



Children and Adolescents with Disabilities in India: Recent Perspective

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Children and adolescents with disabilities constitute a very diverse group having different impairments which affect their functioning and discriminate them in different areas of life like health, education and recreation because of their disabilities. They are highly vulnerable to different kinds of abuse, violence, and some of them have more probability to be placed in the foster care and residential institutions leading to less parental care and love. Children and adolescents constitute an important part of the population of any country, who needs proper care and attention to have a better present and future. More research in this area is needed to prevent, early intervention and treatment as well as for providing quality services and help them to have a smooth transition from childhood to adulthood. This article deals with recent updates and perspectives in the field of children and adolescents' disability and what can be done in the future.

Keywords: Children, adolescents, disabilities, early intervention, inclusive education

CURRENT SCENARIO

Childhood should be the period of thriving and not just surviving as in some cases of disability. According to UNICEF, "Children and adolescents with disabilities must enjoy their rights without discrimination of any kind". But the reality is very different. The programme of child and adolescent health keeps the disability on low priority which needs to be changed. Global health programmes should also focus on children and adolescents with disability (Cieza Kamenov, Sanchez, Chatterji, Balasegaram, Lincetto et al., 2021) because the number of people with disabilities in India has increased by 22.4% to 26.8 million (Sivakumar, 2013).

Another major study conducted in five regions in India found that 9.2% of children aged 2–5 and 13.6% of children aged 6–9 had at least one of seven neurodevelopmental disorders (vision impairment, epilepsy, neuromotor impairments including cerebral palsy, hearing impairment, speech and language disorders, autism spectrum disorders, and intellectual disability (Arora, Nair, Gulati, et al. 2018). Disability is the global crisis and not just the problem of developing countries such as India. Over 1 billion people, about

15% of the world's population have some form of disability. Of this number 110 million to 190 million people of 15 years and older have significant difficulties in functioning and 93 million people less than 15 years of age live with a moderate or severe disability (Chandra, 2017). Although one billion people have some form of disability, people with disability are among the world's most marginalised and discriminated against groups specially the children and adolescents. There are studies which show that numbers of children with disability are growing day by day. One recent global analysis estimated that 291 million children and adolescents experience disability due to epilepsy, intellectual disabilities, or sensory impairments (Olusanya, Wright, Nair, et al. 2020). According to UNESCO, India (2019) report, "there are approximately 78.6 million children with disabilities in India, constituting 1.7% of the total child population. Unfortunately, three-fourths of children with disabilities aged five years and one-fourth between 5-19 years do not attend any educational institution". This data brings the attention to work on this area on a priority basis.

THE CHALLENGE AND NEEDS CREATED BY DISABILITIES

Disability, in any form, impedes in achieving full personal, social and economic potential and places the high burden on individual, family, community, and country levels. Disability not only a health problem but it affects the interaction between individuals with a health condition and personal and environmental factors (such as negative attitudes, inaccessible transportation

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and public buildings, and limited social supports). To overcome the difficulties faced by people with disabilities, it requires interventions to remove attitudinal, environmental and social barriers (Chandra, 2017). According to UNICEF, “Children and adolescents with disabilities are one of the most marginalized and excluded groups in society, experiencing widespread violations of their rights. They are most likely to face severe social, economic, cultural and civic disparities as compared with those without disabilities. Negative attitudes, stereotypes, stigma, violence, abuse, isolation, as well as lack of adequate policies and legislation, and educational and economic opportunities are daily experiences they face”.

Children and adolescents with disabilities, as compared to typically growing, are more likely to be among the poorest members of the population, and are less likely to attend school, have poor reach to available medical services, or have their views heard in society. They are also more prone to violence and abuse, of being placed in residential institutions, and often do not receive proper nutrition or humanitarian support in emergencies due to their disabilities.

It is a high time to work towards the inclusion of children with disabilities as it is not only a matter of rights and social justice, but an indispensable asset for the society in the future. The costs of exclusion are too high for both for the individual and for society to bear. Children and adolescents with disabilities needs to be focus point in order to build inclusive and happy societies. They needs to equally cared for and respected as they hold the same rights as other and can be agents of change and self-determination, not simply the beneficiaries. If not taken care of, children and adolescents with disability who are excluded may grow up as dependent to family and society or to be adults who are less or not skilled to work, have poorer health outcomes and hence becomes the burden on already limited resources of government.

