CHAPTER - 4

FAMILY DYNAMICS-II: SHRINKING CIRCLES OF SUPPORT

The previous chapter traced the experiences of parents and the impact of their child’s autism on their lives and relationships. This chapter will focus upon siblings, grandparents and other members of the family. Siblings should appropriately have been taken up in the previous chapter, as, along with parents, it is they who share the activity settings of day-to-day life along with the autistic child. Moreover, siblings have a lifelong association; their relationship outlives the parent-child one, and in a situation where one of them is disabled, the regular siblings are often expected to assume the role of surrogate-parents and care-givers. We then move on to a discussion of the experiences of grand-parents. We examine the perceptions of maternal and paternal grandparents, their understandings and apprehensions regarding the grandchild’s disability, inter-generational conflict of views regarding parenting, and their dual, sometimes conflicting attachments towards their own children (the mother or father of the autistic child) and the child himself/herself. How other members of the extended family respond to the child’s disability and the impact of the disability on familial interaction are also studied. We conclude with a discussion on the interface between family, neighbourhood and community, and the changing responses to intellectual disability.

4.1 SIBLING EXPERIENCES

We examine the dynamics of the sibling bond through the accounts rendered by both, siblings themselves and their parents. This bond implies a two-way process; autistic children are not merely the passive recipients of siblings feelings; they are also active
partners in the relationship and impact the life experiences and world views of their brothers and sisters in profound ways.

Writing about siblings in a cross cultural perspective, Nuckolls (1993) points out that anthropological studies of siblingship have been sparse, on account of the preoccupation with rules of descent, and kinship studies based on generational and marriage structures. Western studies on siblingship tended to focus on "sibling rivalry" deemed as a critical aspect in the formation of an adult identity based on competition.

However, Weisner (1993) points out that sibling life in South Asia differs from that in North America as South Asian siblings participate in "shared activity settings" throughout their lives. The sibling relationship thus represents a powerful cultural image of an ideal social bond for which members of a culture should strive. We may point out how Indian mythology valourizes the bond between siblings; the Ram-Lakshman duo is emblematic of the loyalty and devotion underlying sibling bonds. The rapidly changing urban scenario against which this study is located manifests in family structures and systems. Family size is decreasing. Couples 'plan' their children and plan fewer of them. Families exhibit greater spatial and social mobility than before; children have to adjust to new neighbourhoods, schools, classmates and social relations. The sibling relationship thus assumes great significance; it embodies the stability, continuity and life-long character that other significant relationships are fast losing. Siblings provide each other with opportunities for sharing, expressing feelings, compromising, understanding mutual collaboration. They learn to play amongst themselves forming the first close social network of life.
A range of studies in the West has shown that having a brother or sister with a developmental disability has an impact on the progress and well being of both the regularly developing child and the disabled one. Birth order, sibling gender, severity of the disability and the socio-economic status of the family can directly impact sibling relationships. The presence of a child with special needs may frequently involve siblings in direct care-giving activities, supervising or entertaining their brother or sister. The care-taking role is deeply ingrained in older siblings in South Asia. In middle-class urban enclaves where both parents work, it is fairly common to observe "latch-key children" who come back to an empty home, and telephonically inform the parents at work that they are safe. The older sibling is entrusted with the responsibility of supervising the younger one and ensuring that she/he keeps out of mischief until the parents return. The preference to send siblings to the same school and the familiar sight of siblings tightly holding hands on the way to the school bus stop and back home are part of our metropolitan landscape. While the preference for one child only is gaining currency with upwardly mobile elites, not having a sibling is regarded as a child's misfortune, particularly when extended-family networks are becoming loose and diffuse.

Children pick up from an early age that their brother or sister is different, even if they do not understand what is actually wrong. They notice the reactions of parents, grandparents and neighbours to him or her and the differential behavioural expectations demanded of them. Whilst they may have deep love for the sibling, they may also harbour feelings of resentment at the time and attention lavished on the autistic sibling. Feelings of anger, embarrassment and guilt may co-exist with a feeling of protectiveness.
The work of Powell and Gallagher (1993) explored the common concerns and anxieties of siblings of children with special needs, including autism. Six general categories were identified:

- Concerns for the child: such as the cause of the disability, availability of appropriate provision, the longer-term future.
- Concerns related to parents: including the perceived differential expectations upon their behaviour and that of the sibling; communication with parents; anxiety about the pressure upon the parents’ time.
- Their own feelings: concern over the relationship with the disabled child; their own health.
- Worries about peer attitudes: how to deal with teasing; informing their friends about their sibling’s needs; anxieties about gaining boy or girl friends.
- Community issues: getting on at school, acceptance within the wider neighbourhood.
- Future problems as adults: having to take up financial responsibility or guardianship; having to liaise with support services.

