CHAPTER-5

EMERGING INSTITUTIONS, NEW OPPORTUNITIES: PARENT SUPPORT ORGANISATIONS, CIVIL SOCIETY AND THE LAW

The preceding chapters have attempted to uncover the manner in which families come to terms with their child’s autism and the various adjustments and accommodations that this process entails. We have seen that the child’s autism impacts upon daily routines, intra-familial dynamics and the relationship of the family as a whole with surrounding networks of kin, neighbourhood and community. We have also highlighted the impact of urban life-styles on family life, parenting practices and familial networks, noting that the social isolation and lack of embeddedness experienced, particularly by migrant families, deprives them of much needed social support and solidarity. At the same time we have also observed how the lack of availability of extended familial bonds “frees” the conjugal unit to deal with the disability in the manner they deem best, without the pressure of family opinion, prejudice or interference. We have noted in particular, the strife and strain that arises on account of the difference of world-views between the generations, sometimes leading to conflict, confusion and delays in securing timely and appropriate interventions and programmes for the child.

Bereft of traditional support structures and struggling with the demands of urban existence, families under difficult circumstances are compelled to seek new opportunities and explore emerging institutions. It is against this backdrop that the role of support groups or ‘communities of co-sufferers’ becomes important. Empirical studies have demonstrated the positive impact of support groups on parental coping. The availability of information, the sharing of experiences, and absence of judgmental attitudes foster a sense of relief amongst families that there are people like them in the world and that they may derive hope from some of the “success stories” they encounter.
Anselm Strauss’s concept of “social world” may be cited in this context. The concept hints at interpretative communities in which members come to identify with a sense of a common reference point:

Social worlds are fluid ‘universes of discourse’ with their own common activities, joint meanings shared sites, communal technologies, and collective organization. ...Not as all encompassing and parochial as ‘community’, nor as fleeting and casual as groups or ‘scenes’, social worlds are very much a feature of the late modern world. They hold together people with common concerns even though they may not be in face-to-face contact with each other and their frequency in the late modern world is in good part attributable to the rise of modern communications media, which make wider universes of discourse more routinely possible than ever. (Plummer, 2000: 209)

Although the term highlights “universes of discourse”, it involves looking at not just forms of communication but also “activities, memberships, sites, technologies and organizations” (Strauss, 1987). The concept has been used by Unruh (1980) to study the “social worlds” of the elderly; Clarke (1998) has conceptualized groups studying reproductive sciences in North America as “communities of practice and discourse” which “form fundamental ‘building blocks’ of collective action through which people organize social life. Society can be conceptualized as a shifting mosaic of social worlds that both touch and interpenetrate..” (Clarke, 1998: 16). Plummer (1995) uses the concept to study the emergence of many new sexual groupings in a late modern world.

It may be said that families of children with developmental disabilities are also in the process of forming a ‘social world’. This social world is a product of and a response to the anonymity of urban existence and the need to forge bonds and networks that transcend family, yet attempt to replicate some of the traditional functions associated nostalgically with extended families, viz., support, nurture and guidance. Faced with the daunting prospect of raising a child with as complex and challenging a disorder as autism, families need to share information, advice, help and support and establish
networks that enable them to access it. The “urban moment” as Sassen (2005) designates it, is characterized by globalization, the rise of new information technologies and the strengthening presence and voice of diverse socio-cultural entities. Cities have emerged as “strategic sites” for “new types of political actors which may have been submerged, invisible or without voice”. (ibid: 466)

The “autism voice” which has emerged in urban India in the past decade and a half could make itself heard due to the revolution in information technology, its accessibility to the urban middle class, the expansion in travel (national and international) and the changing definition of trust and intimacy, wherein friendship circles and people who share the same problem are resorted to in times of crisis and for comfort and support. I came across numerous cases in which families of autistic children, when confronted with crisis like the death or illness of a family member, would prefer to call upon other such families for help rather than their own kin or extended families. Apart from requiring individualized help in times of crisis, families also face the common, omnipresent fear, “what will happen to our children when we are gone?” As the “voice” of their children, they need to lobby for rights and legal safeguards. Families lobbied hard but unsuccessfully to get Autism included in the Persons with Disabilities Act of 1995. However, autism finally received recognition as a disorder by the Government of India with the passage of the National Trust Act for Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities in the year 1999.

The NGO Action for Autism has played an important role in forging the links between individual families, professionals, other civil society players and the state in making autism a part of the disability discourse in India. This chapter traces its genesis and
growth and from the struggle of a lone mother told that her child has a life-long, untreatable disorder, to an organization that provides diagnosis, training, counselling, support and advocacy, all under one roof. It is a remarkable story, a story of immense individual courage and character, and at the same time, a story of and about our times. This “ethnography of the particular”, to use Abu-Lugodh’s (2006) telling phrase, chronicles the way urban living contributes to “othering” difference and at the same time, makes available opportunities and avenues to challenge the othering and construct an alternative discourse.

5.1 ‘ACTION FOR AUTISM’: A CASE STUDY

The case study of the organization taken up in the first part of this chapter will highlight the following aspects:

1) Genesis of the organization
2) Vision and Mission Statements
3) Physical Space and Building Structure
4) Target Population and Clientele
5) Programmes and Activities
6) Staffing and Organizational Structure
7) Funding and Networking

1. Genesis of the Organisation

When Merry Barua’s only son Neeraj was diagnosed “autistic” by a leading psychiatrist in 1987, the word “autism” was practically unknown in the Indian paediatric and psychiatric community. There was no information to be accessed; no-one the family could go to for help, no medication, no specialist schools, no therapy.
There was nothing to do or read – no Internet, no parent support groups, no one even knew the word. Imagine that some one tells you that you have a life-long disorder but that nothing is known about it. What would you do? You’d suddenly be in a world all your own.” (Merry Barua, quoted in Grinker, 2007: 210-11)

Being economically well off and educationally well-qualified, Ms. Barua was able to procure information from the USA and the UK about the disorder and also made arrangements to get herself trained in the USA as a therapist so that she could work with her son. Her attempts to place him in schools (regular and special) failed; teachers were unable and often unwilling to deal with his behaviours which had by then become extremely difficult. Realising that he was not welcome anywhere, Ms. Barua homeschooled him, and was able to help him overcome some of his most undesirable behaviours. She was, at the time also actively networking with a few other families with mentally challenged children that she came to know and was also writing newspaper articles on autism. People from all over the country were beginning to get in touch with her, seeking advice and help which she extended freely.

Ms. Barua realized that she was probably one of the only people in India who had actually received formal training in the management of autism, and was eager to share her experiences and knowledge. Soon, an autistic girl joined Neeraj in the classroom, and “Open Door School” was born in 1994. As news of her work spread, she was approached by more families, desperate to find a place for their children who had been rejected as “hopeless cases” or “unteachable” by regular and specialist schools alike. Her friends in the NGO sector advised her to get the organization registered. There was a buzz in the disability sector about the proposed legislation that was underway, viz., the Persons with Disability Act (which was passed in 1995). The emergent newly registered organization was eager that autism also be included within the purview of the
Act, but despite the strenuous efforts of the few families that comprised its ranks, was unable to lobby the Government sufficiently to do so.

