities.*** This is not available in NSS unfortunately. [99] One source is the UP and TN village survey and results from this are presented in Figure 4.7 below. The important feature in the results is not so much the absolute levels of public and private enrollment in the two states (which reflect quite localized supply and demand factors), but the relative rates of public and private enrollment among CWD and non-CWD. ***The share of CWD in private schools in rural UP and TN is only slightly less than for children without disabilities.*** Given the very low rates of special school attendance, this can be assumed not to be a special school effect only. The result is interesting in that parents of CWD who are in school seem equally willing to make the investment in private education despite the fact that labor market outcomes of PWD are so obviously worse.

Figure 4.7: Share of CWD and non-CWD in public and private schools among those attending, UP and TN, 2005



Source: UP and TN village survey, 2005.

4.20. A final element on CWD attendance is what proportion of those in the government education system are attending alternative schools. SSA data for 2006 indicate that around 3.0 percent of identified PWD are in EGS/AIE schools, and a further 2.4 percent in home-based education settings, the latter in particular a notable improvement from 2004/05. [100] In both cases, there is a strong statewise concentration, with many states reporting no CWD in either form of education.

4.21. ***(iv) Impacts on schooling of a disabled family member:*** The above discussion focuses on children with disabilities themselves. ***A further important issue is the extent to which having a child with a disability in the household may impact the educational attendance of other children in the household.*** In principle, this could be estimated from the NSS, though such analysis has not yet been undertaken. Pending that, the UP and TN survey asked directly about the role of siblings in caring for family members with disabilities and its impact on school attendance. The results are reported in Table 4.3. Encouragingly, they are not dramatic (though see the employment chapter for results on caring time of adults, which are more significant).

[99] The recent SRI survey has data nationally, though such analysis has not to date been done.
[100] See section c below. These can only be considered the shares of identified CWD, which appears to be less than half of all CWD when compared to census sources.

Only around 5 percent of children with disabled members sometimes stay home to assist them, and of those only around 7 percent do so every day. Nonetheless, the impacts in the relatively small share of households affected should not be dismissed: half of households where a child does miss school require one or more days a week of school missed to assist disabled family members in the home.

Table 4.3: Children missing school to care for disabled family members, UP and TN, 2005

	Proportion of PWD households
Share of HH where child sometimes misses school to assist disabled family member	5.2%
Of which:	
Every day	7.1%
More than one day a week	21.4%
About one day a week	21.4%
At least one day a month	32.1%
Other	17.9%

Source: UP and TN village survey, 2005. Bank staff estimates.

4.22. ***Despite the move to more inclusive educational policies, clearly the educational outcomes of children with disabilities are substantially lagging those of the general population.*** This suggests that education of CWD is experiencing implementation problems which are characteristic of many areas of public policy in India. The following section explores the performance of key programs to explore the factors driving these outcomes.

C. Public Interventions to Promote Education of Children with Special Needs

4.23. Given the poor educational outcomes of CWD, this section explores several aspects of implementation of public programs to support inclusion of CWD, and of the general government school system which are relevant to educational outcomes of CWD. There are a range of institutional, fiscal/financial, and learning-related factors where there appears significant scope for improving the ways in which the education system promotes educational outcomes of CWD. Some of them are common to all children, but others are specific to CWD.

4.24. ***(a) Institutional Issues in Special Needs Education:*** Before performance in key programs for CWD, it is useful first to review the institutional arrangements with respect to education of CSN. This is an area that remains problematic in India. ***There are several institutional divisions of labor in the education of CSN which contribute to a lack of coherence in delivery systems.***

4.25. ***The first split in the delivery system for special needs education is between the MHRD - which is responsible for the general education system - and the Ministry of Social Justice and Empowerment, which remains institutionally responsible for special schools.*** This division of labor seems philosophically a remnant of the earlier approaches where CWD were viewed as welfare cases and not like other children. It would also appear to act as an institutional brake on fuller interaction between special schools and the regular schooling system, so that the resource school model for special schools is more difficult to promote. Finally, such a division is increasingly out of step with good international practice in education of CWD.[101] A UN survey of member states in the 1990s found that 96 percent of countries placed education of CWD under their education ministries, though in 58 percent of cases it was a shared responsibility.

[101] Peters (2004).

4.26. ***A second split relates to teacher training, with the Rehabilitation Council of India responsible for special needs teacher training and MHRD which is responsible for general teacher training.*** Following the RCI Act in 1992 and amendment in 2000, the RCI now has wide-ranging set of objectives. These include regulating, training policies and programs, standardization of training courses for professionals and prescribing minimum standards, providing institutional recognition and conferring the rights to award degrees, diplomas and certificate courses for professionals in the country (and extending reciprocal rights to institutions outside of India), and in maintaining a Central Rehabilitation Register for professionals. There remains a basic split between the roles of MHRD and RCI in pre- and in-service training for both regular and special needs teachers which contributes to a lack of coherence in the teacher training regime for inclusive education.

4.27. ***A third split relates to lack of coordination and duplication of efforts in early identification of children with special needs.*** Most states use teachers and anganwadis for early identification. Information on the number of children is captured through what is referred to as household survey. [102] Before the survey is conducted, the anganwadis are oriented on specific formats that are to be used for the survey and have been developed independently by both DWCD and Elementary Education departments. The DWCD format is more comprehensive as it covers all persons with disabilities (PWD), and not just children from 5-13 years of age. The input-driven planning process adopted for SSA records the total number of children identified as being disabled, the number assessed, and the number enrolled in regular schools. Almost no other information is provided on early identification, assessment or enrollment, though MHRED notes this as a strategic choice so as not to overburden teachers. The end result is both an overload of the workers carrying out CSN identification and a database in the education system which can not be considered reliable. As a result, states are involving NGOs more in identification, with 10 SSA states using them in this role as well as their other functions.

4.28. ***A fourth institutional challenge has been to promote convergence between government and NGO/community roles in education of CWD.*** All the programmes under the Department of School and Mass Education have involved NGOs in the implementation of inclusive education programme. Currently, more than 530 NGOs are involved in some capacity in SSA in 26 states. However, the ongoing challenge is to give NGOs a broader role in promoting inclusive education in partnership with the state. NGOs are now involved in assessment camps and training of teachers, as well as a range of other functions, including bridge course, provision of home-based education, providing resource support, development of TLM and other activities.[103] Deepening their role in every aspect of inclusion at each level (state, district, block, cluster, village and school) is an ongoing effort on the part of the Departments of School and Mass Education. In addition, there remains a largely undefined roles for grassroots institutions which could play an important role in promoting inclusion of CWD, including SHGs, Village Education Committees (VEC), Parent Teacher Association (PTA), Mother Teacher Association (MTA), anganwadi workers, Mahila Swasthya Sanghas (MSS), members of cooperative societies, and community based Local Bodies.

4.29. The above institutional issues in delivery of different aspects of education for PWD are by no means exhaustive. Similar divisions can be seen at higher levels in the division between vocational and higher education. However, even at the basic education level, such institutional lack of convergence remains a hindrance to promoting education of CWD.

[102] Survey is a misnomer as in reality it is a complete Census of all households in the catchment area and records information on all school age children in the house, including information on their disability status.
[103] See SSA 2006 re NGO initiatives for inclusion under SSA.

4.30. ***(b) Financial performance of public interventions for education of CWD:***[104] As noted in the policy section, the IED – now within SSA primarily – is the central public intervention to support education of CWD. This section reviews the evidence on its financial performance. Currently, under SSA the allocation per CWD is Rs.1200 per annum. While the norm is child-based, financial allocations are aggregated at district level. Currently – despite the clear policy commitment under SSA - there is no way of guaranteeing that a child with a disability, who attends school in a particular district, and is eligible for an assistive technology device, will actually receive this. This is because the funding is district or at best school based. The funding follows the location and not the child, thus there is no scope for school choice among children with special needs. Survey-based evidence on the coverage of assistive devices (see health chapter) clearly indicates a significant remaining agenda in this area. Box 4.3 compares the three main models of funding education of CWD internationally and their relative merits.

Box 4.3: Main models of public educational financing, with different impacts on CWD and IE:

Internationally, there are three main models for financing education of CWD, each of which has different incentive structures and impacts on both inclusion and educational outcomes. The models and their main features and pros/cons are:

- **Child-based funding** – based on headcounts of CWD, as outright grant to regions, pupil-weighted schemes, or census funding based on total students and assumed share of CWD. This is the most frequently used model internationally and the one followed under SSA. However, there are issues with the model including: (i) concerns on the focus on the disability category of the child vs. actual learning needs and costs. Thus the system is necessarily mechanical rather than needs-based; (ii) the model can be costly where individual diagnosis is required; and (ii) evidence from the EU suggests integration outcomes for CWD are worse that other approaches.

- **Resource-based models** (aka "through-put" models), where funding is based on services provided rather than CWD/student numbers. Typically, this model also mandates units of instruction/programs. Overall, there is evidence of an OECD trend towards these models, which are found to encourage local initiatives to develop programs for CWD. There are, however, concerns on disincentives for schools when CWD progress and funding is reduced. To work well, this approach should be accompanied by some link to outcomes.

- **Output-based models:** These are based on student learning outcomes or some other output. While desirable in principle, there has to date been very limited experience with this approach, (e.g. US No Child Left Behind Act, with financial and accreditation sanctions for failure to meet student achievement standards; UK "league tables"). There are concerns of a natural bias against inclusive education, due to concerns re CWD behind grade level dragging down school average scores. Equally, the circumstances for "failure" are often beyond the school's control (e.g. student absenteeism; unadapted curriculum).

Source: Peters (2004).

4.31. Figure 4.8 presents the share of total expenditure by major states on inclusive education in 2004-05 from SSA. ***Overall, the spending share on inclusive education in SSA is low, at only 1 percent nationally. However, there is major variation in IE spending share between states,*** ranging from over 5 percent in Kerala to well below half a percent of SSA spending in MP, Jharkhand, West Bengal and Rajasthan. ***Equally, expenditure execution on IED was until very***

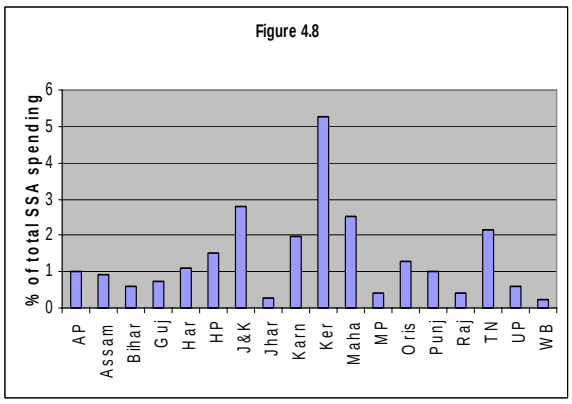
[104] While evidence on service delivery worldwide makes it clear that simply increasing expenditure does not ensure improved service delivery outcomes, expenditure performance in programs is generally a useful indicator of the relative priority given to different elements of public programs. See WDR, 2004.

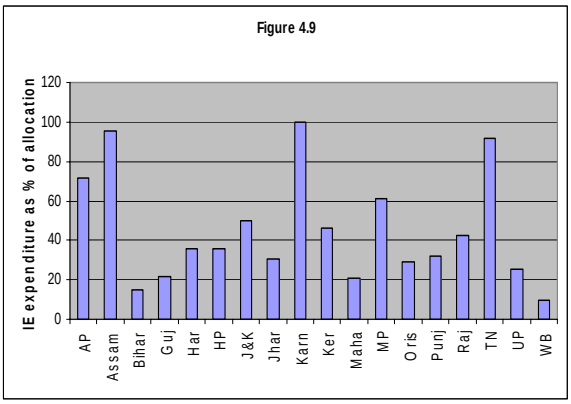
recently low (under 40 percent in 2004/05) and also exhibits huge variation across states, with states such as TN, Karnataka and Assam at very high execution rates, while others perform very poorly (in West Bengal, under 10 percent execution – Figure 4.9) One positive element of the picture is that SSA IE expenditure execution nationally increased from only 26 percent in 2003/04 to around 65 percent in 2005/06, and that states such as Assam and MP showed dramatic improvements in execution over the two years.

Inclusive education spending is a low share of SSA, but some states perform much better than others in terms of expenditure execution

Figure 4.8: Spending on IED as share of total SSA, major states, 2004-05

Figure 4.9: IED spending execution as share of allocation, 2004-05



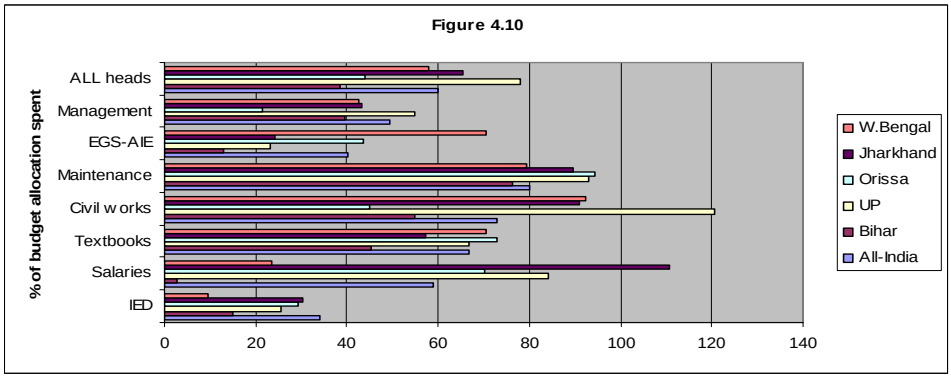


Source: SSA.

4.32. A second aspect is expenditure execution on IED relative to other heads of SSA spending. Figure 4.10 provides insights on the expenditure performance on IED within SSA for all-India and for five of the poorest states (Bihar, Jharkhand, UP, Orissa and West Bengal). ***It is clear that the relative expenditure performance on inclusive education was initially very poor (not much over half the average execution rate across all SSA spending), and consistently so across states.*** This is in contrast to most other heads which are either consistently well executed (e.g. civil works and maintenance) or exhibit strong variations across the states (e.g. salaries). At the same time, recent performance shows marked improvement, with sharp improvement in execution even in poor states. For example, in 2005/06, Orissa nearly doubled execution to 54 percent, UP leapt from 25 to 86 percent execution, and West Bengal went from under 20 to 49 percent.

SSA expenditure execution on inclusive education is poor, nationally and in the poorest states

Figure 4.10: IED expenditure execution as share of allocation for SSA, 2004-05



Source: SSA.

4.33. Overall therefore, it appears in many states that failure to execute spending for IE is one factor in driving the poor attendance of CWD. However, poor resourcing is not by any means the

only factor contributing to both poor attendance of CWD and poor educational outcomes. The following sections review a number of other factors which are important.

4.34. ***(c) Making schools inclusive for CWD:*** A number of factors driving poor educational outcomes of CWD can be grouped under the heading of accessibility and inclusion. ***There are several elements of making schools and learning accessible for CWD.*** They include:

- an effective system for ***early identification of children with special needs,*** both in terms of medical assessment and in terms of identifying their special learning needs and potential
- ***attitudes of parents, communities and education service providers and administrators*** which promote inclusion of CWD and promote them realizing their potential
- ***physical accessibility of schools,*** not only the school premises and facilities but also accessibility from the child's home, which brings in issues like transport systems and roads.
- ***access to appropriate curriculum and learning materials*** which are adapted to their learning needs of CWD, both in content and format
- ***provision of financial incentives and aid/appliance support for CWD*** to facilitate their participation in regular schooling
- ***presence of teachers and education administrators who are sensitized to the rights and needs of CWD in education,*** and are equipped with basic skills and access to resource personnel and materials who can supplement the skills of general teachers
- ***encouraging a special education system which facilitates inclusive education through greater reliance on the community*** (e.g. through CBR), rather than inhibiting it through over-professionalization.[105]
- ***development of coherent government strategies for promoting inclusive education***, which in particular take greater account of the important roles of NGO and community organizations.
- ***an effective system for monitoring and evaluating the educational attendance and attainment of CWD, preferably integrated with the general education M&E system.***

4.35. This section deals with the above elements of accessible and inclusive education for CWD. ***Many of the principles necessary to promote inclusion are reflected in recent policy documents of GoI, including the draft Action Plan. However, implementation has typically fallen short of policy commitments, in many cases far short.*** Implementing coherent strategies for inclusive education is one of the greatest challenges facing education systems in both developed and developing countries. Capacity, resource, and attitudinal constraints make the challenge even greater in India. Making progress on the above agenda will take considerable time. Nonetheless, ***there are many effective and promising experiences in India which suggest that significant improvements in inclusive education are possible in ways that are consistent with the constraints that India faces.*** It is also important that the system succeed on the basics first - primarily identification of CWD and getting them into some form of education from the earliest possible point.

4.36. ***(i) Identification of CWD:*** The bottom-up approach to planning adopted under SSA is expected to provide a clear picture on how many children will need special assistance to participate in the schooling system. Since district-level funding is tied to the identification of children with special needs, the designers of SSA have attempted to define how the process of identification should be done. GoI has developed a simple set of definitions and a disability-specific checklist to help determine children with mild to moderate disabilities.

[105] In this respect, NGOs such as Vidya Sagar have introduced training for special needs resource persons that are of a simpler nature, as have groups such as Mobility India through CBR approaches.

4.37. Once children have been identified as disabled, an assessment is undertaken to determine the nature, type and extent of disability. This is done by a team comprising of doctors, eye and ENT specialists, and general and resource teachers. The child is then *placed* in a particular school-type. While the guidelines calls for all children with disabilities to be placed in regular school settings, they also permit the placement of children in special schools, AIE/EGS centers, distance learning centers and home-based education if it is decided that the child is not in a position to participate in regular school, and the interventions they require will be beyond those that can be offered in a regular school even with a trained and qualified teacher. This reflects the broader transition from a special education to inclusive education model.

4.38. ***There are three key issues with early detection and identification of CWD for education policies:***

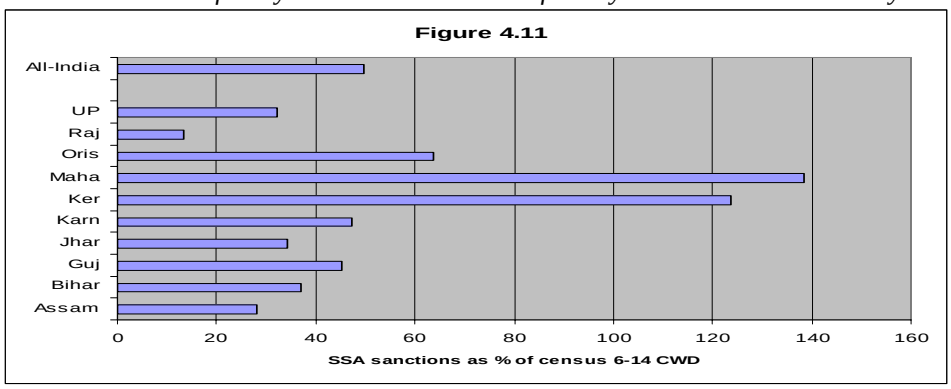
- ***technical and logistical difficulties in early identification***. As noted earlier, some of the issues relate to institutional lack of coordination and duplication. A second aspect of this is the functioning of disability identification camps, which achieved at best partial coverage of CWD.[106] A further concern with testing of younger children is that they need specific preparation for testing, and that the instruments and personnel needed for these may not be readily available in many parts of India.

- ***there are large discrepancies in the number of CWD identified between census data, school-based records through DISE, and PAB survey aggregates used for the preparation of SSA annual prospective plans.*** For example, PAB data find only 1.54 percent of children identified as having special needs nationally, though this is a significant improvement from only 0.35 percent in 2002/03. Even more significantly, there are unreasonably low shares of children identified as having special needs in specific states. For example, data for 2005-06 suggest that only 0.31 percent of children in Rajasthan had special needs and 0.7 percent in UP. In contrast, states such as Maharashtra had 2.45 percent and HP around 2.3 percent of children identified with special needs. In contrast, census data on 5-14 year old children with disabilities nationally suggests that 2.2 percent of children have disabilities. On a statewise basis, the differentials are even more dramatic in several cases, e.g. the number of children identified by PAB in Rajasthan as disabled for 2005-06 was less than 15 percent of the number of 6-14 year old disabled children identified in the 2001 census. For UP, the PAB share was under 30 percent of the census figure. In contrast, states such as Maharashtra and Kerala have SSA CWD numbers well above the census estimates. ***The discrepancies between SSA and census sources suggest major challenges for government in identifying children with special needs.*** Figure 4.11 provides comparative figures for several states on the share of children identified as disabled through SSA and the estimate of all CWD in the 6-14 age cohort as per the census.

[106] E.g, in the UP and TN survey, only 23 percent of PWD had attended a disability assessment camp.

The numbers of CWD identified by SSA relative to census numbers is below half nationally and far less in some states

Figure 4.11: CWD identified by SSA in 2005 as share of 6-14 year old CWD in census by state



Source: SSA and 2001 census (Bank staff estimates based on Rajan).

- ***there have been concerns expressed from educators that identification of CWD is viewed more from a medical perspective and does not focus sufficiently on the learning needs of children with special needs.*** [107] For example, although medical camps were initially envisaged to be used for certification and identification, increasingly in states like Andhra Pradesh, they are being used to identify children suitable for corrective surgery (e.g. children with cleft palettes, etc.). In principle, such camps do address a broader range of needs, but in practice have supply side and other limitations.

4.39. ***(ii) Attitudes to CWD:*** Even very poorly resourced systems can be inclusive if the attitudes of parents, communities and teachers are sufficiently supportive. Chapter 2 demonstrated that positive attitudes to CWD being included in regular schools were rare in rural UP and TN, and that there was virtually universal rejection of children with mental disabilities attending regular schools, even among both PWD and parents of children with disabilities. However, qualitative work found generally a more open attitude to inclusion among teachers.

4.40. There has been relatively little research on the attitudes of teachers towards the education of CWD in India. The existing research on teacher attitudes reveals mixed results. An initial study in the 1990s on the attitudes of administrators, special education teachers and general education teachers towards CWD found that over 50 percent of administrators had misgivings about their education in regular schools.[108] Special and regular school teachers had more positive attitudes regarding integration of CWD in regular classrooms. Administrators however did agree that integration would benefit both children with and without disabilities. A later study on attitudes towards inclusion in Delhi found that almost four-fifths of teachers interviewed had an open approach to inclusion, although three-fifths felt that special schools would be better for CWD. The most recent study looked at the attitudes of general education teachers towards CWD and inclusion in Mumbai. The results are summarized in Box 4.4.[109]

[107] See, for example, Jangira (2005).
[108] Jangira and Srinivasan (1991).
[109] Parasuraman (2002).

Box 4.4: Teacher attitudes to inclusive education in Mumbai

Parasuraman (2002) studied the attitudes of general education teachers towards CWD and inclusion in Mumbai. She specifically explored several demographic variables of teachers, such as, gender, age, income levels, experience, educational attainment, whether the person had a friend or a relative with disabilities, and the frequency and proximity of contact with this disabled person. She found that:

- younger teachers (20-30 years old) and the most senior (50-60 years old) demonstrated more positive attitudes towards CWD, compared with the teachers in the 40-50 age group.
- there were no differential effects due to gender (although other studies have shown this)
- higher income groups have more positive attitudes than lower income groups (< Rs.10,000).
- experience as a teacher demonstrates a pattern that is similar to age in that the youngest teachers (with less than 5 years of experience) and the oldest teachers (with more than 25 years of experience) demonstrate the most positive attitude towards CWD
- the more educated a person, the more positive their attitude is towards inclusion, thus, teachers with a master's degree are more open to inclusion than are teachers with a bachelor's degree or a high school certificate
- knowing someone with a disability was likely to influence thinking on inclusion positively
- however, knowing someone with a disability who was related to you did not have more of an impact than merely knowing someone with a disability, i.e., kinship did not result in more positive attitudes
- both the frequency of contact and the closeness of the relationship did not have any significant effects on positive attitudes towards inclusion of children with disabilities.

4.41. The UP and TN study asked CWD directly about their perceptions of attitudes of teachers and classmates towards them. The results were encouraging, with the bulk of CWD reporting some degree of support towards them in their schools, and only a small number reporting discriminatory attitudes. The results are presented in Table 4.4, with around 85 percent of classmates and almost 80 percent of teachers reported as being very or somewhat supportive.

Table 4.4: Attitudes of teachers and classmates of CWD in UP and TN were positive

	Share of CWD reporting teacher's attitude as…	**Share of CWD reporting classmate's attitude as…**
Very supportive	35.5%	50.4%
Somewhat supportive	43.7%	34.5%
Indifferent	6.7%	5.9%
Somewhat uncaring	4.2%	5.9%
Discriminatory	0.8%	0.8%
Don't know/can't say	9.2%	2.5%

Source: UP and TN village survey, 2005

4.42. ***The limited empirical evidence thus supports the proposition that attitudes of educators towards inclusion of CWD are gradually improving. However, evidence from several states indicates less movement with respect to both general community attitudes and those of parents of CWD.*** GoI, in cooperation with the State governments, NGOs and other stakeholders have recognized the importance of this change in attitudes and have organized numerous *maa-beti samelans*, *bal samelans*, and other forms of interventions to help change attitudes. However, a more comprehensive approach is clearly needed. This is an area where Community-Based Rehabilitation (CBR) can play a potentially important role in mobilizing attitudinal change.

4.43. ***(iii) Teacher Training and Methods:*** As well as positive attitudes to inclusion, training of teachers in the principles and practices of inclusive education is an important element of making the school experience of CWD worthwhile. This covers both pre- and in-service training, for both regular and special educators. Box 4.5 outlines the broad contents of different

IE training options. The impacts of such training are typically improved when educational administrators are also trained.

4.44. Given the overwhelming proportion of CWD in regular schools, the importance of training on special needs education for regular teachers can not be under-estimated. ***However, to date pre-service training of regular teachers includes no familiarization with education of special needs children.*** As a result, the effectiveness of in-service training is even more vital. As of 2004/05, the bulk of in-service training for regular teachers in SSA schools has been the orientation on IE as part of their mandatory 20 days in-service training per year, with around 40 percent of teachers having participated. The share of teachers who had undertaken the 3-5 day exclusive IE course increased also, from only around 12 percent of all teachers in 2004/05 to almost 30 percent by 2005/06. There is as usual large inter-state variation, with states such as Karnataka and Maharashtra having only 10-12 percent of teachers having had either form of IE training, while others such as Kerala, UP and Haryana had achieved very high coverage of teachers (e.g. in UP, more than half of teachers had had the 3-5 day course in 2004/05). However, the number of teachers undertaking the 45-90 day foundation course remained very low as of 2005, at less than 0.2 percent of all SSA teachers. [110] ***While the coverage of basic sensitization courses under SSA is growing, the penetration of RCI training has been negligible.*** As of 2006, RCI had trained a total of 27,252 personnel and professionals, or around 0.6 percent of total SSA teaching cohort.

4.45. ***In the area of teacher training, a key issue of debate is the role of RCI and its certification of training programs and trainers.*** There have been a range of criticisms of the RCI with respect to teacher training. The first is that its genesis and skills base tend more towards a medical mode of disability and that it is thus not well equipped to develop and certify training materials. Additional criticisms include: (i) the development of RCI rules and regulations have generally been done without any consultative process; (ii) punitive actions for failure to comply with articles within the Act; (iii) failure to draw a pragmatic line between the need for standardization in training and the need to promote wide coverage of service delivery and (iv) the need for a meaningful definition of a rehabilitation professional; and (iv) the inability for capacity reasons of RCI to monitor compliance. [111]

4.46. While the legitimacy of RCI as the sole statutory body with authority to recognize training programs and confer degrees to persons specializing in special education is not questioned, an increasing number of trainers, care-givers and experts are questioning the need for a sole agency to be given such a large mandate, and whether the mandate should be shared by specialized agencies that exist across the country. The number of special teachers in the country is extremely small compared to the total number of regular school teachers. DIETS, SCERTS, other public and private teacher training colleges that offer courses on special education are all required to be certified by RCI. Given the tremendous imbalance in terms of the need for special education teachers and IE skills among regular teachers, the concerns of the profession seem worthy of closer consideration.

[110] According to MRHD's AWP&B, 2005/06.

[111] The 16 professional categories under RCI guidelines have vastly different training needs, academic qualifications, and experiences, and yet have all been lumped in as "rehabilitation professionals".

Box 4.5: Training on IE for regular and special educators

In-service 1 day orientation on IE for regular teachers:

- Concept of inclusive education
- Identification of CWD
- Classroom management of CWD

5- day training on IE:

- Difference between integrated and inclusive education
- Types of special Educational Needs (visual impairment, hearing impairment, locomotor impairment, mental retardation and learning disabilities)
- Causes of disability
- Identification of CWD using a simple checklist
- Role of teachers in dealing with CWD
- Use and maintenance of assistive devices
- Rehabilitation in disability

The 90-day foundation course developed by RCI besides the above also exposes the teacher to plus curricular skills. This course is conducted in a distance mode and has a three-week contact programme.

Contents of Teacher Training of Special Schools

- History of Special Education
- Anatomy and Physiology of eye/ear/brain
- Causes and prevention of disability
- Multi-Category teaching
- Plus Curriculum
- Guidance and Counselling
- Prevention
- Use of aids and appliances
- Preparation of teaching-learning material
- Educational implications of different kinds of disabilities
- Practice teaching

4.47. The modes of educational delivery anticipated under IED are diverse and on paper they are impressive. Box 4.6 outlines the main intervention menu that is anticipated under IED and from which states are supposed to develop state-specific strategies for the getting CWD into school and improving their educational outcomes. However, cases where the menu comes together in a coherent and well-executed strategy for IE are much more limited.

4.48. ***(iv) Incentives for CWD to go to school:*** National and state governments have a range of incentives for CWD to attend school, the most important being stipends. These were introduced only in 2002-03, i.e. seven years after the PWD Act, despite provisions in the Act for stipends. According to GoI, there are 32 states/UTs that provide some sort of scholarships/stipends to students with disabilities, typically up to primary or middle school (and in very few cases beyond secondary level). For primary education stipend varies from Rs. 5/- per month in Pondicherry to Rs. 200/- per month in Punjab. [112] The CAG report notes that by mid-2003, the MoSJE acknowledged that it had not taken steps for dissemination of information on the stipend program.[113] Consistent with this, anecdotal evidence suggests both a low level of awareness among CWD and their families of stipend possibilities and inadequate efforts on the

[112] MoSJE website.
[113] CAG (2004), op.cit.

part of the authorities to increase stipend coverage. There are no consolidated data on stipends available, so that it is difficult to examine the scale and impact of stipends.

4.49. Although a key feature of SSA, the provision of aids and appliances is achieved through convergence with other existing programs such as ADIP[114], a scheme aimed at helping disabled persons by providing suitable, durable, scientifically manufactured, modern, standard aids and appliances. ***While assistive technologies are a right under SSA, they are in practice rationed, making them instead a privilege.*** While SSA itself has no excluding procedures, there are specific eligibility criteria under programs such as ADIP with which SSA converges that need to be met before becoming entitled to an assistive technology. Under ADIP, the CWD needs to be certified by a registered medical practitioner that he is disabled and fit to use the prescribed aid or device, and that he or she is in a particular economic bracket, and has not benefited for the same purpose in the past 3 years (1 year for children below 12 years of age). In principle, if states do not provide aids and appliances under such programs, SSA can provide equipment. In practice, the NSS results indicate that such interaction is not seamless and coverage gaps remain.

