

PAKISTAN

Pakistan Country Report–Autism

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INTRODUCTION

Autism has remained a mystery for researchers, neurologists and psychiatrists for centuries. Although the cause of autism is still unknown, a number of strategies have been developed, that have saved so many lives all around the world. There are over 60 million people with autism across the world — of which many Third World countries in Africa and Asia, including Pakistan, do not even have access to any public services. The situation is definitely alarming. In a country like Pakistan, where due to lack of financial resources, reasonable education remains a dream even for an average person, affording rehabilitation services to an autistic child is well nigh impossible.

CURRENT SITUATION IN PAKISTAN

In south Asia, the countries of India, Pakistan, Bangladesh, Sri Lanka and others have recently been exposed to the awareness, research and documentation on Autism spectrum disorders, that has existed in the developed world for decades. Due to which many children have been misdiagnosed as PDD-NOS (Pervasive Developmental Disorder - Not Otherwise Specified) or have been kept locked away in homes due to misguided belief in magic (primitive tribal/religious thought) or due to social stigma. While students of special education at public sector universities have done studies concerning existing students with autism at special schools, these studies have been area or city specific, and not country-wide, hence their findings are not standardized, but are estimated to be about 1 in 500. The population of Pakistan is estimated to be 172,800,048 hence the number of people on the spectrum is estimated to be a minimum 3, 45,600 although due to under-reporting, misdiagnosis and social stigma we can say this number is in reality much higher.

In Pakistan autism is relatively a new phenomenon so far, as only private institutions work in this area. Seminars and workshops are being conducted on this topic to create awareness among parents, professionals and government authorities. However, there is no institute at the government level, which specifically caters to the services for children with autism. There is a need to create awareness about this disorder at the government level.

Prevalence of Autism and general situation is as follows:

- Autism Spectrum Disorder: 1:120 kids
- No Diagnostic and Rehabilitative means even in the major cities of Pakistan.
- No understanding of early detection, sensory issues and home based interventions by child care

specialists.

- Lack of awareness and means of Learning for the Medical & Rehabilitation Teams
- Lack of awareness and means of Learning for the Special Education and support staff teams.

Usually the professionals use ABA (Lovaas Program), TEACCH in combination with Picture Exchange Communication System (PECS), speech therapy and drugs (if required) as treatment options for such children. The basic approach is eclectic. The choice of treatment depends upon the needs of the child. The facilities of Sensory Integration Therapy are also available in a few institutions. Over the past two years the use of biomedical approach has also increased, as some of the parents have found positive changes in their child and they have taken an initiative to promote this biomedical approach for the treatment of ASD.

There are no government funds for this particular problem. However, many of the non-governmental organizations and private institutions help people not only to get such services at a very low cost, but also to help the needy ones by providing uniforms, lunch, paying their fee, etc.

The major challenges that Pakistan faces are lack of awareness and lack of resources. In Pakistan, there are two institutes for the professional training of Clinical Psychologists: Institute of Clinical Psychology, Karachi, Province Sind and Centre for Clinical Psychology, University of the Punjab, Lahore, Province Punjab. The people who are trained from these institutes are given exposure and training under supervision. The clinical psychologist trainees work in the field and are placed in special schools, where they learn the application of different techniques and theories, which are taught to them as a part of their course work.

Several initiatives have been taken by governments, NGOs, INGOs, UN agencies and others for addressing the special educational needs of children with disabilities. Some have demonstrated successful models of special and inclusive education. However, a comprehensive analysis of these initiatives has not yet been undertaken in Pakistan. The regular government school system in Pakistan functions independently of the special school system. Such segregation is also evident in schools run by the private sector. Teaching methods enhance the learning ability of the individual child in a limited manner. The system does not usually allow for a participatory role by the child nor does it stress the development of his/her creative and critical thinking ability.

The attitude of society in Pakistan to people with disabilities is generally positive. It is more favorable in rural areas than in urban areas. However, lack of knowledge about the capability of disabled people results in a low profile for children with disabilities. Lack of educational facilities exacerbates their problems. Those attempting to apply inclusive education at the grassroots have tried to implement indigenous methods to educate challenged children.

Inclusive education is a new concept; a few schools are striving to create an inclusive environment through experimentation with various approaches. These approaches include establishing new inclusive schools; giving access to children with disabilities to existing schools; persuading children without disabilities to join special education institutions; keeping children with special needs within regular school although in separate classrooms; and supporting schools with multi grade inclusive classrooms.

Inclusive schools in Pakistan are restricted to big cities in the private sector and are not accessible to children with disabilities living in remote or rural areas. Also, parents are not willing to send their challenged children to school, as they fear that they will be stigmatized. Distance and other problems related to commuting to school add to the difficulties for these children.

According to the last census, there are 3,286,630 people with disability constituting 2.54 per cent of the population. A survey of the prevalence of special needs children sponsored by the WHO indicated that 10 per cent of the population had some sort of disability, such as emotional disability, visual impairment, hearing impairment, mental retardation, physical disability, learning disability or multiple disability. Of these, only two per cent had access to institutional facilities.

The number of people with disabilities is greater in urban areas than in rural areas. A possible explanation is that the incidence of mortality is higher in rural areas than in urban areas because of the lack of facilities such as safe water, sanitation, health services, etc.