However, its growth and reach in the coming years was to be far greater than its founder ever anticipated. The magazine, *Autism Network* was started in 1994 and has had an uninterrupted publication history since. Volunteer teachers were identified and trained. From functioning in Ms. Barua’s house, the centre shifted to rented premises in Vasant Kunj and then Chirag Gaon in South Delhi. The annual workshop for parents and professionals was inaugurated in 1997 and has proved a great success. The organization, at the present time has evolved into a multi-pronged one offering diagnostic and counselling services, running a specialist school, pioneering and supporting research and advocacy, and disseminating information to parents, professionals and the general public. Being a parent-directed and parent driven organization, as we have described above, it is rooted firmly in the actual experiences of parenting and living with an autistic child. Its genesis and subsequent growth are anchored in this reality. This is probably the reason why families unanimously vouch for the “unconditional acceptance” their children receive here, even if they may have complaints or worries about other aspects of its services or functioning.

2. **Mission Statements and Core Values**

The organization conveys many of its core values and guiding principles on program documents that are published as brochures and reports on organizational activities. A typical AFA brochure is a slim long booklet with a photograph of two children at play on the front cover and a therapist and child in a work-session at the back. Its logo, a smiling child’s face in a piece of a jigsaw puzzle is displayed in the lower right hand corners on front and back page. The symbol of the jigsaw puzzle piece is used by many
autism organizations world wide. The AFA logo depicts the child’s face emerging out of the puzzle piece, symbolizing incorporation into the wider society. Importantly, the face is a smiling one, implying that disability is not a tragedy, that the right to be happy is universal. The booklet has sections that briefly describe autism and the unusual behaviour patterns that enable one to recognize an autistic person. Information about the genesis and development of the National Centre and the services it offers follow, along with a bullet point presentation on “AFA’s Pioneering Activities”. A fund-raising and membership-recruiting form comprises the last two pages. Attractively designed and presented, the booklet is in the English language. Indeed, most of the publicity and information materials of the organization are in English, thereby limiting their reach to a very small section of the populance. The organization’s vision and mission statements prominently printed on the first page of the brochure are as follows:

**Vision**

A society that views the inter-dependence of people of every ability as valuable and enriching and seeks to provide equal opportunities for all.

**Mission**

To facilitate a barrier free environment; to empower families of persons with autism and to act as a catalyst for change that will enable persons with autism to live as fully participating members of the community.

The vision of a society based on “interdependence of people of every ability” implies an inherent belief in the equality of all citizens, irrespective of ability or disability and emphasizes the “valuable and enriching” aspects of such interdependence. What is also implied is that the “less equal” members of society also can contribute to this interdependence in a valuable and enriching way, rather that merely being at the receiving end. The vision of “providing equal opportunities for all”, although an oft-used phrase, assumes greater salience when we remember the nature of disability that
the organization is associated with. As we have seen earlier, the personhood of the mentally disabled is often undermined or questioned; they are seen as not quite human and hence the question of providing them with “equal opportunities” is rarely taken up seriously. As they are deemed to be “eternal children”, in constant need of care and support their rights as individuals tend to be de-emphasised or even violated, as in the well documented case of the hysterectomies carried out on mentally disabled women in Shirur, Maharashtra in 1994 (see Sundar Rajan, 2005). The organization thus envisages a society which grants full personhood to its mentally disabled members, which implies extending all possible opportunities to optimize their potential and live a life of dignity.

In order to realize this vision, the organization conceptualizes its mission in terms of three interrelated dimensions viz., (i) the environment (ii) family (iii) social change,

i) The environment:

It aims to do away with barriers that restrict or prevent the full participation of disabled people in the life of the community, be it physical barriers like ‘disabled-unfriendly’ architecture or public spaces, or less tangible but discriminatory practices like denying them access to appropriate education, recreation etc. We may cite a highly publicized incident in October 2006, when the autistic son of a South Indian T.V. actor was denied entry on an aircraft, citing an obscure rule. The incident was flashed on live television, and CNN-IBN, a 24 hour news channel ran a series of programmes on the plight of the disabled in Indian society following the incident.

ii) The family:

“Empowering families of persons with autism” is one of the core themes around which the organization is built. Empowerment is sought to be accomplished at multiple levels:
(a) The psychological level, wherein families are counselled to come to terms with the child’s disability and better still, acknowledge and embrace it. During the Annual Training Workshop for parents and professionals, Merry Barua usually ends her presentation by narrating the following story. A water-carrier daily carries two pots of water up a hillside. One pot has a crack in it, and, as a result, the water leaks away by the time the water carrier reaches the top of the hill. This goes on for a number of days and months. The cracked pot feels very sad and asks its master to discard it. The master tells the pot to look down at the path they take everyday. Lo and behold! The path is covered with beautiful flowers, whereas on the other side, the side of the intact pot, not a single flower grows. Barua asks parents to see their child as this pot with a crack, which, while unable to retain all the water, nevertheless makes it possible for flowers to blossom in its path. The story usually elicits an emotional response from parents; I have seen many shed tears. Several parents who attended the Annual Workshop reported that it changed their attitude towards their child and fostered acceptance and respect.

The organization also provides families avenues to interact with each other. One of its brochures carries the phrase “you are not alone”. As reported by several parents, reading this simple line gave them reassurance and alleviated their fears and worries to some extent. The “moment of truth” of being told that one’s child will be disabled for life is a life-changing one, as has been discussed in a previous chapter; a profound disruption of order, a “zero-moment”, as one parent evocatively put it. In this difficult circumstance, to interact with other families who have gone through the same experiences can be therapeutic. Many families reported that what made them “trust” AFA was the knowledge that its founders and several of its senior therapists were themselves parents of autistic children. By providing a forum for families facing a similar life-changing circumstance, AFA contributes to their empowerment.
(b) Empowerment through knowledge about the disability, its management and availability of services: Through the Annual Workshop and numerous other seminars, talks and lectures conducted by the organization, state-of-the-art information about autism and the various therapies in vogue are made available to parents and professionals. The publication *Autism Network*, a quarterly journal which carries articles on autism and answers questions posed by readers also acts as an important vehicle of parent education and empowerment.

(c) Empowerment through advocacy and lobbying for rights: The organization claims, with some justification to have “pioneered the autism movement in South Asia” *(Annual Report, 2004-05: 5)*. Working within the framework of a rights-based approach, it promotes empowerment of the family by advocating for the legislative and social rights of persons with autism. It played an important role in ensuring the inclusion of autism in the National Trust Act of 1999 which puts in place, among other things, a scheme of guardianship for persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. Autism has not yet been included in the Persons with Disabilities (PWD) Act of 1995, but the efforts of the organization to ensure its inclusion are still going on.

iii) Social change:

Understanding how the organization views itself as an agent of change, it is important to examine the following dimensions: (a) how disability is defined (b) how personhood is defined (c) the organization’s theory of how change occurs.

(a) AFA’s understanding of disability: One of the deeply entrenched attitudes and beliefs that the organization aims to dispel is the notion of disability as a tragedy, a “fate worse than death”. The information literature, editorials and articles in its
publication *Autism Network*, the content of its training workshop, interviews given by its leaders to the media, counsel given by its therapists, in other words, its discourse, portrays disability as one kind of human difference to be accepted, given support and accommodated. At the same time, it does not 'normalize' the unique difficulties that individual with autism and their families undergo, nor does it romanticize the notion of difference. Speaking about ‘inclusive education’, Merry Barua pointed out that while the ideals of inclusive education for disabled children were laudable, true inclusion could only take place when schools made a conscious effort to do away with exclusionary practices already in place e.g. separate sections for the ‘bright’ children and ‘duffers’. Thus disability is viewed against the backdrop of exclusionary and intolerant social practices which need to be addressed before the disabled find their place in the sun. (Personal interview with Ms. Barua)

(b) AFA’s notion of ‘personhood’: The teaching methodologies adopted by the organization include ‘Applied Behaviour Analysis’¹, ‘TEACHH’², ‘Verbal Behavior Analysis’³ etc., which are internationally recognized methodologies used for working with autistic persons. Detailed discussion on the same is not within the scope of this thesis, however, all are grounded in an understanding of the deep-seated reasons (physiological, sensory, psycho-social) for the particular behaviours displayed by individuals with autism. The practitioners utilize a combination of methods, tailored to

¹ ‘Applied Behaviour Analysis’ (ABA) is the science of applying experimentally derived principles of behaviour to improve socially significant behaviour. As children with autism learn much less from the environment than regularly developing one, ABA interventions teach behaviours in a structured environment, usually one-to-one at a table. ABA is most commonly associated with the work of I. Lovaas.

