

AUTISM

Chapter 1

Introduction and Historical Overview

Introduction

Abhi is eight and has just joined a school. His father carries a packet of glucose biscuits which he keeps feeding him to get him to enter the school. Once in the school Abhi cries and makes a high-pitched screeching noise for a good one hour after his father leaves. He “stims” with his fingers and is unresponsive to his teachers’ instructions. Abhi prefers to sit away from the other children, and spends much of the day with his hands over his ears, unaware of the activities in the class.

Taru is also eight. Unlike Abhi who does not use speech, Taru is very vocal. She likes “talking to” the teachers about human races – Mongoloid, Negroid, Caucasian and so on, and the singer Mukesh: her favourite topics. But she does not recount events that take place at home, nor does she recount events at school to her parents. She is at a loss at what to do at recess, tries to interact with the other children on the playground by talking about Mukesh and Caucasians, and ends up getting teased instead. She excels in her lessons, has no friends, and the bullying at school and subsequent stress levels are so high that her parents are concerned whether she might have to drop out of school in a couple of years.

Chandru is a manager in a nationalized bank. He is handsome, dresses well in a slightly old-fashioned fuddy-duddy sort of way, and is a post-graduate who has held postings in different parts

of the country. Chandru is married and has two sons who are studying at a leading public school. Chandru is viewed as somewhat odd and sometimes ‘weird’ by his colleagues, and as exasperating and rigid by his brothers and sisters. His wife sees him as eccentric but a good man, a good father, and a good provider.

Abhi, Taru and Chandru are all very different and they all have autism. Autism affects people in strikingly different ways despite the similarities in the core impairments. However, in each individual who has autism, the symptoms of autism vary, in severity and expression.

Autism is one of five developmental disorders included under the umbrella of the Pervasive Developmental Disorders. In addition to autism, other disorders in this family are Asperger’s Syndrome, Rett’s Disorder, Childhood Disintegrative Disorder, and when full criteria for one of the above disorders is not met, a child may be diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (often written as PDD-NOS). Autism is characterized by deficits in social interaction and communication, and unusual and repetitive behaviour. Cognitive abilities in people with autism vary between those with average to above average intelligence, to borderline and mild mental retardation, and others who function within the moderate to profoundly mentally retarded range. An oftentimes severely handicapping condition, autism manifests at birth or within the first two-and-a-half years of life.

Many autistic children are perfectly normal in appearance, but spend their time engaged in puzzling and disturbing behaviours that are markedly different from those of typically developing children. They may show little or no interest in people including their parents, and pursue repetitive activities with no apparent purpose. They have often been described as living “in a world of their own”. Some, but not all people with ASD are non-verbal. Some autistic individuals may be remarkably gifted in certain areas, such as, music or mathematics, as depicted in the film *Rain Man*, although this phenomenon (often called savants or savant syndrome) is relatively rare. All of them need help.

An understanding of the current status of autism in India must take into account the progression of awareness and understanding of autism and references to the disorder over the years in published literature.

Historical Overview

People often state that autism ‘happened’ only in the twentieth century. But, just like many disorders which we identify now, autism is believed to have always existed. It was just not identified as a specific disorder. References to individuals whose descriptions are similar to the characteristics of autism have existed through history. Amongst these were the ‘holy fools’ who were a much venerated people in ancient Russia, dating back to the sixteenth century. These individuals were reported to be eccentric, given to parroting, with stereotypic speech and actions, obsessive interests, and lack of social awareness. Late eighteenth century accounts of the ‘Wild Boy of Aveyron’ discovered in a forest in France, who was later named Victor, offers us a description that is remarkably similar to Kanner’s a couple of centuries later. From the accounts of Victor that are available, there is evidence of a

serious impairment in reciprocal social interaction, impairment of sensory attention, lack of imaginative play, evidence of stereotypes and intellectual impairment.

However, while autism has always existed, it is only in the last sixty years that it has been given a name, and described by its very specific characteristics. The word ‘autism’ was first used by Bleuler, a Swiss psychiatrist in 1911 to refer to schizophrenia. Then, over 50 years ago, a young boy named Donald visited the child psychiatrist, Leo Kanner, in his office at the Johns Hopkins University in Baltimore. Kanner was “...struck by the uniqueness and peculiarities which Donald exhibited. He could, since the age of two-and-a-half years, tell the names of all presidents and vice-presidents, recite the letters of the alphabet forwards and backwards and flawlessly, with good enunciation, rattle off the Twenty-Third Psalm. His memory was phenomenal. Yet he was unable to carry on an ordinary conversation. He was out of contact with people, although he could handle objects skillfully. The few times when he addressed someone—largely to satisfy his wants—he referred to himself as ‘You’ and to the person as ‘I’. He did not respond to any intelligence tests, but manipulated intricate form boards adroitly” (Gillberg & Coleman, 1992). Over the next few years, Kanner would see ten other children who were similarly self-absorbed and who had severe social, communication, and behavioural problems.

In 1943, Kanner published a paper applying the term ‘early infantile autism’ to this group of children, characterized by withdrawal and with ritualistic behaviours, and gave medical literature a window to this complex and enigmatic disorder. Children with the symptoms originally described by Kanner are now the minority of those diagnosed with autism, as the quest to understand this condition has expanded into a field of its own. Of

note, while Kanner published his paper in 1943, Hans Asperger in Austria independently published a study on autism in 1944. This work was not translated into English until 1981, but it is clear that Kanner and Asperger, though totally unconnected to each other, wrote about the same syndrome in two different countries.

Subsequent to the publication of his paper, Kanner opined in print that the parents of children with autism were ‘highly organized, professional parents, cold and rational who just happened to defrost long enough to produce a child’. He thereby introduced the concept of the ‘refrigerator mother’. This theory was expanded on by the psychologist Bruno Bettelheim, and it impacted for many years to come. The way parents of children with autism were viewed. Bettelheim believed the mothers of autistic children were highly intelligent, cold, and unemotional, and that the best treatment was to remove children from these supposedly affection-deprived homes, thus establishing a facility known as the Orthogenic School.

The movement against psychogenic theories took off in the early 1960s and was led by parents of the affected children. Many of them were involved with issues related to autism in a professional capacity as well. Bernard Rimland, a psychologist in the US, published ‘Infantile Autism: the Syndrome and its Implications for a Neural Theory of Behaviour’ in 1964. Rimland later founded the Autism Society of America in 1965. Lorna Wing, a psychiatrist in the UK published ‘Early Childhood Autism’ in 1966. In fact, the movement for autism worldwide, particularly in the area of services, has been pioneered by parents of children with autism in collaboration with exceptional professionals such as Sybil Elgar in the UK and Eric Schopler in the US.

While Bettelheim’s notion of the ‘refrigerator mother’ and the belief that autism is caused by cold, career oriented parents has been discarded today in the light of decades of research, the consequences of this notion have had worldwide impact and linger even today. It was many years before researchers gained an understanding of Autism as a developmental disorder of biological origin. In much of the developed world, barring a few persisting exceptions like France, autism is now acknowledged as a disorder that is not of psychological origins. However the same cannot be said of India.

Historical Overview of Autism in India

In general, relatively little has been written on autism in developing countries as compared with what has been published on autism in North America and Europe. However, of all the developing countries, India has by far the greatest wealth of research articles, with over 70 articles, chapters and books which relate to the topic. Interestingly, much of this literature appears to go unnoticed by Indians, and there have been consistent references to many of these publications with comments such as “probably one of the initial attempts in Indian literature to describe and discuss” the disorder. In addition to these published articles, there have been smaller, unpublished research studies, several of which the national autism organization, Action For Autism, has been involved with. This section will present a brief history of autism research and the autism movement in India.

The earliest mention of autism in Indian scientific literature may date back to 1944, from a Viennese pediatrician named A. Ronald working in Darjeeling. Ronald presented an overview of the detection, causes, types and treatment of what he termed ‘abnormal children’ in the very same year

as Kanner's hallmark publication. The first time the term "autism" appeared in the Indian literature was in 1959, and a half-dozen publications appeared through the 1960s. Beyond that there was limited knowledge about autism in the medical community.

In the late 1970s there were a few centres 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. There remained a general lack of knowledge of the existence of autism, so that most had not even heard of the disorder, nor did it receive mention in most medical textbooks at that time. By the early 1980s there began a slow growth of 'awareness' of autism among some professionals, such that they were aware of the existence of this condition. However, it was not necessarily a true understanding in that professionals' knowledge was marked by the belief that it was a form of mental illness or that it was a variant of mental retardation. This is not to imply that mental retardation or psychiatric illnesses are in any way 'inferior' to autism, but to simply highlight that this confusion prevented individuals with autism from accessing treatment that was appropriate to their needs.

From the late 1980s through today, autism in India has experienced an intense period of activity relative to the previous decades. The release and subsequent Academy Award for the film *Rain Man* in 1988 brought autism to the conscious world of the educated in India, just as it did in many countries. Around the same time, one or two

parents in India took the initiative of writing in the media about autism, speaking to students, and creating awareness in the community. 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 and their families. In 1994, a school, Open Door, a specialist school for autism was started.

In 1994, Action For Autism (AFA) started a full time one-year teacher training course in Delhi. AFA also started publication of a periodical 'Autism Network' to share developments in the field and to act as a forum for discussion.

