

Conference on People with Disabilities in India: Status, Challenges and Prospects

**Organized by the World Bank and the Ministry of Social Justice and Empowerment,
Govt. of India
November 21-22, 2007, New Delhi**

Background/Objectives:

The World Bank, along with the Ministry of Social Justice and Empowerment, Government of India, hosted a two-day conference on People with Disabilities in India: Status, Challenges and Prospects. The conference was held in New Delhi, India, from November 21-22, 2007 at The Park Hotel, New Delhi.

The workshop had two main objectives. For the Government of India, the workshop was a useful forum to review policies and programs in the sector and explore ways in which to strengthen the system in the coming years. The World Bank, on its part, was keen to share a draft Bank report entitled “People with Disabilities in India: From Commitments to Outcomes”, and receive expert feedback from participants which would help guide future engagement in the disability sector.

Participation

The workshop included a range of speakers and panelists from the central and state governments, the DPO and NGO sectors, donors and civil society. The workshop was particularly timely in light of India’s recent ratification of the UN Convention on the Rights of Persons with Disabilities. The response to the conference was overwhelming: in total over 150 participants (not including World Bank staff) took part in the conference. Not only were there several disabled people as participants to share their experiences, many also contributed as panelists.

Format and Agenda

As per the design of the workshop, no break-away sessions were planned. This allowed for active participation of the whole gathering in every session and theme and resulted in meaningful debate among different subgroups in the PWD sector. The agenda revolved around eight themes essentially reflecting the topics taken up in the World Bank report. Apart from the inaugural and wrap up sessions, the two-day conference covered the following themes:

- Public Policy and People with Disabilities: Experience to Date and Looking Ahead
- Institutions and Policies in the Disability Sector.
- Education of Children and Young Adults with Special Needs.
- Health System and People with Disabilities
- Employment and People with Disabilities
- Accessibility and People with Disabilities
- Attitudes and Disability
- Social Security and Disability

The detailed agenda along with list of PPT presentations are attached.

DAY 1: PRE-LUNCH:

The **inaugural session (Session 1)** began with Philip B. O'Keefe, Lead Social Protection Specialist of the World Bank welcoming all participants. He invited Hon'ble Minister of Social Justice and Empowerment, Smt. Meira Kumar to open the conference with traditional lighting of the lamp. This session was **co-chaired by Smt. Veena Chhotray, Secretary, MSJE and Isabel Guerrero World Bank Country Director.**

In her opening remarks **World Bank Country Director, Isabel Guerrero** provided briefly the context in which the World Bank was engaged in this sector. She pointed out that India needed home grown solutions to the problem of exclusion of such a large number of people from mainstream society. She hoped that the World Bank draft report would trigger a productive debate on the challenges and opportunities in this area and help the Bank deepen its dialogue with the PWD sector. She pointed out to some of the inherent strengths of the country like a strong policy framework, and a vibrant civil society movement for integration for the disabled into mainstream society. However, PWD (persons with disability) was an extremely heterogeneous group and vulnerable to a variety of technical, social, legal and fiscal problems. She referred to the World Bank initiative in Andhra Pradesh (AP) and Tamil Nadu (TN) in mobilizing self-help groups of PWDs and its support to Sarva Shiksha Abhiyan (SSA) to ensure more children with special needs entered schools. These had enriched the Bank's experience and equipped it better to engage in the sector.

Smt. Veena Chhotray, Secretary, Ministry of Social Justice and Empowerment (MSJE) provided a brief introduction to the government efforts to improve the status of disabled population. She pointed out that the approach in the last 25 years had gradually moved from charity/medical approach to a rights based approach. The umbrella legislation brought out by India on equal opportunities for disabled referred to as PWD Act, 1995 and the National Trusts Act endeavor to cover policy interventions for a very broad range of disabled persons. This had followed quickly after the declaration of the decade for the disabled. However, the numbers were very large (over two crores were affected as per Census figures) and a large number of agencies apart from several central ministries were involved. This implied that a nodal ministry like the MSJE had to take on a coordinator's role at the apex to ensure that other agencies and stakeholders in the centre and the states were able to work in an integrated manner. Dr. Chhotray said that the World Bank report was a timely stock taking exercise in bringing together so much information in one place particularly just a decade after the umbrella Act. This had been done on the request of the Government of India, which hoped to improve its overall performance and outlay in the eleventh plan and take some vital steps for improving the status of the PWD. She broadly touched on the issue of numbers, recruitment and training, education, and involvement of the private sector. She pointed out that the country already had necessary provisions and mechanisms under the PWD Act even for monitoring and evaluation but these needed to be strengthened and implemented rather than replicated. On employment some progress had been made but government was trying to improve recruitment prospects for PWD. The speaker emphasized that States also had to move forward on this. The government was also supporting the private sector with a scheme to reimburse EPF's employers share in case of disabled employees and an allocation of Rs 700 crores had been made to target 100,000 PWD. This would be implemented very soon. A high powered committee is functioning now to streamline issue of certification. The speaker concluded that the ministry was interested in replicating the success stories of the States of

AP and Tamil Nadu reported in the World Bank document and was looking for a productive and enriching deliberation during the conference.

The **Hon'ble Minister for MSJE, Smt. Meira Kumar** welcomed the participants and underlined the fact that this was the first ever workshop to bring so many stakeholders of the PWD sector together onto one forum. She mentioned that another similar consultation was being planned for south India. She complimented the Bank on bringing out a timely and exhaustive report but pointed out to some of the gaps which needed further work. For instance, there were large differences between PWD population estimates by the Bank and the government agencies like NSSO. The government had sharpened its focus on this sector particularly since the 9th five year plan and the move to a rights based approach was becoming ever stronger. India was among the first to come up with umbrella legislation after the Decade of the Disabled was announced in 1993. India also went on to help develop and ratify the UN Convention on Disabled Persons in March 2006 when it was thrown open for signature. Ms. Kumar clarified that the PWD Act was under the nodal Ministry of Social Justice and Empowerment and the spectrum of the Act was very broad including prevention, early detection, rehabilitation, employment, non- discrimination and manpower development and development of barrier free environment. The UN Convention had brought out many new concepts including communication, and access to information, reasonable accommodation and universal design. She felt that the World Bank report was not wholly right in stating that PWD sector was excluded from the process of planning and monitoring in the sector. The government was in the process of amending the PWD Act and the PWD sector had been made a critical part of the consultative process particularly in central and state committees. She mentioned that the consultations were both inclusive and extensive in terms of widespread coverage across the country. She felt that women and children needed special attention. The Minister invited all participants to join the government in a function on 3rd December at Vigyan Bhawan, New Delhi to celebrate World Disability Day. A special stamp in Braille was being released on the occasion for the first time in the country's history.

The minister's address was followed by some questions on specific sections in the Planning Commission report which was going to the cabinet for finalization in the next few days. Many participants felt that the Planning Commission had failed to reflect the recommendations and concerns of the special working group constituted for the sector and in fact downplayed the extent of the problem. The news created some agitation in the house, but finally, the participants agreed to take up the matter later in the interactive session related to the 11th five year plan.

Mr. Philip B. O'Keefe presented the highlights of the World Bank's report [PPT]. At the outset he admitted that the recommendations were likely to be weak and underdeveloped and this was precisely where the inputs of the audience would be needed. One strong motivation for producing such a document was to compile quantitative information from different sources so as to enable both the government and civil society organizations to make their cases and proposals. As a result the report had strong inputs from NSS, administrative data and Bank's own survey in UP and Tamil Nadu. The analysis was strengthened by a series of background papers and consultations. Mr. O'Keefe mentioned that different surveys had come up with varying figures of incidence of disability. This had to do with methodology and also the way people viewed disability. An interesting case was the attitude toward elders whom disability wasn't recognized. Among the key messages, Mr. O'Keefe mentioned that

disability does not decrease as countries get richer. Secondly, PWD are subject to many deprivations in their life, including in terms of education, employment and social stigma. The most marginalized groups were those with psychosocial and mental disabilities. Mr. O'Keefe highlighted the great difference in the data from government agencies and those from other agencies which could be explained by the definitional parameters and methodology adopted in the field. Even the reasons of disability were changing: from communicable diseases in the 1990s to road injuries and traffic accidents in recent years. He pointed out that the UP and Tamil Nadu work had given the Bank an insight into why efforts were not producing better outcomes. Around 90% of the people interviewed were not even aware of the PWD Act. More than 80% did not know about the certificate of disability that provided access to the system in the large countryside; social stigma was a major problem and it was believed that the genesis of the problem was the curse of god. On the positive side, Chhattisgarh State was identified as a good practice State.

