

**Consultation on Identifying Best Practices in Early Detection and Intervention for
Children with Disabilities,
17th February 2010
Vigyan Bhavan**

A Consultation to identify best practices in early detection and intervention for children with disabilities was organized by the National Commission for Protection of Child Rights (NCPCR). *Mr. Lov Verma*, Member Secretary, NCPCR, welcomed the participants by flagging the need to strengthen the policy framework in this field.

2. *Prof. Shantha Sinha*, started her address by thrusting upon the point that the agenda that all children (0-18 years) are same and equal needs to be pushed. Every child should be seen with a legal support and the NCPCR will have to ensure each and every right to all the children of this country. The disabled children must get their entitlements irrespective of their family status and location in the society. Rigorous research work needs to be done in this area so that the field reality is understood as it is and informed view-points should be the basis of all policy decisions and actions. There are only 30,000 trained professionals in the country in this area and services of para medics are essential so that a substantial effort can be made to save every possible child from this life-long trauma. ICDS services have to be strengthened. The system in the ICDS, family, civil society and homes has to be supportive and a plan has to be developed for micro-level interventions.

3. *Mr. P.C. Sharma*, Member, National Human Rights Commission (NHRC), impressed upon the need to identify children with disability and put in force a prevention plan in this area. He shared certain revealing statistics with the group that not all Indian children up to two years of age are still fully immunized, 80% of them are anemic and many of them suffer from locomotive and hearing disability. This is a gross denial of right to life with dignity. Mr. Sharma opined that family is of utmost importance in the early detection plan structure. The issue of children with disability needs to be looked in a comprehensive manner and not broken into several stakeholder's projects and schemes. A sound mechanism for collecting data on children with disability should be put in place.

4. *Dr. Renu Singh*, from 'Save the Children' made a presentation on "Overall Status of Children with Disabilities" and suggested that National Human Rights Commission(NHRC) should be included for all such consultations Her presentation revealed glaring facts that the states of Uttar Pradesh, Bihar and Assam have same number of disabled children as the Pakistan, Bangladesh and Iraq has. The scale of challenge is magnanimous. There is a Constitutional framework in India for rehabilitating disabled children and in the context of school education. We have IEDC and SSA which have incorporated the concern for children with special needs.

Children with disability are subject to multiple deprivations as they are generally from the low socio-economic groups and have limited or no awareness of their rights and entitlements. According to the study conducted by Save the Children ,94% of families with disabled member have not heard of Persons with Disabilities (PWD) Act, 1995 in rural Tamil Nadu and Uttar Pradesh. Dr. Singh also brought the group's attention to the point that disabled children do not make a homogeneous group.

She further explained that a tandem has developed between an acute lack of services for disabled children, attitudinal blocks of the larger society, lack of information among parents as well as service providers, and the missing convergence between various agencies. The resolution of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is, therefore, an ideological one requiring social change, which at the political level becomes a question of human rights.

5. *Dr. M.K.C Nair* from Child Development Centre, Medical College, Kerala started his presentation by informing that they have constituted a group of specialists on rehabilitation of children with disability. The scale of the challenge is huge and needs to be kept in mind while developing a policy perspective. We need to spread information among children about the PWD Act through school and other channels. We must use the channel of Panchayati Raj in order to reach the children with disability and especially for children in 0-3 years of age group because they can be accessed primarily through family. The State agencies need to be mobilized to accept their ownership and responsibility. According to Dr. Nair, we also need to focus on causes behind various disabilities, namely, nutrition, congenital disorders, disorder due to mother's poor health during pregnancy, accidents in early childhood and poverty.

6. *Ms. Angela Taneja* from Action Aid, Delhi began by asserting on the need to develop a macro perspective on the steps to create a culture of early detection of children with disability. He emphasized that a child's survival is not just that the child is not dead. In fact, quality of health and opportunities is more important and that starts right from the moment of conception. We need to focus our policy intervention on malnutrition, which in turn affects child's mental and physical development. ICDS has a mechanism for growth monitoring and it needs to be extended to include psychosocial care and opportunities of learning. Children from lowest socio-economic strata run the greatest risk of falling in the category of disabled because they do not get enough nutritional inputs in childhood and before.