² ‘TEACHH’ is the acronym for the Treatment and Education of Autistic and Related Communication Handicapped Children programme devised by Eric Schopler and his colleagues in the 1970’s in the University of North Carolina, Chapel Hill (U.S.A.) It is a programme of skill development through structured teaching which focuses on the specific strengths of autistic people like visual abilities.

³ The Verbal Behaviour Approach (VBA) focuses on teaching specific components of expressive language and is based on the premise that the meaning of a word is found in its function, not in the word itself. It addresses the issue of people with autism who apparently ‘know’ many words without being able to use the words meaningfully or functionally.
the needs of each child, keeping in mind the local context. One of the significant observations is that while therapists attempt to modify those behaviours which are clearly disruptive or dysfunctional (viz. hitting, head banging, spreading faeces, uncontrolled tantrums etc.), they do not use aversive or punitive methods. Certain idiosyncratic behaviours that a particular child may exhibit, viz. rocking, spinning, finger-flicking etc., which may appear odd or bizarre to ‘normal’ people, are not interfered with, as it is believed they afford the child some relief from the sensory difficulties that s/he faces. Thus the focus of intervention is the child’s comfort or adjustment. Intervention and therapy does not aim primarily at making the child more palatable or acceptable to the rest of the world, rather, it focuses on helping the affected child to fit better into the confusing, chaotic world s/he finds hard to understand and deal with. Thus, a child’s autism is not viewed as an aberrant aspect of his/her personality to be wiped out by all means, rather, an intrinsic part of the child’s personhood, a defining aspect of his/her humanity. ‘The right to be different and be respected inspite of it’, is thus safeguarded as an essential element of personhood.

(b) AFA’s Theory of Change: AFA’s emphasis on the integrity of the personhood of the autistic individual and its critique of the social inequities which foment discrimination at all levels lies at the core of its theory of change. It views itself as an agent of change through the provision of services to individuals with autism and their families in the form of diagnostic and counselling services, teaching and training and imparting work-skills to adults with autism. It also employs individuals on the autism spectrum in the organization. Future plans include the setting up of group homes and sheltered workshops for adults with autism.
The organization, as earlier mentioned, imparts awareness and training to parents, professionals and others through its seminars and workshops. In December each year, ‘Autism Week’ is celebrated. Sponsored concerts, a ‘Walk for Autism’, Diwali Mela etc. are the other activities which enable the organization to interface with the community and create awareness. It also conducts a Diploma in Special Education (Autism) designed to train a cadre of teachers to work within special education and regular educational establishments with children on the Autism Spectrum. One of its innovative programmes was the preparation of an awareness kit for doctors and paediatricians, who are often the first medical professionals a child and its family are likely to interact with and who can thus spot developmental deviances and initiate early intervention.

Through its interface with professional bodies, other NGOs and the wider disabled community, local and national governments, AFA seeks to bring about attitudinal change, (viz., viewing the disabled as citizens with rights) as well as social-structural changes in terms of education, employment, creating a body of trained teachers and therapists, advocacy and legal activism. By acting as an agent of change in the household, educational setting, social and recreational contexts as well as in the domain of law and human rights, the organization aims at bringing disability into the realm of public discourse and policy.

3. **Physical Space and Building Structure:**

The physical space and structure within which an organization operates and the way it organizes and structures that space, give us valuable insights into its core values and modes of functioning. The fieldwork took place during a very interesting phase of the organisation’s 15 year old history; i.e. during the time AFA shifted from a rented
accommodation in Chirag Gaon to its own new building in Jasola Vihar, New Delhi. Due to the paucity of resources, the shift was made when the new building was only partially constructed, as it would have been uneconomical to pay rent as well as put in funds for construction. The foundation stone for the new building in Jasola Vihar was laid by the Chief Minister of the NCR, Ms. Sheila Dixit in July, 2004, and the organization shifted there in June, 2005. The Annual Day of the 2004-05 session (in April 2005) was held in the newly constructed basement. The following diary entry captures the commotion and excitement.

AFA has a basement! And some floor as well. They also have mosquitoes completely impervious to repellents. The function this evening was an unmitigated disaster, of course, what with the lights going out and the action taking place by candle light. No music system, so the poor trainees and teachers SANG all the musical accompaniment. No mike either, so you couldn't hear a word. It was hot (no fan!) and of course, the mosquitoes. Curiously enough, the kids were magnificent. They didn't seem to mind the discomfort, though parents were livid. Why on earth couldn't they hold it the Chirag Gaon mandir like they did every year? Why drag us all to this wilderness? But at the close of the function, the lights miraculously came back on! And the whoop of joy everyone gave redeemed the evening. And, of course, hurrah for the kids. (Personal Diary, April, 2005)

The semi-constructed structure the above extract refers to, is now a four-storey building encircled by a small garden. There is a medium-sized, well maintained lawn at the back, where children go for play, and a small splash-pool where they enjoy water therapy. There is also a sand-pit and swings in the compound. The building is encircled by fairly high walls and there is only one entry and exit gate, manned by a guard. This ensures that once the children are in the building, they are secure and cannot leave without being noticed. Given the fact that some autistic children are "runners", who can give even the most vigilant care-giver the slip, this security mechanism is a source of relief for parents and teachers alike. The basement of the building is given over to
**Aadhar**, the work-skills centre for young adults with autism. A teacher and trainer work with them and teach them how to operate a loom, make envelopes, screen printing handicrafts, cooking, baking and life-skills.

The ground floor comprises the office area and waiting area for parents and visitors. There is also a cafeteria with tea and coffee vending machines. A bakery unit has recently become operational. Classes for trainees enrolled for the Diploma in Special Education (Autism) are located on the ground floor. The library is also located on the Ground Floor. AFA’s ‘resource room’ contains a formidable collection of literature on autism and related issues, which is open for the general public. Members can, on the payment of a nominal fee, issue books and video cassettes. There is a large television and video cassette recorder and children are sometimes shown a short film or programme here.

‘Open Door School’ functions on the first floor. Apart from the classrooms, there is the “Happy Room”, a relaxing room where children can play with toys or do whatever catches their fancy. The classrooms are spatially well structured; each child knows his/her designated seat; there is a cupboard for placing bags and lunch-boxes and a written “schedule” for each child which s/he checks before moving to an activity. Individual Education Plans (IEP’s) for each child are meticulously prepared. These involve academic, vocational and social skills components which are sought to be realized through group-based teaching, individual work sessions, physical activities, music and play. Coordinating the programmes of the sixty-odd children enrolled at Open Door School is the responsibility of the ‘Education Director’, whose office is also located on the first floor. Toilets and washrooms are also provided.
The second floor is given over for the ‘Mother and Child Programme’, one of the innovative schemes run by the organization, wherein mothers (and the occasional grand-mother or father) train intensively under the guidance of a therapist on techniques of working with their autistic child (we shall discuss this in greater detail elsewhere in the chapter.) The Occupational Therapy Room is also located here.