Box 4.6: Service delivery modes for CSN in IED

Service delivery in IED can happen through a variety of mechanisms. The main modes of delivering integrated education services through DPEP and more recently SSA are:

- ***integrated schools***: in that there is a clear and significant departure from Special Schools under DPEP and although there has been continued expansion of special schools, largely under the ambit of the Ministry of Social Welfare, there has been a increased focus on inclusion in general schools.
- ***resource room model***. The resource room allows for children to be educated in an inclusive setting, but with the provision for specialized attention when needed. For example, a child who is unable to access the regular curriculum due to a disability, can be taught the same in the resource room
- ***traveling teacher model*** is a model adopted initially to address the concerns of migrant children and for children in rural areas where sparsely populated areas may have difficulty ensuring the presence of a school. However, the itinerant teacher's function is to be able to cover several schools at the same time, unlike the resource teacher who can at the most cover 2 schools.
- ***dual teaching (for slow learners)*** where children are provided with extra tutorials and over an extended period of time to ensure learning by these individuals
- ***learning corners*** are used in classrooms to help organize class material and to support the development of curriculum. These provide children with special needs to pursue on their own, in a child centered manner, the exercises done in the classroom at an earlier point in time
- ***distance Learning*** is already being carried out through the National Open School and the new EduSat satellite based school TV channels
- ***home based education*** is an option for children with severe or multiple disabilities, who are unable to participate in regular school. In this case, the school actually goes to the house
- ***additional resource teachers and sensitization of regular teachers,***
- ***NGO involvement is a key feature*** of DPEP's and SSA's IED scheme. Several states have entrusted responsibility for IED services to NGOs working closely with the governments in those states.
- ***development of a model kit*** works in complement to the Learning Corners and Itinerant teacher initiative as it allows for well-developed modules to be given easily across several locations
- ***training of trainers and master trainer method.***

Source: Sundararaman (2005), based on "Empowerment through Education, Identification and Enrollment of Children with Special Needs in DPEP".

4.50. ***The results of the UP and TN survey support claims that both the stipend and aids/appliances schemes are not to date working well. For aids and appliances, the results are***

[114] Run by the Ministry of Social Justice and Empowerment or through State Red Cross societies.

supported by NSS findings also (Table 4.5). Almost three quarters of households with PWD were unaware of schemes for free aids and appliances, and less than 2 percent had benefited from them. For stipdends, almost half the PWD households were not aware that education stipends were available and only 4 percent had received them. ***A major problem appears to be lack of awareness of the existence of CWD stipends and possibilities for receiving aids and appliances.*** Analysis of NSS data suggests that failure to access aids and appliances matters for school attendance, with multivariate analysis from the 58th round indicating that CWD who have accessed aids and appliances are 30 percent more likely to be attending school.[115]

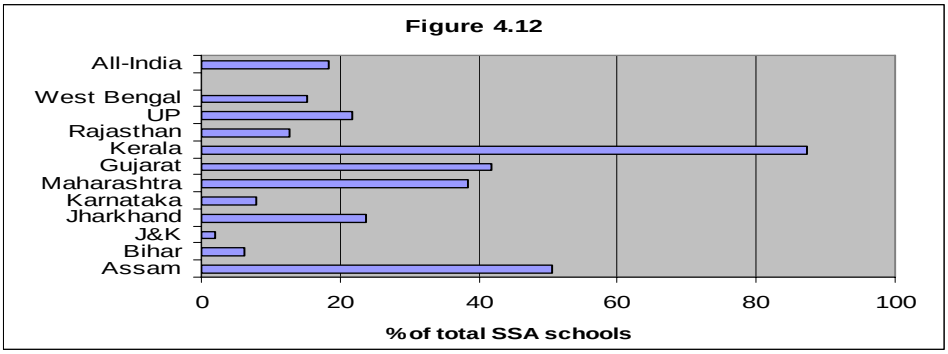
Table 4.5: There is low awareness of possibilities for aids, appliance and stipends and very low shares of beneficiaries in rural UP and TN

	Stipends to CWD for school	Free aids, appliances and assistive devices
Not aware	46.5%	72.3%
Aware only	46.7%	24.1%
Benefitted	4.4%	1.5%
Denied	2.1%	1.8%

Source: UP and TN village survey, 2005

4.51. ***(v) Physical accessibility of schools:*** Obviously a school has to be physically accessible to be inclusive. While typically this is thought of primarily in terms of ramps, other forms of increased accessibility for visually impaired and other CWD are equally important. Physical access includes not only the schools premises and classrooms, but core facilities such as toilets. ***Official statistics on "barrier free access" indicate that basic education in India is predominantly not physically accessible for many children with disabilities, though significant progress has been made in recent years.*** At the same time, the data also indicate that broadening the coverage of schools which are classified as barrier free is achievable, as the performance of states such as Kerala, Assam and Gujarat indicate. Figure 4.12 below reports the share of primary schools which are officially rated as barrier free in selected states in 2005. ***Only 18 percent of SSA schools nationally were considered accessible in 2005, and the share is as low as 2 and 6 percent in J&K and Bihar respectively.*** Nor does the accessible share follow predictable patterns, with generally good performers like Karnataka and well-off states like Punjab with less than 8 percent of schools accessible. At the same time, progress is being made, with the figure for 2006 rising to around 35 percent.

The bulk of SSA schools are not accessible for CWD – nearly all in some states
Figure 4.12: Share of accessible SSA schools, 2005



Source: SSA, based on state Civil Works Units

4.52. Above and beyond schools themselves, there may be issues with CWD getting from home to school. This is an area where very little research exists, and one that is an issue that goes

[115] Sundararaman, op.cit.

well beyond the needs of CWD alone. Nonetheless, difficulties with access to transport and/or simply difficult personal access may be much more pronounced for certain CWD. The UP and TN survey asked about access to public transport, and over 60 percent of PWD respondents reported difficult or no access to public transport due to their disability.

4.53. ***(vi) Accessible curriculum***: [116] To date there remains major differences in curriculum between special and regular schools. The current mode of delivery of such services in India is categorized into two sets. The first is the skills relating to what is called "Plus Curriculum" in special needs education curriculum. It is called Plus Curriculum as it is a specific curriculum for CWD intended to increase their access to the learning environment (for example, Braille, orientation and mobility for children with blindness, use of low vision aids and reading large print by children with low vision sight, speech, language and communication skills by deaf children, communication skills by children with cerebral palsy). They have to learn additional skills for fully participating in classroom learning activities and require additional time.

4.54. The other set of questions deal with adjustment of general curriculum to diverse educational needs arising out of disability, and use of additional learning resources and classroom management to improve access of all children in learning activities. The curriculum options for CWD in general curriculum/school settings are several:

- follow the same curriculum as others, in principle maintaining equity in curriculum access. While in principle this is straightforward, this option still requires development of accessible formats of the general curriculum for children with specific disabilities (e.g. Braille books; visual learning materials for hearing impaired and autistic children). For the most part, such format adjustments have not been made on any large scale in the public system. [117]
- adjustment or/and modification to special needs in areas which cannot be accessed despite assistive aids and additional learning material and aids
- substitution of curriculum content area by alternative content area
- deletion of specific curricular content area since it is not possible provide learning to a child with a particular disability.

4.55. ***There appears to be significant diversity between states in the approaches taken***. For example, field work in Gujarat revealed all four approaches being used. In principle, once a child has been assessed with a disability, an individualized education plan (IEP) is supposed to be prepared for the child. An IEP is a statement that: (i) describes how the child's disabilities affect his or her involvement with and progress in the general curriculum; (ii) sets measurable goals to enable a child to be involved with and progress in the general curriculum, and (iii) outlines the services, program modifications, and supports necessary for the child to be involved with and progress in the general curriculum. Effectively designed and implemented IEPs are a challenging task even in well-resourced and high capacity countries, and will remain a challenge in much of India. However, experience even in poor states such as Orissa shows that through collaborations between the government and NGO sectors gradual results are possible. Partnerships under SSA in 12 Orissa districts have resulted in around 10 percent of CWD in the pilot districts having IEPs developed under DPEP.

[116] The definition of curriculum in this section includes: (i) what is learned and what is taught (context); (ii) how it is delivered (teaching-learning methods); (iii) how it is assessed (exams, for example); and (iv) the resources used (e.g., learning materials used to deliver and support teaching and learning).

[117] Such format adjustments may often be beneficial for the learning of children without disabilities also in terms of making the material being taught more accessible.

4.56. ***An important point with respect to curriculum adaptation for CWD is that international evidence suggests that such adaptations can also have positive effects on the learning outcomes of non-disabled students also.*** While evidence from developing countries is lacking, an eight country OECD study found that adapted curriculum and pedagogy motivated by inclusion objectives resulted in improved educational outcomes for non-disabled students also. A simple example is greater reliance on visual teaching materials, which may be both necessary for hearing impaired students and beneficial for the learning of all students. Further analysis on this issue in India would be highly desirable.

4.57. ***All states have special provisions for CWD taking examinations.*** Writers are provided to blind students and other students who cannot write. The writer is to be a student from a class below the examinee, thus ensuring fairness in the process. While fairness is important, lower classmen and women may be more limited in their own understanding of subject matter and thereby be a poor substitute for a student of the same grade. Field work for this report revealed that the arrangement was characterized by mistrust between the examinees and the examining board. The earlier practice of allowing blind students writing in brail was replaced due to non availability of examiners knowing brail and time consuming and costly translation. The issue needs to be reviewed and alternative ways need to be found. For example, some subjects can be examined through audio mode and the use of computers and ICTs is also be considered.

4.58. Students are often allowed to take extra time to write their examinations, e.g. an extra half an hour is allowed to blind students with writers in Gujarat; AP provides CWD an extra hour to write exams. At present the decision is ad hoc. The Board also allows practical examination in peer pairs (a blind with a sighted) or the practical examiners individually attending and asking question with each step. While the rules are clear on allowing extra time for exams, the UP and TN study revealed that the rules may not always be implemented in practice, with three quarters of CWD reporting that they were not always given extra time to finish exams.

4.59. ***(vii) Strategies to implement IE obligations:*** Apart from the specific elements of IE promotion noted above, there is a need for overarching state (and lower level) strategies for implementing their obligations to provide education of CWD. ***However, most states to date do not have a strategy for resource support in the form of resource teachers or any other specialized support service required by CWD.*** While this is slowly improving in some states, it clear from the data that there remains a basic lack of IE delivery strategy in much of the country. The framework for SSA requires the appointment of a state coordinator for inclusive education, and all states/UT now have such a person in position. As a result, there are many initiatives and a growing number of resource teachers (around 4,693 in 17 states as of 2006), but such initiatives are not always guided by a longer-term strategy.

4.60. ***However, the experience of states like TN offer cause for hope.*** Tamil Nadu has rapidly raised IE expenditure execution from less than 10 percent in 2002/03 to 55 percent the following year and over 90 percent in 2004/05, largely due to a change in policies on how to handle the IE component of SSA. The state recognized the strong capacity and commitment among the NGO community to undertake this task, and the Department of School Education of GoTN tasked credible NGOs to undertake identification and intervention activities. As a result, it has been able to channel resources to these NGOs rather quickly. Not all states will have the existing disability and general NGO base of TN, but the capacity for major expansion in public-private partnership in IE is clear. The TN case points, however, to the importance of better understanding of NGO initiatives in inclusive education. This is addressed in Section D below.

4.61. ***(viii) Monitoring and Evaluation***: A key feature of SSA is its focus on monitoring and evaluation of inclusive education practices for children with special needs and their

performance in the schooling system. This includes quarterly national IE workshops, use of NCERT monitoring tools on attendance and learning achievement of CSN, joint review missions under SSA, and regular visits by the SSA technical support staff. In addition, there are 39 monitoring institutes across the country that look at all SSA interventions, including IE. At the state level, a number of states (including all southern states and a number of lagging states such as Orissa and UP) also rely on their IE resource teachers for monitoring, and in states such as Assam, GP level volunteers are also involved in monitoring. Finally, an impact assessment study on IE under SSA has been commissioned and should be a valuable resource.

4.62. ***While the commitment is there and regular data is collected on a range of IE indicators, analysis suggests that there are challenges in implementing the system, not least identifying all CWD.*** Very few evaluations have been fielded till date on whether the legislative and design aspects are working. The DISE data system for capturing participation of children with special needs in the schooling system has been in effect for about three years, but significant inconsistencies between DISE, NSS and census data suggest that the M&E agenda on IE remains far from complete.

4.63. ***While the areas above are all elements of an inclusive and effective educational strategy for CWD, it is also important to be realistic on what is feasible in what time horizon given the overall context of the basic education sector.*** The IE challenges above need to be viewed in the context of a basic education sector where enrollments have increased substantially in recent years, but there remain many challenges, including significant drop-out rates, crowded class rooms, issues with teacher absenteeism (e.g. a major study found around 25 percent of teachers absent, with around one third of those not engaged in other activities), concerns with the quality of teaching and approaches in learning curriculum, major challenges in assessing learning outcomes etc. There is a risk in such an environment that including CWD into the educational system is put in the "too-hard basket". In that context, an absolute minimum should be fulfilling the commitment to identify CWD and get them into some form of school.

D. Non-government roles in education for CWD

4.64. The preceding section focused primarily on SSA/IED as the major public education initiative for CWD. ***However, education of children with special needs has a long tradition also in the non-government sector, and much of the most innovative work in education for CWD continues to happen outside the public system (or through partnerships where the government finances non-governmental service delivery).*** This section reviews NGO roles in education of special needs children in India, and assesses the potential for an expanded role for partnerships between government and non-government providers.

4.65. ***As with the government sector, the tradition of NGO education for CWD was one of special schools until at least the mid-1950s.*** To some extent, this strong tradition continues, both on an independent basis and through the work of NGO special schools funded through the MoJSE NGO grants. In 2003/04, MoJSE provided grants-in-aid to 657 NGOs for a total of Rs. 71 crores and for the benefit of 2.17 lakh people (though this was reduced to Rs. 67 crore in 2004/05). The bulk of this assistance went for residential and non-residential special schools for different categories of CWD.[118] As can be seen, given the numbers of PWD covered by all MoSJE grants, it is clear that the more significant NGO activities are likely to be those carried out independently or as partners/executing agencies within mainstream education initiatives.

[118] See Officer (2005), citing MoSJE annual reports.

4.66. ***Since DPEP and increasingly in SSA, there is a stronger public policy of linking NGO schools for CWD with the mainstream education system, either as direct service providers of different forms, or as resource centres for regular schools***.[119] The overall concept of support is to strengthen linkages between general and special educators and educational establishments. The main NGO initiatives which are supported through SSA focus on four main approaches:

- using NGO special schools as resource centres for children with more severe or multiple disabilities who require special therapy or support. This may include provision of services by the special schools on a short term basis to CWD in regular schools, outreach support for mainstream schools to deal more effectively with their disabled students, provision of assessment services, advocacy efforts, and joint leisure and curricular activities.
- involving special schools as demonstration centres for both special educators and regular teachers.
- using special school staff as trainers for teachers in regular schools to strengthen their skills to include CWD in regular settings.
- using special schools to develop learning/resource materials for CWD that will also promote improved learning among all children

4.67. ***There is substantial variation by state in the scale and depth of NGO involvement in mainstream education of CWD.*** States such as TN, West Bengal and UP have involved NGOs in all stages of IED implementation since the time of DPEP. Other states are only more recently exploring effective collaborations. It is not possible to provide a comprehensive sense of the range and scale of NGO initiatives under SSA, but documented positive experiences include: [120]

- in Assam, NGOs have been tasked with a wide range of services for CWD in 11 districts, with coverage accounting for over 40 percent of all identified CWD in the state under SSA. While the initiative faced challenges in variable capacity of NGOs, successful interventions have been undertaken ranging from identification of CWD, community sensitization, teacher training, resource support to schools, preparation of IEPs, and regular monitoring.
- in AP, there has been a strong push for residential bridge course for CWD aged 9-14 who are out of school. These courses last for 10 months and are intended to graduate CWD into regular schools, and an estimated 3000 CWD were enrolled in such camps in 2005, which is over 2 percent of all identified CWD in the state. While costs exceed SSA standard annual allocations (per child costs for recurrent and non-recurrent costs are around Rs. 4,800), this is less of a concern given low expenditure execution on IED. Other states such as UP also have positive experiences of partnership in bridging courses.
- Tamil Nadu features some of the most innovative and widespread NGO initiatives in education of CWD, with NGO implementing agencies in 391 blocks of the state as of 2005. Their programs include innovative support for home-based education of children with severe disabilities, which includes training of parents and development of skills in the child for carrying out activities of daily living.
- West Bengal represents a well-designed case of trying to establish resource centres at different levels of the education system. The structure is headed by a State Level Resource office operated by 4 experienced NGOs, which performs a coordinating and planning function. This is linked to District level resource Offices in 20 districts, with around 270 special educators in place as resource people. The training function of the

[119] See SSA report on NGO activities (2005), from which much of the following examples are drawn.
[120] See SSA report on NGO initiatives in inclusive education (2005) for a useful overview.

DLROs has contributed to West Bengal accounting for around 10 percent of all teachers nationally sensitized in IE under SSA.

4.68. NGO initiatives are not restricted to basic education levels. There are many effective pilot interventions at all levels of the education system. One example is the work of The Spastic Society of India in partnership with UNICEF in the Dharavi slum of Mumbai, which promoted inclusion of CWD in ICDS centres. Assessment of educational and other outcomes indicated not only substantially improved outcomes for CWD along a range of dimensions, but also for non-disabled children in the ICDS centres into which CWD were enrolled. [121] States such as TN have achieved even broader expansion of ECD programs to CWD, with over 14,000 3-5 CWD mainstreamed into ECD centres.

4.69. ***It is clear that NGO/government partnerships hold great potential for expanding outreach to and inclusion of CWD in mainstream education.*** However, more assessment is needed of the extent to which the standardized per child allocations under SSA can accommodate different types of interventions. Even in successful states like TN, there are concerns among NGOs that effective publicly-financed support from NGOs to CWD is being sustained through implicit subsidization from the operations of NGOs themselves. Governments will need to do more work on evaluating the real costs of different modes of inclusive education, as a policy commitment to meeting the individual and special needs of CWD needs to be set against both finite resources and a system of education budgeting which often lacks flexibility.

4.70. ***Even with increased and effective NGO involvement, the primary responsibility for guaranteeing the rights of CWD remain with governments.*** Increasing the involvement of NGOs needs to avoid the pitfall of education of CWD becoming a "residual" sub-sector. Integrating management of CWD education under the MHRD may be one channel for ensuring that this does not happen. Using NGOs both as advocates and as a source of expertise fore increasing the capacity of mainstream public systems is another key element of such a strategy.

E. Conclusions and recommendations

4.71. More than most areas of policy with regard to people with disabilities, the education sector has been relatively progressive in policy terms. It has also in principle committed to a progressive menu of options for delivering education to children with special needs. However, it is clearly struggling to turn policy into effective practice for a variety of reasons. It seems that there is a major need to get the basics right: identify children with disabilities more effectively; make the content and format of what they learn relevant and accessible; have resources available with adequate outreach to teachers and children; and work through various channels to convince families and communities that educating children with disabilities is worthwhile. However, all this needs strategic direction on inclusive education at state and lower levels of the system which in most states still appears to be lacking to date, though examples such as Gujarat and TN provide guidance on how this can begin to happen. More specific directions include:

4.72. **Improving identification of children with disabilities and promoting access to schools**: ***This is the absolute priority in the first instance***, as without identification and some form of access, any qualitative efforts to improve the inclusiveness of the education system for CWD will be ineffective. In order to achieve this minimum outcome, it will be important to review the SSA systems for identifying children with disabilities entering the education system. In most states, these systems are failing to identify many children with disabilities, and by

[121] Alur (2004).

operating independent systems, may be overburdening anganwadi workers and others with reporting demands. The weakness of identification is in part lack of local capacity, for which there remain major training needs. Improved initial identification needs to be complemented with strengthening of SSA's simple systems for ongoing school-based assessment of emerging (and often easily reversible) disabilities. However, the broader question relates to pre-school age screening for which MHRD is not responsible, and this is a critical area for further work. All new school construction should be physically accessible and current efforts of retrofitting accelerated. The provisions of the PWD Act to support children with disabilities in reaching school also need more serious attention, ad focusing on the final stages of access is meaningless if children have not been able to access the vicinity of the school.

4.73. **Improving the quality of education services:** GOI should require all states to develop a strategy for delivering education to children with special needs, in order that SSA and other central funds can be allocated in a less mechanical manner. This strategy would assist in improving the currently poor expenditure performance, and more importantly move the system towards a more child-centered allocation which can provide parents and local authorities with more options and greater accountability for resource use. Second, a key element of strategy execution must be making the special needs resource centre model operational. In many states, this will require piloting of different models with good evaluation. Third, current efforts to make the curriculum accessible and adapted to the learning needs of children with disabilities need to be accelerated. For special education curricula, greater efforts to assess the needs of children in activities of daily living and focus learning materials on acquisition of these skills is required. Fourth, as part of this strategy, the Government could also ensure that special education knowledge is imparted to all teachers in pre-service training. Basic training of educational administrators would also be necessary in order to ensure that teachers are encouraged to use their disability-specific skills. In this regard, it would be important to review the performance of Rehabilitation Council of India in its training provision and regulation role.

4.74. **Strengthening education institutions.** This reform would first involve a more direct institutional relationship with MHRD rather than MSJE. Shifting all special education under MHRD, so that planning, financing and monitoring of the education of all children with special needs in the public and aided systems can be done in a coherent manner. Ensuring VECs, CBR groups, womens' groups, and other community organizations are actively engaged in the importance of educating children with special needs, and familiarized with the benefits for all children educationally and socially will also be important. Finally, as in the case of health service delivery, overcoming weaknesses in public sector implementation by developing public/private partnerships, learning from NGO sector innovations in education of children with special needs, and deepening public/NGO partnerships in those states where they are lagging will be important.

CHAPTER 5: EMPLOYMENT OF PERSONS WITH DISABILITIES

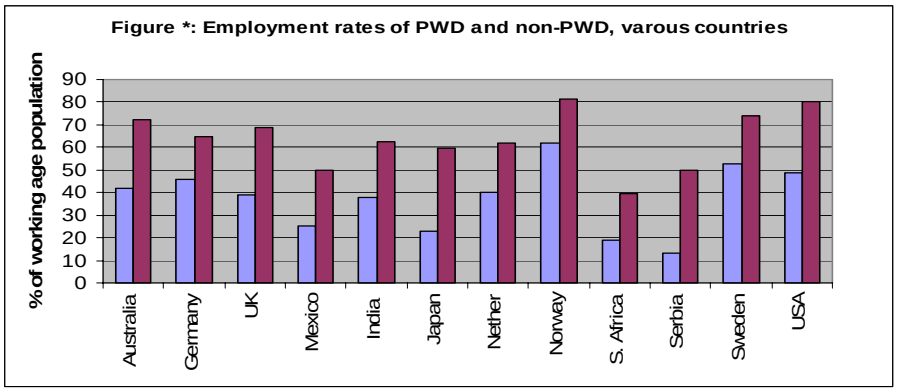
5.1. Employment is a critical element of independent living, and previous research has found that it is a primary aspiration of people with disabilities in India. [122] Earlier chapters have shown that the large majority of PWD in India are capable of productive work, in the bulk of cases without the need for aids or appliances. This chapter explores trends in employment status of PWD in India up to the early 2000s, as well as public and non-governmental interventions to improve employment opportunities for PWD.

A. Labor Market status of PWD

5.2. ***(i) Employment rates: In all countries, the employment rates of PWD are lower than for the non-PWD population.*** This is true even in high income countries with the most progressive employment practices and strong active labor market programs. This can be seen in Figure 5.1. India's ratio of PWD to non-PWD employment rates is around average for the group shown, though one would expect the negative welfare consequences of lower employment rates for PWD in India to be greater due to the much weaker social security system. The country-specific ratio does not appear to be linked simply to income levels, with Japan with a 38 percent ratio and Norway with 76 percent both being very high income.

Internationally, PWD employment rates are significantly below the rest of the population

Figure 5.1: Employment rates of PWD and non-PWD, various countries



Sources: OECD (2003); Mitra and Sambamoorthi (2005). Japan – physical disabilities only. India and Serbia – non-PWD column general population.

5.3. While international comparison is of interest, the more important comparisons are across groups and over time within India itself. Figures 5.2 and 5.3 summarize information from NSS sources for the early 1990s and the early 2000s for both urban/rural and by gender. Some points of interest include:

- ***PWDs have lower employment rates than the general population across all main locational and gender cuts***.

- ***the PWD employment rate actually fell from 42.7 percent in 1991 down to 37.6 percent in 2002.*** The five percentage point difference results in part from the different sample, as persons with mental illness or retardation were not counted as PWD in the 47th round, and were in the 58th round, where they were the PWD sub-groups with the lowest employment rates. However, the finding on a reduced PWD employment rate between the early 1990s

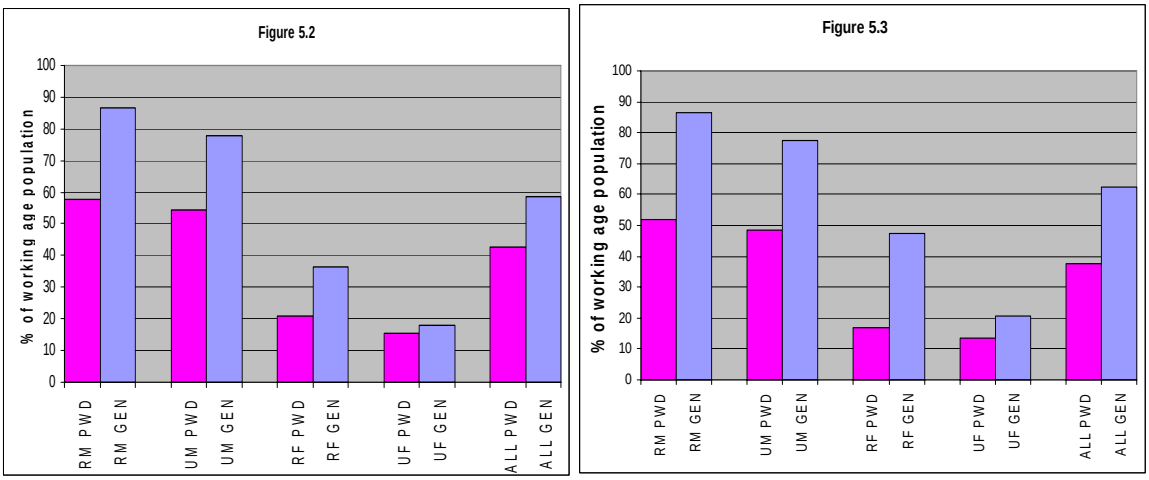
[122] Lang (2000).

and early 2000s holds even when MI and MR people are omitted from the 58th round sample. Excluding MI and MR, the employment rate of PWD still stands at 39.6 in 2002, i.e. 3.1 percentage points lower than in 1991 (and statistically significant). [123] This compares to a fall of only 1.1 percentage points for the general population (from 58.6 to 57.5 percent) between 1993 and 2000. Further research is needed to understand the determinants of the decline in the employment rate of persons with physical and sensory disabilities between 1991 and 2002, in particular to assess if it results from changes in the demographic composition of the population with disabilities, in the increased severity of disability, or factors in the labor market and society.

- While trend comparisons are not possible, the low absolute employment rate among persons with disabilities is broadly support by results from the 2001 census. [124]

Employment rates of PWD in India are lower than the general population for both genders and across urban and rural areas, and have fallen in the 1990s

Figure 5.2: Employment rates of PWD and general population by gender and location, early 1990s
Figure 5.3: Employment rates of PWD and general population by gender and location, early 2000s



Source: Mitra and Sambamoorthi, based on NSS 58th and 47th rounds in 2002 and 1991 (PWD) and 55th and 50th rounds in 1993/94 and 1999/00 (non-PWD).

5.4. In a country as diverse as India, it is interesting to explore statewise aspects of PWD employment. Given the variations in state-level employment rates for all groups, an informative way to do this is comparing the state-specific ratio of the PWD employment rate with that of the non-PWD working age population. This is presented in Figure 5.4. Points of note include:

- ***the fall in the employment rates of PWD relative to the general working age population during the 1990s is almost universal across the country, with the exception of Sikkim.***

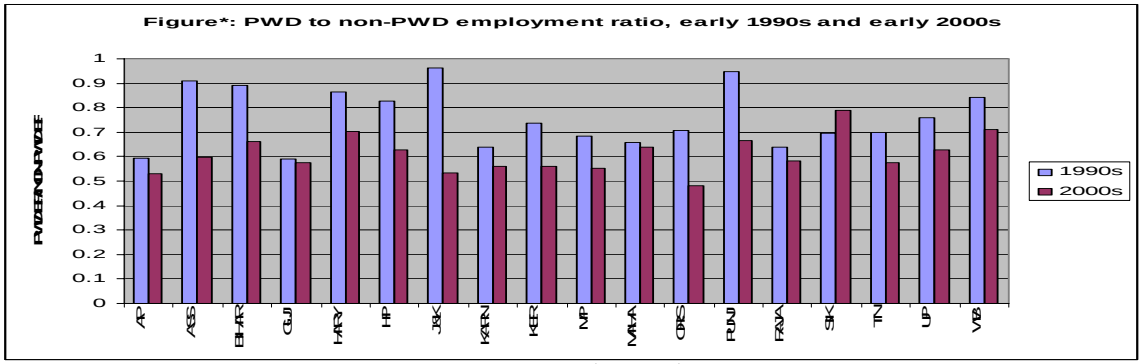
- ***however, the extent of the relative decline varies greatly***, with states such as Gujarat, Rajasthan and Maharashtra exhibiting small falls in the PWD/non-PWD employment

[123] The analysis used usual principal activity status. The NSS thick rounds also report the share of working age population who are unable to work due to a disability. This increased 10 percent between 1993/04 and 1999/00, providing some verification from a much larger sample of an increased negative effect of disability on employment during the 1990s. It is also notable that the share reporting inability to work due to disability was twice as higher for men than women by the 1999/00 NSS round.
[124] Rajan (2006).

ratios, while others such as J&K, Bihar and Assam have seen large falls in the relative employment position of PWD.

The relative employment rates of PWD and the general population vary significantly by state, but have fallen since the early 1990s in nearly all states

Figure 5.4: PWD and non-PWD employment ratio, early 1980s and 2000s

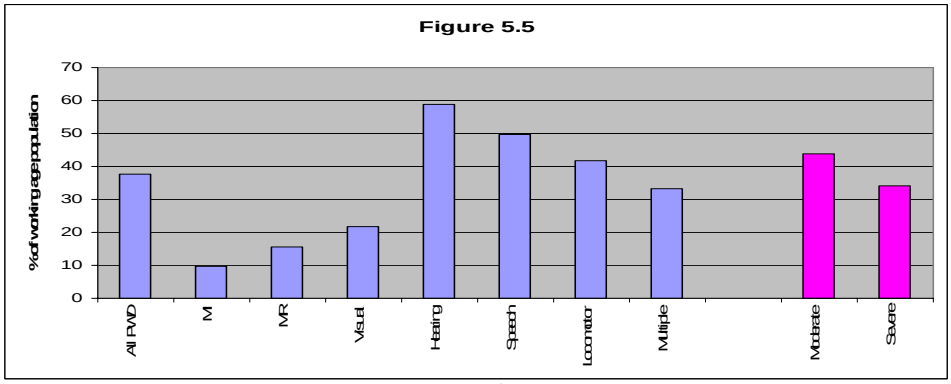


Source: Mitra and Sambamoorthi, based on NSS 58th and 47th rounds in 2002 and 1991

5.5. It is also useful to explore the employment rates of people with disabilities by major categories of disability captured by the NSS. These are presented in Figure 5.5 for 2002. ***All categories of PWD have employment rates below the general population average. However, employment rates vary sharply by type of disability,*** with those with mental illness, mental retardation and visual disabilities having very low employment rates at one extreme and those with hearing disabilities with employment rates around 94 percent of the rate of the general working age population, and those with speech and locomotor disabilities having employment rates above those of the average for disabled people. In addition, those with more severe disabilities have an employment rate around 22 percent (about 10 percentage points) below those with moderate disabilities, or around 45 percent below the rate of the general population. [125]

Employment rates vary sharply by type of disability but less between moderate and severely disabled people

Figure 5.5: Employment rates by disability type and severity, 2002



Source: Mitra and Sambamoorthi, based on NSS 58th round.