7. *Dr. Rajeev Seth* from I.A.P. made his presentation on medical perspectives on childhood disabilities. He suggested that child development as a concept suggests a complex interaction of genetic and environmental influences. The pediatricians are usually the first source of contact for parents; therefore, they need to be sensitized to help the parents appreciate this issue. Early management and intervention can significantly improve outcome and have a profound impact on

the quality of life for children at risk and their families. The doctors must counsel the parents for future pregnancies and while doing that must keep parents' socioeconomic constraints in perspective. General care, immunization and growth/development monitoring are not just important but critical. A preventive approach targeting all children between 1 and 24 months of age reduces the child's chances of stunting, wasting, and underweight (low weight-for-age) by 4–6 %. There is an urgent need to create awareness on child developmental disorders in the academic and activist circles. The creation of indigenous child development centers in our country should be an important thrust area. There is a great need for the universities and institutes of higher education to take this issue as an area of research so that the policy decisions are well-informed.

8. *Ms. Varsha Hooja* from Spastics Society of India made a presentation on 'Status of Disabled' Children in India- Policy and Inclusion. She said that 4-5 million children, under the age of 5 were without any support of services in this sector. 90% of the disabled children in the country live in socially disadvantaged areas in villages and urban slums. They do not receive any services. A research study has been conducted by her organization to identify the reasons behind gap in people's willingness to avail the services for disabled children. Several reasons that the interviewed mothers gave for not attending the ICDS training programme are: hesitancy in questioning authorities, lack of technical and medical perspective, poor opinion of the anganwadi worker, lack of education on the subject, fear of rejection, apprehension about training and the uncertainty of response. There is a total distortion of the policy resulting in non-inclusion of disabled children in the mainstream institutions.

The ICDS policy, although states that it is for 'all' children, does not in practice address the question of disabled children. There is a tacit understanding at the ground level that children with disability can be ignored. Early childhood education is not a priority on the ICDS agenda. Children only come to the anganwadis at the time of supplementary nutrition distribution. The anganwadi workers are not regular in going to the center. Children with disabilities are not found in the anganwadis. The teacher expresses her lack of knowledge of handling children with disabilities as one of the reasons for not including them. The findings indicate that there is a wider malaise in the country, that there's a gap between policy stated and policy enacted and a lack of cohesion in the directives for the implementation of inclusion of children with disabilities in the Government of India programmes.

9. *Dr. Shabnam Rangwalla*, SSI made a presentation on "Early Intervention in inclusive Education in Mumbai, India." She had done a research on tracking changes in children with and without disability over two years. The study proposed to monitor the 'well being' of the children. Specific indicators for well-being were listed. These included social, emotional, communication, creative, motor, and functional skills of independence. The frame of reference for the study is children in the 0-6 years age group. Aim of the study is to identify effective and appropriate practices for the promotion of inclusive education. Target population – *Children of*

0-5 years, Girl Children, Children with disabilities, socially disadvantaged child. Children with disability started attempting to be with others, increased participation in activities, some learning by imitation, improved motor and functional skills of independence. Outcome of the Project were parents in partnership, demystification of special education, de-institutionalisation: shifting the onus from specialists to community workers, involvement of the whole community etc. Engaging the community strengthens the community to take ownership of the programme, demonstration of inclusion is necessary for policy makers, local administrators, and street level bureaucrats to understand how to do inclusion.

10. *Dr. Gouri Reddy*, Nilofer Hospital, Hyderabad, also made a presentation on “Challenges of Early Intervention”. Early intervention refers to the introduction of planned programme, deliberately timed and arranged in order to alter the anticipated or projected course of development. The major three purposes of Early Intervention are:-preventive in nature, treating or curing the condition, it focuses on remediation. Challenges involved are: lack of knowledge of the referral doctor that a child will walk/speak by the 3rd or the 4th year, attitude of the elders in the house, blaming the weight of the child for the delays, understanding & remembering the sequence of the NDT (Neuro Development Therapy). Only 30% of children came from rural areas. Reason for attending EIP and expectation from the visit was treatment in most cases (49%). There is a felt need for dissemination of information and awareness of information regarding developmental delay, mental retardation as well as welfare facilities provided by the government. Pediatricians and other specialists have a major role in identifying children at risk and referring them for intervention at the earliest. Programs that involve parent participation, integrate traditional caregivers, use media such as the radio to disseminate information, active participation of older siblings, children’s needs in conjunction with women’s programs, build on existing resources or networks. In order to derive the optimum benefit of early intervention services, efforts must be directed to: increase awareness about early childhood development and growth in general public with special focus on expecting parents; increase awareness among the medical fraternity; encourage service provider agencies; train the health workers in screening procedures and secure a stable source of funding.

