

Autism spectrum disorder: needs urgent attention

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Autism is a complex neuro-developmental disorder, is not a one but a group of different multiple pathologies which varies in symptoms and severity from one patient to another and according to the recent diagnostic manual (DSM-5), all these different conditions are combined under one term i.e. Autism Spectrum Disorders (ASD). It is usually first noticed in 18 months to three years of age and mainly affects the child's socialization, communication and cognitive functions. Autism is characterized by difficulties in verbal and nonverbal communication, social interaction, limited interest and repetitive behaviours¹. Prompt diagnosis and early intervention can result in marked improvement to an extent that most of these children may go to the mainstream schools. Unfortunately, in our country, majority of these children are undiagnosed due to lack of expertise or awareness among clinicians and parents. The parents are usually silent sufferers and the affected child is more unfortunate, who have to bear the brunt of this disease and mishandled usually.

Regarding prevalence of Autism in Pakistan no reliable data exists at national level whereas its prevalence is about 1:110 in developed countries and its incidence is on the rise^{1,2}. From the statistics of South Asia, one can estimate that in Pakistan, its prevalence may be same as elsewhere in other parts of the world³. Morten et al in 2002 has reported that in Pakistani children the prevalence of ASD and Cerebral palsy are slightly higher (2.57/1000), along with higher rate of severe learning disabilities as well as vision and hearing problems⁴. In 2010, the Autism Society of Pakistan (ASP) was registered under The Societies Act, 1860, as a non-profitable organization. The primary objective of this organization is work for Autistic children which include training, advocacy, fund raising and research and first Autism Resource Centre (ARC) was established in Rawalpindi in 2010. According to statistics of ARC, in Pakistan an estimated almost 3.5 lac autistic people are living. These figures are thought to be under reported due to the lack of diagnosis, dearth of expertise and more chances of misdiagnosis^{5,6}.

Unfortunately, the awareness and knowledge of this fastest growing mental disorder is still very low and has begun recently in last few years in Pakistan¹. Healthcare professionals and common people are usually well aware of mental health disorders like anxiety, depression, etc. but when it comes to autism, the majority of them are totally unaware about what the condition entails. A survey conducted over general physicians in Karachi showed that only 44.6% of the General Practitioners (GPs) had previously heard of autism^{3,7}. Moreover, two surveys regarding assessment of practices and attitudes of health care professionals towards Autism conducted in Pakistan and published in 2011 has also reported various misconceptions and misbeliefs of health care professionals especially in knowledge about etiology, diagnosis, and treatment interventions for autism^{8,9}.

Early diagnosis, intervention and treatment in these patients have been proved in reducing disability but these services are almost absent in our country. Due to the absence of social services system and the inability to provide the basic needs of autistic persons, the family of these children are compelled to lead a stressful and arduous life. It has been observed or reported that these children with ASD especially in rural areas are often kept in chains or locked. Illiteracy coupled with superstition, fear, lack of awareness and treatment facilities perpetuate this violence and cruelty against them in society^{5,7}.

In Pakistan, for assessment, diagnosis, treatment and rehabilitation of autistic person, limited services are available in urban settings where as rural areas are lacking such services where our majority of population live⁶. The assessment and diagnosis of ASD is being made by the General Physicians, paediatricians, general psychiatrists, psychologists, neurologists, and speech and language therapists. Moreover, no formal screening guidelines or tools were being used by these practitioners especially in primary care practices for assessment of autism spectrum disorder^{6,7}. The child psychiatry speciality, and specialized services for autistic children and their families and for children with developmental disabilities, are also scarcely available in our country. Only a handful of paediatric psychiatry departments and child psychiatrists are available and that are in major cities. Moreover, no subspecialty fellowship program is offered in this field except recently announced by College of Physicians and Surgeons, Pakistan for psychiatrists^{1,6}.

The autistic individuals usually have good IQ, having different ways of learning, processing information and most of them have unexpected abilities in music, art, mechanics, and computer technology³. Like other children, the autistic child should be trained from an early age so that they can develop and train in skills based on their interests^{1,5}. Most of these autistic persons can be a true asset in a different workplace and are being used amicably in developed countries. One of the examples is, German software company, SAP AG which are engaging autistic people on the spectrum of different jobs in organization, like these persons pay a lot of attention to very minute details which is extremely helpful in testing a software. In spite of this, the unemployment rate for ASD people are as high as 85% even in most developed countries⁵. Other than institutes, the training and integration of autistic persons in society needs individual efforts. A good example is persons who own a business, store owners or tech entrepreneurs, who can train and hire an autistic individual by helping them to navigate the work environment. In reality, it's not a philanthropy because the employer or organization will be receiving much more in return as autistic can be more precise in their tasks⁵.

In developed countries, along with other health professionals, parental groups are playing an integral role in supporting and educating the autistic children and families. Recently in Pakistan, "Pakistan Autism Meet up" is established. In addition, Children's

Hospital Lahore and Dow University Karachi has launched their program providing a wide array of services for ASD children but much more needs to be done by medical institutes all over the country^{1,6}. A number of organizations privately or from different NGOs are working only in big cities for autistic persons in country but the performance of majority of these institutes is under question. The performance of most of these NGOs or organizations of input in the management of ASD is more of commercial nature and not focused. Moreover, these institutes are not found everywhere in the country and these are not enough for the ever-increasing number of ASD cases¹⁰.

Instead of considering the autistic people as disable and dependent, bringing these individuals with ASD or with other disabilities in the normal mainstream workforce will benefit our nation. This requires an initiative from the state to create awareness of ASD, physicians training for correct assessment and facilities for early intervention. By adopting these important steps we can make the real progress⁵. Moreover, legislation is urgently required in this regard because no specific federal policy or laws exists in relation with education and provision of supportive services for individuals with autism and developmental disabilities in our country. To overcome this challenge, it is important for private and public sector to join hands in providing proper comprehensive assessment, facilities in diagnosis, treatment, education and support services for these individuals and their families all over the country¹. It is suggested that, The National Commission for Human Rights should revive the organizations like National Disability Trust and to provide funding for new initiatives in ASD, such as autism awareness campaigns, teacher training and curricula modification in schools and medical colleges, therapeutic interventions and respite care alternatives for this disorder.

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