Overall, the NGO movement for disability has contributed greatly to promoting the interests of persons with disability and awareness of their rights and situation. However it remains in many ways, an under-exploited resource in terms of fully mature partnerships between the public and NGO sectors.

Towards an Inclusive Society

Society and its response is a critical factor in the inclusion of those with intellectual challenges into the mainstream of life. Stigma is pervasive in the society. Stigma and attendant discrimination result in marginalization of those affected in every sphere of life. Ignorance, misunderstanding and prejudice deepen the severity of the problem as affected individuals withdraw further from the world around them and become practically invisible. This invisibility leads to isolation in every aspect of their life. How many Einsteins, Mozarts, Washingtons, Christies and Socrates' have we lost because of this invisibility?

The dearth of information on the services that they need makes the lives of those with intellectual challenges a constant struggle. Lack of trained professionals, worsens the situation. Many of the actors who are in the sector are overwhelmed by the needs of the community. As such they are concentrated on service delivery and the principal models employed are rehabilitative, medical and educational.

Yet those who have intellectual challenges have needs beyond these. They need legal aid to understand their standing in law and the provisions of various Acts and schemes; they need help with financial planning that can help secure their future; and they need counseling to help them to deal with the emotional and social consequences of their situation. There is need to ensure that the law reflects the positive and ability based understanding of those with special needs; and more research to help devise strategies and solutions for those who need help.

Inclusion is the key for those with intellectual challenges to lead a normal social life by removing differences between 'them' and 'us'. Inclusion underpins the idea of learning how to live with differences and how to learn from

differences. It requires a concerted effort by all concerned with the child with intellectual challenges - their parents and family members, medical and rehabilitation professionals, researchers, lawyers, financial planners, law making bodies, government, and the community at large. Sterling examples of community action are companies such as Mphasis, Domino's, Coca Cola and KFC who employ persons with disability not only in the spirit of compassion, but because they find business sense in doing so.

A 'clearing house' that can act as a platform to collect, collate and disseminate useful information to all concerned is a critical need. Such a platform could provide crucial information related to the rights of those with intellectual challenges. It can direct them to resources that can enable them to live their lives productively and happily. It can help to create the new knowledge that society can use. And it can help to develop policies and strategies to provide an equality of opportunity, respect for inherent dignity, respect for differences, acceptance of human diversity and humanity, and the freedom to make one's own choices in an inclusive and supportive society.

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Excluded from Life

Intellectual challenges of childhood

Disability or Challenge?

Disability is a complex, dynamic and multidimensional state. The term 'disability' is understood to include both physical and intellectual challenges that a person faces; and is more or less disabling depending on the context in which it occurs. The Draft 'Rights of Persons With Disabilities' Bill 2012 defines a 'person with disability' as a person with long term physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder his full and effective participation in society on an equal basis with others.

There are an estimated one billion people with disabilities in the world, with 110 - 190 million having very significant difficulties. Thus one in every seven persons in the world has some kind of disability. In contrast, Indian estimates are astoundingly low; the NSSO (2002) reports a disability prevalence of only 1.8%. of these, only 1% are employed in India as compared to 70% in China. Persons with intellectual disability make up 5.4% of the 18.5 million or so disabled persons in India.

Intellectual disability is a broad concept. It results from a variety of intellectual deficits- many of which are present from birth - and which could affect cognitive abilities, motor abilities, or the ability to have robust social interactions. Better known intellectual deficits include mental retardation, autism, Down's syndrome and cerebral palsy. Others such as mood disorders, Duchene's syndrome, spina



Inclusion is not a strategy to help people fit into the systems and structures which exist in our societies; it is about transforming those systems and structures to make it better for everyone.

Inclusion is about creating a better world for everyone

Diane Richler
President, Inclusion International



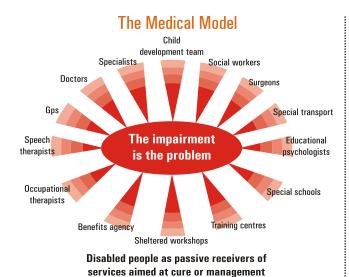
bifida etc. are less well known. There are also deficits which are too mild to properly qualify under above categories; these include conditions such as specific learning disability, and problems acquired later in life through brain injury or neuro degenerative diseases.

Each of these intellectual deficits poses challenges to how persons can relate to the world around them much as the challenges posed by material deficits such as income or education. And just as programs to deal with inequitable distribution of material deficits can help, persons with intellectual challenges can be supported to lead a normal life.

An Alternative Construct

Two approaches have dominated the response to intellectual challenges of childhood.

In the medical model, individuals are seen to be disabled; because of their physical, intellectual, psychological and mental impairments. Thus, disability is taken to lie in the individual as it is equated with restrictions of their activity; and the response is to provide them with cures, treatment and rehabilitation. Such an interpretation of the problem leads to negative interaction such as discrimination and social isolation and creates attitudinal and structural barriers to which the affected individual is subjected.



The second and more modern approach is the notion that challenges that such individuals face are a social construct; much in the same way that gender, race and ethnicity are socially constructed. In the social model the focus is on society, which imposes restrictions on the behavior of persons with impairment. It takes the view that persons with disabilities are rights holders and are entitled to strive to for institutional, physical, informational and attitudinal entitlements from society. Lack of useful education, discrimination in employment, poor access to information and a discriminatory environment are seen to be major social blockades that hinder the life of the intellectually challenged individual.