The third and fourth floors have meeting and conference spaces where future Annual Workshops and Trainings are likely to be held.

The building has plenty of natural lighting which makes it a bright, airy place; in complete contrast to the dark, dingy, cramped accommodation at Chirag Gaon with its flaking walls and the single tiny toilet, barely large enough to accommodate an adult, which served all the children, staff and visitors. However, as Ms. Barua remarked nostalgically, some of the best work of the organization was done within that inadequate space. Every square inch was used to the optimum; classrooms doubled as consultation areas, the terrace was the playground, the rehearsal area for functions and the waiting area for parents and children. The new centre is the outcome of a grant of land at a concessional rate to the organization and the funds for purchase of the land and construction of the building were collected through individual and corporate donations, and fund raising and promotional activities like the first annual ‘Walk for Autism’, participation in the launch of the movie *Koi Mil Gaya*, an art exhibition sponsored by the Confederation of Indian Industry (C.I.I.) and a fashion show with ‘the Delhi Network’, among others (*Annual Report 2004-05: 29*)

The new building has enabled the organization to streamline and develop its multiple activities. At the same time, as some parents expressed it does not feel like the homely, warm place they knew in Chirag Gaon. The dispersal of activities over the different
floors and the business-like atmosphere of the ground floor where the offices and library are housed make it appear like “any other organization”, in other words, its bureaucratization (the inevitable consequence of expansion and professionalisation) has resulted in greater formalism. As one mother put it. “You never had to take appointments before... someone was always there to listen to your problems... now everyone is so busy with something or other...” Another parent said “...ab teachers samajhti hai ki hum bahut badi jagah me kaam kar rahti hai..” (Now the teachers think they are working in a very important place); the implication being that as a result, they do not engage with children and families with the former intensity and commitment.

There is a feeling voiced by some parents, that the goals of the organization now take precedence over the individual child. The new building is thus emblematic of a new kind of organizational ethos, a shift from a chaotic, messy home-like atmosphere to the structured formality of an official one.

It has also become the symbol of the emerging autism movement in the country; as one of the therapists working in AFA for the past several years said, “...public, Government departments, NGO’s take us more seriously... in this country, it’s not enough to just do good work...without the ‘sho-sha’ (fan-fare) no one gives you a second glance.. Chief Minister has come, Sonia Gandhi has come, so now people think we are worth something...”

4. **Target Population and Clientele:**

To the ‘man on the street’ – whatever his age, class or occupation – autism remains an alien word. “Action for What?” They ask us. Yet, over the thirteen years that Action for Autism has been in operation, we have witnessed a phenomenal increase in awareness and understanding of autism. Consequently, the number of diagnosed cases has dramatically increased and one gets the impression that the incidence of autism is sharply on the rise. Certainly, the demand on our services has never been greater. *(Annual Report 2004-05: 9)*
Although physically located in Delhi, AFA caters to families all over India and South East Asia. Its popular ‘Mother and Child’ programme has drawn families from Bangladesh, Nepal, Bhutan and Pakistan along with families from all over India. Diagnostic facilities are also availed by families coming to Delhi from all over the country for the express purpose of consulting at the organization. The Annual Training Workshop also attracts participation from all over the country. However, the model school, Open Door, has deliberately been kept small, so that teacher-student ratios will not be compromised. Training programmes undertaken by the organization, wherein therapists impart skills ensure interaction with organizations in various parts of the country. Autism Network which has a print-run of 2500, and the website which received close to a hundred thousand hits in the year 2005-06 bear testimony to the reach achieved by the organization.

As the narratives in the preceding chapters testify, doctors and paediatricians suspecting probable autism, referred parents to the organization for a reliable diagnosis. The growing visibility of the organization, as a result of media coverage and the well-designed and visible new building also have contributed to expanding its clientele.

As per the details provided in AFA’s annual report (2005-2006) the number of people reached by the organization in 2005-06 was as follows:

<table>
<thead>
<tr>
<th>Diagnosis and Functional Assessments</th>
<th>Open Door Programme (Model School for Autism)</th>
<th>Families attending Intervention Programme</th>
<th>Families Attending Sensory Integration Programme</th>
<th>Circulation of Journal</th>
<th>Visitors to Website</th>
<th>Teachers trained at AFA under DSE (ASD)</th>
<th>Training Workshops conducted</th>
<th>People trained through workshops</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5. Programmes and Activities:

i) Diagnosis and Assessment:

As discussed earlier there is limited awareness and understanding of autism in India, which often goes under-diagnosed or misdiagnosed as mental retardation or psychiatric illnesses. Diagnosis and assessment are therefore a vital part of the services provided by the organization. AFA has so far provided diagnosis and early intervention programmes for over 1000 children (Annual Report, 2005-06: 26). Early and appropriate diagnosis can often make all the difference in future prognosis. It has been noted that AFA has been increasingly receiving referrals from other new professionals as well as parents walking in on their own accord after having read about autism in a magazine or the Internet and finding striking similarities in the presented symptoms.

AFA diagnosed a total of 55 children in 2005-06 and carried out functional assessments of 40 children with a large proportion of children in the 2-4 year age group, i.e., a total of 95 children. In the year 2002-03, the number was 45, in 2003-04, 61 and in 2004-05 it was 68. The need for systematic diagnosis of children affected on the Autism Spectrum Disorder made AFA collaborate with the organisation ‘Autism Denmark’ to develop a Diagnostic Screening Kit. The kit is designed to assist professionals with limited knowledge of autism to detect it early. Prominent hospitals were requested to cooperate in the testing of this kit.

ii) Education:

The ‘Open Door School’, inaugurated in 1994, was the first of its kind in South Asia which offered specialized services to children with Autism.

There are at present only 20 schools in the country with an average strength of 30 students that cater exclusively to children with autism. (www.autism-india.org) ‘Open
Door School' numbers are deliberately restricted to 50-60 students at a time so that each child may receive adequate attention, in the absence of large numbers of trained teachers. However, in order to meet the growing demand on its services, AFA has begun strategizing about increasing its capacities for Open Door. The 'Mother Child Programme' is also a part of the Open Door day programme. In Open Door the children are grouped on the basis of learning and development and have a Specialist Teacher, Junior Teacher and caregiver devoted to a group. Its main objectives to devise, test and tailor new teaching strategies and act as a model and training ground for therapists and parents.

**Highlights**

- Between 2005-06 the Open Door programme was availed by 100 families. Some children were also supported to attend integrated and semi-integrated schools. Sessions like community education program twice a month, community visits and celebration of festivals was undertaken to expose children to a variety of social experiences.

- Community Education Programmes are pretend drills with props, and teachers playing roles related to the concept. The children observe and are then encouraged to participate. Last year the students participated in a visit to a Dentist, visit to Mother Diary, visit to a shop, haircutting, eating at a restaurant, watching a movie in a group etc.

- Festivals, national holidays and birthdays of children and teachers are also celebrated and children encouraged to take part. It may be noted that children with autism often find it difficult to celebrate festivals within their communities due to sensory issues; e.g. the sounds of fireworks, crowds, sensory over stimulation etc.
often result in festive occasions becoming difficult and unpleasant experiences for children and by extension, families. Within the structured and non-threatening ambit of the school, however, children are exposed to these cultural experiences and this enables them to cope better with the experiences and sensations they encounter in the community.