ROLE OF THE PRIVATE SECTOR/NGOs

The private sector/NGOs have also emerged as a strong force to expand and improve educational services for students with special needs. All good practice models in special education are in the private sector. These schools are spacious, financially sound, and have good physical and educational facilities. The government provides partial financial assistance and comprehensive professional support to these institutions. Funding also comes from Bait-ul-Mal and national and provincial trusts for people with disabilities. All these developments have markedly changed the standard of special education in Pakistan during the last 20 years.

Some private institutions have become interested in inclusive education. They have started including special needs children in their schools but have not paid adequate attention to disability-friendly infrastructure development, professional training of teaching staff, use of appropriate teaching-learning methods, etc.

The attitudes of the society, including parents of children with and without disabilities, are generally in favor of inclusive education. The private sector is willing to cater to the needs of disabled children, and is awaiting a constructive plan from the government.

It is important to recognize that it is less costly to provide education for disabled children in mainstream inclusive schools rather than establishing special schools. The additional/marginal cost to transform mainstream schools to inclusive ones is minimal and affordable for the government.

International donor agencies funding social development projects are keen to take up the promotion of inclusive education and provide financial and technical support to the government, NGOs and the private sector.

There should be legislation that makes it compulsory for every public school to admit all children irrespective of their special needs. However, at the initial stages, severely mentally retarded children or children with severe physical handicaps may be referred to a special school.

CURRENT ISSUES OF AUTISM

- 1) The biggest challenge is the stigma attached with the word autism. Acceptance of this problem lacks in society as well as in the members of the affected families. Apart from this stigma, lack of treatment facilities, training facilities and poor attention from the government are some of the major problems that a family with autism has to face.
- 2) There is a lack of comprehensive data on the educational status of children with disabilities.
- 3) There is a lack of trained professionals in this field. We don't have any single institution that trains professionals exclusively for training of children with autism. However, recently some of the institutes have started paying attention to it and have included autism and its treatment options as part of their post magisterial program curriculum; however, they still need institutions to provide practical training to their trainees.
- 4) Again, these schools are only in major cities of the country. In fact, only the elite class can afford the structured services and treatments. Also, there are some NGO's (non-governmental organizations), but usually NGO's work for the whole community of Special Children and not for autistic children specifically.
- 5) Health insurance facility to enable and empower persons with disability to live as independently and as fully as possible becomes important but presently such products are not easily available for persons with disabilities.
- 6) Convention on Rights of Persons with Disabilities aims to promote and protect the human rights and fundamental freedoms of those with disabilities and also respect for their inherent dignity is needed to be implemented in letter and spirit.
- 7) Inclusion of Autism in the Disability Act should be enacted.
- 8) There is a need for Formation of a National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities to address the problems of those persons with disability, particularly the poor who do not have family support and to appoint guardians and trustees for persons with disability. The trust should also finances NGOs to run permanent care homes, respite care homes and day care services.
- 9) Obtaining an accurate diagnosis for children is difficult. Parents may take their child to a pediatrician only to be reassured that their child is just "slow." Unsatisfied, they may visit a psychologist, to be told their child is "mentally subnormal."
- 10) Admittedly, there are not enough services to meet the needs of mentally retarded children and adults in Pakistan, let alone those who are autistic.
- 11) There is also an urgent need to begin planning homes and centers for these children when they become adults: people with autism have a normal life span and many will require supervision after their parents' death.
- 12) Currently, the needs of autistic children in Pakistan are not being met in either the regular or special education systems. With an understanding teacher or possibly an aide, a more able autistic child could function very well in a regular school, and learn valuable social skills from his peers.

- 13) The special schools almost always lack an understanding of effective methods of handling the challenging behaviors of autistic children.
- 14) Children with autism are frequently refused admission in special schools because officials protest they are not equipped to handle autistic children, who are sometimes more challenging than children with mental retardation alone.

FUTURE PERSPECTIVES OF AUTISM IN PAKISTAN

There have been many achievements and breakthroughs, due to the hard work of parents, doctors, special educators and researchers in Pakistan, all have been recent efforts and have started a series of events which will get us where we want to be, maybe not in an year's time, but soon enough. Increased awareness has made parents of autistic children come out from the shadows to seek education and therapies for their children. The recently opened Autism Centre at Gulshan-e-Iqbal at Karachi is a step in the right direction as training in the structured TEACCH and other systems is now being imparted to mothers and special educators here. increasing awareness and getting more government and private sector support to widen the reach and get those across all ages and spectrums into training programs, as well as increasing awareness for other learning disabilities, augurs well for better situation of autism in Pakistan.

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<Questions and Answers after Country Report>

Q1: How do inclusive education funding to support in Pakistan?

A1: Depend on Department of social welfare support but social education school include budget from local also. And MOE (Ministry of Education) support for teacher training.

Q2: On an earlier occasion, "inclusive education" had been practically conducted. As the concept of special education became to apply, its part has been covered by Social Welfare & Women Development Department. That is, "special education" is covered by Social Welfare & Women

Development Department on the other hand, “main education” is administered by Ministry of Education. In recent years, it is necessary to reconstruct “new INCLUSIVE EDUCATION”.

How to succeed an “INCLUSIVE EDUCATION” under the two departments as stated above?

A2: In the future, it might be advisable that Ministry of Education manage the “new INCLUSIVE EDUCATION”. However, it is important to recognize that it is less costly to provide education for children with disabilities, are generally in favor of inclusive education.