The Karnataka Parents Association for Mentally Retarded Children (KPAMRC) followed with a one-year training in 1996. In October of the same year AFA led a delegation of parents of autistic children from throughout India to meet the Secretary of Ministry of Welfare and to lobby for inclusion of autism in the Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Bill. AFA followed this up in the following months with meetings with other policy makers including the Joint Secretary of Ministry of Welfare, the Minister of State for Health and Family Welfare, and the Lieutenant Governor of Delhi.

Starting May 1998, Action For Autism conducted an awareness study in conjunction with the Rajiv Gandhi Foundation. This project distributed packets of information on autism to more than 1,000 paediatricians registered with the Indian Academy of Paediatricians throughout the country, including brochures to pass along to parents of newly diagnosed children. Referrals from paediatricians skyrocketed following this campaign.

By the late nineties a few autism specific organisations started off in different parts of the country, as well as a few schools, chief among them Asha, Ashiana, Communication DEALL, Development Centre for Exceptional Children, Priyanj and We Can. 'Forum for Autism', a parent support group started in Mumbai.

In 1998 Action For Autism held a training by a visiting international expert, the first of a series of still continuing events. Between 1998 and 1999 a series of articles on autism were released to the media to create awareness.

In 2000, a boy with autism from Bangalore, Tito Mukhopadhyay, 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, and brought international attention to Tito and his mother's methods for teaching him.

In 1998, AFA approached the RCI highlighting the need for a teacher training programme specific to Autism Spectrum Disorders. Continued efforts culminated in RCI

introducing a Diploma in Special Education (Autism Spectrum Disorders) in 2003.

By this time a few more Parent organisations for autism had come into being, among them Autism Society West Bengal, Jyot in Goa, CATCH in Bhubaneshwar and Pathways in Pune. At the time of writing there are around 20 small schools around India that specialise in teaching children with Autism.

Recently, internet listservers have expanded the diaspora of Indian families with autistic children to dozens of countries around the world.

As these milestones illustrate, awareness of autism in India has experienced tremendous growth in less than a decade. Growth has occurred in numerous domains: diagnosis, treatment and educational options, parental involvement, vocational options, human resource development, and legislation. The status report of autism in India that follows is able to highlight only some of these areas and cannot provide the depth or breadth that the topic deserves, but aims to provide an overview of the disorder within the cultural context of India.

Chapter 2

Prevalence and Incidence

Once considered rare, the current understanding of autism is that it is in fact one of the more common developmental disabilities. The terms ‘prevalence’ and ‘incidence’ are sometimes used interchangeably, but in fact, they have distinct meanings. The ‘prevalence’ of autism typically denotes the estimated population of people who are autistic at any given time, while ‘incidence’ of autism refers to an annual diagnosis rate, or the number of new cases of autism diagnosed each year.

The first epidemiological study of autism by Victor Lotter in 1966 put the number of those affected at 4.5 per 10,000. For some years this was the most cited statistic, based on large-scale surveys conducted in the United States and England. Subsequently, several other studies over the years have arrived at varied numbers, noting an increase. Interestingly, studies done by Gillberg in 1980, 1984 and 1988 indicated that the prevalence of autism, as described by Kanner, had not increased, and that the increase in the number of children affected by autism was due to more children with concomitant mental impairment receiving a diagnosis of autism as a result of better detection of cases.

Studies by different individuals over same periods of time have often given different results. In recent years the question of prevalence has received considerable public attention within the field of autism, as researchers debate whether the prevalence is increasing. One factor believed to be potentially contributing to this increase in autism

prevalence is diagnostic substitution. It is of course difficult to conclusively determine whether individual children have switched classifications or whether a child might receive another diagnosis in another time. Other factors cited have been delivery of the MMR vaccine, and various environmental factors.

The full debate of this issue is beyond the scope of this report, but the following data are presented to facilitate a brief discussion.

Prevalence and Incidence Statistics about Autism

- Prevalence of Autism: Between 1 in 500 (2/1,000) to 1 in 166 children (6/1,000) have an Autism Spectrum Disorder (Center for Disease Control).
- Prevalence Rate: Approx. 1 in 500 or 0.20% or more than 2,160,000 people in India.
- Incidence Rate: Approx. 1 in 90,666 or 11,914 people in India.
- Incidence extrapolations for India for Autism: 11,914 per year, 250 per month, 57 per week, 8 per day, 1.4 per hour.
- Autism is four times more prevalent in boys than girls in the US (Autism Society of America).
- Autism is more common than Down Syndrome, which occurs in 1 out of 800 births.
- The rate of incidence of autism is increasing 10-17% per year in the US (Autism Society of America).
- Prevalence of autism is expected to reach 4 million people in the next decade in the US (Autism Society of America).

Adapted from:

http://www.wrongdiagnosis.com/a/autism_prevalence.htm

There have been no epidemiological studies of autism conducted in India, nor in any comparable region of the world in order to provide a definitive estimate of either prevalence or incidence. Most estimates are based on population, given that significant differences in prevalence have not generally been observed in different regional areas. Although, there are no studies from India, the numbers are likely to be similar. Estimates of 15 per 10,000 are now typical rising to 64 per 10,000 or even higher if the entire spectrum is included. Adults continue to be under-represented in population estimates of prevalence. Many adults on the spectrum in India continue to be wrongly considered to have schizophrenia or personality disorders. Despite research suggesting otherwise, early myths continue to persist in India today.

Autism knows no racial, ethnic, or social boundaries. Action For Autism (AFA), has encountered parents of autistic children from across South Asia who include physicists, farmhands, politicians, auto-drivers, industrialists, domestic help, royalty, kabadiwallahs, construction labour, physicians, street vendors, teachers, electricians, and scientists, among others. In addition, children with autism are found in happy, well-adjusted families, just as much as in families with unresolved emotional conflicts.

In sum, these numbers make it clear that autism is not at all rare by any definition of the word. However, the majority of people with autism in India have not been diagnosed and do not receive the services they need. This problem occurs in many countries, but is especially true in India where there are still a great number of misconceptions and misinformation, as well as a tremendous lack of awareness about autism among various professionals, who may either misdiagnose or under-diagnose the condition. What complicates the issue further is that autism is sometimes not easy to identify. While we become more proficient in understanding and identifying individuals with autism, the reality is that some people will never receive a diagnosis. Chapter 3 discusses issues surrounding diagnosis and early identification of autism.

Chapter 3

Diagnosis and Early Identification

Historical Overview of Diagnosis in India

Historically, one of the major difficulties faced by parents of children with autism in India has been obtaining an accurate diagnosis. In the 1970s and earlier, diagnosis of autism was rare. Barring a few stray cases, often children who received a diagnosis did so from abroad. In fact, until about twenty years ago, there were a mere handful of doctors even in the larger cities who accurately identified a child with autism. As evidence of its absence from the medical consciousness, autism rarely appeared in medical textbooks, and as a result many doctors were not familiar with the term. Even information about mental retardation often left much to be desired. In an awareness campaign across north India led by the NGO Jan Madhyam in the late 1980s, many families reported that doctors had told them that their child (who had mental retardation) would get 'okay' with time. Often the doctors had not actually given a diagnosis either, and the families came to understand their child's condition as a result of that campaign. In such a scenario, it was not surprising that most doctors professed not to have heard about autism at all. In any case, doctors were not specifically trained to recognize autism early, which is essential in order to obtain the maximum benefits of intervention.

In the 1980s, pressures of 'early schooling', where children were expected to be in nursery and kindergarten schools by two and three years of age began to have an impact on identification of autism.

Once in the presence of other children, differences in development showed up more readily. Schools would often alert parents that their child did not 'enjoy listening to stories', something that was seen as an almost universally enjoyable activity. Teachers might note that a child did not play with the other children, or that he just walked around the class and could not sit in one place. One of the factors that contributes to delayed diagnosis of autism perhaps is that typically developing children may often exhibit the same behavioural characteristics that lead to a diagnosis of autism, such as delay in the development of speech, 'shyness', 'irritability' and so on.

If sufficient concern is expressed by the school, a parent might have taken their child to a paediatrician, only to be reassured that their child was just 'slow'. Most would take the paediatrician's word and carry on waiting for things to change. Some, however, unsatisfied by this reassurance would take the rare step of visiting a psychologist, to perhaps be told their child is 'mentally subnormal'. Convinced that their child did not fit the typical picture of mental retardation, some would then have visited a psychiatrist, to be told that their child had attention deficit disorder, and must be put on medication to control hyperactivity. After months of sedation and unsatisfactory progress, they might have begun a cycle of searching for the correct name for their child's problem.

Current Diagnostic Practices

As highlighted above, in a country as vast as India, there are currently no direct channels to organizations for specific disabilities, such as the National Institute for the Mentally Handicapped, Secunderabad, the regional Spastics Societies, and Action for Autism, New Delhi. Parents must rely on referrals from their paediatricians, psychiatrists, and psychologists, on word of mouth, and through newspaper articles or television broadcasts. By the time families of autistic children become aware that there is a national organization specifically to deal with their needs, valuable time has often been lost. The reason why a correct diagnosis is so crucial in the case of autism is because research has demonstrated the effectiveness of early intervention, specifically intervention that occurs between the age of birth and four years.