Mr. O'Keefe felt that India had one of the more progressive policy frameworks which would evolve over time. He said that the main themes of the conference reflected those covered in the report and it was hoped that experience sharing and expert analysis would help the Bank to enrich the report further and provide all stakeholders an occasion for serious deliberations at a crucial time following India's ratification of the UN Convention.

Ms. Anuradha Mohit, Director, National Institute for the Visually Handicapped, speaking next, admitted that she had not gone beyond the introduction and executive summary of the report but felt that it filled the gap experienced by a lot of people when they needed a ready handbook particularly in writing official letters or formulating PIL etc. She admitted to being both happy and disappointed in various respects in terms of her own overall experience in working in the sector. Small successes in this sector often appeared to be bigger than they really were in the larger picture, and disappointment often followed euphoria. She affirmed that the disability group had been even more marginalized than the SC/ST and backward classes. The World Bank report had not been able to fully capture this but one could hardly expect this when even India's Constitution makers did not represent this sector. Ms Anuradha, speaking from her experience of working as Deputy Commissioner on Disability, pointed to some of the technical gaps in the chapter on institutional arrangements. She underlined the fact that the nature of the institution and its judicial strengths within the judicial framework was important. She mentioned that in India and internationally also there was a settled position in the way the law incorporated entitlements to rights and obligations. They are divided into justiciable and non-justiciable rights. The speaker clarified that in terms of principles of law, the PWD Act 1995 was not looking at justiciable rights but only economic and social rights that could to be achieved progressively. Any discussion on the Act had to recognize this limitation. The assessment of its performance in the World Bank report thus needed to be reviewed and the Report itself could benefit from a stronger legalistic input. She referred to her experience with two quasi judicial institutions, the National Human Rights Commission (NHRC) and Office of the Central Commissioner for Disability and clarified that NHRC was overall the umbrella organization looking at various aspects of human rights. NHRC was in the process of giving specific powers to CCD to give it more teeth. Ms Mohit commended the chapters on employment and education in the Bank report as being academically excellent. However, she felt that more specific suggestions were required to empower policy makers particularly in the present labor market context. As regards education, she found the vision and commitment for the country emanating from the

Constitution of India quite clear and comprehensive, which had been sought to be embodied in the SSA program. Every child needed to have an education and therefore question of early assessment of disability had to be looked at from a different perspective because of the legal standing of education. She affirmed that on the whole the chapters on employment and education were very good, though there was scope to improve further and help policy makers create tangible gains for the PWD sector. She mentioned that sometimes perspectives of certain disability groups seemed to pre-dominate in the Report and thus the perspective did not adequately recognize the needs of other groups and work done by many important institutions like NCERT and NIEPA had failed to find a reference. It was affirmed that a more holistic perspective would add to the robustness of the World Bank report.

Mr. Samir Ghosh, Independent Consultant an independent disability consultant, gave a precise presentation [PPT] and congratulated the Bank for a comprehensive and balanced exposition of PWD sector in India. Looking at PWD sector from a multi-disciplinary view, he felt that the draft was a good starting point and more inputs would emerge from the conference and issues like the regional imbalance within states would be addressed further. He referred to a UNICEF micro-planning survey of 5160 villages in 4 districts in Maharashtra which had covered 100% households and significantly showed a 9-11% disability. Though this was not the main purpose of the survey and the figures not officially recognized, the data was available easily to researchers. Mr. Ghosh remarked that some aspects like recreation and culture and diversity in interpretation of 'access' were issues which needed further elaboration and clarity. Further, NGOs' role was not clear – delivery or advocacy, what was more important? Unfortunately problems were compounded by the low visibility of national programs and insensitive government staff, which needed intensive sensitization. Mr. Ghosh pointed out that during his many visits to different parts of rural India he had not seen any awareness of the needs of the sector even at the Zilla Parishad level, whereas it was imperative to integrate programs into the PRI system at the grassroots as had been recommended in the World Bank report.

Session 2: Public policy and people with disability: Experience to Date and Looking Ahead.

Chair: Dr. G.N. Karna, HURITER , New Delhi

The next presentation [PPT] was given by **Mr. Ashish Kumar, Deputy Director General in the Ministry of Social Justice and Empowerment (MSJE)**. He affirmed that the main sources of information on the disabled population were indeed the Census Report 2001 and the national sample survey organizations (NSSO) data and even these did not necessarily match. This was caused more by definitional and methodological variation than inherent error. Mr. Kumar admitted that there were deficiencies in terms of definitions and methodologies and this had to be improved. International Classification of Impairments, Disability and Handicaps (ICIDH) produced by WHO has to be used and the government was looking at what form it should take to be relevant to the Indian context. Through a number of slides, Mr. Ashish Kumar explained the government set up and structure that was working in the sector and its main interventions in the field. He emphasized the importance of private-public partnership and community level support for identification, certification, and rehabilitation efforts of the government. Mr. Kumar touched upon institutions like ALIMCO and NHFDC and affirmed that both needed to improve their quality of work and

their efficiency. He mentioned the huge network of field organizations including composite rehabilitation centers, district rehabilitation centers, Indian spinal injury centers (through PPP) and the four regional spinal injury centers. In the rural areas 128 of the 199 sanctioned district rehabilitation centers were already functional. The government agenda was to ensure that every district had at least one such center. In the area of education, the concern appears to be the lack of special teachers to look after children with special needs. Accessibility to special schools and resources was lacking. The speaker felt that HRD had to take up issues of more funds. Even in secondary and university education, the lack of adequate trained teachers and enabling environment and special books and materials was a problem. Mr. Kumar said that certain areas of intervention had been identified. The ministry had asked each State government to make at least one state university accessible to PWD. These issues had to be considered while reviewing the PWD Act. The University of Goa was cited as an example of progress in this direction. Mr. Kumar also mentioned shortcomings and constraints faced in the area of improving training and employment opportunities for PWD and felt that vocational centers should be geared with right linkages to equip them for the benefit of the PWD. In this the private organized sector was going to be extremely important. Mr. Kumar further touched on issues like access to the built environment and public transport, access to information, to communication and convergence of social security and poverty alleviation programs with the special needs of the PWD. He agreed that the large number of PWD were in the rural areas and the government's target should be to cover them in all its interventions.

During the **open floor session**, several participants voiced the concern that the 11th five year plan document had fallen drastically short of expectations and allocations were not going to be enough. It was felt that the vision shared earlier may not translate into actual gains. The chairman of this session, Dr. Karna who was also chairman of the working group on disability was repeatedly asked questions regarding his efforts to push the agenda for the PWD sector. Dr. Karna explained the terms of reference of his working group and said that they were only an advisory body and their report had been examined by the Steering Committee before being taken up by the Planning Commission. Mr. Ashish Kumar intervened to suggest that the participants could put down their views on paper and forward them to him to prepare a cabinet note which could still be presented during the final discussions at the cabinet level. He was certain that concrete suggestions from participants could be taken to the minister and the cabinet for due consideration even at this stage.

One comment came on the great gaps found between stated achievements and ground reality. A participant also commented on the low fund utilization record of the government and asked whether pre-emptive steps could be taken to ensure that this situation did not arise. Mr. Kumar responded that the ministry was itself keen to utilize maximum funds but was often handicapped by lack of sound proposals and constraints arising from elaborate clearance and approved systems. He assured the house that the MSJE would not allow funds for this sector to lapse during the 11th plan period.