11. *Professor Geeta Chopra* from Institute of Home Economics, Delhi University, presented an innovative module for prevention and detection of disabilities for poor resource communities. According to a report of WHO, 80% of the cases of disabilities could have been prevented by proper nutrition and care of the children. Prevention lies in knowing appropriate ways of care of pregnant mother and good child rearing practices. To achieve this, there is a need to create awareness on safe motherhood, health, sanitation, hygiene, child care etc. Census 2001 puts magnitude of disability at 2.3%, WHO estimates that 10% of Indian population is disabled, while disability activists put the figure at about 5%. Cost benefit analysis in many countries have shown clearly that the cost of preventing disabilities is many times lesser and far more

efficacious than providing rehabilitative services to the disabled. Despite efforts on prevention, impairment might still occur. With early detection of impairment followed by effective curative steps, one can arrest further deterioration of the impairment. Available research highlights the importance of early detection and intervention by suggesting 50% of intellectual developments takes place by 4 yrs. 50% vocabulary is attained by 8 yrs. 50% of general educational attainments by 8 yrs. Hence, earlier exceptionality is recognized and programmes started, better the outcome for the individual.

Grass-root level workers like the AWW, LHV, ANM, NGO workers, MPRW, ASHA workers etc are hands in glove with the community. They are spread across the country. They are already trained on issues of child care, health care, community based support systems, etc. It was felt that it would be easy to add on knowledge on causes, prevention, identification and management of disabilities to their existing information base. In this context, their job would be that after receiving training using specially developed Module for them on prevention and Early Detection of Disabilities, they would do a broad based screening of all children in their area and refer the cases of children that they suspect as having an impairment/disability to primary health facility for further diagnosis and treatment. The community worker is not expected to play the role of a doctor. She is expected to detect impairments, sound the family, make a referral and act as a bridge between community and the health facility. While conceptualizing the module, care was taken to ensure that the training module should be written in easy to understand language. It should suit the educational, experiential, socio-cultural and linguistic background of the grass root workers. It should be within the learning capacity of the trainees-so all medical terminologies to be avoided. It should be pictorially rich. The comprehensibility of the module by grass-root level worker was the major concern and always remained in sharp focus. It should be easy to replicate. This Special Module de-mystifies early detection of disabilities and brings it within the reach on non-medical, non-professional grass-root level child care and health worker. It is a do-able. It can be translated to regional languages. If it enabled, it can virtually reach the entire country in no time.

12. *Ms. Sneha Mishra* from Aaina, Orissa, began her address by saying that Early Detection and Intervention entails: awareness, seriousness of concern, support to the individual, diligence in follow-up, advocacy through parents, family members, neighbors, extended relations, pre-school teachers (ICDS Workers) and teachers. Early intervention should be institutional, home-based and community centric. Civil society can play a role by disseminating information in the community using multiple communication medium, creating social support group – advocacy group, run information and assistance desk, create community level workers, work as referral points for institutional intervention, create inclusive children's group where the children interactively grow and do the social audit on the protection of child right specifically in light of UNCRC and UNCRPD.

13. *Dr. Sudha Kaul* from Indian Institute of Cerebral Palsy (CP), Kolkata, talked about the challenges in meeting the needs of children with disabilities in different communities. He said that his organization works as a trans-disciplinary team. Professionals share responsibilities and are trained to carry out a holistic, coherent & effective intervention programmes. A pragmatic approach when specialists are not readily available. The key person in the team depends upon the individual's needs of the child with CP.

14. *Ms. Pratibha Karanth*, Director, The Com-DEALL Trust, shared that their organization's early intervention program for children with communication disorders, with a special focus on ASD, aims at – mainstreaming, subsequent to intensive early intervention of the cases with disability. A pilot efficacy study of 30 children enrolled in the program at Bangalore in 2007-08 statistically showed highly significant positive changes in overall developmental skills and highly significant reduction of behavioral issues.