If health care professionals are aware of the diagnostic criteria of autism, diagnosis can occur as early as 18 months. The diagnostic tools most commonly used in India at present are the Diagnostic and Statistical Manual, Fourth Edition (DSM IV) and the International Classification of Diseases, 10 Edition (ICD 10), which have aligned their criteria for the pervasive developmental disorders. The CARS, though not strictly a diagnostic tool, is often used as one.

The most important information one can gather to assist in formulating a diagnosis of autism relates to the child's development in the areas most impacted by the disorder: communication, socialization, and restrictive and repetitive behaviors. There are no absolute markers of the disorder and no single behavior or characteristic that is absolutely required in order to apply one of the PDD diagnoses. However, there are certain common behaviors and features that tend to be more common.

The following are a list of some behaviors that can be used to formulate questions which may be useful in reviewing the diagnostic criteria.

The child with autism may:

- Prefer to be alone; appear unaware of other people's existence.
- Not respond to name and may on occasion appear to be deaf.
- Appear to avoid gaze or show unusual eye contact.
- Not reach out in anticipation of being picked up.
- Not seek comforting even when hurt or ill.
- Not smile in response to parents' face or smile.
- Have difficulty in mixing and playing with other children.
- Not point to share or indicate interest, or not share in others interests.
- Not point to ask for something.
- Not try to attract attention to his/her own activity.
- Not look at a toy across room when adult points at it.
- Not look at things an adult looking at.
- Have difficulty taking turns in turn taking games or activities.
- Not imitate adults' actions.
- Not pretend to play house, talk on phone.
- Have unusual or repetitive play, lack or have limited pretend play.
- Have extreme unusual fears or have poor awareness of danger or not show fear.
- Show delay or lack of language development or loss of early acquired language.
- Rarely or not use gestures to communicate.
- Lead adult by the arm to have needs met, or use adult hand as an object.
- Reverse pronouns.
- Echo words or phrases.
- Have difficulty in initiating and sustaining conversation.
- Enjoy rotating or spinning object, or lining up objects, swirl twigs, flap paper.
- Be occupied with parts of objects like knobs, switches, wheels.
- Show apparent insensitivity to pain.
- Like sameness in everyday routines; may show resistance to change in routines or surroundings.
- Display repetitive actions and ask repetitive questions.
- Not cuddle or stiffen when hugged or cuddled.
- Display unusual behaviour or body movement such as spinning, hand flapping, head banging, or rocking.
- Show extreme distress for no apparent reason.
- Appear unaware of distress in others.
- Display good rote memory for nursery rhymes, commercial jingles, irrelevant facts.

Traditionally, a diagnosis of autism is to be made by a team comprising a psychiatrist, psychologist, special educator, and so on. In many of the larger facilities this is true. But by and large, diagnosis in India is made by a single individual. This can be a paediatrician, clinical or developmental psychologist, special educator or speech therapist with extensive experience working with autistic children, psychiatrist, or a professional involved in providing medical or rehabilitative care or training. Since the purpose of diagnosis is to ensure the child receives the treatment that will address its needs, it is considered appropriate that the child receives diagnosis from any source that ensures that appropriate intervention is provided without loss of time. Currently, diagnosis takes place mostly in the cities and in pockets in parts of the country where there is a knowledgeable professional available. Small towns and rural areas are mostly outside the ambit of diagnosis.

Misconceptions and Diagnostic Difficulties

In 1995-96, research was conducted by a U.S. Fulbright Scholar on ninety-five children in four major metropolitan areas who had a prior diagnosis of autism from a medical professional (Daley, 2004). This study found that participants had as many as six incorrect diagnoses in addition to that of autism. The length of time between their first visit to a doctor and their first diagnosis of autism averaged 2½ years and parents saw an average of four doctors before receiving the diagnosis of autism; some saw as many as ten to twelve. All this clearly indicates that historically, Indian paediatricians, psychiatrists, and psychologists did not quickly and correctly identify the condition, and caused parents to waste valuable time and resources. Worthy of note, the study included only those families who had received a diagnosis, and did not include the thousands who had not, which suggests that these numbers could be even higher.

In this study (Daley, 2004) parents were lucky if they happened to visit centres like the National Institute of Mental Health and Neuro-Sciences in Bangalore and the handful of individual doctors in a few cities who were equipped to make a correct diagnosis. In Calcutta, for instance, all the children who received an accurate diagnosis of autism in the early 1980s had been to the same child psychiatrist. As the study by Daley (2004) reaffirmed, the average age for diagnosis was as late as five years.

What often comes in the way of an early or an accurate diagnosis are misconceptions and misinformation regarding autism. These include:

- Autism is a western disorder. It is rarely seen in the subcontinent.
- Autism affects only the rich.
- Children with autism do not like being held or hugged.
- Individuals with autism do not speak.
- Autistic children do not have eye contact.
- All children with autism are lost in their own world.
- Autism is a result of poor parenting and a proper home environment can cure the child.

Misconceptions about autism and lack of awareness of diagnostic criteria can lead to misdiagnosis in two directions: overdiagnosis and underdiagnosis. Neither outcome is beneficial to a parent who is trying to make long-term decisions for the education and treatment of his or her child. In recognition of the major systemic changes needed to improve diagnostic practice of autism in India, Action For Autism carried out intensive awareness campaigns through the media, through social events, as well as through other means.

In particular, from 1998 to 2001 Action For Autism partnered with Rajiv Gandhi Foundation to conduct an awareness project among paediatricians across the country. In addition to determining a baseline level of awareness among the country's paediatricians, an important aspect of the project was the dissemination of information to participants. Each paediatrician received information on autism, information on diagnostic procedures and tools such as the DSM-IV and the Checklist of Autism for Toddlers (CHAT), and information that they could share with newly diagnosed parents.

A significant outcome of the study was the sharp increase in diagnosis that followed. An additional outcome has been the fall in the mean age for diagnosis. For example, hospitals, clinics, and other centres where diagnostic evaluations are carried out are seeing greater number of children within the age of two and three years. A major contributing factor for this has been widespread dissemination of the CHAT. A checklist that can serve as an excellent and quick screening tool for busy doctors, the CHAT, by testing gaze

monitoring, protodeclarative pointing and pretending in 18-month-old, has in some ways created greater understanding of the social deficits in autism. Therefore, by the beginning of the new millennium, things have begun to change.

However, despite increased awareness, it is a safe assumption that many autistic children still do not receive a diagnosis. Children at either end of the spectrum—those who have significant mental retardation in addition to autism, and most significantly, those who are high functioning or have Asperger's Syndrome are the least likely to be diagnosed. In addition, the increased rate of diagnosis is largely restricted to specific segments in the cities and towns. Diagnosis has still to reach the weaker socio-economic sections in the cities and towns, as well as those living in rural areas. Despite constant media attention and specific awareness campaigns, a very large number of children with autism in India are likely to go undiagnosed, and therefore continue to lack the specialised services they require. Chapter 4 will discuss issues related to treatment in India.

Chapter 4

Treatment

Despite recent advances in our knowledge of causal factors, the exact etiology of autism remains unknown. It has been noted, ‘where there is no cure, there are a hundred treatments’ (Cohen & Volkmar, 1997, p. 950). Nowhere is this truer than in India. In this country, the range of treatments for autism include many or most of the options available in the West, uniquely Indianized versions of these, and “cures” that are distinctly Indian in their flavor.

Despite claims otherwise, there is no known cure for autism. However, it is increasingly evident that educational interventions are helpful for many if not all individuals with autism. Children with autism can show significant development even in the core areas of impairment if the intervention provided is appropriate to the child. This chapter will focus on educational interventions for autism, but will also cover other types of treatment used in India.

Historical Overview of Treatment in India

A common belief in India even today is that individuals with autism have ‘a kind of mental retardation’. Historically, what this implied was that education for children with autism need not differ from that of children with mental retardation. So, while the vast majority of children with autism were not appropriately identified as such, the few who did indeed receive an accurate diagnosis were nevertheless deprived of an appropriate education. Children with autism were also often perceived to

be children who could not really learn, were “untrainable”, and were best left to themselves.

There were, of course scattered schools across the country that were educating children with autism before the 1990s. Amongst them were Spastics Society of Karnataka in Bangalore, Nambikkai Nilayam in Bagayyam near Vellore, Saraswati Puri in Delhi, REACH in Kolkata, the BM Institute in Ahmedabad, and the Ali Yavar Jung Institute in Mumbai, to name just a few. Many of these schools were aware that children with autism had specialized needs but staff sometimes did not have the skills or the training to teach their students adequately. In early 1994, a school specifically for children with autism was started in Delhi, and schools subsequently opened in Bangalore and other cities.

Treatment through education, and certainly autism-specific educational practices, are not the only interventions that have been used in India. Some of the earliest articles on autism in India recommended play therapy (Batliwalla, 1959; Bassa, 1962; Chacko, 1964) while others mentioned the use of electroconvulsive therapy (Dutta Ray & Mathur, 1965; Gamat, 1968), and parental counseling and family therapy (Chacko, 1964; Hoch, 1967; Gamat, 1968). None of these early recommendations were ever supported by research. Of all of the possible interventions, pharmacological treatment of autism has been one of the most widely practiced in India. While there is not currently and has never been a drug to treat

autism, drugs have been widely recommended and prescribed for autism dating back to the 1960s (Dutta Ray & Mathur, 1965; Gamat, 1968).