A review of research and survey findings undertaken by Miller (2001) show that there were excessively high levels of expectations forced upon normally developing siblings, particularly boys. Girls were cast wittingly or unwittingly into the role of parent surrogate. Miller’s own research, conducted through interviews with 24 children and their mothers, focused on their day-to-day activities with the autistic child, the difficulties in interactions between them, compensatory strategies, and parental management and style. The results of the maternal reports suggested that sibling relationships were uniformly positive, with few feelings of jealousy or rivalry, a finding borne out by the present study as well, despite the difference in cultural setting. Miller also noted the preponderance of care-giving and helping activities performed by siblings of autistic children as compared to play-based interactions. Miller argues that
there is a need for young children directly to be taught interactive skills in order to share more play-based activities with the autistic brother or sister.

The study of Kaminsky and Dewey (2002) begins with a recognition of the frequency with which children with autism may engage in behaviours that appear aggressive, impulsive or obsessive and can thus disrupt family life. The difficulties with communication, and anxiety surrounding family outings and public contact may present challenges not just to parents but also the siblings. The authors set out to investigate whether siblings of children with autism have greater difficulties in psycho-social adjustment than siblings of children with Down’s syndrome or siblings of normally developing children. The results indicated that siblings of children with autism are not at greater risk for adjustment difficulties or loneliness. The authors speculated that this could be on account of their participation in support groups, thus leading to enhanced knowledge about autism and more frequent interaction with other families of children with autism. The social support resulting from such participation may facilitate healthy adjustment. This finding has significance for the present study in the context of the participation of families in the activities of the NGO, which, as we shall see, provide siblings spaces to “be themselves” without constantly worrying about the autistic child’s behaviours and what others think of him/her.

As earlier mentioned, eleven of the children in the sample had regularly developing siblings, of which five were elder and six younger. There were eight sisters and four brothers in the sample and their ages ranged between four and seventeen.

Six families of the sample had other children after the elder one was found to have a disability, while nine couples have not as yet expanded their families. Before
proceeding with our discussion on sibling issues, we would do well to reflect upon the fragility and uncertainty of ‘normalcy’ itself.

Micky, (10) a friendly, active child is the younger brother of the autistic Rocky. Micky was diagnosed with cancer during the course of the fieldwork. The family went through an extremely difficult time coping with his illness on the one hand, and his brother’s disability on the other. I observed (and personally felt) the shock and disbelief that all those who knew the child also experienced. The focus of attention of family and friends shifted from Rocky’s difficulties to Micky’s battle for life.

The “taken for grantedness” of the regular child’s normalcy was suddenly subverted. Fortunately, Micky’s disease is now under remission; but in the months when he battled for his life, the fragility of ‘normalcy’, ‘health’, indeed, of life itself, were brought home forcefully. One mother put it thus, “..we never even think of the normal ones.. all our thoughts and prayers and fears are for the other one…”

We would also do well to consider the “absent” siblings, the children parents chose not to have. Marris (1974) observes that a major loss shatters the structure of meaning and breaks the thread of continuity that makes the world intelligible. When parents realise their child is disabled, they have to come to terms with the loss of the normal child they expected, and the normal parenting role they were preparing to perform. The loss of the normal parenting role is seen as a personal tragedy and parents are often advised by members of the family, friends, colleagues and doctors to “go ahead” and have another child to compensate. The disabled child would thus have “someone to take care of him/her” apart from the parents, and the parents would have the support of a normal child. The presence of a regularly developing child is thus construed as a normalising process that will somewhat mitigate the pathology of having a disabled one. *Ek accha*
baccha hona chahiye (There must be one ‘good’ child) is a phrase that was frequently used by respondents.

Vasu and Smita decided quite early (soon after their son Krishna was diagnosed) that they would not have another child, as Krishna’s difficulties took a heavy toll of their physical and emotional energies. They believed it would be “unfair” to the other child to be unable to give it high-quality attention and care. Kartik and Lata were also unwilling to have another child for similar reasons. But now that their son is settled and fairly stable, Lata says she would like to adopt a daughter. She feels it will do Anu good to have another child in the house. He is old enough to actually help to look after and play with a baby, thus it will enhance his self-esteem, make him feel important and wanted. As Anu shows a marked preference for his father’s company, Lata clearly experiences the need for nurturance and reciprocal affection and the sense of unity and bonding that the mother-daughter relationship entails.

The need for a child to “reciprocate love” was also voiced by Priti, Rajat’s mother, whose story was discussed in the previous chapter. She expressed her need to experience a “normal” relationship with a child, to kiss and cuddle, show plenty of physical affection and have it happily received and reciprocated. During one of my visits to her home, both my sons accompanied me. Priti and her husband enjoyed the company of my regularly developing son. Priti plied him with snacks, chatted with him, and her usually reticent husband discussed cricket, computers and cars with him. However, Priti is too scared to go ahead and have another child. She is tired and stressed, her health is not good and she is scared that Rajat may harm the new baby. She says they have left it for too late.
The feeling of “leaving it for too late” was also shared by Hari and Anju, parents of Aashu. They were pressurized and even ridiculed by kin, neighbours and friends for not having another child. In fact when their son was small, Anju conceived again but had a voluntary abortion. She said she could not bear the thought of looking after Aashu and going through the stress of pregnancy and child-birth all over again. Anju recounts that a distant relative who met them after many years was shocked that they had not had another child. He berated them for their paagalpan (craziness). They are exhorted to go ahead even now, as they are still in their early thirties. They held back due to fear (of having another disabled baby), financial worries and the everyday stresses and strains of looking after Aashu’s special needs, as the child is severely impaired and needs help with all his self-care tasks.