DAY 1 - POST-LUNCH

Session 3: Institutions and Policies in the Disability Sector

Chair: Mr. Manoj Kumar, Chief Commissioner, Office of Chief Commissioner for Disabilities, New Delhi

The discussion in this session revolved round institutions and policies. The panelists were joined by **Maj. Gen. Ian Cardoza (RCI)** in the absence of Chief Commissioner for Disabilities. After a brief introduction by the chair, the first speaker was **Poonam Natarajan**, who spoke on behalf of National Trust an agency of GoI responsible for certain specific disabilities (mental and psycho-motor). The institution's mission was mandated by the National Trust Act. The speaker introduced the work of the Trust vis-a-vis specific disabilities and enumerated some of the efforts of the organization to intervene at the grassroots level. Ms. Natarajan mentioned that the National Trust was a fruition of advocacy efforts of parents who had raised the question: "what happens to my child when I am gone?" Thus legal guardianship was a critical area in which the Trust worked particularly in reference to the "profoundly disabled" As regards coverage, each district had a local level committee comprising three members – the collector, an NGO and a representative of the disabled. In her experience the representative of disabled had to do much more. The agency had started training programs in a substantial way but found not many interested in aspects like mental retardation. Ms. Natarajan referred to the World Bank report's Tamil Nadu experience and affirmed that there was a case for strengthening public private partnership. Forty-two NGOs had covered 391 blocks through special educators. Ms. Natarjan, who had participated in the project, felt there were many lessons for others particularly in the way the shortage of special educators had been tackled.

The next speaker was **Mr. T.D. Dhariyal**, Deputy Chief Commissioner for Disabilities. He gave a succinct presentation [PPT] on what his office was doing in terms of their mandate and the institutional framework available to them. The problem was still of 80% resources going to 20% people. A remote villager could not get the disability certificate and access the facilities. Mr. Dhariyal highlighted that monitoring by both CCD and SSD was very important and outlined briefly their functions and powers. He pointed out that proper coordinaion was lacking and dedicated focal staff was also required. However, a recent initiative, one of the most important interventions for certification, was the mobile courts which were able to provide certificates to the needy across the rural countryside. He referred to this as a major outreach effort wherein 3700 cases were handled by 14 mobile courts moving practically door to door in the remote areas. This had increased the confidence of PWD to demand their entitlements. He made a plea for more coordination and convergence at district level as also a professionally driven mechanism for monitoring, documentation of learning and review. Grievance redressal was an important function of the outreach efforts but enough had not been done. Among the key suggestions he included were - a proactive approach; a full time commissioner; organization of mobile courts at district and block levels and a management information system at the national, state and district levels.

The next presentation was by **Rehabilitation Council of India (RCI) president, Maj. Gen. Ian Cardoza**. He found that most debatable issues on the PWD sector boiled down to an understanding of three questions/points: (i) Was disability a problem or a priority? (ii) Is the disabled person's destiny to be taken as a matter of chance or choice? (iii) Not just the government but everyone else in the sector was responsible for positive and affirmative action. The speaker introduced some of the programs taken up by RCI which included training of professionals, sensitization of school teachers and recognition of special institutions imparting training in the disability sector. It was felt that special educators could not be expected to do their best without being treated on par with general education teachers,

i.e. in terms of their salaries and other benefits. He felt that the expectations from RCI were not realistic as most people were not aware of the Council's mandate and constraints.

Mr. Ashok Hans, Executive Vice President, SMRC, Orissa spoke next. He presented a number of slides [PPT] on the functions of SMRC which was mainly to bring down barriers within society and sensitize and raise awareness about the potential and challenges of disabled persons and suggested that financial outlays for prevention itself should be increased. He noted that the participation of PWDs in employment and training had come down after late 1980s with the quick growth of hi-tech sector. He voiced the fear that under the guise of PPP, the state would try to abdicate its primary responsibility towards the disabled population of the country. As far as social security was concerned the speaker felt that even care givers and family members who were affected by disabilities of a member needed some kind of security. Mr. Hans felt that the disability sector had to be better integrated within the overall poverty alleviation program of the government and structural changes for this purpose should be brought about if required.

Mr. Harsh Mander, Director, Centre for Equity Studies said in his presentation that the World Bank report had encouraged private-public partnership, but this recommendation could create distortions in equity as there was danger of state withdrawal. Only the state had the mandate, resources, legitimacy and potent powers to reverse the injustice to PWD sector. There was a need to not only to protect rights of disabled people but also of their care-givers who were in a vulnerable position and lost out on opportunities. It was thus necessary to create demand and pressure in so far as negotiable entitlements were concerned. The speaker affirmed that the issue of rights had to be simplified and demystified so that distinction could be made between what was justiciable in court of law and what emerged from a concerted social voice. He gave three distinct suggestions. (1) Right has to be unpacked, (2) Rights had to finally become judiciable and (3) Need for concerted civic action around the matter of rights. Until this was done rights and entitlements would continue to exist only on paper. The speaker also wanted all official data to be disaggregated and the concern for the PWD reflected in every state policy and not only those specifically meant for the welfare of the disabled. He reminded the audience that ICDS was supposed to include every child in the country, yet there was no data on how many disabled children (if any) actually benefited from it.

Mr. Manoj Kumar in his concluding remarks said that status of implementation of PWD Act was not healthy but the challenges could be overcome as long as there was professional attitude, positive suo moto action, and an outreach approach. He affirmed that apex organizations like RCI needed to carry out core actions as mandated. He agreed that Mental Health Act was an area of major concern and added that initiatives for the PWD sector should be well integrated into three critical focus areas of the government that included: health, education and poverty alleviation. These were all inclusive programs, but general public awareness of the various provisions was poor.

The **open floor session** brought out concerns of the different subgroups within the sector and most comments related to judicial powers of the authorities and whether there was need for a tribunal to look after cases of violations and discrimination in particular. One participant referred to models in Australia and Canada where there was both a Chief Commissioner of Disabled as also tribunals. Another participant talked about shortage of literature in the field

of disability and that the economics of print production which did not allow for greater effort in this direction without some support. A participant from an NGO suggested an annual dialogue as a process of regular consultation between government and people working in the disability sector.

Session 4: Education of Children and Young Adults with Special Needs

Chair: Samuel Carlson, Lead Education Specialist, World Bank, New Delhi

The panel included a discussion on the vision and response in inclusive education and a floor discussion on a number of issues in education including the definition of inclusive education; the need for home-based education; institutional issues in the education of children with special needs; teacher training; and creating accessible and appropriate learning environment for children with special needs.

Ms. Richa Sharma, Deputy Secretary at the Ministry of Human Resource Development, gave a comprehensive presentation [PPT] on the key objectives of Sarva Shiksha Abhiyan (SSA) program. The ultimate aim is the universalization of elementary education providing access, enrolment and retention of all children from 6 to 14 years of age. Within this program, there is a “Zero Rejection” policy which allows for all children, regardless of their disability status, to receive an inclusive education.

The program further details that all children with special needs (CWSN) be taught in an environment best suited to their specific needs, be it in a regular school, special school, EGS and AIE centres (Education Guarantee Scheme and Alternative and Innovative Education), or home-based education. At the core of this multi-option model is the expectation that most (if not all) children will be mainstreamed into the formal education system at some point.

The implementation of this multi-option model is made possible by the level of flexibility offered to the States. Most States differ in the approaches and strategies adopted to achieve the ultimate objective of inclusion. For instance, in Andhra Pradesh, Uttar Pradesh, and Rajasthan there are residential bridge courses for CWSN with the main objective of mainstreaming CWSN for formal schooling. Whereas Rajasthan is conducting these bridge courses entirely through NGOs, Uttar Pradesh is conducting them through resource teachers especially recruited by district SSA Societies.

