COMPREHENSIVE EDIFICATION FOR CHILDREN WITH AUTISM IN INDIA

RICHA CHOWDHARY

ABSTRACT

Inclusive education also seen as an international agenda, partly running parallel to the objective of education for all (Srivastwa 2003; Miles and Singal 2010). India also has been trying to incorporate the international commitments into its domestic law and has developed its own policy related to education for children with disabilities (Sing A.K 2008). Autism disorders are life-long neurodevelopment disabilities with onset before 36 months and are characterized by: Impairments in reciprocal social interactions and in verbal and non-verbal communication skills, stereotyped behavior, interests and activities etc. This disorder represents an abnormality of brain development and function, appearing within the first three years of life. Although the detailed causal mechanism(s) are not known, autism is likely to have multiple etiologies including genetic factors. A range of studies have found that in 10 - 37% of cases, it may be an associated medical condition (e.g. tuberous sclerosis). In the late 1970s, there were a few centers in India that were diagnosing children with autism. A study conducted in the mid-1990s found that many of the older adolescents and young adults who received a diagnosis of autism could be traced to just a few professionals, and those with diagnoses before 1980 had received the diagnosis from abroad (Daley, 2004). Much of the diagnosis was dependent on individual professionals, and knowledge amongst the wider medical community remained limited. In 2000, a boy with autism from Bangalore, Tito Mukhopadhaya, published his first book, ‘Beyond the Silence: My life, the world and autism’. The book includes writings from when he was between eight and eleven years old, which brought international attention to Tito and his mother’s methods for teaching him. Recently, internet list servers have expanded the Diasporas of Indian families with autistic children to dozens of countries around the world. Due to limited studies and literature available in this area of education, through this paper I am trying to gain attention of educators for inclusive education for Autism in India.

Key words—Comprehensive, Education, Autism, Brain development.
Pictorial Introduction and explanation

Introduction of the Problem

For children, the term inclusion is often used in reference to educational settings, which is one form of inclusion. Inclusive education requires teamwork and is a responsibility that needs to be shared by the whole school. Effective inclusion does not simply mean placing a child with a disability in a ‘regular’ school. It also refers to providing more options for all children, and structuring schools in a way which every child including those who are differently abled can learn. All children may experience difficulties in learning at some stage. Therefore support by teachers in whichever environment/ skill set they may be facing problems is crucial.

Inclusive education is a process involving the genuine restructuring of curriculum, teaching methods, and classroom organization that requires constant effort. When the teacher differentiates instruction according to content, process or
product, it increases the likelihood that all students can meaningfully participate in class activities. Activity based learning is well suited to inclusion of learners with a wide variety of educational needs and learning styles.

Teaching materials may also be adapted to match the student’s characteristics and interests. As the teacher plans her lessons and implements instructions for the students, it is important to think about each student’s ability and uniqueness and build on those. It is essential to support learning by providing multiple, flexible methods for both the teacher’s presentation of the lesson, as well as opportunities for the students to display what they know or have learnt.

Equally important is empowering students by allowing for multiple, flexible methods for engagement, helping them to make certain decisions, and set goals on their own. Teachers in inclusive schools can use cooperative groups and peer supports to capitalise on student differences. Establishing a sense of community is essential for creating a successful classroom where all students want to contribute, are respected and cared about. The classroom is where students can learn to value differences, appreciate commonalities, and better understand concepts such as fairness, cooperation, equity and justice.

It is necessary that the teacher learns students’ communication strengths and preferences, and provides individualized sensory supports to maximize learning. Schools often place greater emphasis on academic achievements and may overlook social skills training. If the child’s time is spent in one to one sessions with a resource teacher, then the peer interaction is limited only to playgrounds. These may be difficult for a child with autism as these interactions are free ranging and fast paced. Peer interactions on task-based situations are easier. Therefore opportunities must be set for appropriate and meaningful positive interactions. By supporting meaningful learning outcomes for all students, teachers can endorse the idea that a disability need not be a ‘handicap’ to learning, ability and friendship.

