

REVIEW ARTICLE

Public health dimensions of Autism Spectrum Disorder in India: An overview

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The global prevalence of an early-onset of Autism Spectrum Disorder (ASD) is ~1% and is a priority for the global mental health agenda (1). 78 million people worldwide are affected by autism and the impact on the individuals and families are enormous (2). Autistic Spectrum Disorder is a pervasive neurobehavioral disorder characterized by qualitative impairment in social interaction, communication and repetitive and stereotypic patterns of interests and activities (3). INCLEN study suggests that ASD prevalence across five States in north and west India was as high as one in 125 children between 2-6 years age group and one in 80 among children in 6-9 years age; overall the prevalence in India is estimated to be 1 in 89(4). Autism was first described in 1943 among children born in 1930s and prevalence of autism is on the rise as reported from all over the world. Early intervention can ameliorate the morbidity significantly (5). Autism Spectrum Disorder is a neurodevelopmental disorder which poses a great challenge to individuals and to societies not just in early ages but across lifespan due to its pervasive nature.

The etiology of ASD is not well defined. Both environmental factors and genetic susceptibility are believed to act in concert in pathogenesis. A number of environmental agents like heavy metals have been shown to demonstrate neurotoxic effects ranging from severe intellectual disability to more-subtle changes in function in both human and laboratory animal studies (6). The prevalence of ASD as per 2020

CDC report is 1 in 44 (7). Since its early descriptions, the diagnosis of autism has evolved from autism to autism spectrum disorder, and currently DSM-5 criteria form the basis of diagnosis of autism(8). The AIIMS modified-INDT-ASD Tool has demonstrated good psychometric properties in early detection of ASD in an Indian setting (9).

The most significant hurdle faced by parents of a child with ASD is to reach to a correct diagnosis. Often the differential diagnosis such as low IQ, delayed language milestones or hyperactivity is made, which hampers the appropriate diagnosis and thus delays the interventions.

The diagnosis of ASD is mainly based on observed and reported behaviour patterns presented at an early age, which includes impairment in social communication and interaction accompanied with restricted and repetitive behaviour patterns as qualified under the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria. This study was undertaken to develop and validate the DSM-5 based All India Institute of Medical Sciences (AIIMS)-Modified-INDT-ASD Tool. Though the ASD features are apparent at an early stage, they might not be evident until social demands exceed individual capacities or they may be masked by learned strategies in later ages.

The present-day paediatrician and family doctors now have enhanced knowledge and are aware of ASD; thus early referral, adequate initial investigations are sought for an early intervention. This also creates special need in

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schools and educational facilities to provide a comprehensive and integrated learning at all ages for ASD children. A large segment of individuals with ASD are dependent and there is a necessity of social and financial security or independence based on their diverse functional levels. Based on their skill and special talents the ASD children should be incorporated in the mainstream employment areas. The implementation of these demands and reinforces needs the involvement of potential political inputs to initiate a momentum in growing community of people living with autism.

The varied clinical presentation amongst ASD individuals, disease course and pattern of evolution does not follow a linear path. The mainstream issues in children with ASD are constant difficulties in coping with societal demands, which can be empowered with scientific, medical knowledge (traditional and novel interventions) and a commitment at socio-political grounds.

HISTORICAL PERSPECTIVE (10)

The term “autism” appeared in the Indian literature in 1959. Compared to many developing countries, Indian literature on Autism is not that scanty. Earliest Indian scientific literature on autism dates to 1944 from A. Ronald a Viennese paediatrician working in Darjeeling. Till early 1980’s, the knowledge of autism was limited and moreover the knowledge of autism being a pervasive disorder and affecting all ages was inadequate. In 1991, a parent got together a few like-minded parents and founded Action for Autism (AFA), to advocate for children and adults with autism. Few snapshots about the journey of ASD children/ associations towards the social acceptance and independence are quoted.

In 1994, a parent led initiative by an Open Door school in Delhi started one-year teacher training course and a periodical ‘Autism Network’ to share developments in the field and to act as a forum for discussion.

In May 1998, AFA circulated leaflets with information on autism to more than 1,000

paediatricians registered with the Indian Academy of Paediatricians. Autism specific organisations was initiated in various other organizations like Asha, Ashiana, Communication DEALL, Development Centre for Exceptional Children, Priyanj and We Can. Few other groups like ‘Forum for Autism’, a parent support group was also started in Mumbai.

In 1998, AFA approached the Rehabilitation council of India (RCI) highlighting the need for a specialized teacher training programme for ASD. Continued efforts culminated in RCI introducing a Diploma in Special Education (Autism Spectrum Disorders) in 2003.

Tito Mukhopadhyay, an autistic boy from Bangalore, wrote his first book, Beyond the Silence: My Life, the World, and Autism, in year 2000. The book comprises of his early writings as well as his mother's lessons. Since then, there has been an exponential increase in autism research and public awareness in India.