5.6. A further important aspect of employment rates is variations between PWD and the general population by level of education. This is shown in Figures 5.6. and 5.7 for the early 1990s and early 2000s. Two points of interest are:

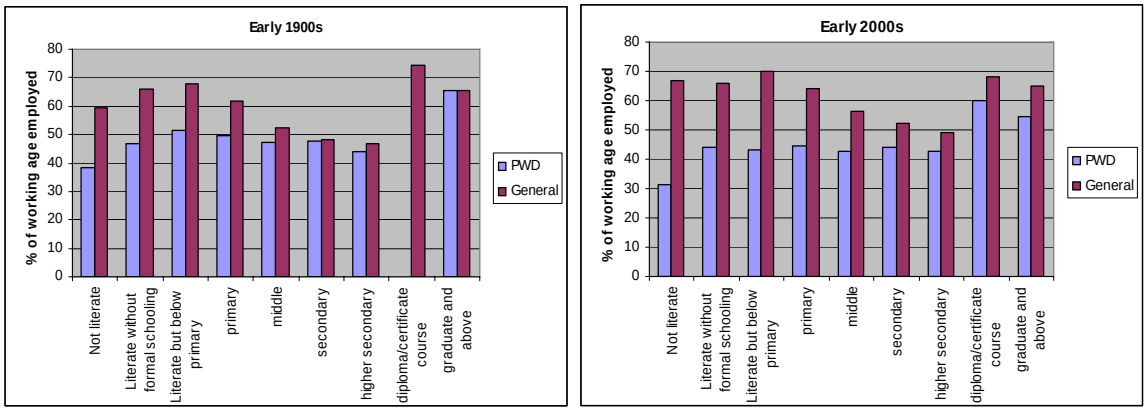
[125] Census data also reveal significant differences in employment rates by disability type, though the relative rates differ significantly from those found using NSS. This is likely to be driven by the differences in definitions of specific disabilities used by the two organizations (see Annex 1).

- ***the gap in employment rates between PWD and the general population is more pronounced for those with the lowest levels of education in both periods.***

- ***the gap between PWD and general population employment rates has widened for all education levels between the early 1990s and early 2000s.*** In the early 1990s, PWD with secondary education and above had very similar employment rates to the general population with the same level of education. By the early 2000s, the gap even at these educational levels had widened, though remained lower than for those with lower levels of educational attainment. For those with low levels of education, the already large gap between PWD and the general population widened sharply in the 1990s. For the illiterate PWD population, their employment rate was 64 percent that of the general illiterate population in the early 1990s but fell to 47 percent by the early 2000s. ***Not only have PWDs lost out in employment terms in the 1990s, but those likely to be poorest (i.e. with the lowest educational attainment) have lost out proportionally more.***

PWD employment rates are lower than the general population at all educational levels, and the gap has widened over the 1990s

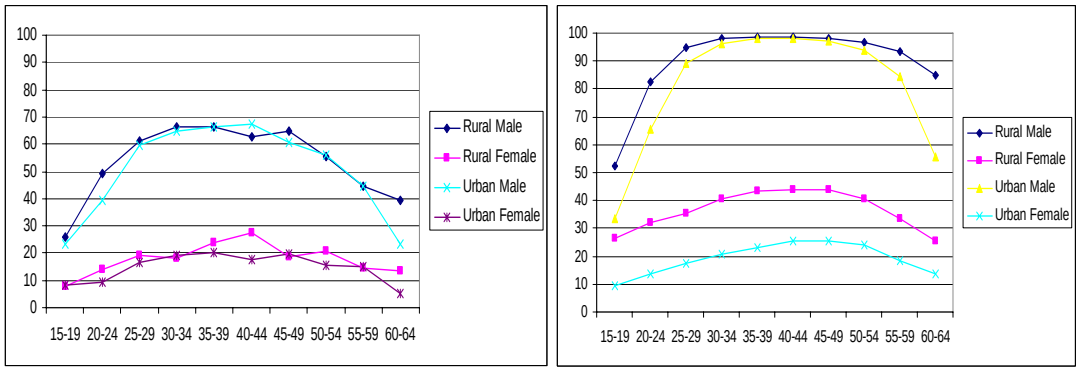
Figure 5.6: Early 1990s; Figure 5.7: Early 2000s



Source: Mitra and Sambamoorthi

5.7. An interesting dimension of employment rates is the life cycle effects, i.e. how employment rates for PWD and non-PWD evolve as people age. This is presented in Figure 5.8. ***The lower average employment rates of PWD are sustained across the life cycle.*** Overall, both PWD and non-PWD exhibit a predictable trajectory of rising employment rates till early middle age and declining rates thereafter, with urban male employment rate trailing off more quickly. However, there are differences between urban and rural patterns. The two points of note are: (i) that rural PWD males and females start with much lower employment rates in the 15-19 age group and basically never catch up. This is not entirely predictable, given that PWD young adults are less likely to be in education; and (ii) in contrast, the starting rates for PWD in urban areas are closer to those of non-PWD (for women, the same). For urban PWD men, the ground is lost early - between entry and the 25-29 bracket - after which they never catch up to non-PWD. For urban women, the (much lower) differences to non-PWD urban women emerge in their late 30s.

Figure 5.8: Employment rates over the life cycle for PWD (LHS) and for non-PWD (RHS)



Source: Mitra and Sambamoorthi, using 58th round NSS for PWD and 55th round for non-PWD.

5.8. ***(ii) Sectoral Composition of PWD Employment: Overall, the sectoral composition of employment among PWD is not substantially different from the general population*** (Table 5.1). The differences of note are: (i) the higher share of PWD workers in agriculture-related activities (i.e. the fall in share in agriculture-related has been less sharp than for non-PWD over the 1990s); and (ii) the higher share of PWD in wholesale/retail trade and hotels/restaurants (hospitality in table). Also of note (not shown) is that disabled people had around a 10 percent higher rate of self-employment than the general population.

Table 5.1: Sectoral composition of PWD and general employment, early 1990s and early 2000s

	Early 2000s			Early 1990s	
	PWD	**General**		**PWD**	**General**
Agriculture Related	54.9	59.2		49.8	61.7
Manufacturing + mining	12.8	11.4		11.7	11.6
Utilities	0.3	0.3		0.9	3.6
Construction (F)	4.2	4.8		2.5	3.6
Trade/Hospitality	14.1	10.4		10.3	8.0
Transport, storage and communications (I)	3.5	3.9		2.7	3.3
Financial/RE/Business/Industry	1.2	1.3		1.5	1.1
Community/Social/Personal Services	8.0	8.3		13.9	10.3
Other	1.0	0.4		6.7	3.1

Source: Mitra and Sambamoorthi, based on NSS 58th, 55th, 47th and 50th rounds.

5.9. The above sectoral disaggregation is useful, but does not reveal much on the more specific characteristics of employment type and status. Insights into these issues for the rural population are possible from the 30 village survey in UP and TN commissioned for this report. These are presented in Table 5.2, which gives the current activity status of working age males and females across disability status. Some interesting observations emerge:

- ***men with disabilities are less likely to be in wage/salaried employment, while the opposite is true for females***.
- men and women with disabilities are less likely to be attending educational institutions compared to men and women without disabilities.
- ***for men and women, the share who report not be able to work due to their disability is substantial*** – over a third of working age PWD men (and almost half of the severe PWD men), and around one quarter of PWD women (and over a third of severe PWD women).

- nonetheless, ***men with disabilities are more likely to report being unable to work owing to disability than women***: instead of reporting an inability to work as their current activity status, women tend to attend domestic duties.

Table 5.2: Current Activity Status among Working Age Persons, rural UP and TN

	Male			Female		
	Non-PWD	**PWD**	**Severe PWD**	**Non-PWD**	**PWD**	**Severe PWD**
Employed	**74.1%**	**53.4%**	**41.2%**	**19.3%**	**16.6%**	**15.6%**
Works on own farm	22.2%	22.0%	13.5%	4.2%	4.1%	3.1%
Self employed (home-based work)	3.4%	3.5%	4.5%	0.3%	1.2%	1.7%
Self employed (work place outside home)	8.1%	8.6%	8.7%	0.9%	0.2%	0.0%
Regular wage/salaried employee	18.8%	9.0%	7.1%	3.7%	5.5%	5.9%
Casual agricultural labourer	10.8%	5.9%	5.0%	9.0%	3.9%	3.1%
Casual labour (non-agricultural)	10.7%	4.2%	2.4%	1.3%	1.7%	1.7%
Does not work due to sickness though have regular work (of any kind)	0.05%	0.2%	0.0%	0.0%	0.0%	0.0%
Does not work due to other reasons though have regular work (any kind)	0.05%	0.0%	0.0%	0.0%	0.0%	0.0%
Unemployed	**9.0%**	**2.6%**	**3.2%**	**2.2%**	**0.2%**	**0.4%**
Not in Labor Force	**16.8%**	**44.0%**	**55.7%**	**78.5%**	**83.1%**	**84.1%**
Attending educational Institutions	13.0%	4.0%	4.2%	7.7%	1.9%	1.7%
Attending domestic duties	2.9%	0.6%	0.8%	68.8%	50.1%	42.2%
Not able to work owing to disability	0.3%	33.9%	46.7%	0.7%	24.8%	35.0%
Retired	0.6%	5.0%	3.2%	1.3%	5.8%	4.5%
Others	0.05%	0.6%	0.8%	0.2%	0.5%	0.7%

Source: Mitra and Sambamoorthi (2006).

5.10. ***(iii) Relative Wages and Work Intensity of PWD:*** An important element of PWD employment is of course wages. This can not be estimated from NSS. However, the UP and TN survey allows for estimates for rural areas from those states. The results are presented in Table 5.3 for each state separately and by gender. The results are more complex than might be expected. Points of note include:

- as would be expected, ***the employment rate of PWD men and women compared to non-PWD is low, and lower again for those with more severe disabilities.***
- ***there is a notable gender difference in the employment situation of PWD men and women relative to non-PWD population.*** The employment rate of PWD women relative to non-PWD women is significantly higher than for PWD men relative to non-PWD men, in the case of TN over 20 percent higher. A possible explanation is that the gender factor with respect to women's employment is an important additional effect on employment rates, which dilutes the independent effect of disability among women on their employment rates.

- ***the relative wages of PWD to non-PWD workers shows substantial variation between the two states.*** The relative wages of PWD in UP are significantly lower for both men and women, while in TN they are over 10 percent higher. Across both states, the variation in wages across the year is greater for PWD men than for non-PWD but not so for women.

Table 5.3: Employment and wage rates of PWD relative to non-PWD by location, gender and severity, UP and TN, 2005

Group	Employment ratio/non-PWD	Wage rate/non-PWD
UP PWD males	0.79	0.89
UP severe PWD males	0.59	0.79
TN PWD males	0.69	1.11
TN severe PWD males	0.53	1.12
UP PWD females	0.87	0.78
UP severe PWD females	0.82	0.77
TN PWD females	0.85	1.14
TN severe PWD females	0.74	1.11

Source: 30 Village survey, 2005.

5.11. An interesting additional dimension captured by the above survey is intensity of work among non-PWD, PWD and severely disabled people. ***When it comes to usual work hours per day and work days per month, there is relatively limited difference between workers with disabilities and those without.*** (Table 5.4) The hours of work of PWD men and women are somewhat lower than those of non-PWD workers, but only by about half an hour per day. Even this small difference is largely offset for PWD women by slightly more work days per month than non-PWD workers. These findings go against the commonly held view that disability places constraints on the quantity of work a person can do. Once PWD are working, they are working about the same amount as non-disabled people.

Table 5.4: The Working Age Employed: Work Hours and Days in rural TN and UP, 2005

	Male			Female		
	Non-PWD	PWD	Severe PWD	Non-PWD	PWD	Severe PWD
Usual Work Hours per Day	7.9	7.5	7.3	7.5	6.9	7.1
Usual Days of Work per Month	23.6	23.8	23.7	20.4	21.5	21.7
Variation in Days Worked across the year	35.8%	42.3%	35.3%	23.3%	21.7%	22.2%

Source: 30 village Survey, 2005

5.12. ***(iv) Impact on Employment of other Household Members:*** The above analysis looks at the labor market impacts of disability for disabled people themselves. It is also important to consider whether there are additional impacts on the employment rates and/or intensity of other household members of PWD. In principle, such effects could work in two directions. One would be if the care needs of the disabled household member require reduced work participation from other household members. However, it could also be that non-disabled household members are required to work more to offset the lower employment rates of PWD in the household. This issue has received very little analysis in the Indian literature, though the one available analysis which addresses the issue suggests that there may be significant negative impacts on the employment of other household members. [126] The following paragraphs explore two elements of work impacts on other household members using the UP and TN data: (i) the impact on whether or not adult

[126] See Erb and Harriss-White, op.cit.

men and women work at all in households with disabled members; and (ii) the impact on how much work they do for those who are working.

5.13. ***Multivariate analysis found that the impacts of having a disabled member on employment participation exhibits a significant gender difference***, with other males 21 percent more likely to be working, and virtually no impact on the employment of adult women. The gender difference can be probably explained by the nature of women's work. In aggregate, the income effect therefore appears to dominate in terms of the impact of disability on the employment of other household adults.

5.14. The survey also explored the impact on both non-PWD household member labor due to caring requirements of the PWD household member, and on the school participation of children (the latter discussed in Chapter 5). Table 5.5 below indicates the share of households where an adult at times stayed home from work to care for the PWD, and how often this occurred. ***It is clear that the impact on the amount of work of other adults in the household is significant.*** Around 45 percent of households with a PWD report an adult missing work sometimes to care for their family member. Among those, 83 percent missed some work every day to care for their household member. The average hours of work missed for carers on days where they missed work for caring was 2.5, or close to one third of the average working day. These are clearly major impacts on the household economy of a large share of households with PWD members.

Table 5.5: Missed work by adult HH members of PWD due to caring, UP and TN, 2005

Frequency of some missed work for caring	Share of households reporting
Any adult missing some work	44.7%
Of which:	
Every day	83.3%
About one day a week	2.9%
At least one day a month	4.2%
Less often than one day a month and other	5.8%
Average hours of work missed for caring on days where some work missed	2.5 hours

Source: 30 Village survey, 2005

5.15. The survey also explored who in the household provided such care. Overwhelmingly, it is provided by parents or spouse, in 57 percent of cases a parent and in 21 percent of cases a spouse.[127] Also of note is that less than 1 percent of households with a PWD member had caring performed by someone from outside the household.

5.16. ***The aggregate effect of having a disabled household member on the employment of other adults is therefore complex.*** Overall, other adults are more likely to be in the workforce. However, they are also found to do less work in a day due to the requirements of caring for their disabled family member.

B. Determinants of employment for PWD

5.17. The above analyses are based on descriptive statistics from NSS and other sources. Their shortcoming is that the employment outcomes of PWD reported conflate the employment impacts of disabilities themselves with other characteristics of PWD, e.g. if PWD are on average older than the general working age population, their lower employment rate may reflect a combination

[127] See Mitra and Sambamoorthi, op.cit. Unfortunately, parental care was not collected by gender.

of age and disability status. Multivariate analysis of the NSS data provides more precise insights into the determinants of employment among PWD. Potential determinants include demographic characteristics (gender, age, marital status), rural/urban, disability characteristics (type of disability, severity of disability, disability at birth), human capital characteristics (education, vocational training, work experience).

5.18. Table 5.6 presents results of a probit model of employment among PWD using the 58th round of the NSS. [128] The results confirm some of the earlier findings. ***The following characteristics are associated with higher probabilities of employment among the PWD sample***:

- living in rural areas, where the likelihood of PWD being employed is over 20 percent higher than in urban areas and highly significant statistically. This is consistent with anecdotal evidence of greater accommodation of PWD in rural work settings and possible income effects.
- being a male
- having a disability since birth, with the effect more pronounced in rural areas
- having a hearing, speech, or locomotor disability. The positive sign of the coefficient of the multiple disability dummy in the rural subsamples is surprising.
- being married has a relatively strong positive effect on the probability of being employed for males, but a negative effect for women.
- increased age is positively associated with the probability of employment. There is a quadratic effect in age in both male and female subsamples, with the probability of employment growing at a decreasing rate.
- having a postgraduate education (with the positive effect much stronger for women) and having vocational training.

5.19. ***In contrast to the above positive impacts among PWD, there are several variables which are associated with a lower probability of being employed.*** These include:

- having a mental illness has a strong (and statistically highly significant) negative impact on the probability of employment. For those with mental illness, the effect is much stronger in urban than rural areas, which is consistent with findings from NIMHANS that mental illness may be more stigmatizing in urban than rural settings (perhaps in part due to the nature of work, but also perhaps related to the additional stigma attaching to diagnosis).[129]
- having mental retardation has an even stronger negative impact on the probability of being employed, and is also highly significant statistically.

5.20. Surprisingly, across all sub-samples, the educational level dummies have coefficients that are close to zero, with the exception of having a postgraduate education. Thus, overall it appears that work experience rather than education increases the probability of being employed for PWD.

5.21. ***For a number of characteristics, there is clear heterogeneity in the impact of certain characteristics between men and women and between rural and urban areas.*** Some characteristics (e.g. the strength of the impact of a hearing disability on employment) show weaker impacts for both men and women in urban than rural areas. Others (e.g. like the impact of being married and the impact of vocational training) show clearer gender rather than locational differences. One example is the impact of postgraduate education among different PWD groups. Another is the strength of the negative impact of mental illness on employment, with the effect far more pronounced in urban areas as noted.

[128] It also accounts for the stratified sample design with weights from schedule 26 of the 58th round.
[129] Insert NIMHANS reference.

Table 5.6: Probabilities of being employed among PWD by various characteristics, 2002

Variable	ALL PWD	Urban male	Urban female	Rural male	Rural female
Male	1.88 *** (0.043)	-	-	-	-
Rural	0.206*** (0.039)	-	-	-	-
Married	0.580*** (0.043)	1.337*** (0.103)	-0.522*** (0.135)	1.176*** (0.059)	-0.073 (0.890)
Age	0.229*** (0.008)				
SC/ST	0.132 * (0.038)	0.044 (0.077)			
Postgrad. education	1.000*** (0.191)	0.940* (0.277)	1.787*** (0.418)	0.235 (0.302)	2.724* (0.792)
Disability from birth	0.425*** (0.040)	0.298** (0.087)	0.216 (0.162)	0.361*** (0.060)	0.762*** (0.107)
Mental illness	-0.789*** (0.102)	-1.596*** (0.194)	-1.689*** (0.420)	-0.614*** (0.115)	-0.393 (0.311)
MR	-1.098*** (0.132)	1.680*** (0.238)	-2.834 (0.763)	-0.825*** (0.170)	-1.350*** (0.302)
Hearing disability	1.993*** (0.084)	1.472*** (0.174)	0.972*** (0.262)	2.716*** (0.134)	1.729*** (0.149)
Speech disability	1.224*** (0.096)	0.695 (0.165)	0.827 (0.341)	1.613*** (0.144)	0.962*** (0.192)
Locomotor disability	0.817*** (0.067)	0.848*** (0.104)	0.771** (0.214)	0.942*** (0.090)	0.532** (0.142)
Vocational training	0.394*** (0.097)	0.224 (0.142)	0.766 (0.234)	0.243 (0.151)	0.825 (0.296)
Received govt. aid	-0.179* (0.052)				

******* = statistically significant at 1% level;** = significant at 5% level; * = significant at the 10% level. Standard deviations in parentheses. Source: Mitra and Sambamoorthi (2005)

5.22. A more aggregated way to explore the impacts of disability on employment probability is to analyze the marginal impact of having a disability on employment. This is presented in Table 5.7 for rural UP and TN, showing the marginal impact on the probability of being employed by state, gender and severity of disability. ***Having a disability reduces the probability of being employed by 31 percent for males in rural Uttar Pradesh, and 32 percent for males in rural Tamil Nadu. In contrast, it reduces the probability of being employed only 0.5 percent for rural females in Uttar Pradesh and by 11 percent for females in rural Tamil Nadu.*** The impact of having a severe disability on probability of being employed is even larger for all groups except TN males.

Table 5.7: The marginal effect of disability on employment probability is high for men, lower for women and higher for those with more severe disabilities

	Males		Females	
	UP	**TN**	**UP**	**TN**
Marginal effect of being disabled	-31%	-32%	-0.5%	-11%
Marginal effect of being severely disabled.	-37%	-32%	-14%	-13%

Source: Mitra and Sambamoorthi (2005) based on VDS.

5.23. For males in the survey, a ***decomposition of the employment rate gap between disabled and non-disabled men*** was also carried out.[130] This provides insights into how much of the differences in employment rate can be explained by observable characteristics (e.g. demographic; educational etc), and how much remains unexplained (and typically attributed to discrimination in the case of people with disabilities). Overall, employment rates among disabled men were almost 30 and over 14 percent lower for disabled than non-disabled men in UP and TN respectively. ***Decomposition of the factors driving the gap found that most of the employment gap is not attributable to observable differences in demographic, human capital or other characteristics. This suggests that there is discrimination against males with disabilities in employment opportunities.*** While there may be other unobservable factors at play, the results are consistent with survey and qualitative findings on negative attitudes towards people with disabilities and employment prospects in the UP and TN survey, which are discussed in detail in Chapter 2.

Summary of employment profile of people with disabilities:

5.24. Some of the main conclusions of the preceding analysis are:

- people with disabilities are substantially less likely to be working than other people. However, the extent of the differences vary sharply by disability type, with those with mental illness, mental retardation and visual impairments the most disadvantaged.
- the gap in employment between disabled and non-disabled people has increased over the 1990s, which is a cause of major concern.
- people with disabilities appear to face different obstacles to employment according to their gender and to whether they live in rural or urban areas. This heterogeneity has important implications for policy and program design, as one size is unlikely to fit all.
- for the most part, education has a limited effect on the probability of being employed for people with disabilities
- it appears that observable characteristics of disabled people do not explain most of their "employment deficit", but rather than other factors – including discrimination – are driving their poor employment outcomes
- having disabled family members has significant impacts on the employment behaviour of other adult members, both in terms of whether or not the men in the house work and in how much work all other adults are able to do.

C. Interventions to promote employment among PWD

5.25. ***It is clear from the previous section that the employment situation of PWD in India is a cause of serious concern. In response, the PWD Act and other government initiatives attempt to introduce a range of interventions which are intended to promote employment and enhance the skills of PWD.*** These include public sector employment reservations, reservations in various anti-poverty schemes such as public works and targeted credit programs, active employment programs, and dedicated credit institutions for PWD. On paper, it is an impressive array of public interventions. However, the Government's most recent assessment of the interventions for the period 1998-2003 is generally critical of what has been delivered to date, and the cost effectiveness of a number of interventions. [131] Apart from the public sector, there is significant activity by the non-government sector to promote PWD skills and employment, some with public

[130] The standard Oaxaca-Blinder method was used. The sample of employed women was too small to conduct the same exercise for women.
[131] Comptroller and Auditor General report, 2004.

financial support, though the bulk without. This section examines the major public interventions, and looks selectively at NGO interventions. [132]

(i) Interventions to promote employment and skills of PWD:

5.26. The main interventions to promote PWD employment covered in this section are:

- public sector employment reservations
- incentives for private sector hiring of PWD
- Special Employment Exchanges for PWD
- National Handicapped Finance and Development Corporation (NHFDC)
- Vocational Rehabilitation Centres (VRCs) under the Ministry of Labour for PWD.
- NGO vocational training initiatives.

5.27. ***(a) Public sector employment reservations:*** As noted in Chapter 7, the PWD Act provides for a 3 percent reservation in "identified posts" for PWD. The posts were meant to have been identified soon after the Act coming into force and updated every 3 years. The initial identification of posts at the central Government level was not completed until 2001 and no formal expansion of identified posts has been completed subsequently. Among states, as of end 2003, a significant number had failed to identify posts in state services for PWD (e.g. Jharkhand, Gujarat, Orissa and Chhattisgarh), with some of them not even having adopted as policy the reservation system of the PWD Act. Others had identified posts only partially (e.g. UP and TN had identified only group C and D posts). [133] The Commissioner's office is required to monitor implementation of reservations. However, despite circulation of a reporting format in 2002, the reporting system remains years out of date, leading the CAG to conclude that the system of reservations "was not being effectively monitored" as of 2004. It appears that the situation has not improved significantly in the intervening period.

5.28. As per data available in 2003 (Table 5.8), only 10.2 percent of all posts in ministries/departments and public establishments had been identified as suitable for PWD. Among that 10 percent of posts, 3.5 percent for ministries and departments and 4.4 percent for public establishments had been filled by PWD employees. ***While the 3 percent quota has been met in the strict terms of the Act, the share of PWD in all posts remains negligible, at 0.44 percent, or around one fifth the share of PWD in the overall population as per census estimates.*** In the case of public establishments, an earlier dedicated survey among large establishments had indicated that around 0.5 percent of employees in 1999 were PWD, suggesting that there had been little progress between then and 2002 in increasing the share of PWD employees. [134]

5.29. ***A second feature of the quota policy is that it applies only to three disability types – locomotor, visual and hearing, with a 1 percent reservation for each.*** Thus even the disability categories of the Act are not all included in the reservation policy, let alone a range of other disabilities. In its current form, the public employment quota for PWD has succeeded on its own narrowly defined terms. It does not, however, appear to have promoted the broader objective of representation of PWD in the public sector workforce which is commensurate with their population share. Indeed, one may question whether the legislated notion of requiring identification of posts may actually have been counter-productive in terms of facilitating public employment of PWD. The core problem in both principle and bureaucratic practice has been the

[132] Background papers by Mitra and Sambamoorthi (2006), and Officer (2005) are the basis for much of the discussion.
[133] CAG, op.cit.
[134] See NCPDEP (1999).

requirement of specific post identification. In principle, such an approach is hard to defend, as it implies that PWD are not generally competent people.

Table 5.8: Reserved posts for PWD identified and filled, early 2000s

Group of posts	All posts	Posts identified for PWD	Employed PWD	% identified posts filled by PWD	% all posts filled by PWD
Ministries and Deparments					
A	57,643	4,305	134	3.11%	0.23%
B	73,851	4,652	205	4.41%	0.28%
C	1,607,243	167,863	6,307	3.76%	0.39%
D	960,025	104,578	3,329	3.18%	0.35%
Total	2,698,762	281,398	9,975	3.54%	0.37%
Public Establishments					
A	204,127	18,244	508	2.78%	0.25%
B	175,159	14,350	1,226	8.54%	0.70%
C	1,013,917	89,789	4,525	5.04%	0.45%
D	435,328	56,615	3,819	6.75%	0.88%
Total	1,828,531	178,998	10,078	5.63%	0.55%
All					
Total	4,527,293	460,396	20,053	4.36%	0.44%

Source: DOPT. Ministries and Departments was reported for 59 M&D in 1/2003 for posts as of 1/2000. The information on public establishments was reported for 237 public establishments in July 2002.

5.30. ***A broader question which the reservation policy raises is how consistent it is with good international practice in promoting employment of PWD.*** Box 5.1 below summarizes experience with public employment quotas for PWD internationally. Overall, many countries have such quotas (e.g. over one third of OECD countries) but the experience in both developing and developed countries has been rather poor, and the trend in developed countries is away from quota-based approaches towards accommodative workplaces. Some of these experiences may hold lessons for India, though it is acknowledged that the culture of public employment reservations is unusually strong. However, even within a quota-based system, there is great scope to have more PWD-promoting employment and procurement policies, as the example of NTPC in Box 5.2 demonstrates.

5.31. ***Even if the quota system is retained, there is significant scope to improve it.*** The most obvious way to expand the scope of the PWD reservation would be to drop the requirement of identifying posts and use as a denominator for the quota the number of all posts in the public service. The list of identified jobs is very restrictive and often arbitrary (e.g. in Group A, the job of an agricultural scientist specialized in econometric analysis is identified as being suitable for an individual who is blind or has an orthopedic disability, but not for someone with a hearing disability). The list of identified jobs is based on the assumption that the characteristics of an impairment are the exclusive determinants of an individual's ability to hold a position at a particular skill level and thus ignores the potential influences of individual characteristics (motivation, age at disability onset), access to employment services, and the characteristics of the workplace and labor market.

Box 5.1: International Experience with Quotas for PWD employment

Quota systems to promote employment of PWD are used in many countries in both industrialized and developing countries. Typically, quotas are not formulated as a percentage of identified posts as in India but in terms of the proportion of all employees who have disabilities. Usually employers with a minimum number of employees - both in the private and public sector - have to fulfill the quotas.

Country	**PWD quota**	**Threshold firm size for quota application**
Korea	2 percent	300 employees
France	6 percent	20 employees
Turkey	3 percent	NA
Poland	6 percent	50 employees
Germany	5 percent	16 employees
Japan	1.8 percent	56 employees

The main variant of the straight quota system is the so-called "quota-levy" system, whereby employers can pay a contribution to an earmarked fund in lieu of employing PWD up to their quota obligation. The funds are used for purposes such as payments to employers for accommodating PWD in the workplace, direct payments to workers with disabilities, and payments to disability service providers. Such a system operates in a number of OECD and transition countries (Mont, 2004; Thornton, 1998).

Quota fulfillment for PWD employment is generally low, between 50 and 70 percent even in developed countries (OECD (2003). In Africa and Asia, quotas are often not enforced (Mont, 2004). A recent study of the European Commission on quota systems in 18 industrialized countries summarized in O'Reilley, (2003) did not find one example of a country that meets its quota target, leading the authors to conclude that "in most countries, the tide is swinging away from quotas – either for their total abandonment (as in the UK), or for other measures (active employment support for individuals or stronger discrimination laws)". Overall, the trend in Europe is towards a PWD employment promotion approach that relies on anti-discrimination legislation, which is an approach used in a number of Anglo-Saxon countries such as USA, Canada and Australia for some time.

5.32. ***Private sector employment incentives: For the private sector, the PWD Act makes provision for a subsequent incentives policy to be put in place, with a target of 5 percent of the private sector workforce being PWD.*** This provides an interesting contrast between the approach for the private and public sectors in the Act, in that the former takes a "whole of workforce" approach, whereas the public sector "share of identified portion of workforce" approach. It seems that an incentives-based approach has more potential with respect to the private sector, where quotas would be unenforceable and possibly undesirable.

5.33. ***However, neither GoI nor states have subsequently introduced a general incentives policy to promote employment of PWD in the private sector.*** At the same time, in the 2007-08 budget, GoI has introduced a specific incentive program for the formal private sector. This would provide a waiver on social security contributions for certified disabled employees for 3 years on their ESI and EPFO contributions, a not-insignificant subsidy.[135] The details of the program are still to be worked out, and of course would not apply to the unorganized sector. The FM's budget speech indicates a target of 100,000 PWD with a salary limit of Rs. 25,000 per month, with an initial estimated cost of Rs. 150 crore annually, rising to Rs. 450 crore when rolled out.

[135] See FM Budget Speech, 2007/08. There was previously a concession under the Income Tax Act for 20 percent of the wages of disabled employees to be reimbursed, but this wad discontinued due to concerns about abuse.

5.34. ***Nonetheless, there has been useful work done through combined NGO/industry efforts which has developed a draft incentives policy for employment of PWD in the private sector***. [136] The proposal focuses primarily on incentives related to corporate income tax, service tax and excise, import duties and VAT on capital expenditures. It has not, however, to date been costed, nor a system of monitoring to minimize abuses proposed. Given the nature of incentives proposed, it would clearly apply only to the organized private sector.

Box 5.2: National Thermal Power Corporation Limited (NTPC) is setting an example in the public sector

NTPC, a public sector company incorporated in 1975 is now the largest power generating company in India with an annual turnover of 259642 million rupees with total staff strength of 23,519 people. Since 2001, NTPC has placed disability on their corporate social responsibility agenda. A two phase targeted recruitment strategy was implemented to recruit people with disabilities into the government identified posts. In the first phase of recruitment, NTPC received 50,000 applicants from disabled candidates for 126 jobs. Following a second phase of recruitment, a total of 387 persons with orthopaedic, visual and hearing disabilities have found jobs at NTPC. This equates to 1.65 percent of total staff, not yet in accordance with the 3 percent reservation.

NTPC has continued to revise and expand their own job lists for persons with disabilities and have currently 71 types of posts which are considered suitable. All staff salaries are defined on the basis of the salary framework with no difference between disabled and non disabled employees, existing disabled employees' salaries range from Rs 8500 to Rs 44000. As the government quota does not cover employment of persons with mental handicaps, NTPC has chosen to outsource 50 percent of its total requirement for office envelopes and file covers (with a value of 5 lakhs) to NGOs, two of which work with mental handicaps (Muskan and Action for Ability Development and Inclusion). When in need of miscellaneous products such as conference bags and greeting cards, NTPC also frequently outsources these through NGOs working with PWD.

With a slowing rate of job growth within NTPC and the organised sector generally, NTPC has also developed other initiatives to increase employment opportunities for PWD. Seventeen crores of the company profits have been allocated towards identifying and supporting innovative schemes which develop vocational skill and sustainable employment opportunities for persons who are visually or hearing impaired. NTPC also realises that social rehabilitation is a necessary adjunct to economic rehabilitation and supports a wide range of initiatives such as medical camps, and provision of aides and appliances.