Manovikas Kendra Samiti and Inclusive Education

School is not just a place for learning academics. It is in the classroom where we learn many life skills. We learn social skills – we learn to compromise, to bargain and persuade. We learn communication – we learn to get attention, ask for help, compliment and describe. We learn language skills which are much more demanding than questions and answers of any tests. Preparation for adult life is the main objective of schooling. Therefore it is desirable that all children go to inclusive schools. This is also in harmony with the UN Convention for Rights of Persons with Disabilities. Since children with autism have distinct learning and thinking styles when compared to the non-autistic population, there is often a misinterpretation of their behaviours and language. Therefore as a prerequisite to inclusion it is essential that all teachers learn more about autism.

Manovikas Kendra Samiti has successfully placed many children with autism in mainstream schools and continually works with these schools to facilitate and sustain their inclusion. Through various training workshops, along with individualized training modules, Manovikas Kendra also empowers mainstream schoolteachers with a better understanding of children with autism, and strategies to achieve their successful inclusion. In addition, the Manovikas
Kendra team also works with schools and government organisations to cater to their specific needs related to including children with autism in the mainstream classroom.

The study of MKS has been done with the branch of Delhi Govt. School and Sarva Shiksha Abhiyan, amongst others, are examples of this endeavour. Special educators from Action for Autism visited a number of the DELHI GOVT.SCHOOL in the centre to sensitize teachers towards disabilities including autism. They also initiated inclusive events wherein students from the Delhi Govt. schools visited Manoviaks Kendra and students from Manoviaks Kendra Samiti participated in celebratory events at the a branches of Delhi Govt. Schools.

In 2008 MKS worked with the Ministry of Human Resource Development, Government of India and developed a manual on inclusive education for children with autism for the Sarva Siksha Abhiyan (SSA). The SSA is the Government of India's flagship programme to achieve Universalization of Elementary Education in a fixed amount of time. Since then, Manoviaks Kendra team members have been conducting regular workshops and training programmes across the country to provide training to SSA resource persons and trainers.

While we support inclusion, we also believe that inclusion should not replace sensitive, specialised training, particularly for children with more support needs and those with severe social impairments. High quality, specialised special education can have an enormous impact on the future functioning of children with autism. The ultimate goal is not just inclusion in school for the sake of inclusion. The term inclusion with respect to the differently abled has a far wider connotation and needs to encompass the life span of the individual, of which the school environment is one component. Perhaps one model for how this can be achieved is through early specialised education where skills for later integration in the mainstream are taught. Inclusion in the truest sense means respecting individual differences, not ignoring them. It also involves respecting the need for an individual to learn and function to best of his capacity, in the environment that suits his individual learning needs the best, while making the necessary accommodations to facilitate the same.

**SOME CASES STUDIES**

*In the absence of any governmental facility, some mothers come together to provide a sanctuary for their autistic children.*

**Case 1**

*In all her years of practising medicine, never once did Dr N. imagine that one day she’d be left stumped about her child’s health. For two years after his birth, her son Inam showed no signs of speaking, like the other kids did, or responding to his mother or any other way of communicating.*

“Well I am a doctor, it was difficult for me to understand why my son would not respond to any of my prompts. He would remain busy in playing games and mobile phones,” says Dr N., a 33-year-old ophthalmologist who works at a major hospital. “I observed that he never spoke like the other children even after he was two-years-old.”
As Dr N. later understood, her child was different from the other children: now about four-and-a-half years old, Ajan was an autistic child.

*Autism or Autism Spectrum Disorder (ASD) refers to a group of complex disorders of brain development. These disorders manifest themselves in children from 18 months to three years of age. They present themselves as difficulties in social interaction, verbal and nonverbal communication, cognition and repetitive behaviour.*

Panicked, Dr N. and her family visited various government and private hospitals in Rawalpindi and Islamabad in search of medical help. They were met with the same answer everywhere: no hospital was equipped to deal with cases of autism.

As fate would have it, Dr N. found help in two mothers who were in the same boat: Ghazala ji and Jushiji, the director and executive director of the *Autism Resource Centre (ARC)*. “One of my friends told me about the ARC; I visited them in November 2013 to seek treatment for my child,” says Dr N. “My son has improved a lot during the last one-and-a-half years; he now likes to play with his elder sister, he also visits the park frequently to play with other kids.”