World Autism Awareness Day is observed on 2nd April each year to raise awareness about the autism spectrum condition. As public knowledge of the Autism Spectrum has grown over the last few decades, there have been optimistic reforms in the health system to promote more inclusivity. The recognition of multitude of other unique challenges apart from those faced by other neurotypical individuals is a first realistic step in this direction.

April 2nd is marked as World Autism Awareness Day to create awareness on the autism spectrum disorder. Over last few decades as awareness on Autism Spectrum has broadened, there have been optimistic reforms in the health system to create more inclusivity. The recognition of multitude of other unique challenges apart from those faced by other neurotypical individuals is a first realistic step in this direction.

PUBLIC HEALTH POLICIES AND DIRECTIVES IN INDIA (11)

The various ministries under Government of India have adapted various measures towards the welfare of individuals with disability ([Table1](#)).

TABLE1: THE PROVISIONS IN MINISTRIES UNDER GOVERNMENT OF INDIA

Ministry under Government of India	Provisions
Ministry of Finance	Tax exemption
Ministry of Labour and employment	Employer provident fund
Ministry of communications and information technology	Punarbhava, web portal
Ministry of Human resource development	Sarva Siksha Abhiyan

Ministry of Social justice and empowerment	National Trust & The chief commissioner of persons with disabilities. Various diverse regulations for persons with disabilities
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Autism is recognised by the government of India as a disability. Caregivers of autistic child and adults living with Autism should thus be made aware about Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 and The Rights of Persons with Disabilities Act 2016, to know about their freedoms and privileges.

The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities was constituted by the Central Government in the year 2000 with objective to enable persons with disability, facilitate support to registered organizations, deal with problems of disabled persons who do not have family support. Ensure protection of rights and full participation of people with disability. The several schemes under its umbrella encourages assisted living with dignity for various time period. Assistance of short term respite care and long term prolonged stay are provided under 'Samarth' and 'Gharaunda' schemes respectively. These schemes provides group home to adults for lifelong shelter and care at affordable price.

Health insurance benefits for all age bands and irrespective of the type of disability, covers regular medical visits to corrective surgeries and post-hospitalization under 'Niramaya', scheme. This scheme provides cover up to Rs 1 lakh with single premium.

Other benefits like health insurance 'Niramaya', which provides cover up to Rs 1 lakh with single premium across all age bands and irrespective of the type of disability, these cover regular medical visits to corrective surgeries and post hospitalization costs as well

Travel concessions up to 75% and hotel discounts under All India Tourism Development Corporation is offered to person with disability, additional travel escort is available on submission of disability certification. An income tax concession under section 80U depending on level of disability is allowed to both the person with disability and the caretaker.

"Punarbhava" is a national web portal on disabilities; it provides information with this regard. It has space for discussion of legal issues, redress grievances, finding employment, help in appliances and assistive devices apart

from disability certificate registrations. Currently certification is only available for autism with MR (mental retardation). This further emphasizes the lack of understanding among policy makers. At present the education system is not adept to cater to needs of autistic children. Adequate training of teachers and availability of special aids to facilitate learning with inclusivity is majorly lacking. Children with even good IQ scores are deferred due to their perceived "trouble- maker" attitudes. This deters their functioning and learning of valuable social skills from peers. Unbending rules and functioning of traditional schools in our country resists off-centre methods which may be the better solution.

Despite the varied presentations and diverse age of diagnoses the desired adult outcome is autonomy and Independence with community participation leading to a meaningful quality of life(12). The "Sarva Shiksha Abhiyan" launched in 2000-2001 with key objective of universalizing elementary education is further strengthened by Right of Children to free and Compulsory Education Act 2009 for children aged 6-14 years and scheme of Inclusive Education for Disabled at Secondary Stage (IEDSS), launched in 2009 for class 9th to 12th. They ensure every child with special needs receives quality education which helps them strive to the above life goal at their best capacity.

Scholarships via "Gyan Prabha" to pursue educational and vocational courses and educational boards like Central Board of Secondary Education (CBSE) giving additional allotted time and optional language studies are small steps forward.

"Vikaspedia" online education resources for health care providers and families which talks about diagnosis, role of genetic tests, imaging and EEG needs in autism and gives information on role of speech therapy, Applied Behaviour Analysis (ABA), Sensory integration and structured planned training. It also talks about TEACCH (Treatment and education of autistic and related communication handicapped children) which is a special education program used in schools and which can be adapted for home based training.

Besides core features education about comorbidities like epilepsy, sleep related problems, self-esteem, physical health and hygiene, adolescent issues, associated intellectual disability, obsessive compulsive behaviours, attention deficits, even gastrointestinal issues like diarrhoea and constipation are neglected areas which cause significant day to day impediment and need to be teased out by the health care provider and to be addressed to enhance quality of life in ASD children and adults. The caregivers should be provided with tools to deal with these aspects along with other challenging behaviours like temper tantrums, self-injury and aggression.

There is no single cure for ASD and there is no one size fits all approach. Many non-scientific miracle cures are misleading and add to the financial and physical burden of caregivers and also delays the specific required intervention. This becomes even more important in low-middle income countries where the socio-economic burden on family may further add insult to injury. Empowerment of parents and caregivers of ASD by information regarding evidence base for each treatment intervention helps to change these perspectives. Intervention programs which incorporate several research-based interventions and address the individual needs of children with ASD and their families should be pushed forward.