SSA offers a number of interventions, including surveys for identification of CWSN, the provision of assistive devices, teacher training in inclusive education, and student assessment in order to strengthen the provision of inclusive education. Furthermore, at the national level, there is a healthy respect for and significant efforts made towards capacity building. A range of resources have been developed to strengthen state capacity including a directory on the various NGOs involved in inclusive education and a manual on planning and implementing inclusive education. In particular, a lot of work is being done in concert with civil society organizations and NGOs. As Ms. Sharma said, *“We know there is enormous expertise [within the NGO sector] and we must harness this and work through them. It is not an abdication of responsibilities but rather an opportunity to learn.”*

Ms. Sharma identified three challenges in adequately addressing the needs of CWSN. The first is the identification of children with CWSN. While there has been tremendous increase

in the numbers of children identified with special needs, primarily as a result of more sensitive identification instruments and increased capacity at the school level to assess children's abilities, there are still gaps. This process needs strengthening. Second, challenge pertains to training teachers in inclusive education. SSA teachers are meant to receive 20 days of training per academic year, of which 3 to 5 days are to be spent on inclusive education. Further, SSA offers the 45/90 training, from which 1 lac teachers have already benefited. This includes practical training in addition to extensive pedagogical focus on teaching strategies, observations, planning and curricula for CWSN. The final challenge that Ms. Sharma brought up was that of providing support and incentives to States to encourage the development of a full set of interventions to meet the needs of CWSN. This could range from material development, the provision of aids and appliances, constructing fully accessible schools, or raising community awareness.

Dr. Mithu Alur, Principal Coordinator, National Resource Center for Inclusion focused her presentation [PPT] on the extraordinary exclusion that children with special needs had to endure. Dr. Alur focused on two areas where exclusion remains a challenge: (1) at the policy level, including structural and institutional barriers, (2) at the program level including SSA, Integrated Child Development Services (ICDS), and Rehabilitative Council of India (RCI). The presentation then moved towards recommendations, including the demonstration of a model that Dr. Alur helped develop in Mumbai.

At the outset, Dr. Alur suggested that there was a dualism and fragmentation in the way that CWSN and their educational needs were addressed. For instance, the separation of the Ministries of Human Resource Development and Welfare (which later became Social Justice and Empowerment) – and the subsequent dichotomy between addressing the educational needs and more broadly the rights of people with disability had led to a fractured and somewhat disjointed system. As a result, the objective of the Ministry of Welfare had become 'to rehabilitate' rather than 'to educate'. And in this vacuum, there has been no attempt to create a cohesive policy on education. Lacking a clear-cut policy directive from the top, CWSN have been excluded at the ground level.

The example of RCI was provided to illustrate how this dualism plays out: While the HRD Ministry provides training to “regular” teachers, RCI under MSJE is mandated to provide training for “special” educators. This structural fragmentation in the roles of the two ministries contributes to a lack of coherence and uniformity in the teacher training for inclusive education. In Dr. Alur's words, this continues to *“perpetuate a mystique of specialization”* that unnecessarily detracts from the push towards Education for All. Dr. Alur further remarked that despite making an enormous contribution to the education and services for CWSN, the NGO sector has also added to the fragmentation. Without continuous funding and good infrastructural support, the impact of the sector has been limited to a micro level.

Dr. Alur also brought out the weaknesses in both SSA and ICDS programs. At the fiscal level, she highlighted both a lack of funding (inclusive education receives only 1 percent of the SSA budget) and a lack of disbursement, with great disparities by State. She also discussed systematic issues in SSA including the lack of a strong data system and monitoring and evaluation program that would enable states to track their ongoing progress and remaining challenges. Dr. Alur's biggest complaint against the ICDS program was the absence of CWSN within the programs due in part to a lack of properly trained Anganwadis.

To demonstrate models of successful inclusion, Dr. Alur provided examples of the Spastic Society of India's schools where components of assessment, education, health, and treatment are provided in a holistic environment under one roof. Similarly, she described two projects – the National Resource Center for Inclusion and the Early Intervention in Inclusive Education – both of which focus their activities on actualizing inclusion at multiple levels including the classroom, community, and policy. The Resource Center has four main units that include policy studies, demonstration, project management and public education. The Early Intervention project has two key components, intervention modules and the research studies. The former tries to demonstrate 'how' to successfully implement inclusion while the latter tracks the changes in the children and the community over two years.

The work of Dr. Alur and her staff has had significant positive outcomes on the community including, but not limited to, the enrollment of over 5,000 children in assessment and remedial programs, the admittance of 3,000 disabled and non-disabled children into inclusive nurseries, and the development of over 300 models of employment.

Certain policy and systemic recommendations were made which included first that the target group, people with disabilities, must be clearly defined. Second, to prevent exclusion from programs and budgetary allocation, there should be a positive discrimination clause included that would specifically include people with disabilities in all schemes run by the government. Dr. Alur also highlighted the need for the development and implementation of a strong data and monitoring and evaluation system, the introduction of Public-Private Partnerships, and strengthening of teacher training programs.

The **open floor session** included the nature of inclusive education in terms of different disabilities, improving efforts made to include children with cognitive and intellectual disabilities, the roles and responsibilities of the HRD Ministry versus those of MSJE, and the potential dangers of home-based education, and the lack of a mention of "inclusive education" in the eleventh Five Year Plan. Ms. Sharma clarified that the intention of home-based education was not to confine certain children to their homes and parents are counseled about the need for mainstreaming their child when appropriate. A participant commented that while the eleventh Five Year Plan discusses the provision of special education, including distance, home based and vocational education, where required, there is no mention of inclusive education. This was indicative of the "fracture" that Dr. Alur described. A participant commented that the specific needs of hearing disabled children are not addressed in the educational system. Both Dr. Alur and Ms. Sharma agreed and Dr Alur added that it was essential to create a continuum of support in inclusive education. She clarified that implementing inclusive education requires adequate preparation. In her words, ***"You have to prepare the ground for inclusion. You have to develop the ethos, prepare the heads, teachers, community, and children."***

DAY 2: PRE-LUNCH:

Session 5: Health System and People with Disabilities.

Chair: Philip O’Keefe, Lead Social Protection Specialist, World Bank, New Delhi

Dr. G N V Ramana, Lead Public Health Specialist, World Bank focused his presentation [PPT] on the importance of prevention in a dialogue on health care and disability. He started by suggesting that seeing people with disabilities (PWD) as patients was the pervasive lens used by health providers, and this was the biggest challenge in dealing with disability in the health sector. He added that in health, there had been little success in moving away from a medical model of disability.

While people with visual and locomotive disabilities were the largest percentage of PWD, Dr. Ramana’s research had shown that within these disability groups, the biggest causes were preventable – 23.4% of people with some form of visual disability have cataracts, 30.9% of people with locomotive disorders suffered from polio, while another 28.5 % were victims of burns and injury.

Dr. Ramana took up briefly six challenges in the improving the implementation of preventive strategies. One of the serious challenges was childhood immunization. After dramatic improvements in the 1980s in this area, numbers of children being immunized has stagnated around the 50 % mark for the last three years. There continue to be wide disparities in performance between the states, for instance some states in the western and southern parts of India have close to 90% coverage while others are as low as 10%. Strategies to bridge this gap include improving infrastructural deficiencies such as vaccine delivery strategies but this will take time.

Next, Dr. Ramana discussed the eradication of polio. Despite very steep declines in the incidence of polio due to tremendous work of the Government of India and World Health Organization, there was still continued transmission especially in western parts of UP. In 2006, eight catch up rounds of immunization were held to try and eliminate remaining cases. Addressing the more comprehensive needs of sanitation and personal hygiene rather than focusing on repeated doses of the vaccine was presented as a potential strategy worth trying out.