The ARC was set up as a dedicated facility for autistic children by Ghazala ji and Jushiji, both from military families, since their children needed support and help was not available. “I took the initiative to establish the ARC in Delhi five years ago because two of my children were autistic,” says Ghazala ji, who teamed up with Jushiji after learning that one of her children was autistic too. “There are 350,000 autistic children in India (approx), according to a recent research of the ARC. One out of 66 children is autistic; this number is increasing with the passage of time.”
The occupational therapy room at Autism Resource Centre, East Delhi, MKS, where autistic children are engaged in activity-based interactions for education.

Contrary to popular belief, however, the western model of inclusion is far from perfect as most parents have to rely on incredibly expensive interventions which are paid through insurance claims that take an average of two to three years due to massive demand. Long waiting lists of parents as well as expensive patented systems (a consequence of capitalism) has led to a fragmented and broken system for autism education in America, with massive variation based on what state and city parents live in.

If you are taking care of a person on the spectrum, it is a life-long learning process as no one has all the answers, and there is a lot of trial and error.
Present Study

In this study we have done with below processes-

Objective

- This study was designed to know about Autism Spectrum Disorders (ASD) are lifelong developmental disorders due to neurobiological conditions and its level.
- Common format across the MKS and will provide the strongest, most robust evidence available to determine the prevalence of ASD in the MKS.

Setting

Preliminary work was conducted with some Associated and Collaborating Partners towards Identification of potential study areas for ASD prevalence’s. It will be important to select a small number of contrasting areas in which to conduct a pilot study to learn the difficulties of implementation on the ground. Researcher and ASD expert’s team have approached. Some of these partners have already defined. The particular region where the study will be developed, but in some other cases the whole school children can be the study stage chosen. However, the following criteria should be considered for regions selected:

- Well defined and delimited geographical and administrative area;
- Stable population
- Compulsory education system at the ages of the study subjects
- Existence of a Public Health Care System covering near to 100%;
- Accessibility to data from educational and special educational sources;
- not a priori selection bias due to the existence of reference services of ASD diagnosis, treatment or special education facilities, which are located outside the area but close enough for children living within the area to access – this could result in missing children within the study area – birth rate should be known or at least it should be available;
- Accessibility to general mortality data statistics (mortality rate and mortality by causes),
- Parents organizations and other regional stakeholders were favor of the study,
- Accessibility to the clinical records of the potential cases,
- Data accessibility from clinics and institutional private services,
- Rural (NTC Delhi) and urban settings was considered.

Design

A cross-sectional design performed

Population

Target population is defined as all children currently living within the target areas selected in the study time period, with age range from 6 to 14 years old, including both genders as well as all ethnic groups. This population will be defined by birth year instead of years of age, once the study starting date is known. The populations selected were 50 children within the age range considered. Expected number of ASD cases will be between 10 and 15 for all participants. Case definition: for the purposes of this study, a case is defined as a child who fits for the target aim (autism, asperer's syndrome, rett's syndrome, childhood disintegrative disorder and pervasive development disorder not otherwise specified respectively).

Inclusion criteria

- Children of 6-14 years of age during the designated study year. Eligible children will selected by birth year and special attention will be given to the definition of the birth year, i.e. that it runs from 1st January to 31st December. This definition is relevant for estimating population size and denominator appropriately.
- Children who officially reside in the designated study area during the time of the study. Sources of information, case ascertainment and procedures education, health and social services, both public and private, as well as parents’ organizations, will be used as sources of information.

Case Appearance Procedure

Stage 1 (identification of potential cases)

- A full inventory of private and public mainstream and special needs schools will be drawn up.
- An inventory of social services for children in the age range selected will be also created.
• Previous agreement with schools and other institutions in the survey will be followed up and a schedule of site visits drawn up.

• School site visits will be conducted and each classroom with pupils aged 5-15 years will be checked through the teachers responsible, who will be interviewed about the children. The experience from the other studies, where this method was applied, is valuable for this aim. The tool for this interview will be a questionnaire which has been recently used by us for this purpose.

• All special needs educational and social services will be checked and all cases described as autistic, Asperger’s or autism-related to, considered. Social services and disability registries checked.