It may be noted that AFA's educational programmes are not merely confined to academic or vocational training, rather, they focus upon integrating the child into the community. This is in consonance with its vision of a society built upon interdependence and participation. The 'Annual Day', a cultural programme staged at the end of each academic session, reflects the organization's understanding of the 'personhood' of the autistic children. The programme, usually based on the enactment of a story has plenty of music (familiar and identifiable tunes from film songs, nursery rhymes etc) with funny lyrics composed by teachers and trainees; colourful props and costumes. “Fancy dress” items eg. “brides and grooms of India” or “festivals of India” etc. are particularly popular. While, on the face of it, it may appear to be a simple affair, requiring little display of skill on the part of the participants, it is, in fact an almost heroic feat to get on stage children with such serious sensory and communication difficulties. One or two parents did say that they considered the exercise a waste of time and a great stress for their child (“he just doesn’t get it.. it means absolutely nothing to him..”) yet, they never withdrew their child from the activity, and attended the programme like all the other parents.

The Annual Day also provided an outlet for some parents to conceptualize their child as “normal”, participating in an activity that all schools do. I noticed the painstaking care with which a mother painted white dots on her child’s forehead, dressing him up as a
Bengali bridegroom, (even though he was onstage for less than a minute), the care taken with costumes, props and make-up. The actual performances were greeted with much applause and enjoyment by parents, siblings and other guests.

iii) Family & Parent Skill Building:

This is one of the core activities undertaken by the organization. As it states in its documents, “Aware and informed parents are the determining factor in ensuring their child’s progress. Empowered parents develop a positive perception besides skill development and naturally benefit their child’s progress. Better understanding of the issues involved in autism lead to creation of an appropriate learning environment at home allowing these parents and caretakers to become effective therapists in their child’s life.” *(Annual Report, 2005-06)*

iv) Programmes:

**Centre Based Home Management**

In this programme for Home Management the parent and a trained AFA therapist design schedules and plans, together. Tailored to each family’s individual needs, they provide structures for daily routines and activities that the family carries out with the child at home. The plan is implemented at home and the family returns for an update at predetermined intervals of a fortnight or more. The Programme also gives families an opportunity to discuss for solutions to vexing issues of behaviours and learning of daily living skills. 112 families availed of the Home Programme in 2005-06.

**Counselling**

Counselling is provided to family members for dealing with issues related to the pressures and stress of parenting a child with autism, parenting the sibling of a child with autism, living in a nuclear or a joint family, second child issues, or any other
concerns that the families may have. Appropriate coping strategies are discussed and developed with inputs from psychologists and medical professionals.

The Hourly Intervention Programme

More than 348 children availed of this regular ongoing programme in 2005-06, up from 329 in the previous year. The therapist works one-on-one with the child, one or more times a week with ongoing observation by parents. This Programme is specially helpful for children who need additional support whether they are preparing for mainstream schools or being schooled at home and specially for ones who are not receiving any other special education inputs.

Parent Support Groups

Social isolation is one of the biggest challenges faced by parents with an autistic child. To meet this crisis AFA facilitates and supports Parent Support Groups in different parts of the country helping forge links between parents in similar situations. Parental narratives in previous chapters have brought out the importance of support groups for families in this difficult circumstance.

The Mother Child Programme

The MCP, one of AFA’s popular programmes reached out to 45 families in 2005-06, as compared to 30 in the previous one. This Programme seeks to maximize the benefits of the time that a mother spends with her child, teaching focused one-on-one intervention tailored individually to each child and taking into account the child’s strengths, emerging skills and weakest skill areas. Semi-structured, daily interactions between mothers and their autistic children are conducted in a group setting. The basic goal is for mothers to develop skills that will improve the quality of their interaction with their
children, raise their confidence and decrease stress. This, in turn, will have a positive impact on the child’s skills.

**Vocational and Living Skills Building**

With respect to young adults with autism, the task of the organisation becomes more challenging. These young adults have in general received diagnoses very late, and lost out on the benefits of early intervention and appropriate education. The objectives spelt out for the rehabilitation of young adults with autism include the following:

- To impart independence in all living skills like Vocational Skills, Independent Functioning, Leisure Skills, Vocational Behavior, Functional Communication, and Interpersonal Behaviour.

- To train adults in Vocational Skills depending on their interest and abilities that will eventually foster economic independence

- To make the life of adults with autism as regular as possible

- To teach certain social skills that would help them to adjust in their environment

- To run Supported Employment Programmes so as to enable them to lead productive lives

- To inculcate a sense of achievement through the concept and experience of ‘Work’

- To encourage trainees to pursue hobbies and leisure activities, to help them make independent decisions.

- To ultimately allow for the provision of regular income to trained persons with autism working at Aadhar (AFA’s Work Skills Centre for adults with autism) as income generating activities are self-sustaining. (*Annual Report, 2005-06*)

The trainees at Aadhar are taught Vocational Skills along with Social Skills. They are involved in various activities like stitching, weaving, envelope making and folder making. They also actively assist in office work. They are also taught cooking, painting *diyas* and pots, making *rakhis*, friendship bands, charts, etc. specially during festival seasons and sell their creations at various events at the Centre and other such events conducted by other disability organisations. The trainees make snacks for breakfast and
sell them at the cafeteria in the Centre. They also look after the staff’s coffee and tea needs.

**Training**

The organisation maintains that the most effective long term and economically viable means of maximizing reach is empowering parents through training. It is also committed to creating a body of informed and trained professionals to propagate effective and proven teaching methods for people with Autism.

Over the years, the organisation has conducted training workshops and lectures at national and international disability fora, hospitals, regular and special schools, universities, governmental departments and programmes e.g. AFA delegates made presentations at the World Autism Congress in Denmark (September, 2004); The Sitaram Bhartia Institute of Science and Research, Delhi (October, 04); Christian Medical Association, Vellore (Sept., -06); *Sarva Shiksha Abhiyaan*, Ministry of HRD, GOI (July, 06); Public schools like St. Mary’s School, Delhi, Springdales School, Delhi and Delhi Public School, Jalandhar (April and July, 2006); The Department of Psychiatry, Kolkata University (Nov., 06) to mention a few. These presentations and workshops focus on medical, educational and mental health professionals. Over the years, the emphasis has widened from symptom recognition, diagnosis and functional assessment to inclusive education, curriculum planning and management for children with ASD and the variety of new therapies. This signals a growing awareness amongst the medical and teaching community regarding the condition and the changing perception that it can be managed with appropriate and timely intervention.
Resource Provisions

With a view to empowering families of children with autism, the organization aims at providing all kinds of information accessible through books, videos, newsletters etc. This is for them to broaden their understanding of autism, receive advice and interact with others.

2500 families and professionals in India and 22 other countries around the world receive AFA’s journal, *Autism Network*. It provides information on good practice and keeps readers in touch with events throughout the country as well as international developments in research and is published three times a year.

The AFA web page, [www.autism-india.org](http://www.autism-india.org), is a much-utilized source of reliable and practical information. The site contains links to resources around the world as well to a bulletin and a helpline.

AFA’s resource room holds an extensive collection of resource materials on Autism in India. It also maintains files on autism and disability related topics, journals, newsletters and media articles from India and overseas. The organization also welcomes researchers in psychology, special education and other disciplines to interact with children and therapists and avail of the resources at their disposal.