Blindness was the third challenge that Dr. Ramana touched on. While there have been significant efforts to curb the numbers of cataract cases in India, quality post-surgical follow up remains a challenge. To address this, the government has decided to eliminate conducting procedures in eye camps; cataract surgeries are conducted in district hospitals while screening continues in camps. This immediately decreased post-operative complications. Providing micronutrient supplementation was the fourth challenge discussed by Dr. Ramana who spoke about the difficulties in facilitating behavior change to take Vitamin A and use iodized salt.

The last two challenges in the area of prevention were improving the access and quality of maternal health and improving road safety. An innovative program, *Janani Suraksha Yojana*, implemented by the Government of India, provides Conditional Cash Transfers to expectant mothers and preliminary evidence is showing an increase in skilled care at childbirth. This

will hopefully contribute to substantively improving preventive care for disabilities. On road safety, Dr. Ramana added that this remains a big challenge as the contribution of injuries and burns to disability is on the rise.

Dr. Vibha Krishnamurthy, Medical Director from Ummeed Child Development Center, began her presentation [PPT] on the importance of early identification and screening by sharing a story about a two and a half year old girl from a rural area in Gujarat. She was repeatedly misdiagnosed, unnecessarily hospitalized, and essentially traumatized by her experience to the point where she stopped speaking entirely. Only after she was brought to Ummeed was she properly diagnosed with autism and is at age 10 finally starting to dress and feed herself and speak using a few signs.

Dr. Krishnamurthy used this case study and more broadly a discussion of autism as a powerful example of the challenges and gaps with early identification in the medical system in India. She pointed out that there were an estimated 4 million children with autism in India but only a very microscopic percentage of these were actually diagnosed. For instance, according to a study conducted in 2005 at All India Institute of Medical Sciences only 62 patients were diagnosed with autism in one year. Similarly, there is a huge time lag between when parents first develop concerns about their child (the mean age was cited as approximately 2 years) and when they are actually diagnosed (almost 5 years). Dr. Krishnamurthy provided a number of compelling reasons for this delay and shortfall in diagnosis including the perception that autism is a “rare disorder” and the belief that the Indian male child starts speaking at a later age.

The presentation moved to a discussion of the importance of early screening as a powerful way to identify children who may need more comprehensive assessment. Using a simple ten question parent-reported questionnaire helps in the early identification, and finally, early intervention with respect to children with special needs. Administering the questionnaire does not require extensive training or expertise nor does it take much time yet it offers superior sensitivity. According to Dr. Krishnamurthy, parents are best suited to identify a disability in their child provided the right approach is used.

Mr. Carmo Naronha, Executive Director, Bethany Society, Meghalaya, echoed the sentiments of the earlier panelists on the need to de-mystify and de-medicalize disability. He mentioned his unique experience in Papua New Guinea where in a school he found everyone using sign language though many had no impairment in hearing or speech. He pointed out that most Ministry-funded projects were cornered by urban areas and State capitals and 90% of grants thus went to 10% PWDs. His presentation was thus very much focused on the needs of the rural poor who according to him made up 90% of the disability community but continue to benefit from only 5% of spending. For this population, in particular, there is a great need for community-based rehabilitation (CBR) services that provide an integrated treatment and services for people with disabilities at the community level. He found it strange that many Indian CBR experts were going to east Asian and African countries to set up CBR programs while India did not have a national program.

Mr. Naronha suggested that first it was necessary to remove the terms “special” and “normal” from the health sector. The more these terms are used, the harder it becomes to have a truly inclusive model. CBR is not a medical intervention but rather a set of

comprehensive services for people with disabilities. *Therefore not disability but CBR has to be mainstreamed.* The second recommendation in reaching the hard-to-reach was to strengthen the mechanism of service outreach at the sub-district level. One of the greatest challenges was finding innovative, timely, and efficient ways to provide services to people at the grassroots level. Finally, Mr. Naronha suggested the development and implementation of a national strategy on CBR that would eventually culminate in a national institute on CBR.

Dr. Nimesh Desai, Professor & HOD of Psychiatry from the Institute of Human Behavior discussed mental health and mental illness as it relates to disability. According to him, the old issue of lunacy and lunatic asylums is not yet far removed from our collective memory. This has led to an acute shortage in rehabilitative and residential places for people with mental disabilities. Currently, there are 2,000 or less locations while the need is for 10,000 or more. Even when initial treatment is provided, follow up care including rehabilitation and shelter is mostly absent. This gaping hole contributes to a new spate of disabilities while providing opportunity for discrimination and exploitation. For instance, a study in collaboration with the National Commission on Women on a situational analysis of homeless women finds rampant and repetitive sexual abuse. The women have little knowledge of services available to them or of their rights and entitlements. Another study conducted by Dr. Desai on urban and rural health finds a tremendous discrepancy between those in urban locations in need of mental health services and those in rural areas. This is in part a result of an alarming deficit of human resources in rural India.

The speaker added that much of his work involved reaching out to all segments of the medical industry on the possibility of both treating most mental illness if not controlling it through medication. There is a tremendous amount of room to integrate people with mental disabilities in mainstream society. For Dr. Desai, this has not yet been effectively communicated to policy makers and he urged mental health professionals to get more involved in this.

Though it has been largely beneficial to the mental illness sector and those with mental disabilities and their families to be grouped with other disabilities in the PWD Act of 1995, when it comes to implementation on the ground it is worthwhile to at least consider a separate paradigm for mental illness or more broadly for the larger group of psychosocial disabilities.

Finally, Dr. Desai touched on some factual inaccuracies related to mental health in the World Bank report. On page 54 for example, it is reported that India has a mental health policy that was formulated in 1982. However, till date India has had no mental health policy to speak of. He further pointed out that the line graph on page 34 of the report that illustrates the age of onset of mental disability needs to be amended. He clarified that with mental illness there aren't really any peaks or "humps" though the diagram and the subsequent discussion describes an early childhood onset followed by age group 20-30 years.

The open floor session centered on some critical prevention issues. A participant commented that 6% of the Indian population (according to WHO figures) suffered from sign auditory impairment. Of these 6%, exactly half are treatable while the others are preventable. Therefore, early diagnosis and intervention can make a significant difference to overall outcomes. The question was raised whether Anganwadi schools were a good starting point

for early identification and screening at the grassroots level, as Dr. Krishnamurthy suggested, when in fact children with severe disabilities were not attending such schools. It was noted that the World Bank report confirms that only 25 % of children with disabilities actually attend primary level schools. There was also a comment made about the need to really strengthen sub-district provision of services at a cross-disability level rather than to continue the proliferation of vertical (single disability) programs. The mental illness sub-sector was identified as group which had lagged behind other PWD groups.

Session 6: Employment and people with disabilities.

Chair: M. Ravi Kanth, Chairman and Managing Director National Handicapped Finance Development Corporation (NHFDC).

Mr. Philip O'Keefe presented [PPT] briefly the findings on employment documented in the World Bank report. He found no good explanation as to why employment rates among PWD were falling. But those living in rural areas fared better. Mental illness had strong negative impact while education was somewhat significant only at the post-graduate level. It was also pointed out that the studies in Tamil Nadu and Uttar Pradesh had confirmed that persons involved with caring for the disabled also lost out on employment opportunities and in almost every HH with a disabled one such person could be identified.

The first presentation following the introductory remarks was by **Mr. Ravi Kant** of National Handicapped Finance and Development Cooperation (NHFDC). He gave a presentation [PPT] enumerating the brief history, aims and goals of the organization and its achievements till date in facilitating employment for the PWDs through financial loans and entrepreneurial training. He also mentioned that NHFDC was operating several schemes of micro-credit assistance to PWDs through numerous NGOs and affirmed that there was a conscious effort to liberalize the assistance policy. The interest rates were quite reasonable at 5-6% with easy repayment schemes. A special scheme for women *Mahila Samridhi Yojana* had also been initiated. He however, agreed that not enough people had been able to benefit and till November 2007, only around 31330 beneficiaries had got assistance through state channeling agencies (SCAs). A total amount of Rs. 152.30 crores had been disbursed. Loan recovery was in some cases a problem and some states like AP had been blacklisted for sometime. He underlined importance of self-discipline and social-discipline and improving efficiency of SCAs to ensure that the mission of the organization was fulfilled. The speaker suggested that State Government should have a separate organization as well as budget for disability welfare. Mr. Ravi Kant concluded his presentation with some stories of entrepreneurial success among the physical disabled, who had benefited from financial assistance schemes of NHFDC.