• A careful revision will be needed for those children with diagnosis where high frequency of autism is recognized (e.g., Down syndrome, etc.) or those with suspected labels regularly used in some countries (e.g., High Functional Autistic and Asperger’s syndrome) are not always recognised due to cultural criteria. This point should be considered after discussion with participant partners because there are no general rules that can be applied; this is a regional cultural issue.

• All these services will be asked about their waiting lists and some information about children on the list recorded. Comprehensive revision of the case records available on socio-educational and parents’ organization’s specialized services carried out.

• Specific health services (psychiatric and pediatric departments as well as those devoted to language therapies) considered as potential sources of ASD children.

• In all of the above services, criteria for selecting potential cases are based on:
  – ASD previous classification documented or related ASD classifications;
  – Non ASD previous classification but special educational needs have been documented;
  – No previous classification nor educational needs documented but teacher’s interview highlighted.
  – Neither ASD previous classification nor educational needs documented but currently undergoing evaluation in either health or education services or parents’ organizations services for language and cognitive problems;
  – Children previously diagnosed by (speech or language disorders).

**Stage 2 (first approach to diagnosis)**

• Fathers/Mothers of those children identified by the teacher as possible cases, asked questions using one of these two questionnaires, the Social Responsiveness Scale (SRS), Constatino JN, 2003, Constatino JN, 2004) or the Social Communication Questionnaire (SCQ) (Corsello C, 2007). The final decision were taken after checking feasibility and reaching some consensus among participants.
• A pediatrician took a detailed developmental history and conduct a comprehensive medical and neurodevelopment examination of all children.

• Children were also observed for their motor skills, attention, listening, speech and language capabilities and any unusual behavior, particularly sensory stimulation, repetitive behaviors, or motor stereotypes were noted.

• Hearing and vision assessed by specialists.

• At the end of this assessment, a clinical diagnosis of the child’s problem suggested and provided to their families by the pediatricians.

Stage 3. (Confirmation of the diagnosis)

Children with high scores either in the SRS or SCQ questionnaire or those strongly suspected (by clinical judgment) of having pervasive developmental disorders in previous stages and further assessed with standardized diagnostic measures (Autism Diagnostic Interview—Revised and Autism Diagnostic Observation Schedule –Generic (ADOS-G). In cases where the one tool suggests ASD and the other does not.

• Psychometric tests such as WISC IV and/or K-ABC II for cognitive evaluation and Vineland Adaptive Behavior Scales (VABS) or may be its second version (VABS-II) for social and communicative evaluation will be also considered and used. • The final diagnostic determination will be derived from a review of all existing data by an expert team.

• Parents of children from special needs services were invited to sign an Informed Consent (IC) for accessing records.

• Final diagnosis will be made using the DSM-IV diagnostic criteria for pervasive developmental disorders, including autistic disorder, Asperger’s Syndrome, Rett’s disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified.

• Socio demographic variables like race, gender, maternal age, paternal age, familiar income level, rural/urban residence area, etc. explored and collected.

• Background and family data, whether or not another child is affected in the same family, when was the child identified, or what was the trajectory of the child in preschool years within the health and the educational system, also recorded because it was useful for local / national authorities to improve detection and early identification.

• Parental stress measures and other viewpoints of the caregivers about their experiences suggested to be also recorded to the local participants’ partners. Final decision were taken after discussion of the feasibility at the state level. To carry out the above two last tasks ad hoc surveys were developed.
Data Collection

Data from all questionnaires saved and a quality control of this procedure will be implemented. In addition to a standard list of demographic variables including race and identifying information, both the earliest and most recent evaluation data relevant to the child’s specific disabilities as well as medical conditions that may be associated with the etiology of the developmental disability were recorded.

Instrumentation

An algorithm describing all the steps used as the procedure guide for following the whole process.

Training

Most of the activities require specialized professional training. The pilot study areas were selected with professionals and created a diagnosis team. This team had the job to train people in ADI-R, ADOS-G as well as other instruments (such as psychometric tests), where this training is required.

