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REVIEW ARTICLE

STATUS OF PERSONS WITH INTELLECTUAL DISABILITIES IN INDIA

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ABSTRACT

In India community based programmes supported by practices of the prevailing religions and localized in the communities, based on the specific needs available expertise and productivity requirements. Out of all the types of disabilities, an intellectual disability poses greater challenges than the other type. Special legislations have been put in place to ensure empowerment of persons with disabilities. Human resource development programmes are standardized by Rehabilitation Council of India. The National Institute for the mentally handicapped has developed many service models. Non –Government Organizations have started special education and vocational training programmes. However considering the nature of the condition, it is essential to see what has been the value addition in the area of intellectual disabilities and what more needs to be done. This paper focuses particularly on the current status of persons with intellectual disability in various stages of their lives ranging from infancy to adulthood in India.

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INTRODUCTION

Historically, India has been an inclusive society. During the 17th century, community based programmes were the rule and not the exception for persons with disabilities, patronized by the state, and supported strongly by the practices of the prevailing religions, and localized in the communities, based on the specific needs, available expertise and productivity requirements (Jayachandran, 2004). Currently, in the independent India after the colonial rule, efforts are being made to recapture the efficacy of the past systems with the refined new developments and trends. In intellectual disability, unlike other disabilities the history of special education has not been very encouraging. The constitution of India is amended (86th amendment) guaranteeing education as a fundamental right (Art. 21A, 2002). Subsequently, prevention and early detection of disabilities, education, employment, economic rehabilitation, community empowerment and community based rehabilitation have all been given priority by the government through various schemes and also support to non government organizations.

Intellectual Disabilities-NEEDS

Out of all the types of disabilities, an intellectual disability poses greater challenges than the other type do.

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Persons with intellectual disability poses greater challenges than the other which is especially characterized by sub – normal intelligence, thus partially or totally restricting the person's ability to perform certain activities in their life. This is owing to impairment in cognitive, emotional, or behavioral endowment. Therefore they have basic needs which basically include activities for daily living, instrumental activities of daily living, reading, writing and arithmetic skills, extracurricular activities, art and cultural activities, independent living skills and community integration etc. Each activity of a person with intellectual disability has a meaning in their life, which they have to acquire through individualized education plan supported by related services, viz. audiology services, early identification and assessment of disabilities in children, medical services occupational therapy, parent counseling and training, school health services ,physical therapy rehabilitation and transportation. The needs of the families having a child with Intellectual Disability are very complex and call for developing support programs for these families.

Acts and Policies

Constitution of India (1950)

After independence, when Constitution of India was framed in the year 1950, 'right to education and right to work, in case of disablement was mentioned in Art.41 of the Directive principles of State Policy. However, it is not a fundamental

right. Mental retardation did not have a special mention in the Constitution. The 86th Constitutional amendment (2002) included a new article (21A) which notes education as a fundamental right: "The state shall provide free and compulsory education to all children of the age of 6 to 14 years in such a manner as the state may, by law, determine". To ensure this right, Article 51A had a clause added that said "who is a parent or guardian to provide opportunities for education to his child or, as the case may be ward, between the ages of 6 and 14 years. In addition, early childhood care and education for children up to the age of 6 years was included in the amendment (Art.45). These amendments have direct impact on children with disabilities in the area of early intervention, education and parental involvement.

National Policy on Education (1986)

In the year 1986, when the National Policy of Education was revised, 'Education of the Handicapped' (as it was called) has a separate subsection (4.9). The plan of action to implement this policy on 'integrated education' included children with mental retardation also. The policy in essence, stated that education of children with milder disabilities will be common with others, children with severe disabilities will be provided special schools, adequate arrangements will be made to give vocational training to children with disabilities, teacher training programmes will be reoriented particularly in primary classes to deal with difficulties of children with special needs and, voluntary efforts towards integrated education will be supported. This effort was the first formal step towards integrated education in India, which included all disabilities including mental retardation. It is to be noted that many children who could cope in the mainstream were in regular schools without any special provisions made for them even before such efforts were initiated. This included predominantly children with loco motor disabilities.

Rehabilitation Council of India Act (1992)

In 1992, Rehabilitation Council of India (RCI) Act was passed which brought about major development in human resource development in the area of disabilities. RCI is a statutory body under the Ministry of Social Justice and Empowerment, (MSJ&E) which is the nodal ministry for disability rehabilitation in the country. The major objectives of RCI are as follows:

- Regulate human resource development in rehabilitation through out the country,
- Certify qualified personnel and professionals in the field of disabilities
- Ensure quality, standard and uniformity in the rehabilitation programmes offered throughout the country.

Human resource development programmes ranging from training of grass root level functionaries to master trainers are regulated by RCI and a standard register of professionals are maintained by RCI. All HRD programmes including those for intellectual disabilities are regulated and monitored by RCI throughout the country. It also ensures that the registered professionals are updated with recent developments in the field

by organizing continuing rehabilitation education programmes and making participation mandatory for renewal of registration. So far, 16 categories of professionals numbering 28,460 are registered by the Council, and 42 long term rehabilitation courses are standardized by the Council which is carried out in various organizations throughout the country. (Ref: Annual report, 2005-06, www.rehabcouncil.nic.in). Among the courses six are exclusively in the area of mental retardation while other courses which include all disabilities cover mental retardation also.