The next presentation was by **Mr. Sujit Gupta** of the Confederation of India Industry (CII). He stated that CII had 6000 members and employed around fifty lakh people of whom only 0.2% were disabled. It was hoped that this figure would be taken to 1% in the next year or so. Mr. Gupta referred to a survey done by his office which had shown very low level of sensitization among the industrial employers; as a result CII had initiated four special forums in each region in association with government and NGOs to sensitize industry on the potential of disabled persons as productive workers and the need to provide them suitable

employment. It was pointed out that several sectors like hospitality and IT were already doing a good job in so far as employment of PWDs was concerned. However, several other sectors also had potential to do the same.

Ms. Sudipta Bhadra representing an organization called Partners in Change (PiC) spoke next [PPT]. She said that it was important to note that the formal sector which was reserving some posts for PWDs and trying to enhance employment opportunities for them, represented only 10% of the employment sector and 90% employment was in the informal sector. In fact a study had revealed that around 54% disabled people were already employed in some form or other in the agriculture sector. Referring to a major survey carried out by PIC in 2006-07, Ms. Bhadra pointed out that unfortunately the public sector absorption of PWDs was also done to meet statutory requirements and factors like stigma, work environment per se and social acceptance were equally important to improving the situation in the workplace. With regard to industry she affirmed that core business strategies of companies did not demonstrate inclusive principles and despite greater awareness of corporate social responsibility, the sheer diversity among the disabled remained a major problem. From the PIC study, certain positive attributes of PWD employment had emerged like good attendance record, low attrition rate, good productive and inter-personal skills, etc. There was a need to produce sector-specific studies like garment, IT, retail, etc. to see how specific categories of disabled could be suitably trained and absorbed in the sectors. The speaker felt it was necessary to also provide fiscal incentives to small and medium enterprises (SMEs) as they had substantial potential for employment of PWDs. Ms Bhadra informed the house that PIC was planning to come out with a portal that would list names and qualifications of PWDs which employers could access to find suitable candidates from the disabled population for positions in their enterprises.

The next presentation was by **Ms. Anubhuti Mittal**, President, HR Consultancy for PWD, an organization working to provide employment to the disabled population. She referred to some of the important points made by the World Bank study and said that there were serious accessibility issues involved. She affirmed that the 3% reservation policy in the Public Sector was not operating in the true spirit of the principle. It was necessary to target a broader spectrum of the PWD sector rather than identity within existing jobs what could be done by a certain group of PWD. It had been found that the general public had almost no knowledge of the disability sector in general or specific problems of certain categories. This meant that potential employers of PWDs needed special knowledge on disability to identify potential positions for employment. She referred to the work by an organization called Worth Trust which had achieved significant success in training and employing persons with disability who were their absorbed in manufacture of brake parts in trucks.

During the **open floor session**, several questions were raised on making technology more disabled friendly and the need for a ready reference on the various sectors of business which could be useful for potential employers. One participant commented on disabilities taking place in mid-career and felt that a senior PWD officer had better chances of creating a proper environment in any organization than others. Another participant mentioned that there was huge gap between the reality in the field and what was said in different forums by ministry officials or other agencies working with PWDs. Major Gen. Cardoza reminded the house that a lot of young man left the armed forces as disabled people and 70% of disabled soldiers lived in rural areas. It was also necessary to bring on board religious organizations like

Ramakrishna Mission and the Church in this sector as they were already a major stakeholder in developmental and humanitarian work.

Mr. Ashish Kumar requested members to put down their concerns on paper and give him a chance to take it up at the appropriate level before the 11th plan document was finalized. He assured the house that the Ministry had the best interest of PWD in their heart and what MSJE needed was support to make a stronger case for better allocations and policy amendments for this large segment of population.

Session 7: Accessibility and People with Disabilities

Chair: Ashish Kumar, Deputy Director General, Ministry of Social Justice & Empowerment

Mr. Sanjeev Sachdeva, Founder and **Ms. Anjee Agarwal**, Executive Director of **Samarthya** began their [PPT] presentation on accessibility by asserting that there was a multiplicity of accessible standards; from the Central Public Works Department's standards to a Manual by the Chief Commissioner for Persons with Disabilities, to sets of personal standards developed by Disabled Person Organizations. The resulting confusion has meant that the standards are not applied uniformly nor are they updated regularly. Similarly, the National Building Codes are recommendatory and not mandatory in nature. Local governments have the power to enforce these codes, but unfortunately because there is no uniformity in building by-laws across locality and because no minimum standards have been developed, accessibility standards have just been ignored.

Samarthya's work is to raise awareness around issues of accessibility with the intention of changing attitudes and generating human capital and resources in this sector. Their primary strategy is to bring together in a spirit of cooperation and coordination user groups and service providers. A cycle evolves where there is sharing of information, policy and planning, implementation and monitoring, and the development of user friendly designs that will benefit all segments of society.

Their approach and their collaborative work have had significant tangible results. A few examples are Indian Railways who have developed a prototype for an accessible coach (including toilets); low floor buses in Bangalore; and Dilli Haat in Delhi which is accessible to people with disabilities. There are 197 accessible bus shelters in the New Delhi Municipal Corporation (NDMC) area. Several other examples of innovative design related to user-friendliness for specific disabilities were cited.

Among the recommendations put forward by the speaker for the future was setting up a National Research and Resource Center on Accessibility, developing cost-effective indigenous solutions, uniformly certifying buildings, and creation of a pool of accredited auditors including architects, engineers, and persons with disabilities.

Ms. Shivani Gupta, from AccessAbility, focused her discussion [PPT] first on expanding the very scope of accessibility because "*Accessibility is the key enabler of inclusion.*" According to her, when people think of accessibility they most often think just of physical access. However, accessibility is not just about access to a service and should include access to information as well. She provided the example of voting: While the polling booth needs to

be accessible, it is also important for a person with disability to have an alternate facility to vote, whether by phone or using some assistive device. The expanded notion of accessibility includes physical access as one piece but also access to services, access to information, building operation and management, assistive aids and appliances, inclusive policies and procedures, and finally attitudes.

Following this, there was a discussion on the policies and legislation, in particular, how accessibility is addressed in the People with Disabilities (PWD) Act of 1995. Ms. Sharma affirmed that accessibility was mentioned in the chapters on education, employment, and non-discrimination. Specifically, it is ensured that children up to 18 years of age have access to free education in an appropriate environment and that appropriate health and safety measures are taken and there is “a creation of a non-handicapping environment in places where persons with disabilities are employed.” Sarva Siksha Abhiyan (SSA) also addresses accessibility, recommending that all school buildings and facilities be accessible by 2020. Finally, the National Policy on People with Disabilities suggests that “to the maximum extent possible” all roads, highways, buildings, transportation systems are made barrier free. There is mention of accessibility in the tenth Five Year Plan, more specifically that public buildings be certified for accessibility, that public utilities such as buses and railways be made accessible, that efforts be made to usher “barrier free” environment in the private sector, and that the Swarna Jayanti Shahari Rojgar Yojana program allocate 3 percent of their resources for the benefit of PWD. However, Ms. Gupta pointed out, no funds had been allocated to actually implement any of the above.