One of the key areas the organization requires to focus upon is making this wealth of information available in Hindi and regional languages. The lack of an indigenous word for ‘Autism’ along with the predominantly English-speaking, middle class profile of teachers and therapists, reinforces the stereotype of autism being a product of Western culture and the ‘malaise’ of modernity, referred to in the Introduction. Conservative estimates put the number of affected individuals to 2 million in India and these cut across regional, linguistic, caste and other divides. The organization needs to enhance
its reach and accessibility by “speaking autism” in the languages understood by the masses, rather than confining itself to a discourse understood only by the English educated elites.

**Awareness and Advocacy**

As has repeatedly been highlighted, creating awareness about autism and lobbying for the rights of autistic people is the core underlying mission of the organization, in order to realize its vision of a society that accommodates individuals of all abilities. At the level of the family counselling, training parents to work with their children and creating social spaces and avenues for interaction are some of the important activities undertaken by the organization. The organization has also initiated capacity building through its training programmes for teachers and therapists so that affected individuals may receive appropriate services and care. At the level of the wider community, the organization has undertaken a number of activities to bring autism awareness into the public realm. The annual ‘walk for Autism’, initiated in 2004 was held in the embassy area of Chanakyapuri where it elicited little public interest. However, with the move to the new centre, the walk was conducted through the locality, in order to familiarize residents with the organization and to activities. As part of the “community education” component of Open Door’s curriculum, students are also taken for visits to the local shops. Mother Dairy, park etc. in the locality, fostering awareness and interaction with the community. During my fieldwork, I would sometimes visit the Mother Dairy shop for refreshment. Its staff spoke to me about how despite their initial apprehension, they were pleased to interact with children from the school. In fact, they were all praise for the orderliness with which the visits took place. Earlier, when the school functioned in Chirag Gaon, the local residents and shopkeepers would help to ‘rescue’ a runaway child and local auto-rickshaw drivers would seldom refuse to carry a parent and child.
from the "paagal bacchon ka school" (the school for mad children). The nearby temple which had a small courtyard was also the venue for several annual day functions.

AFA also participates in the ‘World Disability Day’, melas and exhibitions organized by disability organizations, other non-governmental organizations and corporate houses. This provides an opportunity to interact and network with both, the disability community and the general public. It also participated in the World Social Forum held in New Delhi in December, 2006.

While these multifarious activities indicate a greater participation in community activities, we may speculate about the extent to which these activities actually promote empathy and understanding towards those affected by the disorder. As has been highlighted earlier, the intellectually disabled, unlike the physically or sensorily disabled cannot articulate or lobby for their own rights, nor form a pressure group. Their voices are not heard, they are “spoken for” (Chandoke, 2003: 3020). During one of the “World Disability Day” gatherings a restive, irritable group of autistic children and their stressed teachers had to wait for long hours at the Capital’s India Gate, “demonstrating”, when the children probably wanted to run free and enjoy playing on the lawns. At the same time, it cannot be categorically assumed that they are “voiceless” and should be left to their own devices. The organization thus has to walk a fine line between activism and respecting the agency of autistic persons.

6. Staffing and Organisational Structure

AFA is a parent directed NGO comprising a team of professionals and volunteers. Its governing body, comprising President, Secretary, Treasurer, Joint Secretary and six members is drawn from various areas of professional expertise. The current President is a University teacher, the secretary a disability activist, the treasurer an interior designer.
and the Joint Secretary is in private service. Members include two business persons, a politician, two journalists and a developmental paediatrician. Most of them are parents of developmentally disabled children or work with disabled children. The governing body comprises seven women and three men. They do not receive honorariums and none of them are related to each other in any way. In the year 2005-06, they met four times with an average of seven members present.

While policy matters and decisions pertaining to new programmes, financial matters, etc. are cleared by the Governing Body, on the ground, it is the team of teachers, therapists, volunteers and support staff that are responsible for implementation and day-to-day functioning of the organization. At present, the staff, headed by Merry Barua, Founder-Director, and Indu Chaswal, Director of Education, comprises 49 full-time and 2 part-time employees. 19 people work as volunteers; significantly, 3 persons with disabilities are also employed. The male-female ratio is 1:6. The team includes 3 senior therapists – all parents of autistic children – who have been with the organization for the past several years. There are presently 17 teachers on the rolls of which 7 work on an honorary basis. The team also includes a Clinical Psychologist, Occupational Therapist, Librarian, 7 caregivers (local women trained at the organization) apart from the office staff which includes International volunteers drawn from ‘Voluntary Services Overseas’ (VSO).

The teaching staff meet daily after school to discuss the progress and problems of children teaching strategies etc. The organization describes its functioning in the following words:

"The organization has created non-hierarchical structures and open channels of communication to aid the efficiency of its programmes. Participatory decision-making is reflected in the ways of working at AFA."
Feedback received from staff members indicated an immense dependence on the Director, Merry Barua, and her assent and approval for decision-making at any level. “I’ll have to ask Merry”, is a phrase I heard on numerous occasions. Sometimes, “Merry” was replaced by “Indu”, especially when the former was on tour, but by and large staff relied greatly on the opinions and decisions of these two senior most women in the organization. With the expansion of the activities of the centre, its growing public profile and the preoccupation of its founding members with advocacy and awareness-raising (rather than hands-on teaching and counselling), a second-rung of decision-makers (who may or may not have the authority and charisma of Merry Barua and Indu Chaswal) has not as yet emerged.

7. Funding and Networking

AFA is a non-profit organization whose income is mainly generated by grants from funding agencies and institutions and donations from individuals and institutions. Donations are exempted from income tax as per Section 80GG of the Income Tax Act. The major part of its revenue expenditure is on its programmes whereas capital expenditure has been incurred on building the National Centre at Jasola Vihar, furniture, fixtures and equipment. The organization receives grants from the Ministry of Social Justice and Empowerment, the National Trust and the Government of Delhi. Its other important institutional and corporate donors include the Asian Development Bank, Delhi Metro, Unitech, Alcatel, Sage International, DTDC etc. It also receives funds from international agencies like the Autism Society of Denmark, Department of Foreign Affairs, Ireland to name a few.

AFA’s events have been sponsored by corporate houses like Pepsi Foods, Nestle, Reebok, Orient Fans, VLCC etc. and they list, as their “Partners and Active
Supporters” individuals and organizations from diverse walks of life including the arts, academia and public life. The organization is also rapidly learning the art of ‘celebrity endorsement’ by involving well-known faces and personalities in their awareness programmes they are able to obtain greater visibility and public recall. One such occasion was the participation of the organization in the publicity for the mainstream Hindi film *Koi Mil Gaya* in which the popular actor Hritik Roshan played a mentally challenged young man who was miraculously “cured” by extra-terrestrial intervention!

In addition to these endeavours to win visibility in the public domain, the organization has networked with international disability organizations, notably the Europe-based World Autism Organisation and Autism Societies in diverse countries. It has on its panel of resource persons international ‘autism experts’, scholars in disability studies and psychology, practicing psychiatrists, clinical and developmental psychologists, paediatricians, occupational therapists and special educators.

This brief overview of its funding and networking activities suggests that the organization has made inroads both, in the community of experts as well as the public domain. At the same time, its profile appears rather elitist; its patrons and well-wishers upper class icons eg. Shovana Narayan, Sharon Lowen (both classical dancers); Sanjana Kapoor (theatre person), Karan Singh and Yasho Karan Singh who do not have the mass appeal of popular film stars or sportsmen. Ms. Barua informed that she was very keen to involve such figures as “brand ambassadors” or patrons who would excite public curiosity.