Quality of diagnosis and reliability analysis

• Quality control of the final diagnosis carried out by external experts.
• An analysis of agreement among partners designed.
• Experts carried out their evaluation in blind conditions with regard to the final judgment provided by the local team.
• Different languages and mind state of parents, participating in this project add difficulty to this analysis. To reduce these constraints, evaluators were referred to the same questionnaires, in the English.
• For viewing videos of children explored during the ADOS-G, a bilingual local expert not initially involved in the local team will help the external experts.

Biological investigations

• All children with a possible diagnosis of pervasive developmental disorder not previously identified will be referred to local health authorities, with the recommendation of undergoing some biological investigations, according to local protocol. Coordination with other partners in the study may be possible for conducting biological investigations.

Study areas

• Parents will be invited to donate a blood sample and they will also be asked for authorization for a sample from their children. All of these samples would be stored in according to the rules of the blood bank strategy.

Statistical analyses

Prevalence estimates and asymptotic 95% CIs estimated by race, sex, age. The age considered the age of the child reached in the field study year. A stratified method for calculating the whole prevalence in the participant was used.
Challenges and limitations

The main challenges of the EPAP are the multicultural nature of the population, the lack of a biological diagnostic marker, data accessibility issues, differences in health, education and social services between different countries. Among the samples there are marked national and regional differences in the level of awareness and recognition of ASD as a matter of public concern as well as in the development of diagnostic and intervention services. Another important issue was the level of migration between different regions. One of the principal limitations of EPAP is that its feasibility has not been previously checked; therefore the EPAP will be tested in an initial phase as a pilot study, where issues on the ground such as costs, professional training, and data accessibility, among others, can be experienced.

Ethical issues

The study was approved by a local ethical committee and standardized “Informed Consent” for all to get rid of many difficulties.

Suggestions and Recommendations

After the study we have suggested and informed to MKS about---

Initiatives of Government of India to Promote Inclusive School Education of Disabled Children -

1. SarvaShikshaAbhiyan (SSA) The key objective of SSA is Universalization of Elementary Education (UEE), three important aspects of which are access, enrolment and retention of all children in 6-14 years of age. SSA ensures that every child with special needs, irrespective of the kind, category and degree of disability, is provided meaningful and quality education. Hence, SSA has adopted a zero rejection policy. The goal of UEE, has further been strengthened by the enactment of the Right of Children to Free and Compulsory Education Act, 2009 making free and compulsory elementary education a Fundamental Right for all the children in the age group of 6-14 years. This Amendment has given a new thrust to the education of Children With Special Needs (CWSN), including autism, as without their inclusion, the objective of UEE cannot be achieved.

2. Inclusive Education for Disabled at Secondary Stage (IEDSS) The Scheme of Integrated Education for Disabled Children (IEDC) was launched in 1974 by the then Department of Social Welfare and was later transferred to the Department of Education in 1982-83. The scheme was revised in 1992 and provided educational opportunities for disabled children in common schools to facilitate their integration and ultimate retention in the general school system. This has now been replaced by IEDSS, launched in April 2009. It provides assistance for the inclusive education of disabled children of Classes IX – XII having blindness, low vision, leprosy cured, hearing impairment, locomotor disabilities, mental retardation, mental illness, autism and cerebral palsy. Funds are provided for activities such as identification and assessment, assistive devices, allowance for transport, escorts, readers, uniforms, books and
stationary, stipend for girls, etc. Besides, there is provision for engagement of special teachers, creation of barrier free environment, teachers’ training, orientation of communities, parents, educational administrators, etc.

3. Making Schools Barrier Free All States have been directed to ensure that all primary and secondary schools are made disabled friendly, in a prescribed time bound manner, taking into account the needs of different categories of disabled children. Each district will also have a model inclusive school.