A major concern of parents of a child with ASD is dealing with risk of disease in an unborn sibling, in a family which has 1 child with ASD, has 7% and 4% risk of having similar disease in case of a girl and a boy respectively. Based on these data and questions the parents are asked to seek genetic counselling so that they can take informed decisions.

Many evidences in Indian history justifies the role of legislation in policy making for individuals with disabilities.

Few of the major landmark legislations in India concerning persons with disabilities include the Persons with Disabilities (PWD) Act (1995), Rehabilitation Council of India (RCI) Act (1992) and National Trust Act (1999) (13,14,15). India ratified the United Nations Convention for Rights of Persons with Disabilities (UNCRPD) in the year 2007(16)

The Mental Health Act,1987 has included the key objectives as “An act to consolidate and amend the law relating to treatment and care of mentally ill persons to make better provision with

respect to their properly and affairs and for matters connected therewith or incidental thereto”(17).

The Rehabilitation Council of India Act 1992 (amended 2000) provides a frame for educational training in rehabilitation of individuals with disabilities. It gives information on courses available in special education- B.Ed., M.Ed. and D.Ed. The details of the institutes and admission procedures are specified for Special Education (Autism Spectrum Disorders), courses in speech and language therapy and rehabilitation.

The Person with Disabilities (Equal Opportunism, Protection of Rights and Full Participation) Act, 1995 had mentioned to give effect to the proclamation on the full participation and equality of the people with disabilities.

Office of the chief commissioner for persons with disabilities (PWD) was set up in 1995 under the PWD act and emphasized on the education, employment, creation of barrier free environment and social security of individuals with disabilities including their. The chief commissioner is authorized to monitor the utilization of funds issued by central government. He can also act on complaints concerning non implementation of laws and instructions issued by appropriate authorities protecting the rights of persons with disabilities (18).

National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 focusses on the physical, educational and economic rehabilitation of children with disabilities, barrier free environment, social security, research United Nations Convention for Rights of Persons with Disabilities (UNCRPD) formulated in 2006 emphasizes that there should be no discrimination on basis of disability.

The Rights of Persons with Disabilities (RPWD) Bill passed in year 2014 in India, was mainly drafted under the guidelines of UNCRPD to promote equality of persons with disability and to avoid any kind of discrimination (19)

Few of the initiatives by Ministry of social justice and empowerment (MSJE) like ‘Sahyogi’ and ‘Badhte Kadam’ schemes are introduced for training caregivers, increasing awareness, community interaction and innovation for people living with disability.

“Prerna” is the marketing assistance scheme with an objective to create viable channels for

sale of products and services produced by people with disabilities.

Many of the e-learning modules have been conceptualized, developed and implemented by Department of Pediatrics, Neurology division; All India Institute of Medical Sciences are educative and directive for health professionals in the core area of Paediatric Neurology and Neurodevelopmental Disorders. Android and iOS based Mobile applications for diagnostic tools for ASD, ADHD, epilepsy and neuromotor impairments are available (pedneuroaiimsdiagnostics). Educational material for paediatric patients with Neurology and Neurodevelopmental Disorders are developed and are freely available for caregivers and patients (www.pedneuroaiims.org) (20).

These online platforms enable people with disabilities, their caregivers/ health care providers to update themselves with scientifically approved therapies and other newer therapies which may be in pipeline. These platforms guide and pave a way forward to hone the skills towards care for children living with ASD.

FUTURE DIRECTIONS

Early screening by caregivers and health workers are readily available online resources like the INCLIN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD) (21) and easy accessible information which can be used efficiently. In the current Indian scenario, the biggest challenge is to avail these services to meet the needs of these patients. The strict regulatory policies on certification for disability may although reduce the illegal use of benefits but may miss out on actual in need population due to stringent criteria.

A good start to create these services is public awareness about autism, its effects on functions of a person, realization about how people with autism can contribute to a diverse and well-functioning society.

This requires not just medical care and intervention centres but also a humanistic approach towards patients with disability. Few user friendly instructions in public places which are less distracting with least noise and streamlined workplaces, will be beneficial for people with lower IQ. In cases of emergent situations, ready help should be available at public places, homes and centres where autistic people with severe disability can live comfortably.

The innovative ideas and methods, which are less cost intensive should be promoted as a beneficial tool for early diagnosis and interventions.

There is a huge demand to design implementation research to evaluate effectiveness of evidence-based interventions in ASD in health care settings. (22)

Apart from policy making with the stake holders, generating this need at various strata may drive perspective change in service providers involved in various common activities, which could be challenging to these individuals.

The holistic humanistic approach towards individuals with disability should include upgrading the approach of the paediatricians, healthcare professionals so that early and accurate screening and diagnosis and further receive effective interventions. The healthcare professionals and the policy makers should team up together towards the children with disabilities, so as they are integrated into the mainstream, without stigma or limitations (8).

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