Current Status of Treatment

Currently, the number of schools providing education to children with autism is severely limited relative to the need but the range of services is extremely varied and diverse. These range from autism specific services to mainstream schools. Starting with the first school in 1994, there are now around 15 autism-specific schools in India. These have a student enrollment ranging from 15 to 70. Taken together, this is less than a drop in the ocean for a country of the size of India. The majority of children with autism who attend school do so at the nearest special needs facility accessible. This could be a school for children with intellectual delay, hearing impairment, cerebral palsy, or of mixed disability. A very small number of children with autism are in a special needs classroom in a mainstream school. Overall, the quality of the education imparted is uneven. There is no monitoring of standards. Most schools – even some autism specific ones – do not have staff trained in either behavioural principles or autism.

There is an unknown, and one would imagine a significant number of children with autism who are in regular classrooms. A very large number of these are children who have not received a diagnosis and are likely to be children on the very able end of the spectrum who manage to get by with only a few difficulties. These children do not appear to need urgent attention. However, many children who attend regular classrooms are forced to drop out as they become older and the educational system turns more rigid and inflexible. If the increased academic pressure does not force them out, many leave school because they are unable to deal with the bullying and social

ostracism that often occurs. Thus, an important issue for parents of children in this situation becomes whether or not to reveal to the teacher and school that their child has autism.

Despite various measures undertaken to promote universal education, children with disabilities are not guaranteed an education in India. Therefore, both public and private schools, particularly private schools, accept, reject, and expel children with autism as they please, and this creates a power differential between schools that have long waiting lists and desperate parents.

Since no surveys have been carried out, it is difficult to say how many children with autism overall are in or out of school. It is safe to assume that a large number of children with a diagnosis of autism do not receive any educational service at all. Either there are no services available in their area, or there are no spaces available to accommodate them. Thus, the number of children who are out of school is no doubt significant.

Regardless of the type of school a child with autism attends, there is abundant evidence to show that children with autism can and do make improvement with appropriate intervention. What does ‘appropriate intervention’ look like? The answer to this question is complex: appropriate interventions, at the very minimum, must include a focus on the core deficits of autism, specifically: social skill development, communication, and behavior. Focusing on these three areas alone, however, is not sufficient. The educational program for a child with autism must be based on the unique needs of the student; it must be individualized. For the same reason that children with autism need a specialized training program, i.e., that they often do not respond to the same teaching methods used for other children, children with autism also differ dramatically from one

another. An appropriate educational program will incorporate both the general needs of children with autism with particular needs of the child in question.

In the U.S. and elsewhere, movements have evolved to encompass these teaching principles. These range from established methods such as that developed by Division TEACHC (Treatment and Education of Autistic and Communication Handicapped Children), or Lovaas-inspired methods, both of which are behaviour based: targeting antecedents and/or consequences of behaviour in order to help individuals with autism learn and progress. Interventions specially devised to teach communication as opposed to primarily targeting the development of speech, as well as others that develop social and relationship skills have evolved using various behavioral strategies. Over the years, assistive and augmentative modes of communication have evolved greatly as have techniques to bring about sensory integration. Started intensively and early on such educational strategies, many youngsters have gone on to hold jobs in the community, complete higher education, and generally lead fulfilling lives.

In India, TEACHC strategies were first introduced at Open Door in Delhi in 1995, followed shortly after by ASHA in Bangalore. Over the next few years, the use of TEACHC strategies spread across India through training workshops. This was subsequently followed by a number of professionals receiving training at Division TEACHC. Simultaneously, the practice of discrete trial training, as propagated by Ivar Lovaas, also began to be used. Likewise, one of the earliest sites to focus specifically on communication issues was Communication DEALL in Bangalore, Dikshan in Kolkata and shortly after SAI in Mumbai introduced Verbal Behaviour Analysis, with its focus on teaching language not as a semantic

exercise, but as a behaviour with a function and purpose. In general, the importance of providing education that took into consideration the special needs of children with autism slowly began to 'catch on'. The process has been accelerated by frequent seminars and workshops with leading international speakers that were organized by organisations across the country including Forum For Autism in Mumbai, Action for Autism in Delhi, Autism Society West Bengal in Kolkata, IRIS in Chennai, and KPAMRC in Bangalore. Exposure to international thought and practice is helping to clear away many of the cobwebs that clung to theories of educating children with autism. In addition, these conferences and training programs have brought about an openness of outlook among professionals that are now willing to embrace more current strategies in education.

At the same time that educational professionals are gaining an understanding of autism-specific interventions, it is still important to recognize the relationship between diagnosis and treatment. An accurate diagnosis is meant to help both parents and schools develop effective ways of teaching the child. Though each autistic child is unique — just as all children are with a diagnosis of 'mental retardation' and all children without any disability at all—knowing that a child is autistic can help a teacher understand and accurately interpret the responses of the student. The hope, of course, is that knowledge of a diagnosis of autism will empower a teacher, not prejudice her. However, a common error among educators is to make assumptions about children with autism based on generalizations or stereotypes, without actually identifying a child's strengths and particular needs. Unfortunately, teachers with only a minimal understanding of autism often hastily conclude, "all autistic children enjoy music, so I'll teach this one

using music”, or “all autistic children like to be alone, so I’ll force this one to be with others”.

Ironically, increased awareness of autism among special educators has led, in some cases, to a new type of discrimination. Some schools will turn away children diagnosed as autistic because they feel they cannot provide adequate one-to-one attention, which they have been told a child with autism must have. This, however, is a disservice to child, parent, and school. A higher functioning or more independent autistic child may not need one-to-one attention at all, and is then denied an education he fully deserves. The parents of the child may become frustrated after being told their child can’t attend school, and may begin to resent both the diagnosis of autism and the system which has trapped them. The school loses, as well, because they may gain a reputation among parents as being inadequately prepared. As an example, one mother was told her daughter would no longer be able to remain at the school, because she was not ‘controllable’. This mother responded, “Well, why can’t you control her? Why is my daughter being punished for your incompetence? It isn’t my daughter who has a problem, it’s your untrained teachers.” Not surprisingly, neither mother nor daughter was welcomed back. In an ideal situation, schools and parents would be able to work together to resolve such situations.

In sum, regardless of the type of school setting and the number of hours a child attends, the majority of a child’s waking time is still spent out of school, with his or her family. Because of the clear need to provide a more intense form of intervention to all children with autism, a few organisations like KPAMRC in Bangalore, Ummeed Child Development Centre in Mumbai, Action for Autism in Delhi and Autism Society West Bengal, Kolkata focus on training parents with consequent demystification of professional

expertise. The goal of these programs is to educate and empower parents to be able to provide training to their children in a range of areas, including functional academics, self-help, socialization and language, and to make use of the valuable hours spent out of school. Parent training in the context of many of these organizations goes beyond what is often seen in more developed countries. For many children with autism in India, training from a parent is the *only* intervention they will receive, whether it is because there are no facilities available for the child, or the parent is unable to afford the facility, or because the facility will not accept the child.

Early Intervention

As noted above, children with autism can make significant gains through educational intervention, and particularly when the intervention is early. Early intervention has been shown to result in the child needing fewer special education and other allied services later in life and some children being indistinguishable from their typically developing peers in their later years.

The concept of early intervention in India is still in its infancy. Such intervention relies on a chain of events which, at the current time, is lacking. Namely, a parent must identify some atypical behavior in their child and bring it to the attention of a pediatrician or their health worker; that pediatrician must identify the behaviors as possible symptoms of autism (rather than merely delayed development, a typical development, or another disorder); that pediatrician must also know of a referral to provide to the parent; the parent must follow up on the referral; the agency or individual to whom the child has been referred must concur with the diagnosis of autism and be willing to provide services to the child and family.

Even in the largest cities in India, this chain is likely to miss crucial links at one or more of these stages, thus eliminating the possibility for intervention to occur in a timely manner.

Other Treatments

The growing popularity of the Internet has contributed to openness to new ideas about autism in India, and its influence is not inconsequential. However, information from the Internet has had a flipside as well. In recent years, the focus has shifted somewhat from ‘education’ to a spate of alternative therapies that often make parents hopeful of a cure. Children with autism are often ‘normal’ in appearance, making parents believe that if they could just find the ‘key’ to unlock the enigma of their child all would be well. This makes parents greatly susceptible to proponents of cures that are largely unproven. The propagators of unproven treatments range from animal trainers to performing artists to sometimes even medical professionals. Many of the ‘therapies’ being pushed do in fact have positive effects, not just for persons with autism but for all people. These include activities such as yoga, or keeping Labradors as pets, or horse riding. But they are not therapies that have been proven to bring about any changes in the core areas of impairment in autism.

As noted above, treatment for autism in India is far broader than just educational interventions.

Pharmacological treatment continues to have a foothold in India. A study by Daley (2002) reported that among a group of 95 children, over 50 different medications had been prescribed for their ‘autism’. Seventy five percent of the sample had taken medication in the past, and 42% were taking medication at the time of the interview. Families in this study also reported an extremely wide range of treatments/‘experts’ for their

children. These included: acupuncture, acupressure, Auditory Integrated Therapy, ayurvedic medicine, behavior therapy, magneto therapy, Dimethylglycine facilitated communication, etc., ‘Expertise’ of astrologers, faith healers, *Fakirs*, family counseling, family guru, and such others were also sought (Daley, 1997).