Source: Officer (2005)

5.34. ***Previous work suggests that employment of PWD among large private firms was negligible at the end of the 1990s,*** with only 0.3 percent of the private firm workforce being PWD. ***Among multinational companies, the situation was far worse***, with only 0.05 percent of their workforce being PWD. [137] Even more interestingly, the situation with respect to PWD hiring faces challenges even in the NGO sector. A study in the late 1990s found that, even in NGOs working in the disability sector, only 14 percent of jobs were occupied by PWD, and none of the surveyed NGOs had an explicit affirmative action policy in hiring.[138] More recently, a survey of both mainstream and disability NGOs found that more than half had PWD employees, with around 4 percent of total jobs occupied by PWD. [139]

[136] See NCPEDP.
[137] NCPEDP (1999).
[138] NCPEDP, 1998.
[139] Social and Rural Research Institute (2005).

5.35. ***The generally poor situation with respect to PWD hiring in the organized sector is not to say that there are not a number of private sector firms which have far better performance on PWD hiring.*** These can be broadly divided into two groups: (i) those which offer employment opportunities for PWD as part of their corporate social responsibility agenda; and (ii) those which are driven by strictly commercial criteria in their hiring of PWD. Of course, the two categories are not exclusive, as CSR-driven hiring may in time be increasingly justified by good business reasons. The case of Titan Industries is a case in point (Box 5.3). With 4 percent of their workforce as PWD, Titan management has found that PWD have greater job loyalty and generally greater focus in their work, with at least equal productivity and quality. This is

Box 5.3: TITAN India shows that employing disabled people makes good business sense

Titan Industries is India's and one of the world's largest timepiece manufacturers, grossing approx USD 250 million) last year. In the early 1980s Titan started providing job opportunities for PWD and became one of a handful of Indian enterprises attempting to reverse the job-market bias against workers with disabilities. Currently, persons with disabilities constitute about 4 percent of Titan's total workforce. This includes 29 employees with physical disabilities, 84 with hearing/speech impairments, and 4 with vision impairments, 12 of whom are women.

Titan understood that the watch industry provides several employment opportunities for PWD. Persons with locomotor disabilities worked on polishing watch cases and assembling components, and as machine operators in operations such as sorting, buffing and making ornaments. Persons with hearing impairment were employed to put straps on watch heads, while persons that are visually impaired have found their place in the company's packaging and despatch division. Titan specifically targeted PWD in their recruitment strategy. Appropriate selection procedures were adopted depending on the nature of the disability. The company arranged counselling sessions with the families, to make the transition into the factory smooth. "Titan was clear that persons with disabilities are an intrinsic part of our society and need understanding, support and opportunities, not charity or misplaced compassion," says Mamatha Bhat, who has been closely involved with the initiative.

Hiring was but one component of Titan's plan for persons with disabilities: barrier free workspaces were just as important. For example, the provision of handrails provides support to persons with locomotor disabilities walking within the factory. Supervisors who interfaced with the hearing impaired were trained in sign language. Today, in the strapping department, it is nearly impossible to distinguish the hearing impaired from the others, as everyone uses sign language. Coherent with TITAN's policy of inclusive development, staff with disabilities and their non disabled colleagues work in common areas. Several other steps were taken to build technical competencies and computer literacy of the employees. TITAN worked with a number of NGOs for programmes on awareness creation in the company and personality development for persons with disabilities. TITAN ensured that their HR policies were all non discriminatory, including promotion and ensured effective grievance procedures for all.

Employees with disabilities were housed with non disabled employees, which contributed to their integration with the rest of the workforce. Fortnightly meetings sensitised the company about issues concerning PWD and their families. The introduction of employees with disabilities early in the life of the company contributed to their acceptance as equal members of the workforce, promoting cohesion in the working environment. Apart from providing employment and financial independence, PWD at Titan have improved their social standing and boosted their self-esteem. Around 96 of them are married, with Titan playing matchmaker for eight couples. Most own homes in the Titan township and their children study in the best schools.

With time, Titan has realised that the disabled members of its family are more loyal and far more focused on the job. Despite the physical limitations of these employees**,** productivity and quality have never been issues. Titan Industries has shown that recruiting people with disabilities makes good business sense.

Source: Officer (2005).

consistent with survey findings. Nationally, a survey in the six major metros of 120 corporates found that around two thirds of firms employing PWD were completely satisfied with their performance, and not a single company indicated that it was even somewhat dissatisfied.[140] In a survey in Orissa, while only 4 percent of firms interviewed reported employing PWD, over 80 percent of those that did considered their PWD employees to be an asset to their organization.[141]

5.36. ***(c) Employment Exchange Programs for PWD:*** [142] The Employment Exchanges were established under the Employment Exchanges (Compulsory Notification of Vacancies) Act of 1959. The main functions of employment exchanges are to register and place job seekers, traditionally almost entirely for public sector jobs. As of end-2004, there were 947 Employment exchanges in India. The administration of employment exchanges is with the state or union territory governments. Exchanges are located in urban areas. Most employment exchanges cater to all types of job seekers. Some exchanges are specialized in particular types of job seekers and include the special employment exchanges for the physically handicapped. There are 42 special employment exchanges for PWD nationally. In addition, there are 38 special cells for persons with disabilities in the regular employment exchanges where a special placement officer is attached. PWD may also be registered with regular exchanges.

5.37. Generally, the enforcement of the Act is limited outside the public sector, with very few private establishments reporting vacancies to the exchanges. The link between employment exchanges and establishments in the private sector seems to be overall quite weak, including linkages between exchanges and NGOs active in promoting skill development and employment for PWD. One exception is the special exchange in Chennai where a private sector placement campaign is run in addition to its efforts to place registrants in public sector jobs. As part of this campaign, private sector establishments are being contacted by the special exchange by phone, mail or in person for the placement of persons with disabilities and the special exchange holds a job fair every two weeks with private employers.

5.38. ***The majority of PWD clients of employment exchanges use regular exchanges.*** Only 27 percent of PWD registered with special exchanges, or the special cells of regular exchanges. Among the total 661,000 PWD on the live register of all exchanges, 109,929 were registered as part of special exchanges for physically handicapped and 66,612 were registered as part of special cells for physically handicapped of regular exchanges. [143] Total funding for special exchanges and cells between 1998 and 2003 was just over Rs. 5 crore.[144]

5.39. What is the impact of the employment exchanges for PWD ? There has not been any comprehensive evaluation of special employment exchanges.[145] Table 5.9 gives the numbers of PWD registering, being placed and on the live register of the special employment exchanges and other exchanges from 1994 through 2003. ***It is clear that the placement ratio is very low for both the special exchanges and other exchanges, 0.9 percent and 0.7 percent respectively in 2003.*** While performance among special exchanges in different states is quite variable in relative terms, the highest placement rate (Vadodara) was still under 6 percent in 2003, with the ten worst performing special exchanges placing only 4 people in employment that entire year. ***Just as importantly, the placement ratio has roughly halved over the past decade in both cases, from close to 2 percent and 1.2 percent in 1994 for special and other exchanges respectively.*** This

[140] Ibid.
[141] Swabhiman (2005).
[142] See ILO (2004) for a detailed discussion of employment exchanges, though there is no explicit focus on exchanges and services for PWD.
[143] Government of India (2005).
[144] CAG report, 2004.
[145] The most detailed analysis of a specific special exchange comes from Mumbai. See Acharya (1991).

downward trend probably reflects shrinking job opportunities in the public sector, and the general failure of exchanges to reach out to private employers.

Table 5.9: PWD placed by employment exchanges are very low and placement rates have halved over the past decade (in thousands)

	Registrations	Placements	Live Register	Placement ratio
Special Employment Exchanges				
1994	8.4	1.3	67.1	1.94%
1999	15.1	1.3	96.2	1.35%
2000	14.8	1	101.1	0.99%
2001	12	1.1	107.8	1.02%
2002	11.6	1	110.6	0.90%
2003	10.9	1	109.9	0.91%
Other Exchanges				
1994	35.3	3.2	273.2	1.17%
1999	47.6	2.9	359.7	0.81%
2000	49.9	2.3	384.1	0.60%
2001	48.1	2.4	402.2	0.60%
2002	47.8	2.4	422.1	0.57%
2003	55.2	3.9	551.8	0.71%

Source: GoI (2005).

5.40. The number of PWD placed as part of regular exchanges is not reported, but we can grossly estimate the total PWD placed through all exchanges. PWD represent 1.6 percent of the total live register of all exchanges, or around 662,000 are registered with employment exchanges. If we assume that 1.6 percent of all placements of all exchanges (154,900 in 2003) are PWD, then around 2,500 PWD were placed in 2003 through all employment exchanges. This is clearly negligible, and made more so by evidence of earlier studies that found that around one third of registered exchange clients were already employed and around 12 percent pursuing studies, so that the net employment effect of exchanges appears even lower than gross placement figures would suggest.[146]

5.41. ***It seems clear that employment exchanges – both special and regular – play a negligible role in promoting employment among PWD.*** Moreover, the cost effectiveness of many special exchanges is open to question. Even at an average level, the approximate per unit cost of a placement by the special exchanges in 1998-2003 appears to be over Rs. 7,500. This is not a specific fault of special exchanges, but rather reflects a range of fundamental shortcomings in the employment exchange model in India. Even supporters of exchanges acknowledge that failure to undertake major reorientation of employment exchange activities will result in their increasing marginalization as a source of employment, both for PWD and the non-disabled population (e.g. increasing outreach to the private sector; proposing job seekers to employers on the basis of suitability and not merely length of time on the register as presently). [147] A second general issue is the urban focus of exchanges and the need to develop cost-effective rural outreach and informational strategies if they are to be relevant to the bulk of the PWD labor force. The weakness of rural outreach can be seen from the UP and TN survey, which found that 85 percent of respondents were not aware of the existence of exchanges, and only around 1 percent had actually benefited from their services. [148] A final question with respect to special exchanges is whether they should be entirely mainstreamed, as current demand patterns suggest that regular

[146] GoI (2005), reporting a 1990 survey.
[147] See ILO (2005).
[148] See ORG-MARG (2005).

exchanges are in any event servicing the bulk of PWD clients. An alternative may be to use the current special exchange and cell allocations to fund NGO employment promotion activities, which appear to be more innovative and effective (see Box 5.4). There is nothing to say that public sector employment services can not innovate and develop direct contacts with private industry, as the TN Special Exchange experience shows. However, it seems clear from official statistics that many exchanges are very passive, and that the option of working with the NGO sector in employment service activities could be explored.

Box 5.4: A Jobs Fair Bringing Employers and Disabled people Together for Mutual Benefits.

The Ability Foundation in Chennai ran an "EmployABILITY job fair" in 2004 and 2005. Seven hundred (60 percent women and 40 percent men) highly qualified disabled people (MBA, MCS, Software engineers etc) were introduced to the HR representatives of 32 leading IT/ ITES companies. The EmployABILITY fair gave disabled job seekers an important opportunity to meet face to face and discuss with employers, display their job skills and make an explicit demand that they be hired on merit alone. In one instance there were 45 persons with disabilities who had the right IT skills for one company. In this one day 70 persons with disabilities got jobs.

Persons with disabilities felt very positive about getting interviews and reported that it helped them

- Understand more about the market and their own marketability
- It taught them what an interview entails; the questions, approach, English and communication skills required
- Increased their confidence about their possibility of obtaining a job in the open market.
- Realised that they need to be more confident, and for many improve their communication skills

For the **companies** they benefited as they:

- Recruited people who had the skills and knowledge that they needed
- Understood that ICT and enabling software have heightened the aptitudes and increased the employability of disabled people
- Realized that there is an enormous talent pool of persons well qualified for the IT job requirements
- Improved their understanding about types and extent of disabilities
- Realized that there could be benefits for their company in employing disabled people due to: their proven record of high productivity, lower likelihood of leaving the job (particularly attractive with high attrition rates), is in accordance with Corporate Social Responsibility (CSR), and will be perceived positively by international clients.

So impressed was the TN IT department that it promised all support for an annual job fair. According to the ABILITY Foundation team "This fair emphasized the need for a productive relationship between government, the public sector, the private sector and society at large to bring about sustainable change".

Source: Officer (2005)

5.42. ***(d) Promoting Self-Employment through the NHFDC***: GoI incorporated the National Handicapped Finance and Development Corporation (NHFDC) in 1997 in order to help entrepreneurs with disabilities through financial assistance. NHFDC provides loans to PWD to support a variety of activities: small businesses in the service sector, the purchase of vehicles for commercial activity, small industrial units, agricultural activities, education and training, and self-employment for persons with mental retardation, cerebral palsy and autism.

5.43. NHFDC does not have its own branches to implement schemes, and instead uses State Channelizing Agencies (SCA), non-governmental organizations and in rare cases, commercial banks. Loan default risk is entirely born by the implementing agencies, with SCAs, NGOs and banks having to pay 100 percent of the loan amount back to NHFDC. The rate of loan recovery is

usually above 70 percent. [149] SCA account for most of the financial assistance provided by NHFDC. In most States, the SCA was already in place to implement the schemes for the SC, ST, and other economically weaker sections, and has been given the additional responsibility to implement NHFDC schemes. NHFDC delegates the power to sanction loans up to Rs. 1 lakh to the SCA and the loan money reaches the beneficiary through the SCA.

5.44. As shown in Table 5.10, ***between 1997 and 2005, the number of NHFDC beneficiaries has been very low.*** The number of beneficiaries in the period was 19,643. There is considerable variation across states in the number of beneficiaries, with states like Bihar and UP having very low coverage (9 and 6 beneficiaries respectively). In addition, disbursements have been very low, ranging between 23 and 26 percent of available funds in 1997-2002, in part due to long lags between receipt of funds by SCAs and loan disbursement. [150] In addition, even among the small client base, there is a strong gender and disability bias. Over 80 percent of beneficiaries are men and nearly 90 percent of the beneficiaries of schemes are persons with orthopaedic disabilities. The impact of the scheme is dependent on whether the State gives priority to disability issues and on the competence and initiative of the SCA. It is clear that disbursement is driven by institutional factors rather than size of disabled population, weakness in credit markets, etc.

Table 5.10: Beneficiaries sanctioned and disbursements, NHFDC schemes, 1997-March 2005

	Beneficiaries	**Disbursed (Lakh Rs.)**
AP	602	269.5
Assam *	20	2.0
Bihar *	9	0.5
Chattisgarh	136	71.2
Gujarat	1231	550.7
Haryana	2831	1183.5
HP	294	214.4
Karnataka	1177	246.6
Kerala	1022	655.7
MP	1996	841.2
Maharashtra	2716	1636.2
Nagaland	499	242.6
Orissa	2237	935.7
Punjab	42	8.8
Rajasthan	2211	1264.8
TN	274	84.3
Tripura	25	12.3
UP	6	6.4
WB	582	241.3
Chandigarh	122	37.1
Delhi	406	104.7
Pondicherry	953	430.5
Others	252	153.0
Total	**19643**	**9193.0**

[149] NCPEDP (2003).
[150] CAG, 2004.

Source: NHFDC website reporting cumulative numbers since inception. * = 2003 figures.

5.45. NGOs implement the Micro-Finance Scheme of NHFDC. Under the scheme, NHFDC provides a one-time grant of Rs. 10,000 to the NGO to cover start up costs for the scheme. The NGO may receive from NHFDC a loan of up to Rs. 5 lakhs for disbursement to beneficiaries (up to Rs. 25,000 per person). The beneficiary is charged a rate of interest of 5 percent, of which 3 percentage points is for the NGO to meet administrative costs and 2 points is for NHFDC. In order to obtain the loan, the NGO has to provide security to NHFDC in the form of 25 percent of the sanctioned amount as fixed deposits or 40 percent of the amount as collateral security.

5.46. ***The size of NHFDC's micro-finance scheme though NGOs is insignificant.*** As of early 2003, 132 NGOs had applied for loans through the scheme, and 57 of them had disbursed loans to 1,365 beneficiaries for an average amount of Rs. 0.08 lakh. In sixteen states, there was no NGO partner as of late 2003. The limited interest by NGOs in the scheme may result from the financial conditions of participation that may be difficult to fulfill, in particular the security requirements and limited support for administrative costs. The administrative costs incurred for the implementation of the Scheme vary greatly depending on the number of beneficiaries and the administrative structure already in place within the NGO. It is likely that the one-time start-up grant of Rs. 10,000 for all NGOs is not sufficient for NGOs who do not have the cashflow to wait until the interest income is recouped.

5.47. The involvement of banks is a recent attempt to reach more beneficiaries. The Punjab and Sind Bank was the first bank to take the initiative to implement NHFDC schemes followed by the Oriental Bank of Commerce. It is too early to assess whether the involvement of banks has made it easier for NHFDC to reach more beneficiaries. The challenge for NHFDC is to make its schemes sufficiently attractive financially to get the attention of more commercial banks, and perhaps also to expand its outreach to MFIs and other NBFCs who may have an already developed lending process and client groups. The experience of AP with its Velugu (now IKP) SHGs and micro-financing suggests that non-traditional partners for increasing outreach of NHFDC financing could pay dividends.

5.48. ***(e) Vocational and Apprenticeship Training for PWD:*** Employment and vocational services are provided to PWD in India through a variety of mainstream and segregated agencies and programs, an overview of which is available in Rungta (2004). GoI provides vocational services to PWD through Vocational Rehabilitation Centres (VRCs), first established in 1968 under the Ministry of Labour. The basic model is a PPP one of contracting out to NGO service providers. There are currently 17 VRCs located in state capitals and the Government plans to support seven more. The main tasks of VRCs are to make vocational assessments of PWD and to provide short term training that lasts a year. Some VRCs also provide job placement services. In addition, some VRCs have rural rehabilitation extension centers whereby mobile rehabilitation counselors have disability assessment camps periodically and may organize Community Based Rehabilitation (CBR) in partnership with NGOs. There are 11 rural rehabilitation extension centers.

5.49. VRCs provide informal training to PWD who do not have the necessary education to enter formal training institutes such as Industrial Training Institutes (ITIs) or Polytechnics. There is no educational pre-requisite for eligibility and entry is allowed any time of year. Training is unstructured or semi-structured and is imparted in various trades, including: metal (welding and turning), carpentry, radio and electronic equipment services, tailoring, appliance repair, tricycle assembly and commercial education. Commercial education may include computer training. VRC clients may be rehabilitated in jobs or self employment.

5.50. Working age leprosy cured persons and persons with visual, hearing, locomotor disabilities or mild mental retardation may be eligible to receive VRC services. ***Many PWD are excluded from VRCs,*** e.g. persons with mental illness are not eligible and residential rules may exclude certain segments of the population with disabilities. For instance, the VRC in Chennai provides residential accommodation only to males, and is thus likely to exclude females with disabilities who live in rural Tamil Nadu. In 2004, persons with locomotor disabilities accounted for more than 80 percent of the persons admitted into VRCs, with persons with visual and hearing disabilities accounting for the bulk of the remainder.[151]

5.51. ***VRCs generally do not seem to make any regular effort to update the skills imparted along shifts in labor demand.*** There is a need to identify obsolete courses and substitute them with new ones. In addition, there seems to be a lack of focus on placement. Little effort is dedicated to ensuring that clients secure and maintain employment.

5.52. ***Like other active labor programs for PWD, the size of the VRC program is very small, rehabilitating only about 10,500 persons a year.*** To our knowledge, there is no study that shows that VRC training improved the job prospects and earnings of those who were trained in VRCs compared to those who did not receive the training. There are also limited data on the extent to which participants sustained gainful employment following VRC training. Participants are not followed over a number of years to identify the long term effects of the VRC training. In 2004, 29,124 clients were accepted into VRCs, and 10,490 were rehabilitated. [152]

5.53. Another scheme run by the Ministry of Labour is the Apprenticeship Training Scheme. This provides opportunities for ITI graduates to upgrade their skills through on-the-job training in industrial settings. It is obligatory, under the Apprentices Act (1961) for employers in the public and private sectors to engage apprentices. The Act covers 254 groups of industries. There is a reservation for people with disabilities under the scheme (3 per cent), but the same remains seriously under-utilized. In 2001, 559 persons with disabilities underwent apprenticeship training which equates to 0.03 percent utilization. There were no figures for 2004-5.

5.54. ***(f) Non-Governmental Employment Promotion Initiatives:*** As seen above, the penetration of public sector employment and skill promotion initiatives has been very limited in the decade since passage of the PWD Act. At the same time, a gradually expanding number of NGOs have become active in either vocational training of PWD or direct employment generation. Survey evidence from the late 1990s indicated that around two thirds of disability NGOs were conducting vocational training, and just under 60 percent producing some aids and appliances. Of the 700 NGOs receiving grant-in-aid funding for disability in 2004-05, 190 of them were operating vocational training courses for PWD. [153] The majority of these were informal, with no accreditation process. The bulk of them were oriented towards skills for sheltered, group and self-employment rather than for employees in the organized sector. In addition, there was an emphasis in both vocational and employment programs of NGOs on designated activities for PWD, the bulk of which are traditional crafts (e.g. re-caning of chairs, chalk making, book binding etc), which attract relatively low wages of around Rs.500-1200 per month. [154]

[151] GoI (2005).
[152] A person is considered as being "rehabilitated" if, following VRC, he or she has found a job, is in self-employment, or has been admitted to a formal training program.
[153] GoI (2005).
[154] See ILO (2003).

Box 5.5: Good practice in NGO skills training and employment promotion for people with disabilities:

The NGO sector has shown considerable innovation and impact in skill development and employment promotion of people with disabilities. Two notable cases are:

WORTH TRUST in Chennai has operated training centres and several production centres since the 1960s for people with disabilities, initially focusing on people with leprosy. Training takes two forms: (i) formal 2 year training with government syllabus and certification; and (ii) informal 2 year training fro those who have not finished high school without certification. Both include on-the-job training as well as classroom and workshop sessions. Both focus on jobs as machinists, electronics, welding and other skills. Its producton centres have evolved with market demand metal items to fabricated plastic precision parts, as well as assistive devices. Two of the five centres have ISO 9002 certification. It also provides hosing loans, and counseling for trainees seeking jobs. Its own impact evaluation in 2000 revealed good employment outcomes, with around 80 percent of trainees in jobs, primarily in factories. Some innoviatve features of WORTH's work include: (i) regular monitoring of labor and product market demand, based on which it has changed its course content and focus of production over time; (ii) the counsellign function has been critical to improving the skills of trainees to access open employment; (iii) it ensured that its production centres were located near their markets to improve competitiveness; (iv) it provides training of trainer for similar operations in India and abroad; and (v) it is one of the few NGO or public training institutions for disabled people that has properly monitored the employment outcomes of its trainees.

The **Thakur Hari Prasas Institute** was established in 1968 in Hyderabad, initially as a rehabilitation centre for children with mental disabilities. This work has continued and expanded, but the most innovative element of its activities is its Community-Based Rural Project started in 1992. It has mobile project teams which work with communities initially to identify and then to educate and/or train young people with intellectual disabilities. This can include integration into regular schools for those under 15, home-based skills training for the more severely impaired, and placement in local jobs with on-site training for those over 15. The trades covered included agriculture, carpentry, welding, nursery, and blacksmithing. The teams also identify community members who can assist in training under supervision. The strong involvement of communities has been a key to its success. There has been considerable success in getting the children with intellectual impairments into work, with bulk of trainees now employed full time.

Source: ILO (2003)

5.55. NGO skills training programs exhibit a range of experiences. However, several common elements can be observed. These include:

- ***most have a strong urban bias in training provision***. This is in part due to the nature of rural skills, where more informal passing on of knowledge may occur in many occupations. Despite this, there are useful examples like Jai Bharat NGO in rural Rajasthan which pairs disability-trained community workers with local resource persons with desired skills (e.g. rope or shoe making) to provide informal training in a manner that is suited to rural PWD. There have been concerns expressed of rural PWD being brought to urban areas for training, with problems of resocialization and actual demands for skills taught. [155] Equally, placement rates in urban areas of rural trainees have tended to be low.
- ***many NGOs acknowledge a lack of trained trainers***. While rehabilitation specialists are relatively easy to identify, NGOs note the shortage of professionals with PWD-specific and vocational skills, with only one of the national institutes providing training in VET.
- as in the public sector, ***NGOs frequently failed to undertake sufficient assessment of the local labor market conditions in determining courses for PWD.*** This is in part due to the tradition of a limited range of craft-based skills, and in part lack of pressure from funders for market-relevant training. Nonetheless, the better NGOs are increasingly reaching out directly

[155] Lang (2000).

to the private sector to assess need, in the best cases through local market assessment which have proved very effective, as the case of DISHA from Rajasthan shows (see Box 5.6).

- ***monitoring of employment and wage outcomes for PWD trainees tends not to happen***. Of course, full-blown M&E may be costly, but more structured attempts to get employment outcomes would act as a key indicator of local demand. There are, however, good practice examples like the WORTH Trust who have conducted serious survey-based monitoring of both employment and wage outcomes of their trainees.
- ***there is limited effort to promote integrated training of PWD and non-PWD, and limited cross-disability training even among people with disabilities.*** There will be cases where segregated training is preferred by PWD. However, as it is often perceptions of employers and other non-PWD workers in the market that contribute to poor LM outcomes for PWD, efforts to promote more integrated training would be worth pursuing where feasible.
- ***women tend to be seriously under-represented in vocational training.*** This is driven by a range of factors, including training offered and its male bias in many cases, lack of suitable accommodation for PWD women in residential courses, low household expectations for PWD women etc.
- ***on the job training in firms outside the NGO itself is to date very under-developed.***

5.56. The above points indicate that there remains considerable scope for adjusting the skill development and employment promotion activities of NGOs. However, there is also evidence of considerable innovation and dynamism in the NGO sector which is largely lacking in the public sector interventions to date. The most successful operations in the NGO sector appear not only to be achieving better labor market outcomes than any of the public sector interventions, but also to be flexible enough to adapt their product lines and methods to changing market conditions. It is not possible to provide a comprehensive overview of such successes, but the examples of the WORTH Trust in Tamil Nadu (see Box 5.5), the Indian Institute of Cerebral Palsy in Kolkata, and a public-private partnership in Mumbai indicate the success and capacity of NGO institutions to engage effectively with the private sector to promote good outcome for their PWD clients.

Box 5.6: Knowing your Market: DISHA

DISHA, a local NGO in Jaipur, carried out a study on 16 types of industries to have a better understanding of local employment opportunities and assess skill development needs for adolescents and adults with mental handicaps, autism and cerebral palsy. The study enabled DISHA to identify 18 potential areas for job placement and gain a better understanding of local employers' concerns and potential barriers to employment of PWD. Employers also provided suggestions on resources for training which reduced the need to develop in-house expertise. The results formed the basis for decisions on the skill development courses they would provide in their vocational training unit i.e. cooking, crafts, silver jewellery, block printing, recycling unit.

The investment in understanding the market both for products and jobs has had multiple effects. It has helped bring DISHA closer to employers and hence be in a better position to support job placement of persons with mental handicaps in their companies. It has helped DISHA target job opportunities for persons with mental handicaps in industries where they are seldom seen i.e. Five star hotels, edible product manufacturing units and fabric printing units. It has diversified the training options for persons with disabilities which continue to evolve on the basis of market demand i.e. initially they produced biscuits for sale to hotels now with greater interest in "different types of bread" they are venturing into bread production.

Source: Officer (2005).

D. Conclusions and recommendations

5.57. It is clear from the review of active labor policies in the public sector and private interventions that there are no magic solutions to the poor employment outcomes of PWD. Improving employment outcomes for people with disabilities starts with the education system and community attitudes. Public interventions have achieved minimal coverage over a sustained period, with no signs of significant improvement. There are relative out-performers by state under different programs, but even those achieve low outcomes in absolute terms. NGO programs face inherent challenges of scale and often need stronger linkage to the labor market to improve impact. Several recommendations emerge from the analysis:

5.58. **Improving public sector employment practices.** First, the reservation for disabled workers needs to be reviewed and reformed. If a quota approach is retained, it should be based on a share of all posts in public agencies and discontinue the practice of "identified posts". The Government should also review whether special employment exchanges should be integrated into the regular exchange network. In either event, there must be a systematic engagement with the private sector to assess labor market demand and move away from the current focus on public sector employment. TN and Gujarat provide promising models in this regard. Awareness campaigns for public programs are needed, as knowledge about available programs remains low.

5.59. **Improving quality of private sector initiatives, and strengthening public-private partnerships.** GoI and the NGO and private sectors should jointly review the draft private sector incentives policy for people with disabilities developed by NCPEDP and FIICI to assess its financial and administrative feasibility and adopt those measures deemed workable into policy. There should be dissemination by the Commissioners' offices of good practice in public and private sector enterprises in hiring and promotion of inclusive workplaces for people with disabilities. In particular, a review of the impact and viability of NHFDC should be carried out. At a minimum, the structure of NHFDC schemes needs to be revised so as to give SCAs, NGOs and banks better incentives to participate, and accountability mechanisms for channelling agencies improved. There should also be more experimentation with group-based lending to disability SHGs, which has been shown in states like AP (and in mainstream targeted credit programs) to be more effective than individual lending in expanding credit coverage.

5.60. **Increasing outreach to marginalized groups and regions.** Both public and NGO training for disabled people needs to make greater efforts to include women with disabilities and a broader range of disabilities. They also need to develop simple processes for regular assessment of labor market demand. Pilot interventions for rural outreach of both public and NGO active labor programs are needed, and public funds from existing programs should be dedicated to this purpose. This will require much stronger engagement with communities and SHGs of disabled people.

CHAPTER 6: SOCIAL PROTECTION FOR PEOPLE WITH DISABILITIES

6.1. ***This chapter deals with the main social protection programs for PWD in India***.[156] ***As noted in Chapter 7, this is an area where the commitments of the PWD Act are rather circumscribed***. In practice, even the commitments of the Act on certain social protection schemes have not been met often. Nonetheless, a number of measures are either gradually improving or have potential for expansion, so are worth exploring.

6.2. There are many elements of the social protection system to which PWD and their households may be entitled not due to disability but due to poverty, social category or other indicators. These include most importantly the PDS food scheme for poor households. However, the focus of this chapter is on specific commitments and schemes that PWD are entitled to as a result of their disability (or disability plus some other indicator such as poverty). The main programs discussed are:

- ***reservations under various centrally-sponsored anti-poverty programs*** which operate throughout rural areas of India, in particular public works, targeted credit and publicly-financed housing schemes for the poor
- ***unemployment allowances for PWD***
- ***"social pensions" for destitute PWD***, i.e. monthly social assistance cash benefits
- ***different forms of insurance in cases of disability***, including schemes for civil servants and the formal private sector, existing schemes for informal sector workers in some parts of the country, and proposals for expansion of social insurance to the unorganized sector.

6.3. The social protection system specifically for PWD thus consists of both social welfare and social insurance interventions. However, for the vast majority, insurance-based schemes are not yet a reality. ***Overall, the public social protection system for PWD who are not in the formal sector is in design parsimonious on most states, and in practice offers low coverage and limited financial protection.*** Even in the formal sector, there are a range of issues in design and actuarial soundness of disability (and broader social) insurance systems for the public sector.

A. Poverty Alleviation and Social Assistance Schemes for PWD

6.4. ***(a) Reservations in anti-poverty programmes: The PWD Act commits governments to reservation of not less than 3 percent in all poverty alleviation schemes for the benefit of PWD.*** This section looks at recent performance on a few major schemes: public works under SGRY; subsidized credit for BPL households under SGSY; and the IAY housing program for the rural poor. ***While the Act is relatively clear on the 3 percent reservation, this has been interpreted in somewhat different ways in each scheme.*** For SGRY, there is mention of parents of CWD rather than adult PWD workers, on the assumption perhaps that PWD are not able to engage in work. However, while parents are mentioned as a target group, there is no specific quota target for their employment under the scheme (unlike other target groups like women and SC/ST for whom specific target shares are noted). For the new NREGS, there is no specific mention at all of PWD as a target group in the guidelines. In IAY, people with disabilities are mentioned as a priority target group (among several categories), but no specific quantitative target

[156] States may have additional state-specific schemes for PWD, but these are not addressed here.

is set. In the case of SGSY, the guidelines are more specific, and require that 3 percent of beneficiaries annually be PWD.