4. Capacity Building of Special Teachers a) Course curricula has been developed and standardized by the Rehabilitation Council of India (RCI) for i) Diploma in Special Education (Autistic Spectrum Disorders), introduced in July 2003, and is operational in 11 institutions registered with RCI, producing 20-25 teachers every year per institute ii) B.Ed. Special Education (Autistic Spectrum Disorders) will become operational from the session beginning in July 2010 at 4 institutions across the country b) Some other organizations imparting diploma in special education (ASD) include Spastics Society of Karnataka, Bangalore; School of Hope, Delhi; Action For Autism, Delhi; Jai Vakeel, Mumbai and Pradeep, Kolkata c) State Nodal Agency Centre (SNAC) and State Nodal Agency Partners (SNAP) of the National Trust have conducted trainings on i. Inclusive Education for Private School Teachers to handle the special needs of students with National Trust disabilities in inclusive classrooms. In the Govt. Schools, this is being done under the SSA Program. 38 programs were conducted during 2008-09. ii. Special School Teachers Training - National Trust has specially focused on Early Intervention and Autism. This program was conducted in 15 States during 2008-09. For Early Intervention, the National Trust has a partnership with Voice & Vision (A unit of Hilton / Perkins, U.S.A.), Mumbai for training one Special Teacher in the Aspiration Programmes.

5. The National Award to Teachers, conferred to teachers from across the country by the President of India, has a dedicated category for disabled teachers/special teachers doing yeoman’s service for the education of disabled children

Support for Autistic Children

1. The Central Board of Secondary Education (CBSE) has made several changes in the examination by laws in February 2009 to facilitate the disabled children, including those with autism, giving the Board (public) examinations of Class X and XII

a) Use an amanuensis and be allowed an additional time ranging from 30 – 60 minutes depending on the duration of the paper.

b) Option of studying one compulsory language as against two within the overall spirit of the Three Language Formula prescribed by the Board.

2. A government sponsored health insurance plan “Nirmaya” for people with autism, mental disorders and multiple disabilities was launched in 2008 to provide affordable Health Insurance to persons with Autism, Cerebral Palsy &Mental Retardation & Multiple Disabilities. This has been a breakthrough, since earlier Health Insurance products
did not include people with developmental disabilities. 3. *GyanPrabha* - a Scholarship Scheme for People with Developmental Disabilities, enables them to pursue any employment oriented vocational training, professional course or higher studies (post schooling) from any recognized institution, leading to an economic activity. 4. The amendment of the Income Tax Act, 1961 by Finance Act, 2007, tax benefits have become available to families of children with autism. A 75% concession in railway tickets for the child and an escort is also available if it is noted in the disability certificate that the child will need an escort every time he or she travels. 5. It has become easier for persons with disabilities like autism and cerebral palsy to open and operate bank accounts, by the directive of the Reserve Bank of India asking banks to accept guardianship certificates issued by local level committees set up under the National Trust Act or those issued by the district court under the Mental Health Act. 6. National awards for empowerment of persons with disabilities are conferred by the Ministry of Social Justice & Empowerment, in various categories which includes autism also

**Legal Support For Education Of Children With Autism**

1. The Right of Children to Free and Compulsory Education Act, 2009 makes free and compulsory elementary education a Fundamental Right, for all the children in the age group of 6-14 years.

2. Rehabilitation Council of India Act, 1992, The Rehabilitation Council of India was set up under this 1992 Act of Parliament. This Council regulates and monitors the training of rehabilitation professionals and personnel, and promotes research in rehabilitation and special education. Its functions include determining minimum standards of education, making recommendations to the Ministry regarding recognition of qualifications granted by Universities, etc., in India for rehabilitation professionals, making recommendations to the Ministry regarding recognition of qualification by institutions outside India and inspection in examinations.


4. National Trust for the Welfare of Persons with Autism, Cerebral Palsy, and Mental Retardation. Multiple Disabilities Act, 1999. The Act facilitates, among others, the realization of equal opportunities, protection of rights and full participation of persons with disabilities and provision for appointment of legal guardian of a person with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities. 5. National Policy for Persons with Disabilities, 2006 The Ministry of Social Justice & Empowerment is the nodal Ministry to coordinate all matters relating to implementation of the Policy. The Department of School Education & Literacy is also one of the implementing partners of the policy. The salient features of the policy include educational rehabilitation which includes vocational training for the disabled.
References


Rehabilitation Council of India, Ministry of Social Justice & Empowerment, www.rehabcouncil.nic.in

National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, Ministry of Social Justice & Empowerment, www.thenationaltrust.in

Some of the organizations working in this field in India-

- Action for Autism – Delhi
- Sampoorna Music Therapy Centre – Bengaluru
- SNM Rehabilitation Centre – Jaipur
- Ummeed – Mumbai
- Darpan Autism – Ludhiana