13. *Dr. Jitendra Nagpal*, Consultant Psychiatrist, VIMHANS, began his presentation by saying that National Mental Health Policy (2003) is practically inadequate as far as a child's mental health is concerned. The social construct of disability is now generally accepted that societal barriers place impediments in the way of persons with disabilities, preventing them from achieving their optimal levels. Negative attitudes dominate and disability is thought of as taboo and a stigma. This is all-pervasive and has affected the status in which disabled children are regarded and the way they are separated from the rest of their peer group. Disabled children, because of their lower worth, are denied the rights existing for the 'normal'. Disability is viewed as a personal tragedy, an individual problem concerning not the state but individual families. Social exclusion takes place when human beings are stigmatized and put into narrow pathologised boundaries. Integration is usually applied to situations in which an individual or group of pupils are catered for in a mainstream setting. The organization and curricula provision of the rest of the school population remains essentially the same. Data from the PIED evaluation study indicate that disabled children ranging from mild to severe categories can be classified as per the nature of educational assistance required by them. The classification is-

Category 1: includes children with mild disabilities who can be handled by general classroom teachers with a sensitization training of one week. Around 45 percent of the disabled children belong to this category.

Category 2: includes children with mild/moderate disabilities who need counseling services from time to time. These children can also be handled by regular classroom teachers with minimal training not exceeding two weeks. Around 30 percent of disabled children come under this category.

Category 3: includes children with moderate/severe disabilities who need resource assistance, including corrective aids, and periodical help in academic areas. General classroom teachers who

are given a crash course of three months' duration can perform this role effectively. Around 15 percent of disabled children can be classified under this category.

Category 4: includes children with severe disabilities who require direct attention/preparatory assistance from special teachers. A multi-category teacher or a single specialty teacher may be required for this category of disabled children. Only 10 percent disabled children come under this category. In India, all approaches of integrated education are working. The real acceleration will happen only when education of disabled children becomes the responsibility of State. And special schools are equipped further to meet the needs of multiply disabled children. The general education system needs to be sensitized to the needs of special needs children.

14. *Ms. Rajul Padmanabhan* made a presentation on early intervention for children with cerebral palsy with additional disabilities. She stressed on the need to evolve a long term vision on development of children. Complex connections between the visual and other systems form in the early years, without a detailed examination of visual functioning, it is easy to miss potential problems in the use of vision. It is hard to give useful guidelines that would help plan appropriate services.

15. **Recommendations:**

- (i) ICDS programme needs to be re-visioned with a focus on psycho social care of the children.
- (ii) Additional Anganwadi Workers need to be appointed, with higher qualifications who could function in a focused way in order to identify the potential cases of disability at an early age.
- (iii) A mass campaign is required to increase the awareness level on programmes for disabled children.
- (iv) Another major mass education campaign is required to sensitize the community on the indicators of disability setting in at an early age.
- (v) A network of community workers needs to be created which will serve as a resource group to identify cases of disability in children at an early age. These grass root community workers include AWWs, LHVs, ANMs, ASHA workers.
- (vi) Early detection of disabilities can be undertaken on a mission mode only if the community workers are trained on specially developed methods and materials for them so as to provide them with necessary knowledge and skills to identify children with disabilities in their areas of operation..
- (vii) The exercise of early detection has to be cost effective. Therefore, when surveys are planned, it is impractical to have one survey to identify developmental delays, another to detect sensory deficits and another one for locomotor etc. So, the surveys have to be one time and across disabilities.

- (viii) There are existing manuals on prevention, early detection and early intervention in childhood disabilities. A core group may be formed to review these manuals and combine the best parts from them into one comprehensive manual.
- (ix) There are existing tools/screening tests for early detection of disabilities. These can also be reviewed in terms of the sensitivity and specificity, choosing correctly to avoid false negatives and false positives. Also, the tool should be across disability and not just for screening for developmental disabilities.
- (x) Exercise to be taken up only if all the nodal ministries, to whom the grass root level workers belong, are ready to assimilate the work which emerges from this exercise.
- (xi) Relevant University Departments and Institutes of higher education need to be contacted to undertake research work on the prevalence of different kinds of disabilities and their causes.

List of Participants for the Consultation on “Identifying Best Practices in Early Detection and Intervention for Children with Disabilities”, held on 17.02.10 in Vigyan Bhavan Annexe, New Delhi.