SOLUTION WHICH CAN WORK

Protecting the rights of children with disabilities is the solution. The population of India is the second largest in the world whereas in terms of area it is the seventh largest country. As a result, there are clear challenges delivering healthcare to India's 1.3 billion people spread across such a vast expanse (Funk, & Drew, 2017). In spite of this, there are number of laws, acts and policies are in India for person with disabilities. Internationally, India has signed to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), on 30 March 2007 which was ratified on 1 October 2007 (United Nations, 2012). At national level, The Rehabilitation Council of India Act, 1992 constituted the Rehabilitation Council of India for regulating and monitoring the training of rehabilitation professionals

and personnel. RCI is also looks after and promote research in the field of rehabilitation and special education. It also maintains a Central Rehabilitation Register which is available on their official website and for matters connected therewith or incidental thereto.

Persons with Disabilities (Equal Opportunity, Protection of Rights and Full Participation) Act (in short known as ‘PWD’ Act) came in existence in 1995. It was the legal initiative to recognise the rights and different needs of people with disabilities (Chavan & Rozatkar, 2014). This act included the seven disabilities and also talks about 3% reservations persons with disabilities should get in government jobs and higher educational institutions. PWD act, 1995 is replaced with the Rights of Persons with Disabilities (RPWD) Act, 2016 which has increased the number of recognised disabilities from seven to twenty one (Narayan & John, 2017) and 4% reservation in Govt. Jobs (and 5% in higher educational institutes (Friedner, Ghosh & Palaniappan, 2018). Another law governing disability affairs in India is the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, which is simply known as the National Trust Act, works towards providing opportunities for capacity development of Persons with Disability and their families, fulfilling their rights, facilitating and promoting the creation of an enabling environment and an inclusive society.

The Mental Health Care Act, 2017 provides for mental healthcare and services for persons with mental illness and to protect, promote and fulfil the rights of such persons during delivery of mental healthcare and services. The government of India has separate Ministry of Social Justice and Empowerment where issues related to disability are addressed by the Department of Empowerment of Persons with Disabilities (Morgan, 2018). The government of India has also enacted initiatives such as the Accessible India Campaign to make public spaces and transportation barrier-free for persons with disabilities (Sharma, 2018).

THE WAY FORWARD

In order to move forward, it is important to have a paradigm shift in government and people’s attitudes and the commitment of all relevant parties in the disability and health sectors (Cieza, et al., 2021). Governments need to scale up service delivery with a strong focus on children and adolescents with disability to turn into an assets to society rather than making them a burden by neglecting them. There is a high and urgent need to help broadening the access of services for assessment, interventions, education, etc. nearer to home.

There is also the need for expansion of rehabilitation services and parents or care takers mental health. Our health system needs to integrate all the services at all level for children with disability as well as their care

takers which means providing early and quick access to rehabilitation services to make sure optimal results and lessen the risks of complications that may affect health and overburden health systems (Stucki, Stier-Jarmer, Grill & Melvin, 2005).

Research evidence demonstrate that early intervention at the primary care level can significantly reduce the prevalence of many chronic conditions and delay the onset of conditions, such as for cerebral palsy (Damiano, 2009; Nguyen, Lefèvre-Colau, Poiraudau & Rannou, 2016; WHO, 2019).

Prevention interventions given at the right time to the targeted risk factors can prevent conditions associated with high levels of disability, if not, at least it slows down the impact of disability. It is crucial that governmental and non- governmental organisations plan and organise programmes for creating awareness and providing rehabilitation services will involve sensitising and training the health workforce to make them informed and skilled workforce to deliver specific services. Along with creating a skilled professionals, it is equally imperative to provide support and education to families in order to reduce stigma and discrimination, which is source of many barriers. It is important for all people including the Governments to look at children with disability with new perspective which helps to bring them out from being ignored and invisibility to inclusion at all levels. The high level of commitment is required by the countries to make children, who are among the most disadvantaged and neglected in many societies, their priority for the better and humane society.

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CONFLICT OF INTEREST

The Authors declare to have no conflict of interest.

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