6.5. ***Reporting formats from poverty alleviation programs do not in all cases make it easy to know what share of beneficiaries are PWD. However, where data are clear, it appears that PWD are well below 3 percent of beneficiaries in all schemes.*** Data for SGSY are presented in Table 6.1 below, and indicate that the share of PWD beneficiaries has never been above 1 percent of total swarozgaris between 1999 and 2004. No single state in 2003-04 reported meeting the PWD quota, with AP the best performer at 2.1 percent of beneficiaries. Several large states with high poverty rates reported PWD shares below 0.5 percent of total SGSY beneficiaries (e.g. UP, West Bengal, Orissa, J&K and Bihar). Equally, SGSY coverage rates in the five year period as a share of total adult PWD have been minimal, with 35,914 PWD beneficiaries accounting for around 0.3 percent of total working age PWD (15-59). Even excluding non-workers, the share of PWD assisted by SGSY in the period is only 0.7 percent of the working PWD population.[157]

6.6. ***As with other social groups, a challenge in mobilizing access to SGSY funds is formation and capacity building of SHGs among PWD.*** Without functioning PWD SHGs, revealed demand for the program will always remain low. Many states in their SGSY programs have started to use NGOs to mobilize SHG formation and build their capacity. It seems that such efforts need to include a specific disability focus as well if the SGSY is ever to approach its target levels of PWD beneficiary share. There are promising examples. In AP, efforts to support PWD SHGs under the Velugu program have resulted in formation of almost 15,000 PWD SHGs. While much remains to be done to strengthen capacity, the higher rates of PWD coverage in AP's poverty alleviation programs suggest initial impacts, albeit with some way to go.

Table 6.1: Proportion of PWD beneficiaries under SGSY, 1999-2004

FINANCIAL PROGRESS	1999-2000	2000-2001	2001-2002	2002-2003	2003-2004	Total / Average 99-04
Total Swarozgaris	933,868	1,006,152	937,468	826,267	892,890	4,596,645
PWD Swarozgaris	8,529	6,737	6,059	6,118	8,471	35,914
%PWD/total	0.91	0.67	0.65	0.74	0.95	0.78
Per capita Investment(Rs.)	17,113	21,481	21,284	21,666	22,685	20,846

Source: Ministry of Rural Development

6.7. ***For SGRY – a far bigger program in total spending than SGSY – the reported figures are more difficult to interpret***, as the primary outcome reported is not number of days of employment generated for PWD but works completed for benefit of disabled people. In the two budget years 2002-04, the share of public works categorized as for disabled ranges between 0.2 and 0.9 percent of total works completed in the two SGRY spending streams, well below the quota share of works. Publicly available reports therefore remains rather opaque on actual employment generation.[158] However, CAG reports on public works performance with respect to PWD indicate that the share of PWD beneficiaries in total never reached above 1.7 percent for state reporting in the period 1998-2003, [159] and more recent data from states are consistent with even lower shares (e.g. PWD in Orissa between 2001 and 2005 accounted for only 0.3 percent of total employment days generated under SGRY).

[157] PWD age-specific shares calculated from Rajan (2006), based on census PWD count by state.
[158] See Ministry of Rural Development Annual reports, various years.
[159] CAG, op.cit.

6.8. ***One of the factors driving the apparently poor PWD outcomes on public works appears to be very low awareness in PWD households of the reservation***. In the UP and TN rural survey, fully 94 percent of households were not aware of the reservation on public works schemes, and only 0.1 percent of PWD themselves had participated in any public works.

6.9. While SGRY performance on employment of disabled people appears to be poor, ***the 2005 National Rural Employment Guarantee Act (NREGS) has dropped the reservation for disabled people,*** with no mention of preferences for people with disabilities in either the Act itself or the implementing guidelines. This appears to be clearly inconsistent with the PWD Act, and efforts are ongoing to seek adjustment of the NREGS guidelines. An interesting joint effort between the state Government and disability NGOs is underway in AP to identify additional categories of works which would be better suited to employment of different disability categories. A second significant innovation in AP is that households with a disabled member are entitled to 150 days of public works employment per year, rather than the 100 days for other households under the Act. This can apply to any household member.

6.10. ***Performance on the IAY housing program is also well below commitments of the PWD Act.*** Recent data are available for fewer years, but 2003-04 data indicate that only around 0.8 of all beneficiaries were PWD. Again, there was some range statewise, but – with the exception of Manipur – not state met its quota, with again AP being the best performer with 2.3 percent of beneficiaries as PWD. In contrast, UP and J&K reported no PWD beneficiaries at all in 2003-04, and many states having PWD rates of 0.2 percent or lower of total beneficiaries (e.g. Bihar, West Bengal, Orissa and Karnataka). Data for the period 1998-2003 also indicate very low state shares of PWD to total IAY beneficiaries, estimated to be less than half of percent of all IAY beneficiaries in the period.[160]

6.11. ***(b) Unemployment allowance for PWD: The PWD Act also provides for development of unemployment allowance (UA) schemes for PWD registered with employment exchanges for more than two years who have not found employment***. The commitment is circumscribed by the phrase "within the limits of their economic capacity and development", so that it is not a binding entitlement as such. Table 6.2 presents information on the states and UTs which have developed unemployment allowance schemes for PWD and the amounts of allowances, where available. Unemployment allowance schemes are available in 13 States/UTs and allowance amounts vary from Rs. 50 to Rs 500, which can be higher or lower than disability pension amounts depending on the state/UT. However, the majority of governments which have introduced the UA for PWD are either UTs or small north-eastern states. Among the major states, only Tamil Nadu, AP and West Bengal had schemes as of 2004. ***In addition***, ***there appears to be some uncertainty on which states have such schemes***. The CAG indicates that the MoSJE reported that additional states had introduced UA for PWD - including Karnataka, Maharashtra, HP and Manipur – but that CAG found that benefits were not being paid.[161] In addition, beneficiary data are not available. ***This suggests that reporting systems between states and the centre are less than adequate.***

[160] CAG, ibid.
[161] CAG (2004).

Table 6.2: States/UTs with unemployment allowance (Rs), 2004

State	UA per month
AP	Rs. 75
Haryana	Yes
Meghalaya	Rs. 50
Punjab	Rs. 150 to 400
Sikkim	Rs. 500
Tamil Nadu	Rs. 200 to 300
Tripura	Rs. 500
West Bengal	Yes
Andaman and Nicobar	Rs. 100
Chandigarh	Rs. 150 to 400
Daman and Diu	Yes
Mizoram	Rs. 100/month
Pondicherry	Rs. 400 and 500

Source: MOLE.

6.12. ***(c) Social pensions for PWD***: ***India has social assistance cash payments for destitute elderly, widows and PWD.*** There are other qualification criteria which vary somewhat by state, but broadly relate to the degree of support form immediate family and lack of current income of any significant level. Nationally, all states/UTs for which data are available have disability social pension schemes, with the monthly benefits level in 2004 ranging from as low as Rs. 60 in Chandigarh to Rs. 500 in West Bengal and Goa, around a national average for reporting states of close to Rs. 200. This may have increased since 2006 with an increase in the central funding for elderly social pensions to Rs. 200, which has been mimicked for disability social pensions in most states. Unfortunately, the beneficiary and spending numbers on disability "social pensions" are not consolidated to allow a national picture of coverage and spending. Nor does the NSS ask about such payments specifically.

6.13. ***Household survey data from 2004/05 provides the first nationally representative insight into coverage of disability social pensions, as well as into the incidence of coverage across different wealth categories and social groups.*** The findings are shown in Table 6.3 and 6.4 below. Several points are worth noting:

- while coverage of disability social pensions is low across the entire population (at 0.3 percent of households nationally), they cover quite significant shares of households who have a disabled member (nationally, around 14 percent of such households)
- there is wide variation across states in coverage rates. Given that disability social pensions are state-funded entirely, this reflects largely state-specific priority given to the program. However, the interesting feature is that coverage rates do not vary systematically according to the poverty rate in states (note that cross-state disability rates in official statistics are not very great). Thus some lagging states such as Orissa, MP and Rajasthan have good coverage rates, while some richer states such as TN and especially Gujarat have lower than average rates.
- while state-specific benefit levels varied at the time of the survey, the median benefits reported as received by households indicate that there appears to be fairly low leakage of funds in terms of reporting beneficiaries getting less than their cash entitlements.

Table 6.3: Coverage rates of disability pensions by total HH population and HH with PWD, 2004/05

	% of all HH receiving disability pension	Implied % of PWD receiving disability pension	Median annual benefits among HH receiving (Rs)
J&K	0.2	6.7	3,600
HP	1.1	42.9	2,266
Punjab	0.3	17.2	1,560
Uttaranchal	0.2	8.7	250
Haryana	0.8	37.2	2,819
Rajasthan	0.5	20.0	2,400
Uttar Pradesh	0.3	14.4	1,531
Bihar	0.2	8.8	1,473
West Bengal	0.1	4.3	6,000
Jharkhand	0.2	12.0	1,200
Orissa	0.8	28.8	1,054
Chattisgarh	0.3	14.9	1,436
MP	0.5	21.4	1,681
Gujarat	0.0	0.0	
Maharashtra	0.1	6.2	1,713
Andhra Pradesh	0.1	5.6	633
Karnataka	0.8	44.9	2,273
Kerala	0.6	22.2	966
Tamil Nadu	0.1	3.8	1,575
All India	**0.3**	**14.1**	**1,781**

Source: Ajwad (2006), Bank staff estimates, based on NCAER national HD survey in 2004/05.

6.14. ***While coverage of disability social pensions is quite impressive in a number of states, the distributional pattern of coverage across wealth and social groups is more neutral, indicating considerable spending on the non-poor.*** In addition, as the richest, Brahmin and OBC households receive notably higher benefits than the poor and SC/ST households, the incidence of actual benefit receipts reports by households indicates real challenges in targeting. While the poorest quintile of households receive somewhat higher share of total benefits than their share in population, this is also true for the richest quintile, but not for example for the second poorest quintile. Equally, both SC and ST households capture notably less of total benefits than their population share.

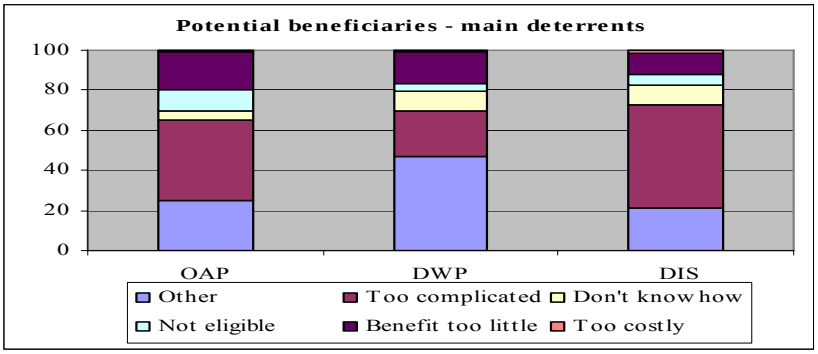
Table 6.4: Coverage of disability social pensions by wealth, location and social category, 2004/05

	% of households receiving benefits from NDP	Median benefits among households (Rs annual)	Share of total benefits capture by group (%)
Poorest	0.4	1,713	25.5
Q2	0.3	1,494	17.8
Q3	0.3	1,605	20.6
Q4	0.3	1,539	12.5
Richest	0.3	2,771	23.5
Rural	0.3	1,856	89.1
Urban	0.1	1,335	10.9
Brahmin	0.2	1,868	3.1
OBC	0.3	1,860	49.0
SC	0.3	1,615	21.6
ST	0.2	1,601	5.0
Other	0.2	1,827	21.2
All India	**0.3**	**1,781**	**100**

Source: Ajwad (2006), Bank staff estimates, based on NCAER national HD survey in 2004/05.

6.15. ***The obvious question is why such a distributional pattern of benefits emerges given the generally poorer status of households with disabled members*** (discussed in Chapter 1). The short answer is that more work is needed to understand the constraints to the poor and SC/ST households with disabled members getting better access to benefits. However, qualitative work and a recent study from Rajasthan give an indication that the perceived complexity of the applications process (including certification as eligible disabled) among potential applicants is a barrier to expanding coverage. Looking at Figure 6.1, the main deterrent to applying for social pensions among those potentially eligible for disability pension is "process too complicated", which put off about half of potential applicants in the 8 districts of Rajasthan surveyed, with almost a further 10 percent citing "don't know how" as the reason for not applying. There is not quantitative evidence from other states which could allow to generalize form this finding, but field visits for this report find that the complexity factor is a recurring theme of potential applicants. The other aspect in several states is that there is a degree of fiscal rationing in aggregate numbers of disability social pensioners, and that the distributional results indicate that the better off manage to access the program at the expense of others.

Figure 6.1: Main deterrents to application for social pensions by type of pension, Rajasthan, 2006



Source: Dutta (2007) based on 8 district social pensions survey, Rajasthan.

6.16. As seen in previous sections, the UP and TN survey explored knowledge of entitlements among PWD. To access the disability social pension or unemployment allowance, it is necessary

first to have a disability card. In the survey, only 15 percent of PWD with moderate disability had such a card and around 21 percent of those with severe disabilities. Shortcomings in the identification and certification system (see Chapters 3 and 4) are therefore to some extent driving relatively low coverage in the social protection system. However, ***there also appears to be low awareness of both social pensions for disabled people and the unemployment allowance scheme***, with over 60 percent of PWD in rural UP and TN not aware of the existence of either scheme and only 9 percent of them having benefited (Table 6.5). While awareness is not as low as several other PWD entitlements, lack of awareness is clearly an issue.

Table 6.5: Awareness of disability certification and cash benefits, rural UP and TN, 2005

Certification as a disabled person	
Not aware	56.2%
Aware	19.8%
Benefited	20.7%
Denied	3.3%
Regular cash benefit to destitute or unemployed PWD	
Not aware	61.5%
Aware	25.6%
Benefited	9.0%
Denied	3.9%

Source: UP and TN village survey, 2005. Bank staff estimates.

6.17. ***(d) Conclusion on poverty alleviation and social assistance schemes:*** Overall, the level of coverage and financial protection provided by the range of interventions reviewed varies significantly across states. ***However, in nearly all cases, the combined social protection that the various poverty alleviation and social welfare programs offer to PWD appears to be rather insignificant.*** This is a product of low awareness among PWD of programs, weak channels for increasing demand in several cases, and in many states an apparent lack of focus on the whole area of social protection for PWD. ***The disability social pension appears to date to have the most effective outreach in several states***. In contrast, the system of reservations under general poverty alleviation schemes has clearly failed to achieve the desired outcomes and consideration needs to be given to alternative approaches to livelihood promotion and other forms of social protection for PWD. The unemployment allowance scheme remains inadequately understood, but does not appear to play a significant role in social protection for PWD.

B. Disability Insurance in India

6.18. ***(a) Overview of current mandatory schemes: Disability can lead to significant declines in household consumption, especially when the affected individual is a breadwinner***.[162] An important instrument for addressing the risk of disability and smoothing consumption is insurance. As in the majority of countries, most disability insurance provision in India is provided publicly and in the form of a mandated benefit tied to the retirement income scheme. ***Only formal sector workers are covered by the mandated disability insurance schemes, although some voluntary provision exists.*** The schemes for public and private sector formal sector workers provide similar benefits but are financed differently (Table 6.6).

[162] See for example, Gertler and Gruber (1997).

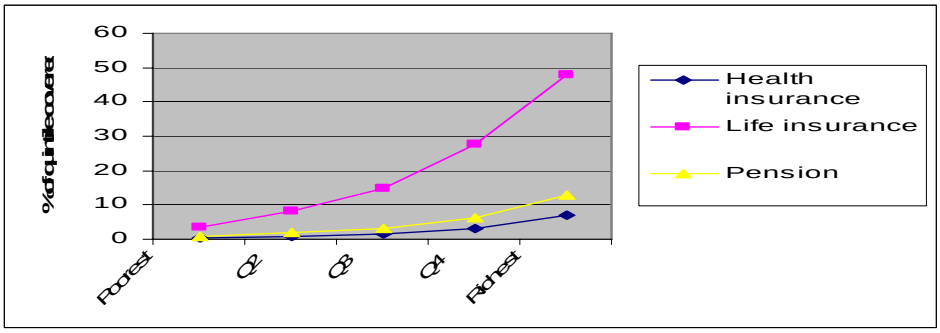
Table 6.6: Contributions and benefit targets for mandated disability insurance in India

Scheme	Contributions	Qualifying period	Replacement rate
Employees Pension Scheme	8.33% that also covers old age and survivor benefit	1 month	1.52% times years of contribution X final 10 months wage with minimum 250 rupees per month
Civil service pension Scheme	None, financed from budget directly	Immediate	1.52% X years of service X final 10 months wage with minimum 1310 rupees per month
Military pension Scheme	None, financed from budget directly	immediate	Basic retirement pension plus 20% depending on rank

Source: Government of India and EPFO

6.19. ***There are at least two problems with the current arrangements for social insurance, including disability insurance***. ***The first is related to the small share of the formal sector.*** When combined, the public and private sector schemes cover less than one in ten workers in the country, and this share has not increased in recent decades. Coverage is therefore low and concentrated in the top half of the income distribution. This can be seen in Figure 6.2. Unfortunately, there is no "clean" picture of disability/serious accident insurance. However, the pension coverage is a a significant extent one proxy due to the provision for disability pensions in formal systems. The more important insurance however in coverage terms is life insurance, which is often bundled with accident/disability insurance. While coverage also remains low and concentrated in the upper ends of the distribution, penetration is notably higher overall, and not as negligible in the second and third quintiles

Figure 6.2: Coverage of health, life and pension insurance, 2004



Source: Palacios and Goyal, 2006., based on MoF/ADB national 2004 survey.

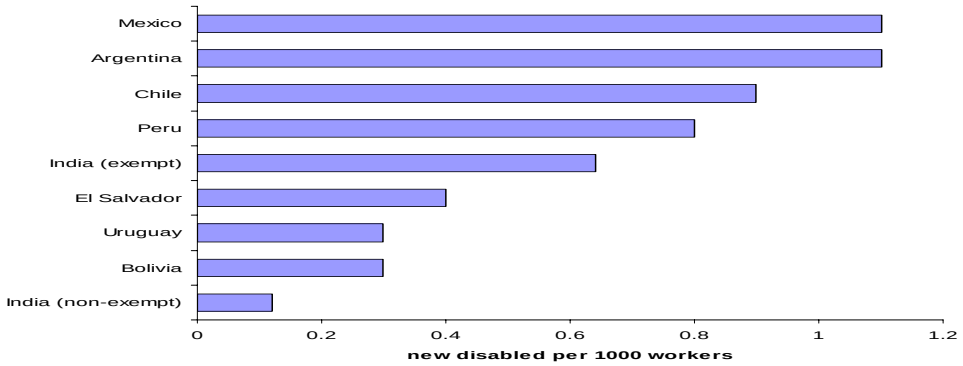
6.20. ***The second problem is related to financing***. In the case of civil servants, the financing comes directly from the budget. No reserves are set aside, just as in the case of old age pensions. This is starting to change however, as a new defined contribution scheme is being phased in for new civil service hires.[163] In the case of the Employees' Pension Scheme (EPS), the benefit is financed out of a common fund and contributions are pooled for old age and disability. Recent actuarial reports have identified an unfunded liability in the EPS signaling sustainability problems. In both cases, the premium required specifically for disability insurance coverage has not been calculated or separated. This is not surprising given that in neither EPS or the EPFO are the contributions (or lack thereof) set so as to generate long term actuarial balance. The new DC scheme that covers newly hired civil servants makes it necessary to rethink the simple - if opaque - financing arrangement for disability insurance that has operated so far.

[163] The disability provisions of this new scheme have not yet been determined (see below).

6.21. An important element in costing disability insurance is the rate of new claims. Data show that rates of disability claims in formal pension systems are higher in the richer OECD countries than in poor or middle income countries.[164] Disability inflow rates in European contributory pension schemes average more than six per thousand working age individuals, many multiples of the same rates found in Latin America.[165]

6.22. Reported disability inflow rates in India's EPFO/EPS scheme are shown in Figure 6.3 below, and compared to rates in seven Latin American countries. ***In India, there is a large disparity in disability inflow rates between the rates reported for workers in the unexempted funds (which make contributions directly to EPFO and EPS) and those in the exempt funds (which operate in large establishments and opt out of the EPFO).*** [166] Notably, the unexempted fund rates are the lowest in the table and nine times lower than those in the exempt funds. The reason for this low rate is not clear especially because the rate of actual disability is likely to be higher among the unexempted workers given that they have lower average wages than the exempted fund workers. Among the possible explanations is the fact that exempt funds can process claims "in-house" without having to approach the EPFO bureaucracy, and may therefore be more efficient in processing claims. The differentials – both in comparison to exempt funds and the other countries shown – raise questions on the efficiency of current social insurance processing systems.

Figure 6.3: Disability inflow rates for contributory pension members in India and selected Latin American Countries, 2000-2002



Source: Grushka and Demarco (2003); EPFO (various). Indian averages for 1996-2001.

6.23. **(b) <u>Disability insurance for the unorganized sector</u>:** ***The latent demand for disability insurance among those not covered by the EPFO and public sector schemes is evidenced by the growing number of self-help groups, welfare funds and micro-insurance offerings in this area.*** However, country wide membership in these group schemes is limited (certainly less than 5 per cent) and not all offer disability benefits. Those that do offer it almost universally pay out lump sum benefits and only in cases of permanent and serious injury.

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[164] Part of the result may be due to the fact that disability incidence rises with age and the average age of workers in richer countries is higher. Yet, it is also clear that working conditions tend to be safer in rich countries and health services are generally better. The counter-intuitive result suggests that in lower income countries either eligibility standards are stricter and/or individual workers find it less attractive to make a claim when incomes are at lower absolute levels.

[165] See OECD (2003) and Grushka and Demarco (2003).

[166] Exempt funds are employer-administered provident funds that have to match the contribution and benefit schedules (including rates of return) of the EPFO. They are restricted to large employers that have received permission to contract out of the EPFO as long as they match the benefits. They account for around one quarter of total membership, and tend to be higher income and bigger firms.

6.24. ***Easily the largest scheme for unorganized sector workers is the Janashree Bima Yogana (JBY), which is a bundled life and total/partial permanent disability product provided by Life Insurance Company of India (LIC), and covered 3.6 mln households as of 2006.*** In addition to the survivor benefit in case of death, JBY provides for Rs. 50,000 to a household in case of permanent total disability and Rs. 25,000 in case of permanent partial disability. This is based on an annual premium of Rs. 200 per household, half of which comes from the insured person and half from a Social Security Fund of LIC itself which was financed by GoI on a corpus basis. The program is targeted to group membership (of 20 and more members) and covers a designated range of unorganized sector occupations. [167] The design of the scheme is interesting from a policy perspective in several ways. First, it is an attempt to incrementally increase coverage, in this case on the basis of occupations or groups considered to have generally lower incomes, but with some capacity to contribute. Second, there is a transparent subsidy intended to provide incentive for voluntary take up.

6.25. Welfare funds are most common in Southern India and in particular, Kerala where some estimates put coverage at more than one in five workers. In a recent review of Kerala welfare funds, Rajan (2002) found a wide variety of benefits including for very specific health conditions (e.g., artificial organs) to cash disability payments. Out of 24 welfare funds covered in the study, 18 offered some kind of disability benefit, but only 5 provided a monthly payment until death.[168] The rest paid one time lump sum benefits. An ILO review of welfare funds in several states also found similar patterns.[169]

6.26. ***The prevalence of disability benefits in micro-insurance schemes appears to be even more limited.*** In its review of 51 surveyed micro-insurance schemes, the ILO found that only one quarter offered disability benefits (although others did offer accident and health benefits that may overlap to some extent).[170] The benefits were almost always in the form of lump sum payments. As an example, the Bharathi Integrated Rural Development Society (BIRDS), with about 9,000 contributors in 173 villages charges a premium for disability and life of 100 rupees per annum and pays a lump sum Rs. 25,000 in the case of permanent disability.

6.27. ***There is very little solid analysis available on how well these schemes function.*** Common challenges include relatively high administrative costs, limited risk pooling and lack of expertise in insurance. Moreover, given the general lack of regulation, there is bound to be wide dispersion in the quality and financial soundness of the different plans. Finally, even where the programs are functioning well, the public policy question is to what extent they can be scaled up.

6.28. ***Another source of disability coverage is the product offered by the New India Assurance Company (NIACL).*** These publicly-owned companies are obliged to offer services targeted at specific groups. Coverage is extremely low however. For example, only 47,000 individual policies were sold for a disability insurance product targeted towards women offered by NIACL between 1998-2004. This is clearly a negligible fraction of potential coverage. Some of the rural insurance schemes with accident benefits appear to have greater coverage. It is unclear whether any of these products are priced on a fair basis or are implicitly subsidized by the insurance companies and ultimately by the state.

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[167] See licindia.com/social_securities_001_benefits.htm

[168] For example, Kerala's headload and toddy workers that become permanently disabled receive 150 rupees per month until death while cashew nut workers receive a lump sum of 2500 rupees and a fisherman or a rickshaw worker are not covered for disability.

[169] ILO (2004).

[170] In her study of health insurance offered by a microfinance institution in India, Duflo (2004) finds that a large share of health shocks are likely to be due to events that would fall under the disability category.

6.29. **(c) <u>New developments and promising initiatives</u>:** ***As of 2006, there are at least two notable initiatives that may eventually lead to significant changes in the coverage and financing of disability insurance in India.*** In 2005, a special commission was established with a mandate to make recommendations on how to expand social security coverage to the unorganized sector. The mandate extended to consideration of benefits in a number of areas including old age, death, maternity, health and disability. The draft scheme is proposed to be voluntary and contributory, but would include a two thirds government subsidy to cover part of the contribution, and a completely subsidized contribution for BPL participants in the scheme. It was submitted for Cabinet consideration in May 2006.

6.30. Separately, a bill had been introduced to Parliament that would introduce a New Pension Scheme (NPS) that would be available to any individual not already obligated to participate in schemes under the EPFO Act. The NPS was originally aimed at the informal sector but recently the central government and 15 state governments have determined that new government employees should enter the defined contribution scheme. ***Thus, when the NPS goes into effect, it will theoretically provide a platform for pension provision that would extend to both civil servants and informal sector workers.***

6.31. By the end of 2005, an estimated 200,000 public sector workers were contributing ten per cent of their wages to their individual retirement account. This was being matched by the government as the employer. When the NPS infrastructure and regulations are finalized, these funds would be invested through professional asset managers through the capital markets. The accumulations over the course of the career would be partly annuitized at the point of retirement, replacing the current, non-contributory defined benefit pension scheme inherited from the colonial era.

6.32. ***Notably, the NPS has yet to define a disability or survivors benefit.*** This will be necessary at some point since these benefits were part of the old package for civil servants and new cases will be observed even during the first months of the scheme. In a defined contribution scheme, the risk of death or disability must be handled as an additional insurance policy and priced separately.

6.33. ***In principle, adding a group insurance policy for death and disability to a DC scheme of this kind is relatively simple.*** In Latin America for example, several countries insure the difference between the balance that is accumulated at the moment that the contingency occurs and the amount needed to purchase an annuity at a predetermined level on market terms. The premium charged for this year to year insurance policy is a function of the disability/mortality rate, the size of the contribution, contribution density[171], the investment return and the level of the prescribed benefit.

6.34. Tying the insured amount to the individual account balance reduces the required premium relative to a stand-alone product. Gruschka and Demarco calculate that under reasonable assumptions for the parameters mentioned above - including a ten per cent contribution rate to the DC account - a replacement rate of 50 per cent could be financed for around 1 per cent of covered wages. The premium may be even lower in the case of Indian civil servants due to low disability rates, a higher contribution density and higher contribution rates (double those in the example).

[171] Contribution density refers to the ratio of contribution years to total years in the labor force. In many countries, this is less than one due to evasion etc.

6.35. ***While the design of the insurance package is straightforward, a number of practical challenges exist in implementation***.[172] First, in India and in most developing countries, relevant mortality statistics are not readily available, at least initially. This could be remedied over time through data collection and actuarial studies. Second, the private insurance market is still at an early stage in development and does not have experience in offering annuity products. Moreover, any attempt to include an indexed annuity would be complicated by the dearth of assets that could be used to hedge such a product. Nevertheless, these obstacles are surmountable as has been demonstrated by actual experience in Latin America.[173]

6.36. Could such an approach be used to reach workers in the informal sector? In principle, the answer would seem to be 'yes', but again, the challenges lie in the implementation and especially the feasibility of controlling moral hazard and adverse selection. ***Encouraging informal sector workers to participate in a defined contribution pension scheme - a simple form of self insurance for old age - is straightforward and is already being implemented in India.*** One example is the unorganized sector provident scheme in West Bengal. In that particular case, the state government provides an incentive through a matching contribution of 20 rupees per month. After three years of operation, the scheme covers around 700,000 unorganized sector workers from a variety of occupations and the figure is rising.

6.37. ***While the DC scheme is the easiest to implement, most workers assign higher priority to short term benefits such as health, disability and life insurance.*** A survivors' benefit is also relatively simple to design and to implement as a group insurance policy subject to the caveats raised earlier with regard to mortality tables and annuitization. Health insurance is clearly the most complicated if the coverage provided is to involve the service providers in any way.

6.38. ***The potential difficulties with disability insurance for the unorganized sector relate to the characteristics of this group of workers.*** Unlike civil servants where job security is high and workers are mandated to participate, many informal sector workers may experience bouts of unemployment or underemployment on a regular basis. They will also have information about their own risk profiles that may lead to adverse selection as those with safer occupations (rationally) opt out. Moral hazard opportunities are less likely as long as the insurance coverage was reserved for permanent and catastrophic types of impairments. Finally, the certification process to determine eligibility would be much more difficult to administer for this diffuse group of individuals, many of whom would be illiterate. This could provide opportunities for fraudulent medical certification or, on the other hand, demands for payments from applicants by doctors. Monitoring such a system would be a major challenge.

6.39. ***One way to address these concerns, at least in the first phase of implementation, would be to focus work primarily with existing groups, including some of those already mentioned.*** Larger groups that could ensure high rates of participation would be accorded highest priority. Another criterion would be agreement to abide by a standardized, uniform certification process. In addition to or instead of a direct matching contribution to the DC scheme, the state government concerned could simply pay for the survivors and disability insurance directly for the group. Again, it would be very useful to prepare the ground for such an initiative by closely tracking the mortality and disability rates of the members.

6.40. ***Recently GoI has developed proposals for expansion of social security to the unorganized sector which represent an alternative possible approach to expansion of disability***

[172] For a discussion, see Palacios and Rofman (2001).

[173] In the early stages, a transparently priced disability and survivors' benefit could simply be self-insured by the government.

insurance. The NCEUS proposal is ambitious in that it seeks to offer insurance for several major risks to 300 million informal sector workers in a span of five years. This includes disability insurance. The ultimate objective of universal coverage is shared by many developing country governments. However, such an expansion of coverage, to be achieved through voluntary participation is unprecedented in terms of international experience and experiences in India. The administrative and recordkeeping challenges alone suggest that the proposed time frame is not feasible.

6.41. ***In this vein, GOI (and specifically, MOLE and MOH) is in the process of building on the NCEUS approach towards a new policy that could be rolled out in stages.*** The first step in the sequenced expansion policy can be seen in the 2007-08 budget announcement of the Aam Aaadmi Bima Yogana (AABY). This is intended to cover around 15 million rural landless households with death and disability insurance for the breadwinner, with the premium fully subsidized on a 50/50 sharing basis by centre and states.

6.42. In time, the combined population of public sector workers, informal sector groups and some individuals could provide the volumes required for economies of scale of operation (say, in the tens of millions of contributors) and importantly therefore, consistent with low marginal costs of recordkeeping and fund management. The planned NPS scheme envisions this scale of operation and the information technology platform needed at a national level to implement it.[174] Meanwhile, the commission to expand social security is tasked with producing a financially viable proposal to extend these kinds of benefits to unorganized sector workers. A convergence of the two initiatives would seem appropriate.

6.43. ***(d) Summary on disability insurance : Fewer than one in ten workers in India has any kind of disability insurance coverage and the financing of existing schemes tends to be either opaque or unsustainable or both.*** The micro-insurance and welfare fund initiatives reveal strong underlying demand, but their diffuse nature increases administrative costs and leads to wide disparities in quality and price of services.