**Discussion**

We have traced the emergence of the organization from a small group of parents drawn together out of the commonly felt need to rehabilitate their children to an active NGO
with multifarious activities and a distinct presence on the disability stage. The prime mover behind the organization, whose distinct voice and strong persona reflects in every activity, document and debate is that of its Founder Director Merry Barua. Her charismatic leadership, deep involvement with every activity undertaken at the Centre and her politics have imbued the organization with its distinctive character. In terms of its philosophy and politics, the organization is probably years ahead of most disability organizations in the country which as yet view disability as a personal tragedy and rehabilitation as charity. Indeed the discourse of the organization is clearly at variance with prevailing societal and institutional understandings of disability.

Bridging the gap requires the creation of a cadre of leadership that also embraces an inclusive politics and philosophy. It may be noted that whilst the majority of teachers and volunteers at the Centre are well-trained and committed to the job they do, few of them appear to share the societal and political vision of the Founder-Director or are able to articulate this vision with the skill and clarity she is justly renowned for. On the other hand, those who can take this task ahead are too caught up in the existential struggles of their own lives and are withdrawing from active participation in the activities of the organization.

What a group of dedicated and committed families set up is thus being availed of but not furthered or extended by other families. In a sense, the organization has assumed the role of a sort of extended family, with Ms. Barua as its "Mater Familias". Several families, in an interesting extension of their personal predicament have voiced the fear, "after Merry and Indu, what?" At the same time, younger parents are not willing to actively take up the mantle and fill in the breach.
With the expansion of the activities of the organization, a new breed of professionals is being inducted into its ranks, specifically in the area of administration and interfacing with civil society. Many of these people do not have family backgrounds of disability and are thus viewed by some families as “outsiders” who “do not understand”, as referred to in an earlier section. At the same time, the field of special education is fast becoming a viable career option, attracting young graduates from the fields of education, psychology and allied disciplines. They come to the organization to train, gain experience and then move on. This is in sharp contrast to those teachers who joined the organization in order to be able to learn how to work with their own autistic children, and who stayed on for several years. Parents compare the “new lot” of teachers to the “more committed” teacher-mothers and feel let down when the teacher leaves the organization. The transition from an “extended family” type of structure to an organization staffed by trained professionals who are driven by career compulsions is an inevitable consequence of expansion and multiple activities. For families especially the “old-timers” who have come to expect individual attention and care from the organization, this transition is sometimes hard to deal with. The close, intense, intimate atmosphere that prevailed in the early years has given way to a more formal and official one; the school caters to 60 children in addition to those who come for home-based programmes, consultations, Mother-and-Child programme etc. hence it is difficult for staff to cater to families the way they did when the organization was new.

The challenge for the organization is to maintain and strengthen the foundations upon which it was built; viz., supporting and empowering families with members on the Autism Spectrum while expanding and bringing autism into public discourse through advocacy and awareness raising activities.
At the same time, it is incumbent upon younger parents and professionals to carry the movement forward; to mobilize public opinion, lobby the state and policy makers for facilities that the Centre has as yet not been able to provide. The case study of Action for Autism highlights the dynamics underlying the mobilization of individuals and groups in anonymous urban settings and the manner in which a “common suffering” bring together people of diverse backgrounds. The process is facilitated by quintessentially urban phenomena like the mass media, telecommunications and spatial mobility which enable the exchange of ideas, information and resources. In the context of disability, such organizations enact the role that has virtually been abdicated by the state, viz., the provision of facilities necessary for those affected by the disability to develop their potentialities to the optimum, contribute meaningfully to society and receive by right the care they are likely to need all their lives, especially if their families are unable to provide for them.

5.2 THE ROLE OF THE WELFARE STATE

In the Constitution of India, the role of the state in the promotion of people’s welfare is recognized in unequivocal terms. The Fundamental Rights uphold the equalization of gender, caste and class differences. The Directive Principles take it further. Article 41 of the Directive Principles directs the state “within the limits of (its) economic resources and capacity” to “ensure the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement and in other cases of undeserved want.” Justice Krishna Iyer has praised these provisions as reflective of the Indian Constitution’s faith in “administrative engineering” and its “comprehensive backing for humanitarian jurisprudence in the area of retardates and handicapped classes” (1980: 193, cited in Sundar Rajan, 2005: 125)
However, as Sundar Rajan points out, directive principles do not have the force of law, and despite the constitutional commitment to creating a welfare state, successive governments have placed limitations on achieving it. She asks, "...what are the responsibilities acknowledged by the state towards those citizens who have second class status as a result of disability or other forms of deprivation? More crucially, how far is it able, or willing, to fulfil them?" (ibid: 125-126)

Harriss-White (1999) points out that the alleviation of disability in the developing nations in particular is an issue of low priority in "public choice theoretic terms" (1999: 151). The political and economic costs of such welfare measures are high, but their benefits low. Coupled with the apathy of society at large towards these sections of the population, this means that welfare programs require "ab initio convincing justifications that the social health of disabled people is a necessary precondition not only for economic growth, but also for social welfare." (ibid: 143-144)

Out of an estimated four million mentally retarded people requiring services, only eighteen thousand received any through institutions funded by the National Institutes of Mental Health (ibid: 151) "For the mass of disabled people, the state does not exist." (ibid: 19) In the context of autism, we may point out that it was recognised as a disability by the Government of India only in 1999. Therefore, no statistical data is available on its prevalence. As we have earlier mentioned, only estimates based upon prevalence rates in other countries can be made, and as per these estimates, the number of autistic people in India is said to range from 2 million to 4 million. (www.autism-india.org)

Sundar Rajan (2005) draws our attention to the recent trend in welfare administration of the increasing relegation of care functions to non-governmental organisations. "This is
offered as a matter of administrative convenience: since bureaucratic functioning is top-
down, cumbersome, and also, the state seeks to rid itself of low-priority functions,
ostensibly those better served by smaller, decentralized mechanisms.” (2005: 127)
Interestingly, the currents of liberalization that have influenced this process, are also
responsible, incidentally and diffusively, for social transformation.

“The expansion of markets has been accompanied by factors that have contributed to
interventions in the social sector; among them, the increase of funding from foreign
agencies both to government and to NGOs working in these areas; ..the recent
establishment by the United Nations of human rights agendas covering the disabled and
the mentally retarded; the prescence and scrutiny of their observance by international as
well as national human rights organizations; and the diffusive but real influence of the
gaze and the example of the West.” (ibid: 128)

There is also an increasing middle-class sensitisation and visible popular support for
issues that had earlier engaged only activists in movements, which is in marked contrast
to the “pervasive public indifference to larger social issues said to characterize Indian
society.” (ibid: 129)

However, the issue of “what happens to the child after the parents are gone?” is as yet
unaddressed, and a source of extreme stress and worry to all the parents spoken to
during the course of the study. We may once again emphasise that in the Indian
context, it is the family that is automatically deemed responsible for looking after
disabled members, obtaining whatever resources and facilities they can for the care of
the disabled person, and in the absence of such facilities, managing as best as they can.
While this study focuses on mental disability within an urban middle-class context, the
plight of countless individuals condemned to live a sub-human existence due to poverty
and ignorance can well be imagined. State-run residential institutions for the mentally
disabled are woefully inadequate, lacking infrastructure, trained personnel and
appropriate attitudinal orientation. Privately run residential institutions are few and
those that exist are either prohibitively expensive or else lack quality-control
mechanisms and monitoring. Given these constraints, an effective and culturally
appropriate method of ensuring life long care and support to affected individuals could
be through a system of community care or group homes managed co-operatively by
families with adequate support from the community and state. While such measures
have yet to be initiated by civil society players, the problem of adult autistic people
being cared for by aged parents or siblings is becoming more and more acute. With
traditional family networks dwindling, family size becoming smaller, migration
(national and international), the almost automatic assumption of care-giving
responsibilities being taken over by siblings and the extended family is being
challenged. In this context it becomes important to study the legal provisions in place
for the continued maintenance and care of individuals with mental disabilities including
autism.