This transition from an individual, medical perspective to a structural, social perspective has been described as the shift from a 'medical model' to a 'social model' in which people are viewed as being disabled by society rather than by their bodies.But disability in itself should be viewed neither as purely

medical nor as purely social as the persons with disabilities can often problems arising from their health condition while facing discrimination from society.

The shift from the medical to the social model is a shift that is premised on a rights-based approach. Inclusion of children with disabilities and their families is rooted in the concept of equity. Central components of inclusion are access to standard healthcare services, and active participation in the community by removing social barriers.

Situation in India

Actions of the Government: India is mindful of its responsibilities towards its citizens who experience intellectual challenges in spirit - this commitment is enshrined in the Constitution of India and reflected in the National Policy on Persons with Disabilities (2006). The Policy recognizes that Persons with Disability are a valuable human resource and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in the society. India is also a signatory to the United Nations Convention on the Rights of Persons with Disabilities which states "all persons with any kind of disability enjoy all the human rights and fundamental freedom". The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 aims to offer equal opportunities in public employment by reserving vacancies for persons with challenges. Intellectual challenges have been emphasized in the documents of the 12thFive Year Plan. In September 2012, the Ministry of Social Justice and Empowerment placed a new Bill (Rights of People with Disability) before Parliament which provides a special emphasis on intellectual challenges.

The Ministry of Social Justice and Empowerment is the nodal ministry for all matters relating to the implementation of policies for affected individuals. The Ministry has recently set up a separate department - the Department of Disability Affairs to coordinate and undertake initiatives to address disabilities. Medical and rehabilitation services are of utmost importance for the effective participation of the intellectually challenged individual. The government has established the National Institute for the Mentally Handicapped which serves as an apex body in the area of mental retardation. Another crucial component in moving towards inclusion is educational services. Government initiatives such as Education for All, the National Policy on Education, Sarva Sikhsha Abhiyan and the Right to Education are some of the platforms that provide the rights of equal education to all children, including those facing intellectual challenges. The Rehabilitation Council of India was set up as a registered society in 1986. Through the Rehabilitation Council of India Act (1992), it became a statutory body

of the Government of India. The mandate of the Rehabilitation Council of India is to regulate and monitor services provided to persons with disability, to standardize syllabi, and to maintain a register of all qualified professionals and personnel working in the field of rehabilitation and special education.

Yet, the situation is far from rosy. Accurate data on the actual number of people with disabilities, the extent of their disability, and their requirements is not accurately available and poses a huge constraint to formulate appropriate action. Reservations for persons with disabilities provided for by law, is not effectively enforced. The Rehabilitation Council of India has approved 436 institutes that train rehabilitation professionals in the country. However, experts agree that there is a crisis of trained rehabilitation professionals who can address the issues of children with intellectual challenges. In 2009, it was estimated that 300,000 rehabilitation professionals (of which 250,000 special educators) are needed to address the country's needs. In sharp contrast, only 38,000 professionals are registered in India.

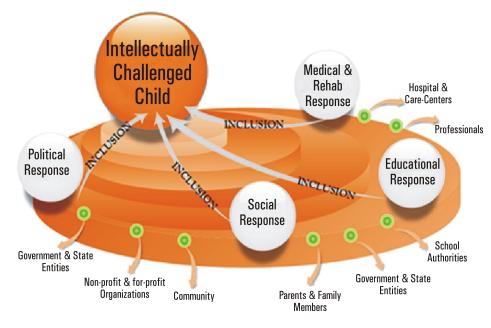
Inclusion is much more than the child with special needs fitting in to his school environment. It is about the classroom becoming responsive to the needs of the child with intellectual challenges; of the child adapting to the world around them through basic life skills; and being supported to interact with and

accept their peers from varying backgrounds. A quick scan of the status of educational institutions for the intellectually challenged suggests two things. One, there is a need for more number of schools to cater to the population. Two, more schools need to be established in rural settings as 75% of those with challenges live in rural areas.

Actions by the non-governmental sector: Initiatives by non-governmental sector assume a greater importance given the inadequacies of government institutions in addressing the issue of intellectual challenges of childhood. The role of non-governmental organizations(NGO) in building a climate of inclusion is of particular significance.

The National Policy on Persons with Disabilities (2006) makes provisions for participation of the sector in service delivery and encourages their greater involvement in policy making. There are an estimated 1.2 million NGO in India employing about 19.4 million persons. Current Planning Commission NGO partnership data suggests that there are some 10,000 NGO who work with differently-abled persons. Yet data on the Ministry of Social Justice and Empowerment website indicates that the Ministry provided just over Rs. 24 Crores to 57 organizations in the public and NGO sector for all disabilities in 2010-11, not a very large sum given the needs of this sector.

Pathways to Inclusion



A large number of NGO and private professionals work in the field of intellectual challenges of childhood. Some provide services organized by professional domain such as speech therapy or loco-motor aids, while others work across conditions such as mental retardation, autism and learning disabilities. A common area of partnership is training and technical assistance, apart from direct provision of services. In the last decade, cross-cutting disability organizations and networks have begun to emerge.

Yet the sector is not without its problems. There is a strong urban bias in presence and activities of NGO. A shift in the focus of these organizations from educational and rehabilitation services to advocacy and related functions such as access to justice and participation of the intellectually challenged individual in voting has been noted. Despite the strongly positive reports, there remain concerns about weak monitoring of NGO performance and accountability for use of public funds.