After going through some successes and failures in dealing with accessibility, Ms. Gupta looked at the weaknesses and gaps in the system. Her first point was that accessibility, in the PWD Act, was not a right but as an “add-on” on the economic capacity of the provider (“within the limits of their economic capacity and development”). The Act itself only applies to government and public sector, and does not even extend to public use buildings such as theaters, restaurants, etc. And the Act fails to give any kind of direction on policies and regulations that should be drafted by other ministries to have inclusion as part of their mandate. There are no actual standards defined when it comes to accessibility and moreover, the terms *accessibility*, *non-discrimination*, or even *public building* are not defined leaving much scope for conflicting interpretation. Finally, there are no measurables to chart the progress or the direction being taken.

As a result, none of the secondary legislations have incorporated accessibility. There is poor institutional coordination between ministries and departments in the public sector. Professionals, such as architects and engineers have little or no awareness about accessibility issues. And accessibility is not being incorporated into the tremendous infrastructure development taking place in the rapid growing economy of India. Ms. Gupta provided several recommendations that included: (1) Accessibility has to be made a matter of right; (2) Accessibility, non-discrimination, and public buildings/space have to all be clearly defined; (3) Access has to include access to services; (4) Inclusion has to be made critical to public spending; (5) The secondary legislations have to address inclusion; (6) the PWD Act must give timeframes and monitoring procedures; and (7) Accessibility standards should be binding and there needs to be some punitive action against non compliance.

Mr. Sarabjit Singh, an independent consultant, in his presentation discussed capacity building in the context of accessibility [PPT]. He modified and adapted the procurement system used by the World Bank to reflect the status of the system and help identify gaps. The guidelines are based on four pillars. For a system to perform properly, the first pillar is the legislative framework. The understanding here is that in order to have accessibility, one needs a legal framework which is not just an act but also the instructions, guidebooks, secondary legislations, etc. The second pillar is institutional and management capacity. This includes the organizational structures and management capacity to lay down the framework. There is the institutional architecture of the system but more important is how the framework operates in practice. The third pillar is the operations and PWD assessment which evaluates how every facility works. Is it accessible? How did it operate in practice? How do you assess if it is operating properly or not? What do disabled people themselves say about how it is operating? The fourth pillar is transparency which looks at whether there are appropriate measures to address potential non compliance of the implementation of the system in accordance with legal and regulatory framework. For example, when looking at a building it involves whether the whole process of certification was transparent or not. Each of these pillars includes several indicators by which they are measured and based on that a final assessment is made. A rating is given on a scale of 0 to 3 where a score of 0 implies complete non-compliance.

Mr. Singh's analysis brought out that on the first pillar of the legislative framework the current system receives a score of 2 out of 3. On the second pillar of institutional and management capacity, Mr. Singh gave a score of 1 on 3. The third pillar of operations and PWD assessment got a score of 0 while the fourth pillar of transparency got 1 on 3. Based on the following gap analysis, Mr. Singh provided several recommendations on each pillar to improve its rating. Strengthening the legislative framework would involve providing principles for deciding economic capacity; providing a list of statutory duties; developing qualifications for certification; and developing a handbook of acceptable practices. Institutional and management capacity can be improved by ensuring that planning, budgeting and financial rules include accessibility; completion reports include accessibility; a regulatory model that can enforce judgments is developed; there is a strong information system; and an institution of accessibility and universal design. The third pillar of operations and PWD assessment can be strengthened by the development of rules, procedures, training and documentation for entity managers/operators; by developing a mechanism for NGO partnership and interaction with operators; and by establishing procedures to resolve disputes with operators for non maintenance of accessible features. Finally, on transparency, Mr. Singh recommended the development of a legal framework for the periodic audit of facilities for their accessibility; establishing a timeline for the resolution of disputes; providing information on accessibility for dispute resolution; and enforcing penal measures for entities and individuals.

During the **open floor session**, several comments and suggestions were made to take into account the needs of people with multiple disabilities, in particular people with visual and hearing impairment or people with mental illness when thinking about accessibility. The various groups within the PWD sector underscored their own individual problems. While the persons representing the visually handicapped wanted more material in Braille including those emerging from forums like this workshop, a participant speaking for the hearing impaired wanted to know why they could not have driving licenses in India when it was

allowed in many countries and data showed that this group was doing quite well in terms of accidents record. There was also a short discussion on the benefits of marketing accessibility as a public good that benefits everyone and not just PWD. As one individual commented, ***“Inclusion and accessibility benefits everybody, if we talk about it as a moral imperative we lose our audience.”*** One suggestion made was that hand tactile facilities had to be promoted more than other facilities for the blind. Mention was made of a new policy coming up with civil aviation that would help PWD. There was a question asked about accessibility issues in rural areas since most of the discussion was urban-focused. Mr. Sachdeva said that Samarthyaa had worked with rural areas in Karnataka and Gujarat, as well as some post-tsunami work in Andaman. They had recommended to several state ministries to conduct a study on rural population needs.

As a side note, a participant informed the gathering that after extensive meetings with the Planning Commission they revised the section on disabilities and it substantially met the needs of the diverse stakeholders involved. This announcement was greeted with applause and the chair thanked the participant for sharing the news.

DAY 2: POST-LUNCH

Session 8: Attitudes and Disability

Chair: Ms. Sruti Mohapatra, Secretary General, Swabhiman, Orissa

An award winning film entitled “I, Alok” arranged for by the NGO Brotherhood was shown on disability as the first item of session.

Ms. Sruti Mohapatra of Swabhiman gave a presentation on attitudes as it was reflected in government policy and in society and culture. She mentioned several instances from her own life as examples of attitudes embedded in institutions and individuals. She stated that it was important not only to sensitize and build awareness but include simulation exercises in such programs, so that participants could actually have experiential learning. One wing called **Sandhan** was in fact working with school students with this approach which included using wheelchairs and blind folding. Ms. Mohapatra referred to disability day organized in Orissa which was featured in the media. Speaking of Hindu mythology, she said that it reinforced both positive and negative attitudes as it was basically ambivalent in its depictions. But the belief that disability was a result of past sins was very old and continued even today.

The next presentation was by **Mr. Zamir Dhale**, Advocacy Officer of Sense International. Being both visually and hearing impaired, Zamir addressed the audience using tactile language through an interpreter. Zamir referred to not only his own case but two of his close friends who faced social discrimination and were unemployed because of their disabilities. Both were computer literate and able to travel independently. Then he mentioned the story of a girl who was disabled and also had other health problems. His presentation brought out the poignant reality and the tough lonely life of the deaf and blind. But he gave some success stories also of people who had overcome their disabilities to live a fuller life. Zamir mentioned that he was working for Sense International as an advocacy officer and trying to help others facing his situation. He concluded by saying that his own interpreter was his vital link to the external world.

Mr. Deepak Jain from SAARTHAK gave a brief presentation on mental health particularly the problems of living with schizophrenia. He said that a lot of answer lies with one's attitude to mental disorder. He brought out three case studies including that of a woman to show the special challenges that their lives brought to them. The anguish, anger, frustration of living in a society which does not accept mental problems as just any other illness, was made amply clear.

The **open floor session** produced several comments from participants including the lack of availability of literature on disabilities, low interest level of media for PWD issues and the difference between India and the Western world with regard to attitudes towards the disabled. One participant suggested that attitudinal change was also required among PWD themselves in so far as expectations from society were concerned.

The presentations after this looked at media and public discourse. **Ms. Rema Nagarajan**, from the Times of India admitted that disability per se did not make news but a lot of news related to PWD could not find space because they were not well packaged. She explained the intricacies of developing a proper copy to ensure publication in a newspaper. She clarified that most stories concerning the PWD sector was not "hard" news. At the same time a story which was supplemented with interesting facts and figures on a broader canvas had a better chance to get published. She felt the nodal ministry and agencies like the CPD (Commissioner for Personal with Disabilities) should become more proactive in pushing awareness about the sector to ensure a place in media.

Dr. Mala Kapur Shankardass, Managing Trustee & Chairperson from Little Things Matter, gave an exposition on aging and disability [PPT] and found the World Bank report needed to cover the subject more adequately. The NSSO 58th round had brought out data on age related disability particularly blindness and loco motor disability. Dr. Kapur mentioned that despite so much work being done on aging and age related issues not enough effort had been focused on age related disabilities which required community response and services.