C. Recommendations

6.44. Policies and programs should help improve awareness and targeting of safety net benefits to the poor and develop innovative approaches to extend coverage of disability insurance.

6.45. **Improving the safety net.** A first step in improving the poor performance of safety net programs for disabled people is familiarizing implementing officials and PRI representatives of the commitments under the PWD Act. Once such familiarization is done, the next step is for implementers to make efforts to raise awareness of schemes and PWD entitlements. In parallel, efforts need to be made in the public and non-governmental sectors to mobilize PWD themselves, so that there is more bottom-up demand on the delivery system. Formation and capacity building of PWD SHGs could be an important part of both strategies. Developing more focused efforts are also needed for specific programs, including: (i) for SGSY, targeted efforts to mobilize formation of SHGs of disabled people; (ii) for NREGS, adjustment of the national guidelines to include disabled people and efforts to identify both categories of works well suited to disabled people and processes for ensuring their adequate inclusion; and (iii) for social pensions, review of states with poor coverage, and relaxing the eligibility criteria for disability social pensions. It would also seem sensible to consider a base level of funding from the central government on disability social pensions, just as happens presently with the NOAPS scheme for destitute old age

[174] See CRA document.

people. The transfer under NOAPS was increased to Rs. 200 in the 2006-07 budget, and equity considerations suggest that disabled social pensioners should be treated on a similar footing. The experience of NOAPS with much higher beneficiary numbers suggests that this would be a highly affordable initiative in fiscal terms.

6.46. **Expanding disability insurance.** In order to address the demand that clearly exists for disability insurance, a low cost platform with standardized products and uniform regulations is likely to be the only approach that can be scaled up at the national level. Such a platform has recently been proposed under the New Pension System to deal with old age pensions for both the informal sector workers and civil servants. However, it will be necessary to have far more coordinated efforts across different arms and levels of government to link various social insurance initiatives to such a platform. Equally, the role of intermediary organizations such as MFIs, NGOs, and perhaps PRIs will be critical in improving program outreach and playing a role in contribution mobilization and claims processing if transactions costs are to be kept manageable.

CHAPTER 7: POLICIES AND INSTITUTIONS FOR PERSONS WITH DISABILITIES IN INDIA

7.1. The socio-economic profile of PWD and insights into community attitudes provided in previous chapters suggest that there remain major challenges at several levels in realizing the rights of PWD in India. This chapter explores the policy and institutional framework for promoting full participation of PWD in society.[175] Overall, ***India has one of the more developed national policy frameworks for disability of developing countries, though there remains scope for improvement, in particular at the sub-national level. However, as in many areas of social policy, challenges of institutional capacity and coordination have contributed to implementation that frequently leaves much to be desired.*** The intersection of policy and institutions is therefore critical to understanding the factors that drive current outcomes for PWD and might contribute to improving them.

7.2. While the primary focus on institutional discussion in the chapter is public institutions, it is clear that non-public actors are particularly important in the disability field relative to other areas of social policy. These include persons with disabilities themselves, NGOs, DPOs, community-based groups such as SHGs or CBR groups, the private sector, and households. While there is a clear need for improvement in the functioning of public institutions dealing with disability, there is equally – perhaps even more importantly – a need for deepening synergies between the public sector and non-public actors, in particular disabled people.

A. Policies for disability in India

7.3 India has a long experience of policy and practice with respect to disability, including collection of census information on disability from as early as 1872, and special schools and institutions operating since the 19th century. Like many countries, it also had specific provision for people with mental illness and retardation under the Indian Lunacy Act of 1912. The Constitution of India acknowledged also general state obligations to PWD in Article 41, and the State List under "Relief of the disabled and unemployable". Subsequently, specific measures such as employment concessions were introduced from the 1960s. [176] However, ***it was not until the 1980s that policy commitment to full participation of PWD in Indian society evolved.*** The outcomes of this policy shift were realized in several key pieces of legislation[177]: (i) the Mental Health Act, 1987; (ii) the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (PWD Act); (iii) the Rehabilitation Council of India Act, 1992 and amended in 2000 (RCI Act); and (iv) the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (National Trust Act). The cornerstone among these is the PWD Act, which is discussed in the following section.

[175] The chapter has benefited from background papers by Bhambani (2006) and Officer (2005). See also Baquer and Sharma (1997), Erb and Harriss-White (2002), Mani (1988), and Harriss-White (1996).
[176] See Harriss-White, op.cit.
[177] Policy was also strongly influenced by international developments, including the Asia and Pacific Decade of Disabled Persons (1993-2202) and the UNESCAP Biwako Millennium Framework for Action, which recommitted Asia-Pacific countries to "promote the goals of an inclusive, barrier-free and rights-based society for persons with disabilities" during the period 2003-2012.

7.4 ***(a) The Persons with Disabilities Act:*** The main provisions of the PWD Act are outlined in Box 7.1. It seems clear that the Act is informed by approaches beyond a pure medical model, in that many aspects of PWD lives are addressed, including societal attitudes. At the same time, the direct linkage in the Act between definitions of disability and entitlements necessitates a definition of disability which derives from threshold levels of physical and mental impairment which are defined in a largely medical sense. ***While the philosophy of the Act therefore represents a major step forward in disability policy in India, its underlying philosophy can be considered a hybrid between medical and social models of disability.***

7.5 Broadly, ***the entitlements and commitments towards PWD under the Act can be divided into two main groups:*** (i) entitlements which are absolute and thus in nature of legal rights. Some of these existed as rights prior to the Act but were reiterated or strengthened in the Act itself (and have in some cases been refined subsequently); and (ii) commitments that are given either in rather general terms or with the explicit proviso "within the limits of [governments'] economic capacity and development". These can be described as "contingent entitlements" under the Act and are not unqualified rights. The division is not entirely clearcut, as subsequent jurisprudence has in some cases strengthened general commitments.[178] In a number of cases, follow-up action is also anticipated by states or other relevant authorities.

7.6 ***Despite the PWD Act being a ground-breaking piece of legislation, there remain a number of policy shortcomings in its design that are worth highlighting***. These include both general issues which apply to several areas of the Act, and others which relate to specific sectoral heads. A number of them were raised by GoI's own Amendment Committee in 1999, but have not subsequently found their way onto GoI's agenda. [179]

7.7 ***(i) General Policy Issues in PWD Act:*** Some of the cross-cutting policy issues with respect to the PWD Act include:

- ***the Act covers only designated groups of PWD, which is by no means completely inclusive of categories of disability.*** This is in part driven by the linkage in the Act between the relevant legal definition of disability and the entitlements under the Act that flow from that. There is a natural reluctance on the part of policymakers to commit to entitlements for a wide group in the face of limited financial and other resources. Nonetheless, there is no reason in principle why the definitional and entitlement aspects of the Act need be completely synchronized. Providing for a more inclusive definition of disability while retaining more restrictive entitlements by disability type has been proposed by the Amendment Committee for the PWD Act. [180] The Committee proposed expansion of the Act's definition of disabilities to include multiple disability, autism, thalassemia, haemophilia, filiariasis, cerebral palsy and moderate/severe speech impairment. It also provided a more precise definition of mental illness, which in the current Act is vaguely defined as "any mental disorder other than mental retardation". These proposals seem eminently sensible. On the latter point, amendments to the Act proposed by the Ministry in 2006 also represent a step forward in trying to have a more workable definition of mental illness.[181]

[178] Human Rights Law Network (2005).
[179] See Amendment Committee report, 1999. The recent draft National Policy for PWD also acknowledges the desirability of a number of the amendments proposed by the Committee (see below).
[180] See Amendment Committee report, op.cit.
[181] The proposed revised definition is "...disorder of the mind that results in partial or complete disturbance in the person's thinking, feeling and behaviour which very often results in recurrent or persistent inability or reduced ability to carry out activities of daily living, self care, education, employment and participation in social life. See Ministry of Social Justice and Empowerment, GoI website.

- a second overarching policy issue with the Act relates to commitments which are subject to the "limits of economic capacity and development" of the relevant authorities. The formulation represents an attempt to balance policy commitments and fiscal and institutional realities.[182] While the approach is reasonable, ***the Act fails to outline any process for determining broadly what are the appropriate levels of policies and interventions which might be expected at different levels of economic development within India.*** This could not, of course, be a very precise process, but without some indication of what are reasonable expectations of states at different levels of economic development, it is difficult to know what constitutes reasonable compliance effort on the part of the authorities. As a result, what are justiciable rights in sections where this proviso is used remains quite uncertain. The uncertainty is significant, as this approach is used in important sections such as identification of PWD, prevention and treatment of disability, and access rights of PWD.

  In the absence of a process for benchmarking reasonable performance by states on the contingent entitlements of the Act, the courts have become the main point of reference for PWD to enforce performance by governments. In this respect, the courts have sought to promote the rights of PWD in a variety of areas.[183] The courts have tried to balance PWD entitlements with fiscal concerns. However, the resources and time needed to access the courts effectively are significant, and are likely to exclude many PWD.

- ***the above point raises the wider one that the Act's entitlements and commitments are supported by a weak enforcement mechanism.*** The institution mandated with monitoring compliance with the Act – the Office of the Commissioner – has weak powers. The Commissioners' office has authority to look into deprivation of PWD rights and on-implementation of various rules, laws etc. which have been developed to promote the welfare and rights of PWD. ***The fundamental limitation of the office is that its only legal sanction in case of a breach is to "take up the matter with the appropriate authorities".*** The Office does not itself have enforcement powers of a court or administrative tribunal. It can and does make orders, but can not enforce compliance. As such, its effective powers are either "naming and shaming" or encouraging referral to the court system. While these have been effective remedies in some cases, there are clear limitations. This issue is discussed in the institutions section.

- ***the overall approach of the Act has rather limited roles for actors outside the core administrative framework***, including NGOs/DPOs, civil society, PWD themselves and PRIs. There is no explicit role for PRIs mentioned, though the Act was passed after the 73rd Constitutional amendment. With respect to the NGO sector, it is mentioned at several points as either a point of consultation (e.g. on formulation of PWD rehabilitation policies) or as a potential implementer (e.g. on disability research and training of teachers). However, the overall policy and delivery model remains a rather traditional administratively-driven mechanism, with limited sense of genuine partnership in policy development and service delivery between the public and non-public sectors***. Perhaps most notable of all is that DPOs are not mentioned in the Act at all, nor any obligation for governments to consult directly with PWD when developing policies, designing interventions or monitoring performance.*** The assumption of the Act appears to be that disability NGOs will act as conduits for PWD views and action.

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[182] The approach is not uncommon internationally. A number of rights under the UN Convention on Economic, Social and Cultural Rights are framed in a similar contingent manner.

[183] The case law and comparative international jurisprudence is very well outlined in Human Rights Law Network, op.cit.

7.8 ***(ii) Sectoral policy issues in the Act:*** There are also several sector-specific policy issues worth noting. They include:

- ***Employment:*** With respect to ***public sector employment***, the Act provides for 3 percent of "identified posts" to be filled by PWD. The current list of posts (identified only in 2001) is restrictive, arbitrary and based purely on impairment, without consideration of personal or environmental factors. There are also no sanctions for non-compliance. This is discussed further in Chapter 6. ***The overall approach is one that is not considered good practice internationally, even in systems where a quota approach is used.*** A second feature of the quota policy is that it applies only to three disability types – locomotor, visual and hearing, with a 1 percent reservation for each. Thus even the full disability categories of the Act are not included in the reservation policy.

- ***Education: While the thrust of the Act to ensure that CWD are in school is clear, its guidance on the most appropriate type of education and who should take the decisions on that issue is less so.*** The Act provides that education of CWD should be in "an appropriate environment". However, it has a multiple track of promoting integration of CWD into regular schools, setting up of special schools, and home-based education. While the different approaches need not be contradictory, the Act provides limited guidance both on which approach should be considered preferable and on who is to take and enforce decisions on what is considered an appropriate educational environment for individual children. Subsequent policies have provided some more guidance on the issue, but whether it remains the right of parents where to school their children is unclear.

- ***Health:*** Apart from being subject to the economic capacity proviso, the provisions of the Act in the area of health are very limited. Perhaps the most notable point is that the obligations of the authorities are so generally phrased that they are difficult to interpret in terms of enforcement. Thus, the authorities should pursue "various methods for preventing disabilities", "take measures" for promoting pre-, peri- and post-natal care, and "create awareness" of disability issues. ***The combination of the economic capacity proviso and such general language makes it difficult to consider the provisions on prevention and early detection of disabilities as more than statements of intent.*** The fact that the subsequent jurisprudence on health issues relates almost entirely to issues of custodial treatment of mental health patients and their capacity in personal law seems to support this conclusion.

7.9 ***As of 2006, the Ministry has proposed a number of amendments to the PWD Act which are under consultation.*** The general areas for proposed revision are:

- ***revision of definitions of a number of disabilities, including mental illness, cerebral palsy, low vision, mental retardation and other impairments.*** For several of the conditions, a positive element of the proposals is that they take into account more explicitly the impacts of impairments on functions and activities of daily living. On the other hand, there is a question as to whether the Act itself is the most appropriate place for precise medical and other definitions of disabilities, or whether the implementing Rules may give more flexibility in adjusting definitions over time.
- ***revised provisions on the institutions responsible for various areas of implementation and oversight of the Act.*** Some of this is (appropriately) moving precise definition of institutional composition and other details into the implementing Rules. Others make the mandate of bodies such as the central Coordination Committee more general and overarching in nature.

Box 7.1: Key entitlements and commitments under the PWD Act, 1995

The PWD Act has both binding entitlements and more general commitments. The key provisions are:

Education: The following are binding on Government (i.e. not subject to economic factors):

- Governments shall ensure that every CWD has access to free education "in an appropriate environment" until the age of eighteen.
- Governments "shall initiate or cause to be initiated" research by public and non-governmental agencies for development of both assistive devices and special learning materials for CWD in order to promote equal opportunity in education.
- Governments shall ensure teacher training that produces "the requisite manpower" for teaching of CWD both in special schools and integrated settings.
- all public educational institutions and other receiving aid from Government shall reserved not less than 3 percent of seats for PWD (i.e. for PWD over 18 years).
- government should prepare a "comprehensive education scheme" for CWD which includes transport or financial incentives, barrier free access, supply of book, uniforms and learning materials to CWD, adjusts the examination system as necessary, adapts curriculum for CWD.

Employment: The Government shall:

- identify posts for PWD in public establishments and update the list every three years.
- reserve not less than 3 percent of identified posts for PWD, with 1 percentage point reserved for people with blindness/low vision, hearing impairment, locomotor disability or cerebral palsy respectively (though any department or establishment can be exempted by notification)..
- every employer should have a record of all PWD employed in that establishment.
- Governments and local authorities shall formulate schemes for promotion of employment of PWD which *may* provide for training of PWD, relaxation of age limits in employment, measures related to OHS, provisions for financing such schemes etc.
- Reservation of not less than 3 percent in all poverty alleviation schemes.
- "within the limits of their economic capacity and development", Governments *shall* provide incentives to both public and private sectors for employment of PWD with a target of at least 5 percent of their workforce to be PWD.

Prevention and early detection of disabilities: All commitments in this area are given with the proviso "within the limits of their economic capacity and development". With proviso, Governments should:

- Undertake surveys on causes of disability.
- Promote "various methods" for preventing disabilities.
- Screen children at least once a year for identifying at-risk cases.
- Provide facilities for training PHC staff.
- Conduct or sponsor awareness campaigns on hygiene, health and sanitation, and on causes and prevention of disabilities.
- "take measures" for pre-, peri- and post-natal care of mother and child.

Affirmative Action: Governments shall frame schemes for:

- Provision of aids and appliances to PWD
- Preferential allotment of land for housing, business, recreation centres, special schools, research centres, and factories run by PWD entrepreneurs.

Non-discrimination in access: All commitments in this area are given with the proviso "within the limits of their economic capacity and development". With proviso, Governments should:

- Adapt all forms of transport to make them accessible to PWD.
- Provide for a variety of assistive devices in the built environment, including auditory signals, ramps in public buildings and health facilities, Braille signage, accessible curbing, marked zebra and railway crossings, warning signals as appropriate etc.

- ***in the area of education, the proposed revisions aim to give a more specific obligation to states and local authorities to develop IE strategies and schemes.*** This increases consistency with initiatives under the lead of MHRD.
- ***other sectors such as employment attempt to spell out more precise obligations of employers and mandates of institutions.*** However, it is not clear how the proposed revisions will result in more effective functioning of actors such as Special Employment Exchanges.
- ***strengthened provisions on regular gathering of data on the socio-economic status of PWD.***

7.10 ***(iii) Implementation of the Act:*** Previous chapters discuss in detail outcomes to date in implementation of the PWD Act. A generic policy question however is the extent to which states or other relevant authorities have met their commitments under the PWD Act to frame state-specific entitlements or schemes. As could be expected, the relative performance of states in this regard exhibits major variations, with some states quite active in framing schemes and trying to strengthen institutions, while others have to a large extent ignored their obligations under the Act for follow-up measures***. GoI's most recent assessment of performance at central and state level indicates that overall implementation performance has been poor, and in a number of areas very poor, with an overall evaluation that the "act is being poorly implemented" eight years after its enactment.*** [184]

7.11 There are a range of institutional reasons which contribute to this outcome and are discussed below. ***However, there also appears to be more basic questions of relative political commitment between states.*** Better performance has not simply been a case of better-off versus poorer states, or high versus low capacity states. Some poor states (e.g. Chhattisgarh) have made serious efforts to elaborate their policy commitments. However, CAG in 2004 identified a number of states in most areas of the Act which had taken no action to fulfill their obligations as of end-2003. These include prevention and early detection of disabilities (where even large states such as Maharashtra, West Bengal, Jharkhand and HP had taken no action in the 8 years following the Act), several elements of education, employment (where several states had failed to identify any posts for PWD), affirmative action, and provision to promote access of PWD.

7.12 ***(iv) Awareness of the PWD Act:*** A key ingredient of effective implementation is awareness. A decade after this landmark legislation, what is the level of awareness of both the Act and specific entitlements under it ? Recent survey evidence from villages in TN and UP gives some insights. ***Overall, awareness of the PWD Act in the states studied remains very low, and lower among households with PWDs than those without them.*** This is shown in Table 7.1. Only around 4 and 7 percent of PWD HHs in UP and TN respectively were at all aware of the Act, and around 8 and 9 percent of non-PWD households. Among those who were at all aware of the Act, the share who were very familiar with the Act was also low, particularly among PWD households.

Table 7.1: Awareness of the PWD Act is very low and lower among PWD households than others

	UP PWD HH	UP non-PWD HH	TN PWD HH	TN non-PWD HH
Aware	4.1%	7.5%	6.8%	8.9%
o/w very familiar	6.3%	26.1%	7.4%	11.1%
Not Aware	95.9%	92.5%	93.2%	91.1%

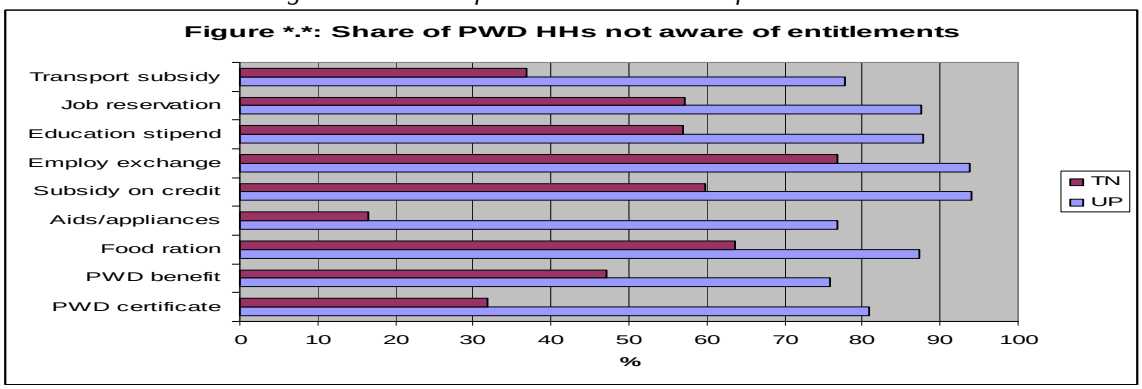
Source: UP and TN Village Survey (2005).

[184] CAG (2004).

7.13 The survey also asked about awareness of specific entitlements under the Act. ***While awareness of specific entitlements was significantly higher than of the Act itself, it remained low for most benefits, with well less than half of PWD households aware of entitlements.*** (Figure 7.1) A second important observation is that awareness was substantially higher in TN than UP, and for some entitlements such as disability certificates and subsidized credit. Perhaps the most striking finding is that over 80 percent of PWD households in UP were not aware of the process of certification as a PWD, which is the key threshold requirement for access to nearly all others. [185] However, the TN findings (and work in Gujarat) suggest that there is considerable variation across states on the issue, with the relative strength of civil society and NGOs important.

Awareness of entitlements under PWD Act is also low, though with strong state variation

Figure 7.1: Share of PWD HHs not aware of entitlements



Source: UP and TN Village Survey (2005).

7.14 The above findings are supported by evidence from states such as Orissa which have also found low awareness of the PWD Act entitlements among a range of civil society and public sector actors. [186] The findings point not only to a general need for raising awareness of the rights of PWD (and suggest that greater reliance on non-governmental channels of information dissemination may be worth considering), but also the need for more focused information outreach to the core target group of PWD households themselves.

(b) Recent developments in disability policy:

7.15 ***(i) National Policy on PWD:*** In 2005, the MoSJE developed a draft National Policy for Persons with Disabilities. This was approved by the national Cabinet in February 2006 and is available on the Ministry website. [187] Overall, the Policy follows the structure of the PWD Act. Several observations can be made:

- ***the policy represents progress in policy terms on some shortcomings of the PWD Act.*** These include: (i) greater recognition of the role of NGOs and CBOs in service delivery and policy for PWD, including the need for more consolidated information on NGO activities, increased efforts to address regional imbalances in disability NGO coverage, etc; (ii) a more elaborated approach to education of CWD (though the core issue of who decides where a CWD does to school remains unclear); (iii) a clearer acknowledgement of the role of media in

[185] More evidence is needed from other states. In contrast to UP, around 71 percent of persons with disabilities in Gujarat were found to have disability certificates in rural and urban areas (Handicap Internationall and Unnati, 2004).
[186] See Swabhiman (2004).
[187] http://socialjustice.nic.in/disabled/welcome.htm.

awareness raising about disability issues; and (iv) acknowledgement of significant issues in collection of statistics on PWD (though the draft offers no strategy for how disability statistics can be improved).

- ***the Policy often repeats general commitments of the PWD Act, though remains more general on concrete strategies for implementing them.*** This major shortcoming is not for want of insight into the shortcomings of current policy and practice. For example, the POlicy sets out succinctly the reasons why the current disability certification process has not functioned well. However, in terms of the forward-looking agenda, its merely urges state Governments to adopt "simple, transparent and client-friendly procedures". There is no strategy for how the situation might be improved. This is one example, but such lack of concrete strategies is found in many parts of the document. This is not true in all areas (e.g. health strategies are outlined in somewhat more detail). However, overall there is very limited sense in the Policy that even GoI's own assessments indicate serious implementation problems. Simply reiterating the general commitments of the PWD Act is unlikely to be sufficient to reinvigorate the disability sector.

- ***there remains limited reference to the role of PWD themselves in policy development, implementation and monitoring and evaluation.*** DPOs are not mentioned in the Policy, nor are PWD themselves. Rather, they remain agents who interact with the public policy and delivery systems either through public agencies or at best NGOs. While the Policy notes that "PWD are an important resource for the country, and seeks to create an environment that provides them with equal opportunities, protection of their rights and full participation in society", this critical insight is not reflected in the main Policy.

- ***there remains no strategy for integrating disability concerns into the work of PRIs.*** While the importance of PRIs is acknowledged, this remains an under-developed element of the Policy given the increased importance of PRIs in many areas of service delivery.

7.16 ***(ii) Education policy:*** An important point to note at the national level is that policy has progressed significantly in some areas since the PWD Act. In particular, in the area of education, ***policy towards inclusion of CWD into mainstream education has become increasingly clear in recent years***, and the policy statement of the MHRD in 2005 represents a more robust and concrete commitment to realizing the right to education of CWD. This is discussed in detail in Chapter 4.

7.17 ***(iii) State policies on disability:*** An additional aspect of disability policy that has remained relatively neglected is development of state-level disability policies. ***To date, the only states that have draft disability policies are Chhattisgarh and Karnataka, though Maharashtra has a state level Action Plan for implementing its commitments to PWD.*** The draft Karnataka policy for the most part mirrors the structure and major provisions of the PWD Act. For the most part, it is a state-specific endorsement of various initiatives for promotion of rights of PWD. In a number of cases, it repeats the PWD Act entitlements and commitments, and repeats general instructions to frame relevant schemes (e.g. reservation in poverty alleviation programmes; education). In others, the general commitments of the Act are put in a more state-specific context (e.g. health). In still others, there is more specific guidance on circumstances in which PWD should avail commitments under the Act (e.g. exemptions on property tax for PWD). For the most part, however, the draft state policy does not provide much more specific commitments or implementation guidance than the Act itself.

7.18 ***In contrast, the Chhattisgarh draft state policy – the Comprehensive Disability Policy Framework for Chhattisgarh – can be considered "best practice" within India, and could provide a model for future national and state-level policy development.*** The Policy provides

more thorough context and strategic direction for disability policy, allowing for greater prioritization in planning and implementation. The Chhattisgarh policy is outlined in Box 7.2, and in 2007 was approved by the state Cabinet, and will be submitted to the Assembly.

Box 7.2: Good Practice in State-level Disability Policy-The case of Chhattisgarh

Despite being a poor and new state, Chhattisgarh has developed an impressive draft state level policy on disability – the Comprehensive Disability Policy Framework. Overall, the draft Chhattisgarh Policy provides useful guidance for other states in policy development. Some important features are:

- it has explicit discussion of different models of disability and frames policy accordingly
- it acknowledges India's international obligations in the area of disability policy
- it has clear statements of both overall and sectoral policy objectives, indicating the overall policy stance on all major issues
- at the next level, it provides guiding principles in aiming reach policy objectives
- it acknowledges that "self-representation" of PWD in disability policy and practice is critical
- it identifies special cross-cutting areas in need of special attention, including mental illness, gender issues, and prevention and early detection of disabilities
- it establishes a State Disability Council as an institutional means both of raising the profile of disability issues and improving coordination
- it sets specific coverage/performance targets by sector, thus moving towards monitorable indicators of progress
- it is explicit on strategies to mobilize public financing for the sector.

7.19 **(iv) UN Convention:** ***As of March 2007, India is a signatory of the UN Convention on the Rights of Persons with Disabilities.*** The Convention is a milestone in the priority accorded by UN members to disability, and GoI is undertaking consultations during 2007 to familiarize stakeholders on its implications for India. While further consultation is needed, some areas where the Convention is likely to have implications for disability policy in India include: (i) a wider definition of "accessibility", going beyond the physical environment which is the focus of current access policies (e.g. access to information); (ii) greater focus on what "economic capacity of states" means in practical terms; and (iii) expansion of the definition of disabilities to include some areas like developmental disorders which are not covered under the current Act.

7.20 **(v) Conclusion:** ***Despite its many positive features, there is scope for improvement in the policy framework for disability in India, particularly at state level where policy development has been largely piecemeal. The more fundamental issue is the extent to which the entitlements under the Act have been realized in the decade since its passage.*** The issue that the rest of this chapter addresses is institutional mechanisms which the Act had put in place to enforce entitlements and increase accountability of providers, and how effective have they been in practice.

B. Institutional Issues in Implementing Disability Policies

7.21 ***Given the diverse range of issues that PWD deal with, it is not surprising that there are major challenges of institutional coordination in disability policy.*** These are between levels of the public sector (e.g. centre/state/districts and lower), within levels of the public sector (e.g. between social welfare, health, transport, education, and labor departments), and between the public and non-public sectors at all levels of the system. While this section focuses primarily on

more formal institutions in disability policy and service delivery (both public and non-public), it is also important to stress the importance of informal institutions – the most important by far being families with disabled members. ***Given market and government failures, the family remains by far the most important institution in the lives of PWD in India.*** [188]

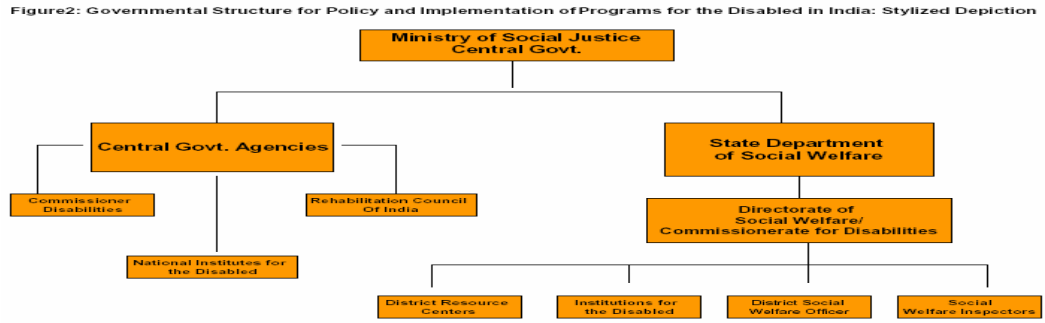
7.22 ***(a) The formal institutional framework for disability: There is a complex institutional framework for operation of the disability sector in India (***see Figure 7.2). The nodal agency for disability is the Ministry of Social Justice and Empowerment (MSJE), whose overall mandate is to promote the interests of "disadvantaged and marginalised sections of society". This includes Scheduled Castes, Backward Classes, minorities, PWD, aged persons, street children, victims of drug abuse, and others. There are inherent challenges for any nodal ministry in such a multi-sectoral field as disability. To that extent, there is no "natural" nodal Ministry for disability issues as there may be in sectors such as education or telecommunications. That said, there are areas where having MSJE as lead agency seems questionable and out of line with better international practice. The primary example is special education. Presently, this is under the mandate of MJSE, as are in-service training initiatives for teaching of children with special needs through RCI (which is administratively under MJSE). The consequence of this is that the vast majority of CWD have their education under the mandate of MHRD while those in special schools are under another Ministry. There does not appear to be a good rationale for this other than institutional inheritance. Equally, better practice internationally is to have education of all children under educational authorities (see Chapter 4 for further discussion).

7.23 ***In the period 1998-2003, just under Rs. 1042 crore was spent by MSJE on the" welfare of PWD", with the largest expenditure category the national institutions and corporations for disability, support to NGOs in service delivery to PWD, and spending on aids and appliances.*** This represents a negligible portion of total budgetary spending. While precise comparisons are difficult, for 2000-2001 budget year, MJSE's spending on disability would account for around 0.07 percent of total GoI expenditure, and for 2002-03, it accounted for around 0.05 percent of total. In the most recent budget year (2005-06), the share had fallen even further to only 0.047 percent of total allocation. Interestingly, the nominal allocation for 2005-06 was lower than for either 2000-01 or 2001-02. ***Such spending figures indicate the low priority placed by GoI on its core programs for PWD.*** While spending under other ministries may have risen in some cases (e.g. education, where spending on IE under SSA has increased significantly in recent years), unfortunately, MJSE do not have consolidated figures on a cross-ministerial basis for spending on PWD by other ministries, so that it is not possible to have an aggregate picture.[189]

7.24 Apart from specific sub-sectors where the nodal function of MSJE appears to be of questionable value, there is a broader challenge of "convening power" for a Ministry which is overall a low spending agency relative to several ministries which it must coordinate (in particular, education, health, transport and public works). Again, there is no ideal solution to such an issue, but ***what it points towards is the unusual importance in disability of inter-sectoral institutional coordinating mechanisms.***

[188] See Harriss-White (1996) for an insightful discussion of informal institutions in the field of disability, including the market.
[189] CAG, op.cit.