1. Prof. (Ms.) Shantha Sinha, Chairperson, NCPCR, New Delhi.
2. Ms. Sandhya Bajaj, Member, NCPCR, New Delhi.
3. Ms. Dipa Dixit, Member, NCPCR, New Delhi
4. Mr. Lov Verma, Member Secretary, NCPCR, New Delhi.
5. Mr. P.C. Sharma, Member, National Human Rights Commission, N. Delhi.
6. Mr. K.S. Money, Secretary General, National Human Rights Commission. N. Delhi.
7. Mr. P. Pincha, Special Rapporteur, National Human Rights Commission, N. Delhi.
8. Dr. Savita Bhakhry, Senior Research Officer, National Human Rights Commission, N. Delhi.
9. Shri Javid Pasha, Secretary, Karnataka State Human Rights Commission, Bangalore.
10. Sri K Madhusudanan Nair, Secretary, Kerala State Human Rights Commission, Thiruvananthapuram.
11. Shri A K Rakesh, Secretary, Gujarat State Human Rights Commission, Gandhi Nagar.
12. Shri Ajay Kumar, Secretary, Bihar Human Rights Commission, Patna.
13. Shri B Mishra, Secretary, West Bengal Human Rights Commission, Kolkata.
14. Shri Ng. Nongyri, Member, Manipur State Human Rights Commission, Imphal.
15. Shri M.M. Vidharathi, Member, Delhi Council for Protection of Child Rights, Delhi.
16. Mr. Satish Chandra, Commissioner Disabilities, Govt. of Jharkhand.
17. Mr. Das Suryavanshi, Commissioner Disabilities, Govt. of Karnataka, Bangalore.
18. Shri Deepankar Banerjee, Commissioner Disabilities, Govt. of Madhya Pradesh, Bhopal.
19. Shri Khilli Mal Jain, Commissioner Disabilities, Govt. of Rajasthan, Jaipur.
20. Ms. Poonam Natarajan, Chairperson, National Trust (M/SJ&E), N.Delhi.
21. Shri T.D. Dhariyal, Dy. Chief Commissioner, Office of the Chief Commissioner for Persons with Disabilities, N. Delhi.
22. Shri Arvind Kumar Dwivedi, Director, Deptt. of Handicapped Welfare, Govt. of U.P., Lucknow.
23. Dr. M K C Nair, Child Development Centre, Medical College, Thiruvananthapuram, Kerala.
24. Ms. S Roy Chowdhary, Dy. Commissioner (Disabilities), Govt. of NCT of Delhi.
25. Dr. Geeta Chopra, Associate Professor, deptt. Of Child Development.
26. Smt. Radhika M. Alkazi, Managing Trustee, Alternative Strategies for the Handicapped (Aarth-Astha), N. Delhi.
27. Dr. Uma Tuli, Founder Secretary, Amar Jyoti Charitable Trust.
28. Dr. Renu Singh, Save the Children, Bal Raksha, Bharat.

29. Shri Sanjeev Rai, Save the Children, Bal Raksha, Bharat.
30. Dr. Rajeev Seth, Secretary, I.A.P., Delhi.
31. Ms. Merry Barua, Director, Action for Autism, New Delhi.
32. Ms. Indu Chaswal, Action for Autism, New Delhi.
33. Ms. Sudha Kaul, Indian Institute for Cerebral Palsy, Kolkata.
34. Shri Jitendra Nagpal, Consultant Psychiatrist, Vidyasagar Instt. Of Mental Health and Neurosciences (VIMHANS), N.Delhi.
35. Shri R Jalvi, AYJ National Institute for Hearing Handicapped, Mumbai..
36. Ms. Varsha Hooja, Spastics Society of India, Mumbai.
37. Dr. Shabnam Rangwalla, Spastics Society of India, Mumbai.
38. Dr. Dharmendra Kumar, Director, PDU Instt. For the Physically Handicapped, N.Delhi.
39. Ms. Rajul Padmanabhan, Director, Vidya Sagar, Chennai.
40. Dr. Gouri Reddy, Nilofeur Hospital, Hyderabad.
41. Dr. Samir Dalwai, Pediatrician and Director, New Horizons Child Development.
42. Ms. G. Shyamala, Director, Action for Ability Development and Inclusion.
43. Ms. Saraswati Narayanan, Bal Vidyalaya (The School for Young Deaf Children)
44. Mr. Anshuman Abhishek, M.A. Criminology, National Instt. Of Criminology and Forensic Science, Ministry of Home Affairs.
45. Ms. Anjela Taneja, Action Aid India, Delhi.
46. Ms. Pinki Rani, Athak Prayas, Delhi.
47. Ms. Pratibha Karanth, Director, The Com-DEALL Trust, Bangalore.
48. Ms. Sneha Mishra, AAINA, Bhubaneshwar, Orissa.
49. Shri Alok Bhuwan, Manovikas, Delhi.
50. Mr. B.K. Sahu, Registrar, NCPCR, New Delhi.
51. Mr. M.S. Gill, D.S.P, NCPCR, New Delhi.
52. Mrs. Sushma Ghai, PPS, NCPCR, New Delhi.