Mr. Satish Kumar, General Secretary, Brotherhood spoke of the work of his organization in sensitizing journalists, other media people, and filmmakers. He referred to a series of workshops organized by working journalists with the support of RCI and Indian Institute of Mass Communication. The speaker felt that this was an important part of community effort to bring social issues to the forefront.

The **open floor session** produced comments and questions on the role of media in highlighting critical issues of the sector. One participant commented that NGOs and professionals working in the sector could not be expected to write good press releases or understand the behind-the-scenes dynamics that operated in the media world. Another participant felt that the media was too interested to sell its products through celebrity news to have much time for serious issues. Comments were made also on the social responsibility of the media and the example of Indian DD channel was given which started sign language news when the matter was pointed out to the then PM Mrs Indira Gandhi. Ms. Nagarajan explained the constraints inherent in the industry but admitted that the media had a social responsibility which could become more focused through public awareness and pressure..

Session 9: Social Security and Disability

Chair: Mr. Anil Swarup, Director General, Ministry of Labour Welfare

Mr. Anil Swarup, Director General, Ministry of Labour Welfare, gave a brief overview of social security programs, in particular for the unorganized worker. Because this sector makes up over 90 percent of the entire workforce, there is a focus on providing services and schemes to specifically address their needs. For instance, a lot of work is going into rolling out a national health insurance scheme where each family (of upto five members) below the poverty line is given insurance, where their only payment is a yearly premium of 30 rupees for an otherwise cashless service. Using “smart card” technology, the ministry is taking one-fifth of the country’s districts (and an additional 1/5th every year for the next four years thereafter) and providing this service. Families are able to go to any hospital within their network and because their information is saved on the smart card they are able to avail of medical service. Any pre-existing condition is also covered, which is valid throughout the country. Mr Swarup felt that this was just the beginning and the program would soon be further refined and its coverage expanded to reach the remotest of areas.

The costs of the program are shared by the central government which is contributing 75 percent while the states pay 25 percent. On the service providers’ side, it is mandatory for hospitals to tie up with the card. The beneficiary is, according to Mr. Swarup, *“without hassles because the hospital settles directly with the insurance company.”*

Mr. Robert Palacios, Sr. Economist, World Bank discussed anti-poverty and social security programs for people with disabilities (PWD). He analyzed four broad types of programs in his presentation [PPT]: (1) reservations under various centrally-sponsored anti-poverty programs, in particular public works, targeted credit and publicly-financed housing schemes for the poor; (2) unemployment allowances for PWD; (3) social pensions for destitute PWD, i.e. monthly social assistance cash benefits; and (4) 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 new initiatives on social insurance to the unorganized sector.

With the anti-poverty programs, Mr. Palacios affirmed that though the PWD Act commits to a reservation of 3 percent in all poverty alleviation schemes for the benefit of PWD, where data is available it appears that PWD have been well below 3 percent of the beneficiaries in all schemes. World Bank reports find, for instance, that for the Swaranjayanti Gram Swarozgar Yojana (SGSY), the share of PWD beneficiaries in the total did not reach above 1.7 percent for states reporting in the period 1998-2003. Similarly, the number of PWD benefiting from the IAY housing program are also well below the targets of the PWD Act. Data are available for fewer years, but 2003-04 data indicate that only around 0.8 of all beneficiaries were PWD.

With unemployment insurance, again, the PWD Act provides for only “within the limits of [employers] economic capacity and development,” which is not a binding entitlement as such. It is also additionally challenging to compile data due to large state variations in existence and generosity of the program. According to Mr. Palacios, only Tamil Nadu, Andhra Pradesh and West Bengal had unemployment schemes as of 2004. Other States including Karnataka, Maharashtra, Himachal Pradesh and Manipur had introduced programs, but again, the World Bank found that benefits were not being paid out.

Disability insurance as well has not made a significant impact on PWD. A primary reason for the low coverage is that the benefits have been largely confined to the formal sector, and therefore more concentrated among the better-off. The largest scheme for unorganized workers is Janashree Bima Yogana (JBY), which is a bundled life and total/partial permanent disability product of LIC and covered over 3.6 million households as of 2006.

By contrast, social pension programs for destitute PWD are far more pervasive. Although the data available does not allow for a thorough analysis of beneficiary and spending numbers on disability social pensions, and despite significant variation in state spending, it is clear that these programs are the single most important PWD-specific benefit in the social protection system in terms of coverage and the level of benefit received.

According to Mr. Palacios, apart from social pension, most social security programs have not met their specified targets mostly because of lack of awareness, information, and not knowing what one is eligible for. That explains higher coverage in some programs or variations across some states. The government, along with civil society organizations, need to make more of an effort to raise awareness in this regard.

During the **open floor session**, questions and comments were asked on a number of topics. First, a few individuals were concerned about how the health insurance program described by Mr. Swarup would impact PWD or how accessible the smart card technology would be for those with disabilities or limited literacy. Mr. Swarup affirmed that the insurance would be provided to everyone regardless of disability and that this mandate was very clear. He clarified that anyone able to pay the premium is enrolled in the program, and no extra premium would be charged to PWD. He added that he intended to collaborate with local NGOs to raise awareness and carry the scheme to the people. The government will be organizing district and state level workshops to sensitize people on the scheme. Another group of questions were around what criteria/documentation was needed to get registered for the program to which the response was that nothing was required. The list of those families below the poverty line as issued by the Planning Commission is available and that is all that is required.

Session 10: Closing Session – The Way Forward

Co-chair: Mr. Ashish Kumar, MSJE and Philip B. O’Keefe, World Bank

This was the wrap-up session summarizing the discussions of the two days deliberations. **Mr. Ashish Kumar** from the ministry, speaking first, said that many aspects given in the World Bank report had been discussed in the past two days. It also emerged that many aspects had been missed out in the report. This conference was an enriching experience as it brought together expertise and experiences of the whole sector and pointed to ways in which solutions could be found. Mr. Kumar hoped that many of the suggestions that had emerged would finally find their way into amendment of PWD Act and future policy and programs. It is necessary for the nodal ministry as also other stakeholders of the sector to now seriously identify the critical issues to be addressed following the signing of the UN convention.

Mr. Kumar reminded the house that the 11th plan was an opportunity not only for the ministry but for the sector as a whole to make the best use of the resources available. He felt that well documented proposals and innovative projects seeking funding would be welcome and clarified that the responsibility of fund utilization also lay with the fund users. Finally, Mr. Kumar mentioned that international cooperation for this sector had been given a fillip under the UN convention, and MJSE and World Bank were looking forward to more collaborative association in the near future in the sector. He concluded by saying that he hoped the association would fructify in new projects assisted by the World Bank.

Mr. Philip B. O’Keefe speaking on behalf of **World Bank** first thanked everyone for their enthusiastic participation and patience. With regard to the World Bank report he expressed his happiness that the way forward was clear in terms of the work entailed in revision and finalization of the report. He once again invited the participants to send in any written comments/suggestions for inclusion in the proceedings or for consideration during finalization of the report. Mr. O’Keefe referred to three categories of effort in terms of revision work. (1) *factual corrections*; (2) *Interpretation*: these were cases where the Bank study had not interpreted certain information correctly or accurately (i.e. RCI’s role, etc.); and (3) *Inclusion of new ideas/experiences*: this would enrich the report and was the main rationale behind sharing this draft with such a large gathering. He felt that it had clearly emerged that in the Indian context, policy and programs to address PWD issues had to penetrate the rural areas below the district level to be really meaningful.

Mr. O’Keefe expressed the hoped that the World Bank would continue to do productive work in this sector and was quite willing to take up new projects in association with the ministry. He also admitted that the PWD sector did not have a high profile within the World Bank itself and asked the participants to provide the necessary “push” to ensure that PWD issues were included within the Bank’s overall development and poverty alleviation agenda.