Figure 7.2: Governmental Structure for Policy and Implementation of Programs for the Disabled in India



7.25 ***To address the concern of inter-sectoral coordination, the PWD Act mandates central and state-level Coordination and Executive Committees*** (the latter intended as the executing arm of the former). Together, these Committees are intended as "focal points on disability matters" and to be key institutions in development of comprehensive disability policy development. They should meet every 6 and 3 months for the Coordination and Executive Committees respectively. ***Unfortunately, the track record of these coordinating institutions in states and at the centre is poor, with few exceptions.*** GoI reports indicate that meetings in most states happen very rarely, with a number of major states (e.g. Gujarat, Bihar, Kerala) having had only one meeting of their Coordination Committees since the passage of the Act, and others such as Rajasthan and Orissa reporting no meetings at all. Similar lack of action seems to apply to State Executive Committees. [190] CAG found that the shortfall in meetings of these core committees as of end-2003 was between 43 and 100 percent at state level and 50 percent at the national level. It is unclear if the situation has improved in the meantime.[191] ***It thus appears that the disability field is characterized by a nodal Ministry with relatively weak convening power, and coordinating institutions which are in many parts of the country barely functional.***

7.26 ***The above situation makes the role of the Commissioner for Persons with Disabilities (CPWD) even more crucial.*** The PWD Act mandates an Office of the Commissioner for Persons with Disabilities, with the Chief Commissioner at national level and State level Commissioners' offices in all states. It is tasked as the primary public institution with respect to regular oversight of the Act – the "watchdog" for the disability sector. These offices are mandated to coordinate the work of various agencies, to monitor fund utilization on disability programs, and "take steps to safeguard the rights and facilities made available to PWD". An important element of the last function is the grievance mechanism of the Commissioners' offices, which have a quasi-judicial complaints and hearing mechanism.

7.27 An area where the Chief CPWD Office has, given its staffing and other resource limitations, improved performance in recent years is grievance redressal. The number of settled cases through its quasi-judicial process has increased markedly in recent years, rising from 718 settled claims in 2003-04 to 1,333 in 2005-06. The proportion of pending cases in total registered has also fallen. Of total cases in recent years, around half were initiated suo moto by the CPWD office itself, though this proportion is falling, perhaps reflecting greater awareness of its grievance redressal functions. Of cases registered in 2004-05, over half were employment related (both hiring and issues of transfers, promotions etc), with the remainder spread thinly across benefit issues, harassment claims, education and other matters.[192]

[190] See Annual Report for 2003-04 of Chief Commissioner for Persons with Disabilities.
[191] CAG, op.cit.
[192] Annual report of Chief CPWD Office, 2004-05.

7.28 ***There is little detailed analysis of the performance of the Commissioner system outside its own reports. However***, ***the most recent GoI report suggests significant issues of low capacity to perform their mandate effectively***. CAG evidence for the period 1999-2003 indicates several concerns related to: (i) poor monitoring of use of funds; (ii) lack of clarity on grievance redressal mechanisms; and (iii) limited advocacy work in a number of states. The analysis points to significant issues with lack of staff and low capacity in Commissioners' offices. These concerns are supported by field work for this report in Rajasthan and Karnataka (two states considered to have better functioning offices), which found skeletal staff in both offices. In Rajasthan, the Commissioners' office consisted of one Additional Commissioner (there has been no Commissioner since end-2003) and his PA, with no support staff. The office had failed to register any grievance cases of PWD since 2002. The same study also noted that full time Commissioners exist to date only in a minority of states. [193] An additional generic concern is the lack of legal expertise in the Commissioners' offices, particularly at state level, despite the importance of their quasi-judicial role in enforcement of the Act.

7.29 Beneath the state level, the nodal function in disability tends to be an additional charge for District or Additional Collectors and BDOs. These act as initial points of grievance redressal for PWD. Apart from these additional charges, states vary significantly in whether or not dedicated staff exist at lower levels who are specifically dedicated to PWD issues. For example, in Karnataka, there are District Disability Welfare Officers, while these are not present in Rajasthan. Essentially, dedicated official functionaries cease at best at district level, below which additional charges are the mode of oversight and service delivery.

7.30 ***Karnataka has been one of the more active commissioners' offices, and has piloted a number of initiatives***, for which is has been recognized as the model state for implementation of the PWD Act. This is despite the office being subject to similar resource constraints as many others. The distinctive feature of the Commissioners' office in Karnataka is that is has carved out a role which is somewhat independent of the state Social Welfare Department. Some of the innovative features of the operation of the Karnataka office are presented in Box 7.3.

7.31 ***A further significant institution in the disability field is the National Trust For Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability***. Its objectives are to: (i) enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong; (ii) strengthen facilities to provide support to persons with disability to live within their own families; (iii) extend support to registered organizations to provide need based services during the period of crisis in the family of persons with disability; (iv) deal with problems of persons with disability who do not have family support; (v) promote measures for the care and protection of persons with disability in the event of death of their parent or guardian, including evolving procedures for appointment of guardians and trustees for persons with disability requiring such protection.

7.32 ***(b) The missing pieces – PRIs and disability: As noted in the policy section above, PRIs are largely absent in public sector disability policy and practice. This results in an institutional framework for disability which is increasingly out of line with the constitutionally-mandated developments in decentralization of service delivery and oversight.*** The relative lack of attention to PRIs continues in the National Policy. In addition, the field work in rural UP and TN for this report revealed that panchayat officials were generally just as ignorant as the rest of the community, not only on the entitlements of PWD, but also in terms of knowledge about causes of disability and attitudes to PWD. An important initial step of an institutional strategy for integrating PRIs into the disability institutional framework would thus be including disability sensitization in the general training courses which PRI officials will undertake in coming years.

[193] Bhambani (2006).

Efforts by the NGO sector to sensitize village officials have show positive results in rural Rajasthan (see para. 35). This would be particularly important at the gram panchayat level, given evidence of public sector institutional shortcomings in the disability field as one moves further down the system. While GPs will have many issues of weak capacity for some time to come, current evidence suggests that existing institutional arrangements for disability are largely ineffective at the village level, and that new approaches are needed.

Box 7.3: Innovations in Karnataka by the Disability Commissioner's Office

The Karnataka Commissioner for Disabilities has introduced several progressive practices. These include:

- ***District Disability Management Reviews (DDMRs):*** This involves regular reviews at state and district levels of all schemes which are targeted to PWD. The process is intended to identify gaps/shortcomings in policy, program coverage, and implementation. Quarterly reports are solicited from relevant departments in specialized format and the results publicized in the media. Collection of information is facilitated by a District Disability Welfare Officer. While reporting is timely, there remain concerns about the reliability of information from line agencies.
- ***Lok adalats for disability:*** The Commissioner's office has organized periodic *lok adalats* (peoples' courts) in districts for PWD to air their grievances with respect to entitlements. The *adalats* are chaired by a senior official of the Commissioners' office. All district officials – including Collectors and officials from social welfare, education, health PRI and other departments – are expected to be present. The process has in some cases led to immediate resolution of PWD issues, or in others accelerated judicial intervention.
- ***Partnerships with voluntary organizations:*** The Office has actively pursued partnerships with VOs to overcome its capacity constraints. For example, the Alternative Law Forum in Bangalore offers free legal aid to PWD through the Office. This not only includes issues with respect to PWD Act entitlements, but broader issues of access of justice for PWD.
- ***Active use of media:*** The Office has been one of the most active in raising awareness of disability issues, and in using media to reach its PWD constituency. This includes publicity about violations of PWD rights. Apart from print media, the Commissioners' office has regular phone-in programmes, which have involved people from throughout the state in direct phones to officials of the Office.

Source: Bhambani (2006).

7.33 ***(c) PWD access to public institutions: Very little empirical evidence exists of the interactions of PWD with the official institutional network.*** This issue is discussed in detail in sectoral chapters which follow. However, the UP and TN survey asked questions on PWD interaction with the public administration and delivery network, and the results provide insights on institutional constraints to access to services and entitlements. Several findings emerge:

- reflecting the limited downward reach of the disability institutional network, the institutions from which PWD most often reported receiving services and benefits were at district level, though panchayats were growing in significance. Results are shown in Table 7.2.
- ***a substantial share of PWD report difficulties in receiving disability benefits and services.*** Around 43 percent of respondents indicated that they had not received any benefits or services, with a further 20 percent reporting receiving only some of their benefits or services.

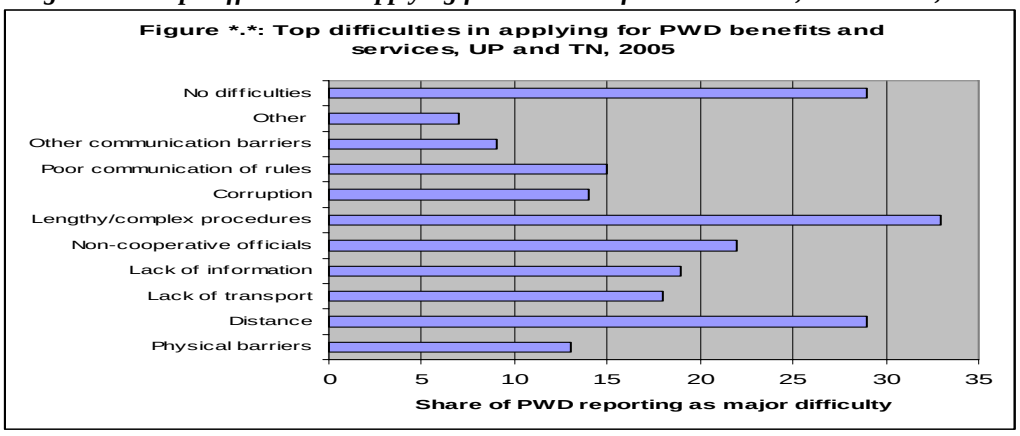
Table 7.2: Institutions providing benefits and services to PWD in rural UP and TN, 2005

Institution from which received benefits	***Share of those accessing services reporting*** *(multiple answers possible)*
Panchayat office	20.7%
PHC	6.7%
District or other hospital	45.7%
BDO	21.6%
District welfare office	38.5%
District disability official	19.7%
District Chief Medical officer	15.9%
State welfare or disability official	4.4%
Other	9.1%

Source: UP and TN village survey. Bank staff estimates.

- ***in terms of the major difficulties faced in applying for disability-specific benefits, a range of factors were at play.*** Close to 30 percent of PWD reported no difficulties in accessing services/benefits. Among the over 70 percent who did report difficulties, three broad groups of difficulties emerge: (i) physical access problems, due to distance, lack of transport or physical barriers; (ii) problems with procedures and/or officials administering the system; and (iii) communication difficulties. The results are shown in Figure 7.3.

Figure 7.3: Top Difficulties in Applying for PWD benefits and services, UP and TN, 2005



Source: UP and TN village survey. Bank staff estimates. UP to three difficulties could be reported.

7.34 While the above results are from two states only, they are consistent with field findings in Rajasthan and Karnataka, and with a variety of studies on PWD access to services.[194] Together with the generally low awareness of entitlements, they suggest that ***public institutions need to develop far more effective outreach strategies if PWD are effectively to access their entitlements.*** An obvious area for policymakers to consider is how the PRI system can be mobilized in such outreach, given that only one fifth of current PWD beneficiaries are using that channel to access services. A second issue is how the public sector can more effectively partner with the non-governmental sector and civil society to achieve greater grassroots penetration of awareness and access to services. The following section looks at the role of the NGO sector in the disability field.

7.35 ***(d) The NGO sector and disability: In light of the major challenges in the effectiveness of public sector institutions for PWD, non-governmental institutions assume***

[194] See, e.g., ActionAid (200*) re Rajasthan and (200*) re AP; Swabhiman (2004) re Orissa; and Handicap International and Unnati, op.cit. for Gujarat.

unusual significance. The role of NGOs is also important to consider in light of the relative obligations of the state and civil society, with a number of practitioners in India seeing an over-reliance on NGOs in the disability sector. [195] A positive feature of the 2006 National Policy is that it gives very clear recognition of the role of NGOs in service delivery, and encourages their greater future involvement in policy development and other areas.

7.36 NGOs working in the field of disability are indispensable to supplement and support the efforts of the state in cases where the market fails to be a reliable or accessible source of services. As one would expect, disability NGOs divide along several lines: [196]

- ***place of operation***. There is a strong urban bias in disability NGO presence and activities. There is also a strong state-wise concentration of disability NGOs, with a generally stronger presence in southern states. In addition, states where NGOs are very active are not necessarily ones with a concentration of disability NGOs (e.g. Rajasthan).
- ***area of focus***. While there has traditionally been a strong focus on education and rehabilitation activities, a wider range of issues are being taken up by disability NGOs (e.g. access to justice; participation in voting). This reflects to some extent a difference between disability NGOs with a service delivery focus and those with an advocacy focus.
- ***philosophical tradition***: As in the NGO movement more broadly, disability NGOs reflect a variety of traditions, including Gandhian, Christian, Secular, Hindu, and Muslim. [197] In some sectors, some traditions have had strong presence (e.g. Christians in special education).
- ***the large majority of disability NGOs have been on a disability-specific basis, with cross-disability NGOs and networks only emerging in the last decade***. To date, there has been a higher share of NGOs providing services for the blind and hearing impaired than for persons with locomotor disabilities and mental retardation. NGOs dealing specifically with mental illness continue to be very limited. One result of the disability-specific focus of NGOs has been that until recently the sector often did not speak with one voice. [198] However, Tamil Nadu shows that this fragmented tradition is being overcome in some states.

7.37 A recent sample survey of the non-profit sector in India puts the total number of NGOs at 1.2 million. They employ nearly 19.4 million persons, many of whom work on a voluntary basis. [199] ***There are no comprehensive statistics on the numbers of NGOs that work in the disability sector, but the numbers of rganizations known to be working in disability has increased***. Data from the mid-1990s suggest that there were more than 2000 NGOs working in the area of disability. [200] More recently, the Delhi DRC reports 5,231 such NGOs. It is not possible to identify the number of rganizations working with different types of disabilities.

7.38 According to MSJE, in 2003-2004, grant-in-aid funds of just over Rs. 71 crore were provided to 657 voluntary organizations and benefited 217,000 PWD. [201] During 2004-05, the amount was reduced to Rs.67 crores for 700 voluntary organizations. The majority of funds were allocated to residential and non-residential schools for different categories of disabilities. ***There were distinct differences in government allocations to NGOs between states, which are not***

[195] See, e.g. Rao (2004).
[196] Erb (2002), NCPEDP (1998) and Officer (2005). The term "disability NGO" in the following refers both to NGOs dealing only with disability and general NGOs which include a disability focus in their work.
[197] Harris-White, op.cit., notes that Hindu religious organizations – with few but notable exceptions such as Rama Krishnan Mission and Seva-in Action – have failed to mobilize disability NGO activity, in contrast to groups such as Jains and Parsees.
[198] Lang (2000).
[199] Srivastava and Tandon (2005), which is a useful empirical source on the NGO movement in India.
[200] NCPEDP (1998).
[201] MSJE (2005).

systematically related to the number of PWD in the state or their share in the national total PWD population. [202] There is a need to look at how funds can be allocated across states to ensure greater equity in NGO and PWD coverage. In addition, NGOS addressing disability issues appear less reliant on government funding when compared to the entire non-profit sector in India, with an estimated one quarter of disability NGO funding from Government and around 32.4 percent of general NGO revenues from Government funding.

Box 7.4: Disability For a in Tamil Nadu

There is evidence of good collaboration amongst NGOS and between NGOS and the state in Tamil Nadu:

Vellore District Disability Network: 12 disability related rganizations meet quarterly to share resources for the rehabilitation of persons with disabilities. The District Disability Rehabilitation Officer is present and occasionally the Disability Commissioner

Disability Forum: A disability forum of 23 NGOs (disability specific and development) is facilitated by the Organisation for Development Action (ODA). This forum shares information, knowledge and refers between NGOs. There is reluctance by some rganizations in this forum to lobby for change as they receive government support and were concerned about what impact their involvement may have on access to state resources. Hence issues identified in this forum are used for lobbying the government directly by ODA and other interested parties.

In August 2005, a **State Resource Training Centre for PWD** was set up in Chennai under the National Programme for Rehabilitation of Persons with Disabilities (NPRPD). Different NGOs with disability specific expertise are providing their voluntary services for training of persons with disabilities. The centre will showcase good NGOS practices.

A weekly radio programme call **Thiramaiyin Thisayil** (In the Direction of Your Abilities) is broadcast by Ability Foundation in association with all-India radio. It focuses on issues and policies which affect the rights of PWD. Other NGOs also use the show as a vehicle for spreading information on vocational training programmes, and to publicize events such as job fairs. Letters and responses from remote rural towns of TN indicate significant penetration.

Source: Officer (2005).

7.39 Disability NGOs operate with many different methods and goals and hence with diverse actors. Examples of interactions among NGOs and between NGOs and the public sector in Tamil Nadu are presented in Box 7.4. It is not possible to characterize these patterns of interaction in a comprehensive manner, but general patterns can be seen, including:

- ***links between the Government and the non-government sectors***. Many NGOs have links with public agencies, predominantly for direct contracting out of services, technical assistance and training. A common source of interaction is with RCI, with NGOs operating special educators' courses for teachers, though numerous other examples exist in the fields of vocational training and rehabilitation. While results have in many cases been positive, there remain concerns about weak monitoring of NGO performance and hence accountability for use of public funds.[203] However, very few NGOs have had direct influence on disability policy development. There are certain key forums to which select NGOS are invited, e.g. five NGOs working with different disability groups are also involved in each of the central

[202] See Officer, op.cit.

[203] CAG reports that MJSE blacklisted a number of NGOs which had proved to be fake/non-existent, predominantly in UP. While this is a positive step, it also reflects poorly on the vetting procedure of state departments which had proposed the NGOs for funding. See CAG, op.cit.

and state co-ordination and executive committees. However, ***for the most part consultation between the public and NGO sector on disability policy issues remains under-developed, both at the centre and in most states.*** In addition, NGOs in some cases are acting as watchdogs of the public sector delivery mechanism, as examples such as VSS in Rajasthan and their oversight of the disability certification process attest. The monitoring and evaluation role for NGOs seems one that could more explicitly be developed within public interventions, provided that conflicts of interest in service delivery and monitoring can be minimized.

- ***interactions between disability NGOs and DPOs*** are for the most part absent in the states reviewed for this report. This remains an area in need of development for the NGO sector as it is for the public sector, with many NGOs still speaking *for* PWD. DPOS or PWD-led NGOS should be key collaborators in the design, monitoring and evaluating of training and employment projects and strategies. This is not necessarily simple, as DPOs will frequently require capacity building to engage both with NGOs and with public sector actors. In this respect, CBR is in some states a promising vehicle to act as a bridge between DPOs and other actors in the disability field. Equally, states such as AP and Karnataka have good experience with creation and empowerment of PWD SHGs in their broader rural development initiatives.

- there are indications of growing ***collaboration between disability NGOs and development organizations*** to identify and support in economic rehabilitation PWD in remote rural areas. While many of these initiatives are highly localized, larger projects such as DFID's Poorest Areas Civil Society Programme, and World Bank supported efforts in AP (and more recently TN) suggest that there is potential for such collaborations to achieve significant scale.

- ***collaboration among NGOs*** has been under-developed until recently. This is now improving somewhat, with national networks growing both on areas of common interest where capacity is limited (e.g. the Disability Law Network), and more broadly. This process still has a long way to go, as even within NGOs working on specific disabilities, coordination is often weak. With respect to disability-specific coordination, the experience of NGOs for the visually impaired offers an example of national coordination with positive results on policy. The other direction which shows promise in states such as Tamil Nadu and Orissa is state-specific disability networks which can mobilize the combined strengths of disability NGOs. The need for such coordination is imperative not only to realizing the full potential of the NGO movement, but also to minimizing uncoordinated initiatives which can undermine the coherence of the disability movement (e.g. researchers attribute the existence of four forms of sign language and around 12 different forms of Braille in India to earlier uncoordinated activities of NGOs in different parts of India).[204]

- ***interactions with communities and PRIs:*** While rural penetration is in need of improvement in the NGO sector as it is in the public sector, the history of direct engagement with communities by disability NGOs – particularly through the CBR movement – suggests that they may also be a useful vehicle for engaging with GPs to raise awareness of disability issues. The example of Mamta Punarvas Kendra NGO in Shri Ganganagar district of Rajasthan provides an excellent case in point. The NGO has worked in one block to sensitize sarpanchs, GP members, patwaris and gram sevaks on disability issues, with field work for this report indicating that these efforts are already showing positive impact in implementation of poverty alleviation schemes. In addition, the NGO head has now become a panchayat samiti member.[205]

[204] See Harriss-White (1996).
[205] Bhambani (2006).

- ***collaboration between NGOs and the private sector*** is growing, including in areas such supply of products to companies, training support and placement services. Experience in collaborations on training and employment is discussed in Chapter 5.

7.40 ***Overall, the disability NGO movement has contributed greatly to promoting the interests of PWD and awareness of their rights and situation. However, it remains in many ways an under-exploited resource in terms of fully mature partnerships between the public and NGO sectors.*** There are acknowledged shortcomings in the capacity of the disability NGO sector to grow into an expanded role, both in its own right and as a partner of government. These include lack of coordination within the NGO movement; need to include PWD themselves within NGOs and to partner more with DPOs; need to develop better internal systems for resource management and program M&E; need to broaden the skills base of NGOs from the traditional core of special educators and rehabilitation professionals to new skills such as legal advice, ITC-related training capacity, etc; need to increase penetration in rural areas, which will in turn demand new modes of service delivery for organizations often reliant on urban professionals as their personnel base. Despite these challenges, the disability NGO movement remains a critical actor in promoting full participation of PWD.

7.41 ***(e) Informal institutions and PWD: Previous research has confirmed that informal institutions – primarily the family – remain the most important factor in the lives of PWD.*** [206] This section discusses briefly the role of informal institutions, focusing on the family and SHGs of PWD.

7.42 The failures of government, market and collective action in relation to disability reinforce the critical role of families in the lives of PWD. Other chapters provide evidence on the critical role of families – particularly the women in families – in providing support to PWD who require caring and other forms of support. For example, among the more than half of PWD in rural UP and TN who required at least some caring on a daily basis, this was provided by people outside the immediate household in less than 1 percent of cases. Such roles become increasingly important with ageing. The family also plays a major role in assisting the PWD to find employment, as results from the survey also indicate.

7.43 ***The family is not however an unambiguous source of support by any means for PWD.*** This can play out in several ways:

- the family may be over-protective of PWD members. This can be seen to some extent in the attitudes of parents of CWD to inclusive education reported in Chapter 4. It can also be seen in attitudes of parents in UP and TN towards employment of their PWD family member
- the family may – consciously or not – favour non-disabled household members over PWD (e.g. health evidence of this in child nutrition outcomes within households)
- the family may be a direct source of harm to the PWD member (as evidence from Orissa on physical and sexual abuse of PWD women reported in Chapter 2 suggests).

7.44 In some respects, the legal framework and customary law plays a role in the relative position of PWD within families. This has many dimensions. For example, both Hindu and Muslim traditions allow for dissolution of marriage in cases of mental instability of one partner. This is reflected in the 1955 Hindu marriage Act. There are also more specific examples like the prohibition on people with epilepsy and mental illness adopting children. In contrast, succession to property is not constrained under law by disability of any form.

[206] See Erb and Harriss-White (2002); Desai (1990); Coleridge (1993).

7.45 ***Previous research and that for this report indicates quite clearly that there is a major awareness raising agenda on disability among family members of PWD.*** This can range from increasing knowledge on the causes and treatment of disability, entitlements under public schemes and availability of NGO and private services for PWD, exposure to success stories of PWD to raise awareness of the potential of PWD with the right opportunities, and other issues. While awareness campaigns often focus on the community, it seems even more critical as a first step to target families of PWD and PWD themselves (for whom self-esteem and other issues contribute to self-limitations in many cases).

7.46 ***The growth of the self-help movement also holds out significant potential for PWD.*** [207] While experience with disability-specific SHGs is relatively limited in much of the country, certain states indicate the potential of PWD to mobilize and the potential for such mobilization to produce results. Karnataka is a case in point. Organizations such as Action for Disability and Development (ADD) India and Samuha have had sustained experience in promoting and building the capacity of PWD SHGs. In the case of Samuha, the SHGs are structured on a three tier level, with federations at taluk/district levels and a statewide network. Field work for this report reveals that these groups have improved accountability of district authorities in service delivery, as well as raising awareness among PWD of their rights, and issues related to detection, prevention of disabilities, and livelihoods. [208] The experience of ADD in promoting formation of and strengthening PWD SHGs, and the achievements of those groups, is presented in Box 7.5. The Karnataka SHG experience is also linked to the relatively widespread penetration of Community-Based Rehabilitation (CBR) in the state (CBR is discussed in Chapter 3).

Box 7.5: ADD India and the sangham approach to PWD SHGs

ADD India has had a sustained program of support to SHGs of PWD in Karnataka and Tamil Nadu. As of 2004, it was estimated to have included around 20,000 people in its SHGs, a sharp increase from around 5,000 people in the mid-1990s. It has promoted SHG of PWD on a cross-disability basis, using a model of SHG with 7-20 members which meets twice monthly. Office bearing is rotated among the membership on the basis of elections. The SHGs (known as *sanghams* or associations) discuss the whole range of PWD issues in their village, and also take matters up with the local authorities. Many of them have a mutual savings system from which members can borrow either in emergencies or for income generation purposes. The sangham membes also participate in village development activities such as immunization drives. The PWD sanghams also link with womens', youth and other groups to lobby on matters of mutual interest. The sanghams have also mobilized greater political participation among PWD. For example, in AP in the late 1990s, 31 PWD were elected to local panchayats (of a total of 78 standing), and members ensure regular representation in gram sabhas. In order to spread their expertise in facilitation and support to PWD SHGs, ADD have a training programme for NGO staff who wish to support similar efforts. The partnership with other NGOs is a key element of ADD's model of promoting PWD SHGs.

Source: UNESCAP (1997); ADD (UK) annual report, 2003-04.

7.47 The challenge in SHGs is often to go to scale in terms of wide coverage. This may be an even bigger challenge for PWD SHGs, where capacity building needs may be greater in some cases. However, the experience of the AP Velugu programme (now IKP) indicates that wide coverage of PWD SHGs can be achieved within the context of major programs. As of late 2005, AP had over 130,000 people with disabilities formed into almost 15,000 SHGs which are in some areas federated at mandal and district levels. A similar initiative is also in progress in TN under a World Bank-financed community development project. While strengthening their capacity and

[207] UNESCAP (1997) provides a useful overview of experience in the Asia-pacific region with SHGs of PWD.
[208] Bhambani, op.cit.

moving to improved outcomes for PWD remains a challenge, the AP experience deserves close attention to assess the scope for a widescale PWD SHG movement.

C. Conclusions and recommendations

7.48 ***There are both policy and institutional reform needs in the disability sector. At this point, a focus on outcomes for people with disabilities would suggest that the priority should be on institutional reform and strengthening***, reviewing the institutional framework in the disability sector and strengthening the capacity of institutions to deliver on policy commitments. Nonetheless, several broad policy reforms remain important. They include:

7.49 **Policy Reforms.** Disability policy reforms are needed in several areas: First, there should be serious consideration given to broadening the categories of disabled people included in the PWD Act, which may in any event be necessary in light of the new UN Convention to which India is a signatory. This may also require a de-linking of definitional inclusion of different groups with specific entitlements under the Act. While fiscal and other capacity issues suggest that not all disabled people may be supported through public interventions, this does not seem a good reason to exclude them from inclusion as PWD under the Act. Legislation and policy should ensure that clear obligations for involvement of persons with disabilities themselves at all stages of policy development, implementation and monitoring. Second, MSJE and central and state Commissioners' offices should develop programs in collaboration with DPOs and NGOs for awareness raising of officials, service providers, PRI representatives and communities on programs for people with disabilities. A periodic monitoring of awareness, with particular focus on lagging states and remote regions, should be put in place to assess impact. States should be strongly encouraged to develop their own disability policies which elaborate a credible strategy for meeting their commitments under the PWD and other acts. The example of Chhattisgarh offers a useful example of such a policy. Finally, there should be a process for basic benchmarking of feasible policies and programs for people with disabilities in the areas which are currently subject to the economic capacity proviso.

7.50 **Institutional reforms** would seem desirable in several directions: First, the institutional framework at all levels needs to have a substantially strengthened direct role for persons with disabilities themselves. Second, responsibility for specific programs for PWD should be brought clearly under relevant line Ministries in some cases, e.g. bringing all education policies under MHRD as noted above. Third, GoI may like to consider overhauling the current coordinating mechanism into a National Commission for PWD, which would have the status and convening power which is currently under-developed in the sector. It is important that such a body be a coordination and oversight agency, and not be viewed as a separate "silo" for disability. Such an initiative would only make sense if the structural problems of coordination within and between levels of government, and between the public and non-governmental sectors are addressed. It would also require a transition strategy if the current Commissioners' Offices are to be merged into a future Commission, so that there is not simply duplication of responsibilities. In this light, any move towards a Commission should not forestall the urgent need to strengthen the capacity of Commissioners' Offices to perform their current functions, in particular on grievance redressal. Fourth, the enforcement mechanisms for the Act need to be clarified and strengthened. One option would be a Disability Tribunal with direct enforcement powers. This has pros and cons, as there is a risk of "over-judicializing" the grievance mechanisms for PWD and thus reducing their access. An alternative is obviously strengthening of both central and state Commissioners' offices to play their grievance redressal function more effectively. A review of human resource and financial capacity of central and state Commissioners' offices is also needed, and guidelines on minimum staffing levels introduced. The national policy and legislation needs to reflect the

growing role of PRIs and use it as an opportunity to extend institutional reach to the village level, and more importantly to increase the local channels for accountability of public and other disability service providers. NGOs should also be brought more actively into both policy and implementation, but with strengthened financial accountability and monitoring of program outcomes. Finally, there needs to be more direct engagement between both public and NGO sectors with PWD themselves and their families, with SHGs being a logical vehicle.

CHAPTER 8: ACCESS FOR PEOPLE WITH DISABILITIES [209]

8.1. Many of the rights provided for people with disabilities in India can not be realized without ensuring that the services to which they are entitled are accessible, and that barriers to access in their broader environment are reduced. Accessibility for people with disabilities can mean many things, ranging from physical access to services and the built environment, to access to appropriate services such as adapted curriculum and rehabilitation services, to access to civil and political participation, including voting and the justice system. The focus of this chapter is largely the more narrow one of physical accessibility for people with disabilities and standards and outcomes in India. The issues are touched on already in some of the sector chapters, in particular education. Overall, while India has standards on promoting access to the built environment and basic services, it faces major challenges in implementation due to a combination of institutional coordination challenges, poor enforcement mechanisms, and lack of awareness of the needs of people with disabilities.

8.2. ***(a) Public policy and access: The provisions on access for people with disabilities in the PWD Act are framed as contingent entitlements***, i.e. obligations on the authorities are subject to the proviso "within the limits of their economic capacity and development". As such, the authorities are encouraged to take various interventions to promote access, but the nature of the legal obligations is somewhat vague. [210] Indeed, there are no specific enforcement provisions or sanctions for failure of authorities to be proactive in undertaking their obligations under the Act. Nor is a mechanism spelt out for how authorities should move to implement the Act's provision, e.g. amendment of bye-laws etc. As a result, people with disabilities have relied on a combination of general non-discrimination provisions of the Act and the specific provisions on access. The main provisions specifically related to access are:

- "special measures" (not specified) to adapt rail, bus, aircraft and vessels for easy access by PWD, and adaptation of toilets, waiting rooms etc.
- adaptation of traffic signals, pavements etc to permit use of built environment for PWD, including adaptation of traffic signals, adjustment in curbs, etc.
- provision of ramps, braille and auditory signage etc to permit use of public buildings and health and rehabilitation institutions.
- provision for research on modifications in offices and factories to promote access.

8.3. Several observations can be made on the Act's provisions for promoting accessibility. ***First, the general approach is one of accessible design or adaptation of public facilities and to some extent the built environment, rather than universal design.*** Accessible design refers to buildings that are accessible by PWD, while universal design is buildings or products that are accessible by all, including PWD. The former tends to result in access channels for PWD which are separate, while the latter provides for design solutions that accommodate all people in the same manner. For example, an accessible building might have a separate ramp entrance, while a universal design building would not have steps at all. The draft national Policy for Persons with Disabilities recognizes the distinction, and commits rather ambitiously that "all future infrastructure development will ensure universal access."

[209] This chapter has benefited from a background paper by Singh (2005).
[210] See Human Rights Law Network (2005), which describes the Act's policy framework for access as "a half-baked policy rather than a definitive law".