Some of the treatments listed above may in fact be helpful to children. However, there is a tendency by both parents and professionals to be subjective in their evaluation of whether or not a treatment is effective. For example, there are therapies which involve the ingestion and or injection of powders and liquids, drawing of blood and bodily fluids, immersing the children in various baths, and changing their diets. Oftentimes, positive changes in children are attributed to the treatment, while negative impacts – which mostly remain unreported – if at all reported, are attributed to wrong application of the therapy. Many of these new therapies – and a new one comes into vogue every few days – are often promoted with ‘studies’ conducted by the manufacturers or distributors of the therapy. In addition, some propagated treatments are extremely expensive. Interestingly, the very expense acts as an attraction for using these treatments. While parents often balk at the cost of special education, many are willing and happy to scrape together huge amounts to pay for unproven and often dubious but expensive treatments.

It is not surprising that parents, and some educators, would be taken with the possibility of a quick cure. In contrast, behaviour based education requires tedious hours of one-on-one work by well trained professionals. It is often an unattractive option for desperate parents, particularly since the situation is exacerbated by the very limited number of centres providing such education. In conclusion, treatment for autism in India is varied. While

educational and behavioral approaches are the only consistently demonstrated method for change in children with autism, most children in India do not have access to any services, let alone services that are specialized for their needs. As more teachers become trained, more schools are opened,

and more children are admitted into mainstream schools, the situation will hopefully improve. Much of this change is dependent on changing societal attitudes, which is part of the topic of Chapter 5.

Chapter 5

Societal Attitudes Towards Disability, Parental Involvement and Family Issues

In the preceding Chapters, we have touched on the experience of parents as they navigate a diagnosis and seek appropriate treatment for their children. Parents are, of course, central to every aspect of their children's development and are therefore rightly integrated into a discussion of specific domains related to children with autism. Parents are also members of the broader society, and thus, parental involvement, attitudes, and family issues are also both a reflection of the larger society and must be viewed within that context. In this Chapter, we will review some of the more prominent impacts of the broader society on families and children with autism, and will also discuss some of the unique aspects of parental involvement and family issues related to autism in India.

General Societal Attitudes

When families have difficulties in dealing with the child's disability, the prejudices they bring to the diagnosis are largely a reflection of the society of which they are a part. In general, societal attitudes toward autism in India have been similar to attitudes toward other disabilities. Disability is seen as a result of sins committed in previous lives, and the notion of bad *karma* is still widely evident. Indian society tends to look down on a family with a disabled member, as the family is seen to have 'deserved what it got'.

Given the lack of awareness and discussion of disability in the larger society, it follows that

parents are often slow to recognize some of the important symptoms of autism. For example, for first-time parents, early differences in social interaction may not be recognized as atypical, or they may attribute their child's behavior to personality differences, such as believing that their child is just more independent or 'mature' for preferring the company of adults to children (Daley, 2002), or 'a thinker' when their child is non-verbal. Negative attitudes about disability in the broader society only compound the problem of identification of symptoms in a new parent. When one's extended family—neighbors, and the broader society—all place such a premium on children as a reflection of their parents and conversely, that the cause of a problem in a child is so quickly attributed to them, parents have ample reason to keep their concerns to themselves.

Yet, whether out of their own choice or because they are prodded on by others, parents will ultimately seek help. As described in Chapter 3, parents often spend a long, frustrating period trying to get a correct diagnosis for their child. When parents finally receive a diagnosis of autism they may find it difficult to accept that their 'normal' looking child may have a lifelong disorder, and are further bewildered by the complexity of the ways autism affects individuals. Sometimes professionals seek the easy way out by telling parents their child has 'autistic-like features' or a 'just a little bit of autism'. While such information may be motivated by a desire by the professional to cushion the news,

or to maintain a relationship with the family, doing this is actually a disservice since it merely delays the process of the family accepting the diagnosis and getting help.

Parental Reactions

Given that Indian society views disability as a ‘tragedy worse than death’, it is not surprising that families may feel the desire to hide the diagnosis, or even the individual with disability, from the world in order to avoid societal censure and ridicule. Coming to terms with a diagnosis of disability in a child is never easy. Families almost always go through a process of grieving with emotions that may range from confusion, guilt, shock, frustration, anger, denial, anxiety, shame, resentment, inadequacy, depression, to the question “Why me?” When the diagnosis is one of autism the situation is even more complex. Compared to other disabilities, a child with autism might be physically normal and healthy at birth, and for the initial years parents may imagine they have a regular child. Some parents experience confusion and helplessness if their child is non-responsive or aloof, or if as often happens their child experiences a regression following a period of apparently typical development.

However, diagnosis is only the first step. Having received a diagnosis of autism, parents generally do not know what to do next in order to help their child. In some cases, they are overwhelmed by the prospect of a diagnosis with no referrals or recommendations whatsoever. In other cases, they become frustrated when they seek out educational or social support and schools or professionals who can guide them with their child and find very little that is specific to autism, or are referred to agencies that have no space available for their children. Attempts to integrate their children in the broader society on their own can

be taxing for parents. Since many children with autism look ‘normal’, people unfamiliar with the disorder often mistake their tantrums and social inappropriateness as evidence of spoiling, or parents are viewed as uncaring and unable to handle their child.

In recent years, many parents have experienced a new and potentially equally frustrating situation. Due to the explosion of knowledge through the internet, parents come to learn the crucial importance of immediate intervention in long term prognosis of children with autism. Knowing this and yet not having the tools is extremely frustrating, and can increase a parent’s sense of helplessness. Some parents may feel as though, ‘what is the point’ of trying anything, if their child cannot access the plethora of intervention options available in other parts of the world. Others may contemplate how to move their entire families across the country or across the world. However, many enterprising parents are also able to access information, accept the limitations of the Indian situation, and do what they can to adapt different approaches to their own situation. Of course, it is important to note that the above description is true primarily of parents in urban areas, as those in rural areas mostly do not have this information, nor do they typically receive a correct or any diagnosis. *‘Bachhe pagal hai’*, the blanket term that is slowly fading out in cities and towns, still prevails in the rural areas.

That families are able to move beyond the prejudices of society is a tribute to human resilience and spirit. Yet parents of children with a disability invariably face a frustrating contradiction even when they try to maintain a positive view. On the one hand, society views disability through an extremely negative prism of ‘better dead than disabled’. On the other hand, the most common criticism parents face from society, including from

professionals, is that they are not accepting their child's disability. Along this same vein, mothers often report that when they do, in fact reach a point of acceptance of their children and they take the trouble to dress up and resume 'normal' activities, they are then termed 'uncaring' mothers. The perception of the mother of a child with disability as someone who should give up on life and don the proverbial sackcloth and ashes, remains very strong in India.

There is no question that parents of children with autism in India experience considerable stress. A child with autism has socially challenging behaviours, which frequently lead to the loss of friendships, social isolation, and loss of a career or career changes. The fallout of the pressures of life following a diagnosis of autism include disintegrating marriages due to the challenges of dealing with the disruptive behaviours of the child, complaints from neighbours, and loss of sleep. Assumptions and aspirations are challenged. Life for the family changes forever. The little intervention that is currently available only addresses the child; few families in India have access to mental health professionals or an outlet for their own feelings. Services to support parents with coping strategies to deal with stress of parenting a child with autism and help them develop a positive attitude is non-existent, with the exception of a few parent-initiated support groups.

Part of the lack of services and support for parents is because of the strong belief in the 'professional knows best' school of thought in India, where parents are not supposed to know anything about handling the child. Parents are not expected to have an opinion in the kind of interventions that the child is put on. They are often actively disallowed from attending training meant for 'professionals' regardless of the fact that the parent might be well educated, intelligent, and

well informed about autism. On the other hand, when professionals are not able to help the child, which is quite understandable in a complex disorder like autism, parents are often given the sole responsibility of caring for and educating the child. With only a few exceptions, the limited services and support that exist for children with autism in India are geared toward the child rather than the family.

As the descriptions above make clear, parents of children with autism in India face a myriad of challenges, both as a result of the inherent hurdles of having a child with a disability and the impact of a society often impedes rather than promotes the integration and acceptance of children with disabilities into its midst. However not all is bleak. Recent studies have consistently reported that families with a child with disabilities can and in fact do have positive perceptions which lead to better quality of life for the family, and scope for maximizing the child's potential. Though precipitated by a specific event, formation of positive perceptions is usually a process, which can occur simultaneously or a longtime after the event (Gupta and Singhal, 2004).

Thus, while the impact of an autistic member in the family often is seen to be perceived by society as a negative event, the outcome may not always be so. In fact, the diagnosis of autism has made some families stronger, more tolerant and accepting of each other, and helped them find an inner strength that has turned them into advocates helping not just their own child but the larger population of children with autism. Marriages are strengthened in the shared efforts to cope with the changed situation. Siblings grow to be empathic, open-hearted adults who help educate others in their community. Lost friendships are replaced by new friendships from among other families of children with autism. In India, as in many

countries, parents have led the movement for people with autism, and through their strength and determination, the prospects for children with autism are continually improving.