Persons with disabilities (Equal opportunity, Protection of Rights and Full participation) Act (1995) : – (PD Act)

- PD Act was enacted to ensure Rights of persons with disabilities. Among the 7 disabilities covered by the Act, mental retardation is one. For intellectual disabilities, the legally accepted terminology by this Act in India is Mental retardation. The Act has 14 chapters and covers areas including
 - prevention, early detection,
 - education,
 - employment,
 - affirmative action,
 - nondiscrimination,
 - manpower development,
 - social security
 - Research and development.

By this act, there is a Chief Commissioner of disability at the National Capital at central level and every State has a State commissioner of disability. He/she ensures accessibility, protects the rights and has judicial powers to address grievances of persons with disabilities. So far, over 6000 cases of persons with disabilities have been settled through the court with the help of chief commissioner's office. (Ref:www.ccdisabilities.nic.in)

National Trust for welfare of persons with Autism, Cerebral Palsy, Mental retardation and Multiple disabilities Act, (1999): (NT Act)

National Trust aims to provide guardianship to persons with disabilities covered by the Act. The main objectives of the Act is to

- enable and empower the persons covered by the act.
- Strengthen facilities within the family
- Support registered organizations to provide support to families when in crisis
- Support those who do not have family support
- Care and support to the disabled person in the event of death of the parent/guardian
- Appoint guardian/trustees
- Facilitate equal opportunity, protection of rights and full participation.

Non government organizations (NGOs) actively participate as registered members of NT. In every district, local level committees are formed headed by the district head (District

collector and Magistrate), and having 2 other members, one a person with disability and the other an active NGO. This committee addresses the issues and concerns of persons with disability covered by this act. At state level, State Nodal Agency Center functions and at Central level Chair person of the Trust coordinates and directs the functioning of the Trust. The Trust also trains a large number of care givers nationwide through training of master trainers in different parts of the country to reach out to all the states and districts. With the enactment of these three Acts in the 1990s in India, programmes of persons with disabilities are strengthened in the country and the awareness has increased multifold, having an impact in the lives of persons concerned. The Ministry of Social Justice and Empowerment is responsible for the enactment and implementation of these acts.

National Institute for the Mentally Handicapped

MSJ&E has also established National Institutes for various disabilities. National Institute for the Mentally Handicapped (NIMH) was established in the year 1984 and it serves as an apex body in the area of mental retardation. It has, as its objectives, human resource development, research and development, service delivery models, documentation and dissemination, extension and outreach programmes. It is head quartered in Secunderabad and has its regional centers in Delhi, Mumbai and Kolkata. Establishment of NIMH has resulted in strengthening the HRD programmes in the country and has brought out a number of publications in the area of mental retardation as an outcome of research projects. It has also resulted in creating awareness about mental retardation, education and training facilities, vocational training and placement, parent support programmes and schemes and benefits for persons with mental retardation in the country.

Parent Cooperatives

Currently there are nearly 200 parent associations in the country with membership of over 4000 parents, Under the guidance of NIMH, a National Federation called *PARIVAAR* functions as a central organ for all the parent associations that provide constant and regular support to the families. Services include emotional support, information about condition and referral resources, information about government schemes, organizing conferences for parents to elicit the needs and difficulties to be placed before the Government. Currently, there is a trend towards inclusive education. There is an effort towards allowing flexibility in the curriculum and examination system. National institute of open schooling (NIOS) is one such provision, where children facing difficulties in learning academics have a provision to learn at their own pace with a modified curriculum. Another massive effort by the government is the introduction of Sarva Siksha Abhiyan (SSA) which means 'Education for All' nationwide in order to meet the constitutional commitment to ensure free and compulsory education to all children in the age range of 6 to 14 years. (Ref. 86th amendment of the constitution, clause 21A). It is expected that SSA will provide quality elementary education to all children by 2010. SSA aims at enrolling and retaining children, especially the most vulnerable and disadvantaged ones in primary schools. The teacher training programmes

have content coverage on inclusive education and establishment of resource rooms in regular schools. Special Teacher trainees at graduate level are given skills and competencies for inclusive education. Parallely, special teachers at diploma level are also prepared to work in special schools to cater to children with severe mental retardation. There are also efforts to convert the existing special schools as resource centers for inclusive education through SSA.

Vocational Education and employment

In the government sector, currently there is a 3% job reservation for persons with disabilities but it does not include those with mental retardation. Generally, the avenues for persons with mental retardation includes open employment, sheltered employment and supported self employment and the options are made by the individuals and/or his care givers based on the ability level of the person and the environment in which he lives. For instance, an individual with mild intellectual disability living in urban area is found efficient in working in an open employment setting such as a printing press or a phone-fax-photocopy Center while another with similar ability level in rural area is found to be competent in managing dairy or poultry farm under supervision.

What next

India is a signatory to a number of UN resolutions most of which have been responsible for development of various action plans and implementation in the country. To name a few, the UN resolution 37/52 of 3rd December 1982 is a significant one, aiming to achieve full participation, equality and protection of rights of persons with disabilities. Asia Pacific Decade (1993 – 2002) extended for another decade (2003-2012) focusing on major policy areas gave a thrust to the programmes in the country. India is a signatory to Biwako Millennium Framework (2002) for action towards an inclusive, barrier-free and right based society for persons with disabilities. All of these have provided direction towards progress in the area of disabilities. It is hoped that through this conference a road map for viable programmes for persons with intellectual disabilities will be drawn and implemented, thus helping persons with intellectual disabilities lead a dignified life as proud citizens.

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