8.4. ***Second, the legislation fails to distinguish between the existing stock of public buildings, services and public infrastructure, and future construction and development.*** While retrofit adaptations may in some – though not all – cases be costly, the same is rarely true of either universal or accessible design which is allowed for at the design stage. For example, it has been estimated that making buildings accessible adds less than 1 percent to total construction costs in several OECD countries.[211] While similar exercises have not been carried out systematically for India, information for example from Delhi Metro indicates that accessibility features added during design added a similarly small fraction to total construction costs.[212] It would thus seem useful to make such a distinction in policy, more so as monitoring and enforcement with respect to new construction, public transport etc. places more reasonable demands on administration, and clearer obligations on service provision organizations. Such a suggestion was made in proposed amendments of Amendment Committee for the PWD Act in 1999, but has not been taken up.[213]

8.5. ***Third, the provisions of the Act, and to some extent their subsequent interpretation and implementation, show a relative focus on access for people with disabilities in urban areas.*** This is to some extent understandable, but as a result lessens the focus on the types of access priorities of rural people with disabilities. These in many cases may be more fundamentally focused on access from the home to buildings or facilities than on access to facilities themselves. The latter clearly remains important, but does not become relevant if the person with a disability can not access the facility in the first place. The UP and TN survey results indicate that in a number of cases, physical accessibility of the end facility appears to be less of a problem in the village covered than the basic transport links that get the disabled person to the vicinity of the facility. Even in urban areas, work by DPOs with the railways has revealed that access stages well before railway carriages themselves often prevent use of public railways. [214] It may be useful in future policy development to focus for rural areas more closely on the "mobility/accessibility chain", i.e. the key steps which a person with disability needs to take from home to the service or building, and what links in that chain prove the most binding. [215] Such an approach of course raises a much more challenging set of institutional coordination and resource issues, but would assist at least in focusing policymakers on the key constraints in the mobility chain for rural people with disabilities.

8.6. ***Fourth, the access provisions of the Act – like all those where the commitments are subject to economic capacity proviso – have no provisions or process outlined for either determining appropriate minimum standards of access*** at different level of development or for sanctions on authorities that fail to make any efforts to improve accessibility. This will increasingly need attention now that the new UN Convention on rights of persons with disabilities has entered into force, which requires states to "develop, promulgate and monitor implementation of minimum national standards and guidelines for the accessibility of public facilities and services" (see Box 8.1).

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[211] Schroeder et al. 1979, Ratzka 1984, Cholet and Steinfeld 1979, and Grinnel et. al. 1993. Some accessibility features need add no cost, e.g. wider doorways for wheelchair users may cost more for the door frame, but the need for less wall space constructed can offset that cost.

[212] See Singh (2005). The paper also stresses that even net costs for accessibility should be viewed as investments in promoting greater participation for disabled people, which may pay for themselves in terms of improved employment rates, health facility usage etc.

[213] See Committee Report, which proposes that all public transport "whether constructed or acquired" and all public conveniences to be built in future are accessible.

[214] Samarthya (2005).

[215] There is work for example on adapting mobility devices for rural populations, such as the joint project of the National Institute for Design in Ahmedabad and ICACBR from Canada. See Sharma (2006).

Box 8.1: International and regional standards on promoting access for people with disabilities

Accessibility for people with disabilities has been increasingly stressed in regional and international initiatives. A few of the key milestones in this respect are:

- The 1993 UN Standard Rules, which commit states to recognize the importance of accessibility in promoting equality of opportunity for people with disabilities.
- The UNESACP Biwako Millennium Framework for Action for 2002-2012 which committed states to an inclusive and barrier-free environment for people with disabilities, with specific reference to rural settings.
- The UN Convention on the Rights of Persons with Disabilities has the following provisions on accessibility:

1. "…State Parties shall take appropriate measures to ensures to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and rural areas. The measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

(b) Information, communications and other services, including electronic services and emergency services.

2. State Parties shall also take appropriate measures:

(a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for accessibility of facilities open or provided to the public;

(b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;

(c) To provide training for stakeholders on accessibility issues facing persons with disabilities;

(d) To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

(e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;

(f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

(g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

(h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an earl stage, so that these technologies and systems become accessible at minimum cost.

8.7. ***Fifth, there is no obligation to consult people with disabilities themselves on both priorities in improving accessibility or on design aspects.*** This is a key process need in terms of prioritizing investments in accessibility. Experience such as that of the Delhi Metro indicates that such consultation need not tax administration too greatly, and that the

improvements resulting from such consultations can accrue not only to disabled people, but also a range of other users of services (e.g. the elderly; pregnant women; children).

8.8. ***Finally, awareness of the PWD Act and subsequent developments to promote access remains low,*** both among people with disabilities and often among service providers. For example, in the UP and TN survey only 57 percent of households with disabled members were aware of travel concessions for disabled people. On the supply side, less than 10 percent of transport providers interviewed in Orissa were aware of the PWD Act, though there was greater awareness of specific concessions.

8.9. ***While the PWD Act can therefore be considered a starting point in promoting accessibility, there is clearly a significant need to build on it.*** There has been progress on the policy side in promoting accessibility since the Act. A committee convened by the Ministry of Urban Affairs and Employment issued Guidelines and Space Standards for Barrier Free Built Environment for Disabled and Elderly Persons in 1998. This is intended as a guiding document to central and state authorities in modifying their bye-laws, and applies to most construction other than domestic buildings. A related policy document from the Chief Commissioner for Disabilities "Planning a Barrier Free Environment" outlines a similar set of guidelines. [216] In addition, the latest 2005 revision of the National Building Code (NBC), developed by the Indian Bureau of Standards, includes provisions for buildings, services, and facilities for people with disabilities. The NBC acts as a model code for construction by Public Works Departments, other public agencies and private construction companies.

8.10. All three documents above do not have direct force, though are of course important standards and sources. In order to make them legally binding, they need to be adopted into local building bye-laws for construction and systems for approvals. To date, around 10 states have modified their bye-laws to this effect, with others in the process of doing so. Even for the states that have introduced such revisions in bye-laws, there remains a need to tie them to approval and monitoring mechanisms. In this respect, the requirement in UP that the Estimates Finance Committee should not sanction any public facility construction which does not have barrier-free access provides a promising example.

8.11. ***(b)*** **Experience in Promoting Access:** ***There is much evidence, both quantitative and anecdotal to indicate that accessibility remains a largely unrealized goal in India to date.*** To some extent this is not surprising, given the major challenges in enforcement of construction standards in the country, and more fundamental questions for example of title to land and encroachments. Also, documentation of inaccessibility traditionally was scarce, though the situation is changing rapidly in larger urban areas. The work of Swabhiman in Orissa and Samarthya in Delhi are good examples of increased efforts on the part of NGOs to document access problems for people with disabilities. Such efforts have been complemented by the training initiatives of the Office of the Chief Commissioner for Disabilities. Their findings indicate a major awareness raising and implementation agenda.

8.12. ***One of the major issues in promoting access for people with disabilities is that of institutional coordination.*** Particularly for the built environment, there will in most cases be a range of line agencies and other local authorities responsible for infrastructure. This frequently results in no single agency considering itself responsible for making the built environment accessible, and/or to problems with very partial accessibility in the face of uncoordinated action.

[216] NGOs have also been active, e.g. an informal accessibility resource group in Gujarat has produced the "Design Manual for a Barrier Free Built Environment".

The comparison of institutional arrangements and outcomes for two large infrastructure initiatives in the same city (Delhi) are outlined in Box 8.2 by way of illustration.

8.13. ***The institutional issues in promoting access reflect deeper challenges of accountability***. As noted above, the policy of the PWD Act itself is not of great use in terms of establishing clear lines of accountability for ensuring that accessibility standards are adhered to. Part of the issue is a common central/state/local authority division of labor and the incapacity of the centre as a vehicle for enforcing accountability. A second element is the general ineffectiveness at state level of the Coordination and Executive Committees tasked with oversight of the Act. However, the most progress is likely to be made at the specific project level. This will require focusing on planners, designers, service providers and users. For planners and designers, there is often a lack of knowledge of principles of universal design and of the legal requirements to ensure accessibility. There is also commonly a lack of clarity about where accountability for ensuring accessibility in executed works lies. A distinct but equally important awareness raising agenda remains also with service providers and disabled users of buildings and services.

8.14. ***Despite the challenges, channels are growing for promotion of accessibility for people with disabilities, at least in urban areas. First, the courts have played a role in promoting the access commitments of the Act***, both directly in relation to physical access provisions (e.g. to transport), and in broader areas of civil participation such as access to polling stations under the non-discrimination provisions of the Act and the Constitution.[217] The cases regarding accessible public transport have explicitly tried to balance the need for access with impacts on public finances. For example, the Supreme Court in 1999 ordered Indian Airlines in Javed Abidi vs. Union of India to provide ambu-lifts and aisle chairs for people with locomotor disabilities. This was phased in on the basis of IA's claims that such installation was economically unviable. With respect to elections, the Supreme Court also made orders in 2004 for ramp access to polling stations, at least in urban areas in Disabled Rights group vs. Chief Election Commissioner. While these are positive developments, court-enforcement will necessarily remain the exception rather than the rule, due to the cost and time demands of accessing the legal system. It is important to have both more specific policies and a supportive institutional framework if access commitments are to be realized more fully. Interestingly, very few access-related cases have been brought before the Commissioners' offices, with the few that have being *suo moto*.

8.15. ***One of the simplest but more powerful tools in promoting accessibility has been the growing practice of access audits***, generally by NGOs, in some cases supported by Commissioners' offices. There are many NGOs in different states now conducting such audits, including Samarthya in Delhi; a resource group in Gujarat of NGOs, academics, architects, planners, builders and designers, professional institutions and media, coordinated by UNNATI and the Blind Peoples' Association; Able Disabled People All Together (ADAPT) in Mumbai; Swabhiman in Orissa; and Arushi in MP (to name only a few). Access audits have been carried out on a range of services and institutions, including transport, public buildings, health institutions, cultural sites, and other places, both public and private. Working with media has typically increased the impact of audits and both public and private "auditees" have usually proven willing to introduce accessible or universal design, often at rather low cost. The approach is expanding. For example, Samarthya runs a Training of Trainers Courses to create a resource pool of access auditors. The trainers have basic understanding of diverse access needs, competence to conduct access audits, and recommend and monitor implementation of new as well as old constructions. Trainers undergo an experiential exercise, and orientation on mobility concepts, communication, signage and anthropometrics. Samarthya has provided training for

[217] HRLN, op.cit.

RCI, MoSJE, GoI, and a number of NGOs, many of whom have been associated with the reconstruction work post-earthquake in Gujarat and post-Tsunami at TN and Andaman Islands. Currently over 400 Master Trainers exist in the country.

Box 8.2: A Tale of Two Cities in One: Indraprastha Project and Delhi Metro

The comparison of outcomes on two infrastructural initiatives in Delhi is illustrative of the institutional coordination challenges facing accessibility for PWD, and of how they can in some cases be overcome.

Motivated by the Asian and Pacific Decade of Disabled Persons, a square kilometre of New Delhi (the Indraprastha Institutional Area) was chosen as a pilot for implementing an accessible built environment for people with disabilities. The nodal agency for the project was the Union Ministry of Urban Affairs and Employment. However, the infrastructure in the area fell under several different agencies: roads were under the Municipal Corporation of Delhi; bus stops under the Delhi Development Authority; institutional buildings under the Central Public Works Department, and traffic signals and crossings under the Commissioner of Police. These reported to different entities and government. Despite a steering committee, financing for the initiative remained fragmented across agencies. The project was ultimately implemented, though with limited input from people with disabilities in the process. Subsequently, the area has reverted to its original level of inaccessibility, largely due to lack of concerted ownership among the several agencies involved.

The Delhi Metro project provides a positive counterpoint. The project is also under the MUAE. However, the institutional arrangement is very different, with a single purpose entity established in 1995, owned jointly by GoI and GNTCD. The Delhi Metro Rail Corporation involved disabled users when scaling the facilities and asks for regular access audits. Importantly, people with disabilities are viewed as customers, and thus the Delhi metro is designed to be easily accessible for them. Escalators and accessible elevators are available at all stations. In addition, disabled commuters can also expect accessible seating on the trains. Other specific facilities for disabled commuters are:

- Audible warnings and announcing devices wherever possible
- Ticket gate exclusively for disabled passengers
- Tactile tiles on all common passages with tactile warnings for abrupt change in height or near hazardous areas
- Signs printed in braille in the lifts to indicate floors
- Elevator control buttons positioned at heights that are accessible to wheelchair users
- Accessible toilets on every floor
- Grip rails on the walls of the elevator car
- Wide doors for lifts
- Ramps at the entrance of every station
- Adequate landing space at the start and end of every ramp
- Reservation for employment of physically challenged

Samarthya, a local NGO, also carried out an access audit on a sample station in 2002. The DMRC took into consideration Samarthya's recommendations and made the requisite changes to signage and symbols, the height of the ticket counter, installed seating on the platforms for elderly and persons with mobility difficulties and created curb cuts for parking places reserved for persons with disabilities. The Delhi Metro can now be considered among best practice in the developing world as far as access for people with disabilities is concerned.

Source: Singh (2005); Officer.

8.16. ***In addition to NGO activities, the Chief Commissioner's Office has since 2001-02 supported training for access audits***, which have resulted in 366 people being trained. . In addition, the Office has worked with a Delhi-based access group auditing prominent public buildings, with positive impacts in achieving improvements in audited sites. While this is

laudable, there are concerns that many of those trained are not stakeholders with necessary influence, and that emphasis on people who might have a catalytic impact (e.g. architects, PWD officials, builders and user groups) may be a more strategic approach.

8.17. ***There are also promising initiatives by specific public sector agencies in promoting accessibility, notably under the Ministry of Railways.*** Given the importance of railway transport for the poor in particular, MoR has begun a program of access upgrading in all "A" category stations in larger cities intended to increase accessibility for PWD and others who may have difficulty in movement such as the elderly. It is planned to move to Catgory B and C stations in a phased manner. This is supported by the National Institute of Orthopaedically Handicapped in Kolkata, and financed from the "passenger amenities fund", which was over 200 crore in 2003/04.

8.18. ***An important need in promoting access for people with disabilities is training of architects, engineers and planners in principles of universal design and accessibility***. This would apply to those designing buildings and public spaces, transportation vehicles of different forms, and those involved in approval of development plans. Issues of universal design are beginning to become an area of focus in some educational institutions in India, [218] but to date exposure to either universal or accessible design principles is not a standard element of curricula. Such a direction is anticipated in the Ministry of Urban Affairs guidelines, but these remain to date aspirational statements rather than policy or practice. It will be important in moving towards inclusion of such elements in curriculum that the universal design is seen not only as relevant to people with disabilities, but many others who may have access issues, such as elderly, pregnant women and children. GoI recognizes this need and there are proposals for greater financial support for designated academic institutions which could become centres of excellence in barrier-free access and universal design. Some of these could be training/teaching centres, preferably based in respected existing institutions such as IITs, while others such as the Central Building Research Institute in Roorkee and the Central Road Research Institute in Delhi could also support deeper research.

8.19. ***An additional measure which could assist people with disabilities in improving their access to transport is simplification of rules.*** In some cases, this relates to the requirement for renewal of certification, as e.g. in Karnataka annual renewal of concession passes is needed even for those with permanent disabilities. In other cases, there are either somewhat complex sub-rules on what transport one can access (e.g. in Rajasthan, concessions are applicable only on certain categories of buses and only during daylight hours. The concession also only applies to buses traveling within the state and not beyond).

8.20. ***A further important process measure in improving accessibility would be an obligation to consult people with disabilities themselves in prioritizing investments to promote access, and in monitoring access outcomes.*** The provisions of the PWD Act focus largely on end-point access issues. To what extent these are the key constraints on access of disabled people is less understood, and an obligation on local authorities to consult on major infrastructural developments could help bring the user perspective closer to design and execution processes. Such consultations could assist in prioritizing investments. It would also seem useful to build in a requirement of social audit by people with disabilities in selected social and other infrastructure, along with a procedure for such findings to be discussed with policymakers and service providers.

[218] See for example work of graduate students from IIT, Kharagpur.

Conclusions and recommendations:

8.21. It is clear that promoting access for people with disabilities is a long term agenda. Nonetheless, there remains considerable room for improving the policies, procedures, and processes which will be necessary to provide a solid platform for action over the short, medium and long terms. Some recommendations that emerge include:

- both national and sub-national policies on promoting access for people with disabilities should be required to include consultation with disabled people in setting priorities.
- states and/or municipal authorities which have yet to amend their building bye-laws to comply with the 1998 guidelines should be encouraged to do so in the nearest future. These should allow for clear sanctions in case of failure to comply with accessibility standards, and administrative clarity on official accountability in cases of failure to comply.
- MoSJE in collaboration with Commissioner's offices, the Ministry of Urban Development and Employment, and the states should work towards benchmarking minimum national standards of accessibility to which authorities could be held accountable. This are a necessity under the new UN convention.
- the recommendation of the Amendment Committee for the PWD Act which would strengthen obligations on access for all new public buildings and built environment should be taken up.
- access audits by Commissioners' offices, NGO and others should be increased, with a strengthened follow-up mechanism for implementing remedial measures identified.
- public funds for the welfare of disabled people should also be used to support research on their access priorities, development of assistive devices for improving mobility of disabled people, implementing cost-effective universal design, and analysis of the impacts and costs of failure to provide accessible environments. While these are all possibilities under the PWD Act, in practice there has been very limited research on these subjects.
- there should be systematic involvement of disabled people and other civil society actors in monitoring of accessibility through requirement of access audits on all significant public infrastructural projects, including social infrastructure.
- university and in-service training courses for architects, engineers and planners should include exposure to principles and practices of universal design and accessibility as a standard course element. Financing for designated centres of excellence in this area should be made available.

ANNEX 1: COMPARING THE INCOMPARABLE: DISABILITY ESTIMATES IN THE CENSUS AND THE NATIONAL SAMPLE SURVEY [219]

1. Disability prevalence estimates often differ across and within countries. In India, according to the 58th round of the National Sample Survey (NSS), there were 18.5 million persons with disabilities in 2002 compared with 21.9 million reported by the Census of 2001. This translates to a 20 percent difference in the prevalence estimates. It is important to try and understand the differences in prevalence estimates from the Census of India of 2001 and the 58th round of the NSS. This annex explores the factors that contribute to the differences between the two sources, including different sampling designs and disability definitions.

2. The Census and the NSS have different sampling design. The Census is an enumeration of the entire population of India while the NSS has a nationally representative stratified sample.

3. In both sources, disability was self-reported. Different definitions of overall disability and disability types may have contributed to differences in estimates.

Overall disability:

4. The Census of 2001 does not have a general definition of disability. Instead, a question on type of disability was included in the population enumeration section as follows: "If the person is physically/mentally disabled, give appropriate code number from the list below: in seeing, in speech, in hearing, in movement, mental." The Census thus has a functional limitation question, which prompts respondents to report their type of functional limitation (e.g., in seeing, hearing).

5. In schedule 0.0 of the 58th round of the NSS, some broad information about the households (e.g., housing conditions, disability) were collected during the household listing. This information was required mainly to identify and develop a frame for selection of households for subsequent schedules, including schedule 26 administered only to households with persons with disabilities. In the NSS, a person is considered disabled "if the person has restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being". Disability is thus defined as an activity limitation in the NSS.

6. The disability question and the definitions of different disability types used in the Census and the NSS are presented in Table A2.1. Prevalence estimates are reported in Bhanushali (2005).

Type of disability:

7. In both sources, persons who report being disabled are asked about their limitation types (mental, locomotor, visual, hearing, speech). Despite similar sequence in the identification of disability types, there are also tremendous variations in prevalence estimates of types of disability across the two data sources.

8. Visual: (Higher Census – Lower NSS) According to the Census 2001, nearly 50 percent of PWDs are visually disabled, compared to 15.3 percent in the NSS. For visual disability, the Census includes persons who have blurred vision and have had no occasion to test their vision. It thus includes persons who may be able to see with spectacles. In contrast, the NSS does not consider whether or not a person's vision has been tested and focuses on the ability to perform tasks requiring visual acuity.

[219] This annex is drawn from the background paper by Mitra and Sambamoorthi (2006).

9. Hearing: (Lower Census, Higher NSS). For hearing disability, persons who can hear only with one ear are counted as disabled in the Census, while they are considered as nondisabled in the NSS. In addition, the Census refers to hearing ability when the person uses hearing aid (if at all) while the NSS refers to a person's hearing ability without the use of hearing aid. Among PWDs, 5.8 percent have hearing disabilities in the Census compared with 16.6 percent in the NSS.

10. Speech: (Lower Census, Higher NSS) The NSS has a broader definition of speech disability than the Census. In the NSS, persons who cannot speak, speak limited words or with loss of voice, or with stammering voice are classified as being speech disabled. In the Census, speech disability covers persons who are dumb, or who cannot be understood. A person who stammers but whose speech is comprehensible is not considered as speech disabled. As a result, based on Census data the estimate of persons with speech disability is much lower (7.5 percent of PWDs) than in the NSS (11.7 percent of PWDs)

11. Locomotor: (Lower Census, Higher NSS) The NSS has a broader definition than the Census. The NSS includes persons with paralysis, amputation, deformity, dysfunction of joints and dwarfism as having locomotor disability. Persons with dwarfism or deformity are considered disabled even if they are not limited in the movement of their body or limbs. In the Census, locomotor disability covers the absence of all toes, all fingers, deformity, the inability to move without aid, the inability to lift and carry any small article. The differences in the definition of locomotor disability are consistent with the much higher rates of locomotor disability prevalence in the NSS (10.6 million, 57.5 percent of PWDs) than in the Census (6.1 million, 27.9 percent of PWDs).

12. Mental: The only disability prevalence estimates that are relatively close between the Census and the NSS are those regarding mental disability (2.26 million persons (10.33 percent of PWDs) in the Census versus 2.1 million in the NSS (11.34 percent of PWDs). This result is surprising given that the NSS and the Census use very different definitions for mental disability. In both sources, comprehension appropriate to age is used to capture persons with mental retardation. However, there are fundamental differences in the way mental illness is defined. The Census refers to persons who are "insane", while the NSS identifies persons who exhibit behaviors like talking to self, laughing/crying, staring, violence, fear and suspicion without reason. The definition of mental disability is also based on a general daily living limitation in the Census while it refers to several specific functional and activity of daily living limitations in the NSS ("activities of communication (speech), self-care (cleaning of teeth, wearing clothes, taking bath, taking food, personal hygiene, etc.), home living (doing some household chores) and social skills").

Concluding Remarks and Recommendations

13. As noted above, three disability type definitions (hearing, speech and locomotor) are more inclusive in the NSS than in the Census. The reverse is true for visual disability where the Census definition is wider than that in the NSS. The vast differences in prevalence estimates between the Census and the NSS illustrate how essential it is to document the disability definition used, sources and caveats and to exercise great caution while comparing prevalence estimates or using statistics related to disability.

14. The introduction of the measurement of disability within surveys and the census is a very complicated task and there is no simple recommendation as to what is the best approach. Of course, having consistent definitions in the Census and the NSS would facilitate the comparison

of prevalence estimates across the two sources. In addition, efforts should be targeted toward improving the definitions of disability types within each data source.

15. In the Census, the definitions of disability types can be improved as follows.

(i) There are inconsistencies across disability types as to whether the functional limitation applies to a situation where an assistive device is used. For locomotor disability, it refers to a person's limitation without using aid while for hearing, it refers to a limitation experienced despite the use of hearing aid. Such inconsistencies certainly make it difficult for field staff to collect the data and for researchers to interpret the results.

(ii) In addition, in the Census, the term "insane" is used to define mental illness: this term is subjective and using it to classify persons seems inadequate.

(iii) Finally, the definition of visual disability needs to be narrowed down so that persons who have mild visual limitations and have not been tested for vision acuity are not counted as disabled.

16. As for the NSS, the definitions of disability and disability types and the scope of disability data collection should be revised as follows.

(iv) The current definitions of disability and disability types are a mix of activity limitation (general definition, visual and mental disability), functional limitations (e.g., speech) and impairments[220] (in locomotor disability, dwarfs and persons with stiff neck of permanent nature who generally do not have difficulty in the normal movement of body and limbs will also be treated as disabled). As a result, it is unsure what exactly the NSS based prevalence estimate encompasses. There should be separate questions getting at impairments, functional and activity limitations.

(v) There is scope for improving data collection on disability by including disability questions in non disability schedules in the NSS. Fewer than a handful of disability questions would facilitate the comparison of the welfare of persons with and without disabilities. A disadvantage of the data from schedule 26 is that it only covers PWDs, and makes it therefore impossible to compare the welfare of persons with and without disabilities at a given point in time. For instance, in the rounds of the NSS that collect employment data for large samples (e.g., 55th round), PWDs are not identified. As a result, some questions that are essential to understanding the standard of living of PWDs cannot be tackled with existing data. Is there discrimination in access to employment against PWDs? Is there underemployment among PWDs? Adding disability questions to selected rounds of the NSS could go a long way in giving researchers the data needed to try and answer these questions.

[220] Impairments are anatomical or physiological abnormalities or losses.

Table A.1: Disability definitions in the Census and the NSS

	2001 Census	2002 NSS (58th round)
Disability Question	Q15 If a person is disabled, enter only one of the five disabilities for that person, in codes, as given below :- In Seeing 1 In Speech 2 In Hearing 3 In Movement 4 Mental 5	**Disability:** A person with restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being is treated as having disability. It excludes illness/injury of recent origin (morbidity) resulting into temporary loss of ability to see, hear, speak or move.
Disability Type Definitions		
Seeing/Visual	**Seeing:** A person who cannot see at all (has no perception of light) or has blurred vision even with the help of spectacles will be treated as visually disabled and code `1` will be entered under this question. A person with proper vision only in one eye will also be treated as visually disabled. You may come across a situation where a person may have blurred vision and had no occasion to test whether her/his eyesight would improve by using spectacles. Such persons would be treated as visually disabled.	**Visual disability:** By visual disability, it is meant, loss or lack of ability to execute tasks requiring adequate visual acuity. For the survey, visually disabled will include (a) those who do not have any light perception - both eyes taken together and (b) those who have light perception but cannot correctly count fingers of hand (with spectacles/contact lenses if he/she uses spectacles/contact lenses) from a distance of 3 meters (or 10 feet) in good day light with both eyes open. Night blindness is not to be considered as visual disability.
Speech	A person will be recorded as having speech disability, if she/he is dumb. Similarly persons whose speech is not understood by a listener of normal comprehension and hearing, she/he will be considered to having speech disability and code `2` will be entered. This question will not be canvassed for children up to three years of age. Persons who stammer but whose speech is comprehensible will not be classified as disabled by speech.	This refers to persons' inability to speak properly. Speech of a person is judged to be disordered if the person's speech is not understood by the listener. Persons with speech disability will include those who cannot speak, speak only with limited words or those with loss of voice. It also includes those whose speech is not understood due to defects in speech, such as stammering, nasal voice, hoarse voice and discordant voice and articulation defects, etc.
Hearing	A person who cannot hear at all (deaf) or can hear only loud sounds will be considered as having hearing disability and in such cases code `3` be entered. A person who is able to hear, using hearing-aid will not considered as disabled under this category. If a person cannot hear through one ear but her/his other ear is functioning normally, should be considered having hearing disability.	This refers to persons' inability to hear properly. Hearing disability is to be judged taking into consideration the disability of the better ear. In other words, if one ear of a person is normal and the other ear has total hearing loss, then the person is to be judged as normal in hearing for the purpose of the survey. Hearing disability will be judged without taking into consideration the use of hearing aids (i.e., the position for the person when hearing aid is not used). Persons with hearing disability may have different degrees of disability, such as profound, severe or moderate. A person will be treated as having 'profound' hearing disability if he/she cannot hear at all or can only hear loud sounds, such as, thunder or understands only gestures. A

		person will be treated as having 'severe' hearing disability if he/she can hear only shouted words or can hear only if the speaker is sitting in the front. A person will be treated as having 'moderate' hearing disability if his/her disability is neither profound nor severe. Such a person will usually ask to repeat the words spoken by the speaker or will like to see the face of the speaker while he/she speaks or will feel difficulty in conducting conversations.
Movement/Locomotor	**Movement:** A person who lacks limbs or is unable to use the limbs normally, will be considered having movement disability and code `4` will be entered here. Absence of a part of a limb like a finger or a toe will not be considered as disability. However, absence of all the fingers or toes or a thumb will make a person disabled by movement. If any part of the body is deformed, the person will also be treated as disabled and covered under this category. A person who cannot move herself/himself or without the aid of another person or without the aid of stick, etc., will be treated as disabled under this category. Similarly, a person would be treated as disabled in movement if she/he is unable to move or lift or pick up any small article placed near her/him. A person may not be able to move normally because of problems of joints like arthritis and has to invariably limp while moving, will also be considered to have movement disability.	**Locomotor:** A person with - (a) loss or lack of normal ability to execute distinctive activities associated with the movement of himself/herself and objects from place to place and (b) physical deformities, other than those involving the hand or leg or both, regardless of whether the same caused loss or lack of normal movement of body – will be considered as disabled with locomotor disability. Thus, persons having locomotor disability will include those with (a) loss or absence or inactivity of whole or part of hand or leg or both due to amputation, paralysis, deformity or dysfunction of joints which affects his/her "normal ability to move self or objects" and (b) those with physical deformities in the body (other than limbs), such as, hunch back, deformed spine, etc. Dwarfs and persons with stiff neck of permanent nature who generally do not have difficulty in the normal movement of body and limbs will also be treated as disabled.
Mental	A person who lacks comprehension appropriate to her/his age will be considered as mentally disabled. This would not mean that if a person is not able to comprehend her/his studies appropriate to her/his age and is failing to qualify her/his examination is mentally disabled. Mentally retarded and insane persons would be treated as mentally disabled. A mentally disabled person may generally depend on her/his family members for performing daily routine. It should be left to the respondent to report whether the member of the household is mentally disabled and no tests are required to be applied to judge the member's disability.	Persons who have difficulty in understanding routine instructions, who do not carry out their activities like others of similar age or exhibit behaviours like talking to self, laughing / crying, staring, violence, fear and suspicion without reason would be considered as mentally disabled for the purpose of the survey. The "activities like others of similar age" will include activities of communication (speech), self-care (cleaning of teeth, wearing clothes, taking bath, taking food, personal hygiene, etc.), home living (doing some household chores) and social skills.

Sources: Bhanushali, K. (2005) and Government of India (2003a)

ANNEX 2: BRAZIL'S REFORM OF CENSUS QUESTIONS ON DISABILITY

1. Brazil has moved in its most recent census from a fairly traditional approach to asking about disability to one based instead on a functional approach consistent with the International Classification of Functioning. This led to a dramatic rise in disability prevalence between the 1991 and 2000 censuses – from 0.9 percent of the population in the earlier year to 14.5 percent. This points to the importance of how disability questions are asked. India's present method of asking about disability in its 2001 census is much closer to that of the 1991 census in Brazil, and not surprisingly yields the official prevalence rate of just over 2 percent.

2. The questions on disability in the 1991 census were:

Do you have any of the following physical or mental disabilities ?

1. Blindness
2. Deafness
3. Paralysis of one side of the body
4. Paralysis of the legs
5. Total paralysis
6. Loss of a leg, hand, foot or thumb
7. Mental disability
8. Other
9. None of the above

1. The questions in the 2000 census were:

1. Do you have any permanent mental disability that restricts your daily activities (such as working, attending school, playing etc)
   - Yes/No
2. How do you evaluate your capacity to see ? (with glasses or contact lenses as needed)
   - Unable
   - Severe permanent difficulty
   - Some permanent difficulty
   - No difficulty
3. How do you evaluate your capacity to hear ? (with hearing aid if used)
   - Unable
   - Severe permanent difficulty
   - Some permanent difficulty
   - No difficulty
4. How do you evaluate your capacity to walk/climb stairs (with prosthesis, walking stick or an auxiliary device if used)
   - Unable
   - Severe permanent difficulty
   - Some permanent difficulty
   - No difficulty
5. Do you have any of the following impairments (Choose only the first that applies based on the order of the list below)
   - Permanent total paralysis
   - Permanent paralysis of the legs
   - Permanent paralysis of one side of the body
   - Loss of a leg, arm, hand, foot, or thumb
   - None of the above