Apart from the question of whether or not to have additional children, either for care of the autistic child or for other reasons, siblings of children with autism in India experience a different type of childhood. One parent described this in the following way:

"I always feel as parents, we may often directly or indirectly influence the child to behave like a parent to their autistic sibling. We feel proud that, say, our five-year-old is like a 'mother' to her twelve year old autistic brother. I feel that in the beginning this may go well as the normal child may show more mental maturity than her peers, and also at the same time get into the good books of parents and well wishers. We can definitely include our normal child in our day to day activities and maybe we can plan a few activities which the normal child can do with her affected sibling, like play activities, listening to their favourite music, turn taking games, and arranging the table before a meal, etc. However we need to keep one thing in mind, that in the process of looking after the disabled sibling by the normal child, the latter should not be deprived of his or her own childhood."

Family Issues

Several family issues related to children with disabilities, and autism in particular are unique to India. Even while trying to help their child develop and grow in the present, many families are consumed with questions of what will happen to their child after them? Some families wrestle with the question of whether it is 'fair' to burden a non-autistic sibling with that role, while other families may beget an additional child with that purpose explicitly in their mind. However, this decision is not one to be taken lightly. While autism is clearly genetically determined, it is unlikely that the result is of only one gene. As such, parents of a child with autism have a 5 to 10 percent chance of having another child with autism. There are recent discussions among parents of creating long-term living options for their children, but even the existence of a few facilities will only partly assuage fears in parents about their children's future. Even parents with the means to provide for their children after their own death note that all the money in the world cannot guarantee that their child will be well-cared for, loved, and nurtured, and that money meant for the child will not be misused.

Chapter 6

Vocation, Employment and Adult Life

Provisions to meet the educational needs of individuals with autism are geared to enabling them to lead as independent a life as possible in adulthood. This implies that education would provide the individuals with work skills that would make them eligible for seeking employment, obtain employment, retain their jobs, be able to live independently, and have adequate leisure skills. Yet the few educational opportunities that currently exist are more focused on the development of cognitive skills and on ‘academics’ and pay little attention to the needs of individuals for when they become adults with autism. This near-absence of appropriate educational opportunities severely limits the possibility for employment—and therefore, the opportunities for independent living—for the vast majority of individuals with autism. In order to maximize the options for adults with autism to be independent as adults, current services and planning must also take into consideration the need for training in vocational skills, job opportunities, living options, and recreational opportunities.

Vocational Training

Training in work skills among young adults and adults with autism needs to focus on their strengths. In general, individuals with autism perform best at jobs which are structured and involve a degree of repetition. They thrive in an environment that is structured and well organized. Persons with autism often excel in tasks involving numbers, book keeping, data input, accounting,

and tasks involving rote memory. In a job setting, they may have a good eye for detail and meticulous application of routine tasks. Given the social deficits of autism, they are best at jobs that do not involve a lot of dealing with the public, do not rely too heavily on social skills, and jobs which are routine and predictable. Most persons with autism will do happily and well on a repetitive type of job, such as putting a shuttle through a simple loom repetitively to weave long swatches of fabric, or silk screen printing. These are tasks that the non-autistic may balk at. They are also good at jobs where they might have to speak a lot, but can speak without interruption about their own interests. Training in vocational skills and employment for individuals with autism should thus focus on these strengths.

Some of the difficulties they face are with interpreting verbal and non-verbal communication, such as idiomatic language, facial expressions and body language, difficulties in jobs that require dynamic social interactions. Initiating and maintaining conversations on general topics may not be of particular interest to them. Similarly, jobs that require them to look beyond their narrow interests towards abstract ways may be difficult. Vocational training must teach skills to get a job, but more importantly, also directly teach the skills that are needed to keep those jobs.

Currently Action For Autism has a work skills training unit and that too is at a nascent stage. A few individuals have gone into the work arena, but finding open employment for most remains a

difficult task. AFA's experience has shown that those with Asperger's Syndrome who complete mainstream education but have interpersonal difficulties, training in work place etiquette and rules is imperative. By and large vocational training for persons with autism is really non-existent.

Making the Work Environment Barrier Free

- Use of visuals in most areas.
- Written rather than spoken instructions.
- Clear guidelines of expectations.
- Clearly laid out rules of the office.
- A routine that remains fairly unchanging.
- Items of tools that are used remain fairly unchanging.
- A visual schedule for the day.
- Job broken down into parts and put down on paper.
- A list giving the order in which a task is to be performed.
- Minimal situations of having to unexpectedly leave work on hand and concentrate on something else.
- Distraction-free seating *versus* an open area with high noise levels.
- Work area / location that does not change frequently.
- Fairly consistent interpersonal contact with not too many unexpected changes.
- A team that does not change frequently.
- Feedback that includes positive experiences, as well as advice on changes.
- A mentor to guide on social rules of the workplace.
- Training in disability awareness for colleagues on the difficulties in communication and social interaction which often results in others misunderstanding them.

Employment Opportunities

In addition to training in vocational skills, there are autistic individuals who are in open employment or in sheltered workshops in India, and these individuals cope with their special needs and adapt to the work environment, even in the absence of required training and supports. People who have autism are currently employed as artists,

librarians, stock keepers, data entry operators, other office workers, computer operators, mail and dispatch staff, assembly line workers, accounts, and in sheltered work settings. In the successful cases, the work environment has provided the necessary support and have adapted to the needs of the individuals. Much of this has been serendipitous and without an awareness of the individual's diagnosis of autism. Yet as both educational and workplace environments become increasingly competitive, individuals with autism will need certain provisions in order to access the workplace.

Barriers to successful employment may arise because Autism Spectrum Disorders (ASD) is a hidden disability and coworkers not aware of the nature of the person's disability may easily misunderstand them. In addition, most jobs require an interview process which relies on communication and social interaction skills, areas of particular difficulty for a person with ASD. With appropriate training and matching of skills to jobs people with autism can learn meaningful job skills that enable them to successfully work in competitive employment, supported employment, or in sheltered workshop programs.

The communication difficulties faced by people with autism may mean that they cannot explain when a problem arises, despite having good language skills and a wide vocabulary. So it may be crucial for the manager or one particular colleague to keep an eye on the employee with autism to help the person prioritise their day. This may not be in a supervisory way, but may be seen as the role of a support worker. As an example, an office can use a support worker to point out details that may cause offence; and the employee with autism can be instructed to communicate with their support worker about interpersonal difficulties, rather than directly telling the person concerned.

Social Aspects of the Job

It is not unreasonable to imagine that other employees will be confused by the nature of someone with an autistic spectrum disorder. The nature of the social and communication difficulty is such that many of the things we take for granted are missed by the person with autism. This includes office etiquette such as the appropriate distance to stand from someone and appropriate topics of conversation at work. Coworkers may wonder, 'How can someone know so much about a subject and yet make totally inappropriate comments? Surely they must know that this is offensive?' But as Temple Grandin explains, the person with an autistic spectrum disorder is unlikely to know this at all:

"I soon developed a reputation in Arizona for being an expert in my field, but I got into trouble socially. I did not understand that people have egos, and that protecting their ego was often more important than their loyalty to the company. The other engineers resented me. Technically I was right, but socially I was wrong." (Grandin, 1996).

"Honesty is another positive feature (of people with autistic spectrum disorders). There is little danger of dishonesty over expenses, or other infringements of office rules, because of a strict adherence to regulations, and employers often come to place a great deal of trust in employees with autism, whatever their level of functioning." (Howlin, 1997, p. 192)

Living Options

Independent living options for adults with autism in India are currently non-existent. There are mixed disability facilities, but most do not want to handle any individuals perceived to have

challenging behaviours. A few residences currently do have residents who have autism; some of these are supported by the National Trust.

There is a range of living setups that might be appropriate. Keeping diverse needs and means in mind one may think of group homes and supervised living arrangements, to institutions; regardless of how regressive the latter might seem to be. People with autism can learn skills to live as independently as possible through specifically designed programs in group homes and supervised apartments. The aim of all services has to be to offer access to as full, enjoyable and meaningful a life as possible to each individual. Programs must be designed to offer additional help in communication and social skills and to compensate for difficulties in imagination – all barriers to achievement of a full and enjoyable life.

Recreation and Social Life: Opportunities and Issues

Individuals who have autism, generally have to be taught to develop leisure skills, something that most of us do naturally. However, once taught, they may develop diverse leisure interests and often enjoy the same recreational activities as their non-handicapped peers. A large number enjoy music and many are great singers, working on puzzles, computer games and physical activities that can be done on their own yet alongside others such as swimming, hiking, camping, cycling, and roller skating. Because of their socially awkward ways they are often made to feel unwelcome at sports facilities, except where the parents are able to surmount such hurdles. However, there are other public areas that people with autism visit. Increasingly one finds people with autism enjoying meals in restaurants and tolerating long hours in theatres and to enjoy the experience.

Chapter 7

Human Resource Development

Rehabilitation training specific to any disability has to be based on the premise that (a) the individual with disability is capable of learning, (b) that there are ways of teaching that are specific to that special need, and (c) that there is a significant population requiring the benefits of any such training. In professionals' perceptions in India, Autism did not come under any of these for a very long time. As recounted elsewhere in this report, the needs of this population were grossly misunderstood and often underestimated.