5.3 MENTAL DISABILITY AND THE LAW

This section draws upon information provided in the Training Modules prepared by the
Human Rights Law Network pertaining to the legal provisions for persons with
disabilities. Laws reflect the thinking and understanding of a society at a particular time
in history. Before 1995, there was no comprehensive law in India outlining the rights of
persons with disability in our country. While physical disabilities resulting from injury
in the workplace were and still are covered under Acts such as the Workman’s
Compensation Act or the Employees State Insurance Act, mental disabilities were
subsumed under the Indian Lunacy Act. The act made no distinction between the
mentally disabled and the mentally ill and dealt with the institutionalization of people with mental retardation and mental illness. It was repealed and replaced in 1987 with the Mental Health Act. In an effort to separate the concerns of people with mental retardation and mental illness, the Mental Health Act deals with the institutionalization and guardianship of people with mental illness. While it addresses the issues of establishment of psychiatric hospitals, admission of affected individuals in such facilities and appointment of guardians and managers of property of such persons, it fails to address such issues as education, employment, social security or any kind of affirmative action, reflecting societal perceptions of such individuals as “unfortunates” who need charity, rather than opportunities to lead a fulfilling life.

The Asia-Pacific Decade of Disabled Persons launched in 1993 adopted the proclamation on Full Participation and Equality of Persons with Disability in the Asia Pacific Region. Many countries in the region framed laws that specifically supported the rights of persons with disabilities. In India too, much debate and discussion led to the framing of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, which was the first such comprehensive law for the rights of the disabled. The PWD Act outlines the rights of disabled people and the responsibilities and obligations placed on the Government of India, State Governments and other local governmental bodies for the realization of these rights. For the first time the law clarified who a person with disability is in the country. The Act recognizes the following categories of disability:

1. Blindness
2. Low Vision
3. Leprosy-cured
4. Hearing Impairment
5. Loco motor Disability
6. Mental Retardation
7. Mental Illness
For the first time, people with mental illness were recognized as persons with disabilities and holders of rights under the law, not just as people requiring medical care and institutionalization. However, the law did not take into account the very special needs of a group of people with severe disabilities like Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. Even though Mental Retardation and Cerebral Palsy were included in the PWD Act, provisions for their long-term care were seen as inadequate by parent groups. As for Autism and Multiple Disabilities, they did not find even a mention, perhaps because of the relative paucity of information available and the fact that Autism routinely tended to be mistaken for either mental retardation or mental illness. Parents' groups and disability activists felt that the law did not address the issues of their protection and support once their parents were no longer there to look after them. As a result of the strong advocacy of parents' groups across the country (including AFA), The National Trust Act came into being in 1999. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 envisages the setting up of a Trust which will be managed by a Board of Trustees. The Board will be the body that decides matters related to the implementation of the law.

Aims and Objectives of the Trust

a) To enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong;

b) To strengthen facilities to provide support to persons with disability to live within their own families;

c) To extend support to registered organizations to provide need based services during the period of crisis in the family of persons with disability;
(Chapter-3, Objects of the Trust, N.T.A., 1999)

It is significant to note that the objects of the Trust emphasise independent living within the family and community rather than incarceration and institutionalisation and stress upon inclusion within the community for which facilities and support mechanisms are to be strengthened by the State. The emphasis on family and community living marks a shift from considering the affected individual as a 'patient' in need of specialized medical interventions to a member of the community, requiring access and empowerment; i.e. a shift from the medical to social model.

Another important issue tackled by the Act is that of ‘Guardianship’. All individuals need care and protection to some degree in their lives. However, some people with disabilities particularly those under the purview of the Act sometimes require extensive care-taking and protection all their lives, and may even require another individual to represent them and make decisions on their behalf.
Guardianship is seen as an essential protective measure for members of these four disability groups. It refers to legal control of one person over the other. It is also referred to as substituted decision making, especially for people designated by the law as being 'of unsound mind', who are deemed as unfit to enter into legal contracts. The Contract Act of 1872 defines a person of 'sound mind' as follows: “A person is said to be of sound mind for the purpose of making a contract, if at the time when he makes it, he is capable of understanding it and forming a rational judgement as to the effect upon his interest.” Persons of ‘unsound mind’ are therefore deemed incapable of understanding the implications of contract or making rational decisions, even though ‘mental disability’ is not specifically mentioned to include it. This is one of the major legal reasons why guardianship is deemed necessary for the mentally disabled. The other, of course is the ‘big question’, viz., what will happen after the parents are gone?

One of the most significant aspects of the NTA is that the law recognises that all people do not require guardianship and that guardianship may be required for different purposes, viz., (1) care and property and/or (2) maintenance eg. A person with Cerebral Palsy may be quite competent to take decisions regarding sale/rent of property and other financial transactions, but may need support for carrying out activities like bathing, dressing, etc. On the other hand, a person with Autism or Mental Retardation may require assistance in all aspects of life; from daily needs to education to signing legal documents or any type of contract. Guardians may be appointed after the person with disability attains 18 years of age. Before that (as for all people) the parents are the natural guardians.
The people who can take the initiative to have a guardian appointed or become guardians themselves are

1) Parents
2) Relatives
3) Registered organizations

Section 14 of Chapter VI of the Act states that a parent or a relative of a person with disability can ask for a person of his/her choice to be appointed a guardian. The application will only be entertained once the consent of the guardian is obtained. A registered organization may also ask for the appointment of guardian. Organizations working with persons in these four groups are able to register themselves with the Trust and thus become part of its decision-making processes and schemes.

It is significant that this provision brings guardianship into the public domain. It is normally assumed that issues of guardianship and care taking are within the family situation. By giving registered organizations the responsibility for guardianship, the law puts a greater element of accountability on them and makes provisions for those who are deprived of family support.

The all-important matter of guardianship is dealt with by 'local level committees' (LLCs) constituted by the Board of the N.T. These three member committees are constituted by an officer of the Union or State civil service not below the rank of District magistrate or District Commissioner of a district, a representative of a registered organization and a person with disability as defined in the relevant clause of the PWD Act of 1995. The LLCs not merely appoint guardians, but also monitor whether guardianship is being properly carried out and in the case of neglect or abuse, can initiate steps to divest the guardian of his charge.
Although the provision of guardianship does not really address the fears and worries of parents regarding the future of their children, it nevertheless enables families to access services and programmes as well as schemes on behalf of the person with disabilities. Management of assets and properties is also facilitated. Perhaps one of the most important aspects of the NT is the involvement of registered organizations and parent groups at the level of implementation, viz., the LLC. The Act came into existence as a result of the extensive lobbying on the part of parent groups and its implementation requires the active participation of these very groups and disability organizations. It embodies the manner in which disability is ‘moving’ from within the ambit of family management into the realm of public discourse; and the changing role of the family not merely as custodian and care-giver of its own disabled member but a decisive voice in securing the human rights and dignity of all individuals with disability.