Historical Overview

India has a long history of rehabilitation training, with the earliest being for the locomotor impaired and for the visually impaired. While some of these trainings are under the Medical Council of India, a very large number are regulated by the Rehabilitation Council of India. Particularly in the areas of mental disability, the role that the Rehabilitation Council of India plays is significant.

The development of human resources for autism specifically relies on the presence of children with autism in significant numbers, the acknowledgement of their specific needs, and the acceptance that specialized teaching can lead to development in the core areas of impairment. For a very long time there was a strong belief that autism was largely indistinguishable from mental retardation, and hence there was no need to 'waste resources' in providing training for those who teach individuals with autism. In addition it was felt to be a rare condition and not of particular relevance

to the subcontinent. Given this, it is not surprising that human resource development in the area of autism has only recently begun.

It is crucial for anyone teaching a child with Autism Spectrum Disorders (ASD) to first understand the distinct learning and behavioural characteristics of children with ASD, and their atypical cognitive and social development. Many teachers trained to teach children with Mental Retardation (MR) sometimes view the impact of ASD as merely on behaviours. But ASD is more than behaviour. Individuals with ASD have pervasive impairments in communication and social skills, difficulties in joint attention, in processing auditory information in the classroom, in retrieval. Most have difficulties in generalizing skills taught, in sequencing, and in transitioning. Many have specific learning disabilities. ASD affects the individual's ability to integrate sensory information and regulate their emotions. They have uneven development so that they may function at a higher than their age in some areas and be far below in other areas. Without clarity of understanding, teachers can often misinterpret functional abilities and do more harm than good.

Since children with autism have often been viewed as having 'bad behaviours', if a child in a school did not exhibit any challenging behaviours then intervention was believed to have been successful. It appeared irrelevant to educators that children did not achieve even a fraction of their potential.

Development of Diploma in Special Education (Autism Spectrum Disorders)

Two organisations in different parts of the country started teacher training programs in the early nineties: KPAMRC in Bangalore and Action for Autism in Delhi. With the coming in force of the RCI Act in 1992, a need was felt to have training under the RCI. However, though there was initial resistance to this move because of various misconceptions, this was subsequently overcome and a Diploma in Special Education (Autism Spectrum Disorders) was started in July, 2003. The programme is currently being administered by four organisations which have been selected to provide the training on a pilot basis. Based on the outcome, the RCI plans to extend the course to other organisations.

At the inception of this course, the faculty available did not have all the qualifications and/or the experience that is mandated for administering the course. As a result, a few of the organisations had to do with individuals with backgrounds in other disabilities. This is to be expected in a new discipline. Some organisations have had the benefit of individuals with training and experience overseas. The limited remuneration in the field of special education in India did nothing to encourage this trend. However, as more teachers get trained in the course and gain experience, it is expected that some of them could take on the role of faculty for subsequent training.

Diploma in Special Education (Autism Spectrum Disorders)

<i>Training Centres</i>	<i>Number of trainees in each year</i>			
	<i>2003-04</i>	<i>2004-05</i>	<i>2005-06</i>	<i>2006-07</i>
Spastics Society of Karnataka, Bangalore	10	7	14	14
School of Hope, Delhi	<i>Not received</i>	16	10	<i>Not received</i>
Action For Autism, Delhi	11	9	9	13
Jai Vakeel, Mumbai	<i>Not received</i>	<i>Not received</i>	<i>Discontinued</i>	<i>Discontinued</i>
Pradeep, Kolkata	<i>Not started</i>	<i>Not started</i>	10	15

Since most special needs schools also have significant numbers of children with autism, but had teachers who did not have the know-how to teach the children. From 1995, Action For Autism started giving practical Training Workshops that gave such professionals the tool to help their students. Workshops were also organized for parents to enable them to understand their child's condition and help them learn. The success of the workshops saw requests come in for the AFA team

to give workshops in different parts of the country. Workshops were also organized to be given by visiting international experts. Currently, the value of workshops both as initial training tools as well as continuing education program is well established and various organisations now undertake such activities.

Several specific groups of professionals may be able to contribute significantly to providing

training. Since communication is an area of significant impairment in autism, speech language pathologists, when they have a clear understanding of autistic behaviour could potentially play an important role in providing training. As institutes of speech and hearing introduce courses on speech language pathology with a segment on autism, it will add to the pool of resources available. Another group of professionals which can contribute to training for individuals with autism are occupational therapists, who can address proprioceptive and vestibular issues and sensory issues as well. Currently a few occupational therapists who have developed an interest in autism receive trainings through workshops by individuals like Dr. Anjali Joshi of KEM in Mumbai, and competently address these needs in the therapy they provide.

Child and adolescent psychiatrists can provide medication to deal with anxiety and depression thus enabling the child to learn and also enabling careers to put in place behavioural intervention following which the medication can be withdrawn. However, all professionals need a clear understanding of the spectrum if they are indeed to help the child. As the understanding of

autism in the country is still limited, this is reflected in the larger circle of rehabilitation professionals who provide services to individuals on the spectrum. There is also little scope to acquire the skills required to address issues on the spectrum.

Families require therapists who can address a range of issues without having to knock on multiple doors. This is where the value of the RCI's DSE (ASD) training lies. Well administered, this training can produce well-rounded teachers who can address every area of concern of parents and it focuses on creating a group of professionals who serve as the central pivot of services. The start of the training has been slow but steady. So far around 200 teachers have been trained. There is a huge demand for the trainees who pass out. The demand comes from a range of services: autism specific schools, mixed disability schools, as well as mainstream schools. The number currently trained, of course, is a drop in the ocean. But it is a start. The upside is that professionals who do not have specialized training in autism too are benefiting from working alongside colleagues who have undergone the training. From this experience it is clear that additional trainings need to be introduced.

Chapter 8

Advocacy

Advocacy for disability is a relatively recent development. Autism, therefore, has an even shorter history. The government no doubt plays an important role in disability issues. However, no government action for autism would have happened if it were not for the pressure from the non-governmental sector driven by parents. During 1994, while the draft of the Persons with Disabilities bill was being debated, efforts by Action For Autism to bring autism into the picture was mostly met with bemusement. Officials in the ministry as well as experts in the field of disability felt that autism was not an 'Indian' condition and therefore not worth consideration. Many had not heard of autism. It was the efforts by NGOs that forced the government to begin to consider autism.

In time the Persons with Disabilities Act was passed, but the efforts to bring autism center stage continued. These included making representations to the senior levels of the then Ministry of Welfare, sensitizing staff at every level in the state and central ministries. Since advocacy flows from awareness: regularly placing articles in the print media (visual media was yet to gain the prominence of the 21st century), holding public events where large numbers of the lay public were exposed to autism, and sensitizing members of the medical community.

In 1996, Action For Autism started a more focused campaign for the acknowledgment of autism as a condition that was distinct from other developmental disabilities and with distinct needs

requiring specialised services. It prepared a well-researched, and comprehensive document referencing disability and autism in legislation in different countries and submitted the document to the then Ministry of Welfare. Subsequently government action reviewed the status of autism in the legislation. One outcome of this was that when the bill for the National Trust was being drafted, a member representing the autism community was appointed to the drafting committee. Once again, when as a result of sustained advocacy the then Ministry of Welfare appointed a committee to suggest amendments to the Persons With Disabilities Act a member representative for autism was appointed along with representatives for mental retardation, visual impairment, hearing and locomotor impairment. Under the chair of outstanding legal professional Dr. Amita Dhanda, the committee came up with a paper which unfortunately left on the back burner and forgotten. Subsequently, however, the National Trust Act for Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities came into effect from 1999.

The aim of advocacy is to ensure full rights and participation for individuals, therefore early activism in autism had to focus on more basic issues as well. Efforts in different directions continued and an important one was advocating for educational rights. In order to enable individuals with autism to be empowered to participate fully in society, they need to have access to education.

Marked by a poor understanding of educational needs, autism was sometimes perceived as ‘another form’ of mental retardation and at other times as ‘another form’ of mental illness – depending on whose perspective one was looking from. No particular educational needs were seen to apply to those with autism. If a child with autism was pliant and ‘appeared’ to be learning, that was considered sufficient. It was with the establishment of specialised educational services starting with Open Door School in Delhi which showed significant progress in children, and propagation of the methods used, that forced educators to take notice of the specific learning disabilities that often accompany autism, and the specialised teaching techniques that they can benefit from. Thus far any inclusion had happened by default rather than design. Now, advocating for their educational needs not merely opened up possibilities of planned inclusion for autistic learners, but also the scope for learning for many who were given up as ‘hopeless’ cases.

Inclusion is an ongoing process. Sustained advocacy by NGOs has led to some new

mainstream schools including a resource room for special needs with provision of mainstreaming and finally full inclusion. Simultaneously, it has also ensured greater understanding of the impact of intervention leading to a range of other educational services for those on the spectrum.

With the passing of the Rehabilitation Council of India Act in 1992 and the stipulation that rehabilitation professionals all have RCI certification, it became imperative that aspiring practitioners to teach individuals with autism had access to training that would confer such certification. Several years of sustained activism eventually made possible a training course under the RCI that would make this possible. The main objective of organizations such as AFA in an advocacy role has been to force policy makers to move from their dismissive stance towards autism to one of acknowledgement of this complex and common disorder. Some gains have been made in this regard but a very great deal still needs to be achieved.

Chapter 9

Future Perspectives

Despite great strides worldwide in the study of autism, and tremendous growth in our own country, general understanding of the condition remains at a nascent stage. In India, work in the field has been minimal, whether in research, service delivery, or human resource development. To date, much of the progress made has been driven by NGO initiatives, which are largely parent-driven and with limited backing of major governmental bodies.

This report on the status of autism in India has covered a range of topics. Without question, additional resources and advances are needed in each of the domains covered. However, there are some areas of particular urgency, either because of its near absence in the current situation or because of its potential for widespread impact. In this Chapter, we will outline some areas that fall within both of these categories.

Epidemiological Studies

Currently, there are no clear studies on the number of individuals with autism in India. Most studies and reports are based on the numbers reported in the USA and the UK. An important need is an epidemiological study that will provide a clear indicator of the numbers affected, and thereby provide the push for action required.

Early Diagnosis and Early Intervention

Current understanding of autism clearly indicates the strong relationship between early

intervention and improved prognosis. Numerous studies have documented the powerful effect of early intervention on later outcomes, which include gains in language, social skills, functional skills, and inclusion in regular classrooms. However, early intervention can only take place if there is early diagnosis, and that in turn can happen only when sufficient number of medical professionals have the requisite knowledge, the exposure, as well as the tools to provide that diagnosis. Because many children in India do not receive an accurate and early diagnosis, any scope of achieving their potential is destroyed.

The pioneering study by Dr. Simon Baron-Cohen, Jane Allen and Christopher Gillberg (1992) using Checklist for Autism in Toddlers (CHAT) demonstrated that it is possible to detect autism in toddlers at 18 months and is effective too. It is essential that a broad spectrum of professionals are made aware so as to ensure accurate and early diagnosis. Work has to begin on providing information on screening for developmental disabilities as well as a better referral process to all professionals who may play a role in diagnosis, as well as those who could aid in screening. This includes general medical practitioners as much as psychiatrists and paediatricians, community health workers, educators, psychologists, CBR workers, personnel in Child Guidance Clinics and Local Level Committees set up by the National Trust, to list a few.

Societal Attitudes

There is, of course, the issue of societal attitudes. In October 2006, an 11-year old child with autism was not allowed to board an airplane due to an outdated law on mental illness. This incident is just one example of how lack of public awareness impacts families of children with autism throughout India. Negative attitudes often permeates the understanding of the best of professionals. When we speak of a disability as a 'problem' and speak of 'hope' in treatment we start off with a negative perception. And this is the perception that colors all that happens with the child. For societal perceptions to start changing, perhaps the lead has to come from those who are seen to be the leaders in the field of disability.

Awareness about Autism Spectrum Disorders has increased significantly since the 1960s, yet even today policy makers and education and health professionals not directly involved in the field of Autism Spectrum Disorder may have limited knowledge of these disorders. Ongoing education and awareness programs about the needs of children and adults with an Autism Spectrum Disorder, and the possibilities for intervention and effective treatment is critical.

Well-Informed Health Professionals

Currently, medical textbooks have little information on autism. Experience in the sector suggests that medical textbooks need to be updated with information not only on autism, but also developmental disabilities in general, so that early screening and diagnosis enables children to receive the support they need on time. Lack of adequate information also impacts on advocacy as medical professionals have a very important voice in policy issues. This is therefore an area that requires urgent action.

There continues a strong bias towards a belief in parental neglect leading to autism, as well as a continuing bias towards a medical model of treatment. Families often make repeated trips to hospital clinics while the child loses crucial learning years. An emerging area is biomedical interventions, which may in some cases play a role in treatment for autism. However, because of the ease of implementation (in contrast to educational approaches), biomedical interventions are slowly, and inappropriately, taking over as the prime treatment in many cases. There is urgent need for a well informed medical fraternity that can help direct practitioners in the right direction.

Interventions

Current understanding indicates that teaching based on behavioral models are the most effective treatment options. However, such interventions are effort intensive and take a great deal of planning, monitoring and hard work, and can seem less inviting than other interventions. However, behavior based education must be the focus for the future, since it is the only demonstrated intervention that will enable individuals with autism lead as inclusive a life as possible.

Evaluation of treatment options is therefore urgently required. A few organisations in the field have the expertise to do so and with adequate funding could carry out randomized controlled studies on treatment options.

The focus of early intervention for children with autism too has to be reviewed. In the Indian school system, with the focus on academics as opposed to all round development, early intervention for children with autism too has an excessive focus on academic work. Since this does not address the different learning styles of the

autistic learner, it makes it less likely that children will be successfully mainstreamed. Wider and more intensive dissemination of information on teaching the student with autism will have to be undertaken.

Support to government schools – where most of the country’s children study – for including children with autism needs more attention. Checks and balances have to be put in place to ensure that children with autism are not asked to leave private schools because of their diagnosis.

In the coming years, social understanding has to find adequate place in curriculum for the autistic learner. AFA’s experience has shown that for those who complete mainstream education but have interpersonal difficulties, training in social understanding as well as work place etiquette and rules is imperative. In addition, vocational training for persons with autism is extremely limited in India and needs urgent attention.

Training of Professionals as Holistic Practitioners

In the West, particularly in the US, there can at times be a bias towards one or another form of intervention, leading to an ‘ours versus theirs’ syndrome. The fact is that we can step outside that syndrome, see what is best in each methodology propagated, and use it to the advantage of our children. And therefore, unlike the US, from whom we borrow most of our treatment options, we do not have to have professionals who only practice ‘Treatment A’ *versus* ‘Treatment B’. Rather our focus, and the focus of training, has to be a clear understanding of Treatment ‘A’, ‘B’ and ‘Z’; an understanding of which ‘Treatment’ is beneficial for which child; and at what stage of its development. To understand, for instance, at which stage must communication therapy be the prime focus *versus* teaching independent work skills, or

an understanding of social rules. Thereby lies the importance of training professionals as holistic practitioners.

Therefore, in the long run, the need for the sector is for teachers with a holistic approach. Despite growing middle class affluence, a large segment of the population in India is of limited means. The requirement for such families is for one-stop therapists. For autism, this means teachers who understand the distinct learning and behavioral characteristics, and the atypical cognitive and social development and behaviors, in individuals with autism; teachers who have a comprehensive understanding of autism and autism-specific techniques, and who can approach students with a trans-disciplinary approach. And teachers who, along with special education, have clarity on behaviour management techniques, and understanding of social development and language development, as well as family counseling. If families can encounter such teachers, they will not have to run from therapist to therapist for receiving a range of specialised interventions.

This is where the value of the RCI’s DSE (ASD) training lies. This training can produce well rounded teachers who can address different areas of concern of parents as it focuses on creating a group of professionals who can be the central pivot of services. The start of the training has been slow but steady. So far around 200 teachers have been trained. There is a huge demand for the trainees who pass out. As interest in autism grows and more students with a background in developmental psychology and child development get interested in this enigmatic disorder, what is required next is *an intensive practice-oriented post-graduate training* to tap this potential group of practitioners.

Parent Training

Even the most intense and regular training will not ensure enough practitioners for all the children with autism in India. When a child is diagnosed with an Autism Spectrum Disorder, their parents or primary carers must become experts overnight in order to effectively support and advocate on behalf of their child. The option then is to inform, and train parents so that they are empowered to become competent caregivers. Parent training has an important and equal role in future prognosis.

Further, with the exception of a few parent-initiated support groups, few families of children with disabilities in India have access to mental health professionals or an outlet for their own feelings of grief and helplessness is an urgent need.

There is urgent need for services to support parents with coping strategies to deal with the stress of parenting a child with autism.

Rights and Self Advocacy

Awareness about Autism Spectrum Disorders has increased significantly since the 1980s. However, policy makers and health professionals still have limited knowledge of these disorders unless they are directly involved in the field. Therefore Non-Government Organisations will have to continue to play an important role in advocating for the right of those with autism. Informing policy makers as well as society at large will need to be intensified. If policy makers are effectively informed they will be able to take well-informed decisions. For effective framing of policies as well as implementation, a sustained partnership between a proactive government and

NGOs can be extremely effective and fruitful and needs to be given emphasis.

The range of opinions expressed regarding the listing autism in the Persons With Disabilities Act are determined by each holder's perception of autism. Autism may or may not be marked by intellectual impairment. People with autism have complex needs which if well understood would highlight the need for inclusion in the Act. Despite the large number of individuals with autism in the country and the sharp increase in the numbers being diagnosed, children who are included in mainstream classrooms will continue to be asked to leave as soon as they receive a diagnosis. Others who have difficulties with motor coordination will continue to be refused permission to use computers to write for their exams. There will continue to be discrimination in public places. The fact that the PWD Act is silent on autism will continue to be used in justification. Inclusion in the Act can help push for changes in the above areas and can in fact facilitate societal change.

That the inclusion in the PWD Act can help push for educational reforms is the strongest argument in its favor. A number of individuals with autism have the ability to be self advocates. The impact of personal accounts by individuals such as Temple Grandin, Stephen Shore, Gunilla Gerland, Wendy Lawson, Ros Blackburn on our understanding of autism, has been invaluable. Yet unless they have the opportunity to develop their full potential, few will have the ability to speak for themselves. All over the developed world, individuals with autism are becoming a vocal group, speaking up for their rights. India too needs to move in that direction.

Experts who contributed to the section on Autism

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