Anju said, “..we feel we have made a big mistake... its very important for such a child to have an able brother or sister... but if we go ahead now, the second child will still be so small when Aashu grows up...” (Aise bacche ke liye ek acchha bhai ya behen hona bahut zaroori hai.).

The Need for ‘Normal’ Siblings

The fear of having another disabled child and the exhaustion induced by looking after him/her were thus the major inhibiting factors. Not wanting to ‘burden’ a child with the expectations of assuming the care-taker role or the belief that ‘justice’ would not be done to it were ideas voiced by some couples, notably those with more Westernized leanings. We have earlier cited Western literature that views siblingship in terms of rivalry and competition for scarce resources; clearly, some metropolitan Indian families have internalized this conceptualization. The notion that the care of disabled individuals
would automatically pass from parents to adult siblings is getting eroded; the need for alternative structures of support thus becomes all the more acute.

However, the majority of the families in the sample expressed that having a regularly developing child was essential for the well-being of the family. In fact, one of the mothers said that it was preferable to have another disabled child rather than none at all, because siblings gave each other “company”, a resource that has become very scarce in the times we live in. A number of the respondents nostalgically recalled their own childhoods, growing up with siblings, and cousins, not lacking for “company”; they compared it with the lives of their own children and those around them, who return to “empty homes” and only have the T.V. or computer for company.

While many parents admitted that their regularly developing children had to undergo some hardships and neglect on account of their sibling’s autism, they also believed that these children were more mature, responsible, understanding and caring than others their age. Not a single parent expressed dissatisfaction or disappointment with regard to their regularly developing children; all of them stressed the deep love and affection felt by siblings towards each other. While they did feel the regularly developing child often had a ‘raw deal’, they believed that their families were more healthy and balanced.

Parents said that it was important to have siblings because it meant “having someone of your own”, “knowing that somewhere, out there, there is someone with whom I share a special bond”, feeling “emotionally connected with someone who shares one’s blood”. Their autistic children, they believed, needed this kind of bond even more, because of their difficulty in relating with others and making friends. Shaili, mother of Sanju (8) and Simi (4) informed that Simi is very protective of her autistic elder brother. If the parents get angry with him, she scolds them. She follows her brother around the house,
tells him what to do, scolds him if he does something inappropriate. She appears to understand him instinctively. The mother narrated an incident when, during a drive, Sanju suddenly became very agitated. The parents could not understand why, but four year old Simi did. They had passed a Mother Dairy ice-cream stall, and Sanju, who loves ice-cream wanted his favourite treat. Their mother says that Sanju’s social responsiveness “pretend play” and “turn-taking” skills have greatly improved due to his sister’s presence.

Sindhu, mother of 12 year old Chinky and 8 year old Tara, says that they consciously decided to have another child, even though they knew the genetic risks involved. Both parents say that Tara has helped Chinky to relate better to people. He enjoys her company, takes her for a ride on his bicycle and picks her up at the colony gate when she returns from school. He often buys her favourite sweets at the neighbourhood shop and gets visibly agitated if she is late. Tara is very protective of her brother, and covers up for his social lapses or clumsiness. Sindhu recounted that at a birthday party, Chinky spilled a cold drink; Tara cleaned up the mess with her napkin and apologized to the hostess on his behalf. She loves her brother because “voh kabhi bhi maarta nahi hai” (he never hits her), and is mild and gentle compared to other boys of his age.

Some of the anecdotes narrated by parents and siblings indicated that the presence of a sibling enabled the autistic child to experience and deal with complex emotions and social situations like jealousy, competition for attention, teasing, playing, bullying, fighting with each other etc. which provide crucial inputs in terms of socio-emotional development. Role taking and understanding the perspectives of others are areas in which autistic children have difficulties. The presence of siblings, parental accounts suggest, helps autistic children to learn these skills. Describing her two sons fighting
“like puppies”, a mother said she rarely intervened in these fights, allowing her boys to 
“have it out”. “Its amazing, how chaalu (smart) he’s become.. (the autistic boy).. he 
doesn’t allow himself to be bullied, he gives back as good as he gets..”

Another mother informed how some of the difficult behaviours of her son seem to 
almost magically disappear when his tiny four year old sister bullies and beats him. 
“She is a real dictator! She keeps criticizing him.. he is very sajjan (well-behaved) with 
her.. he does not react, just keeps smiling!”

The presence of siblings thus has a ‘normalising’ impact, not merely in terms of 
providing parents with a ‘normal’ child around the house, but also because it enables 
the autistic child to experience bonding and relationships apart from those experienced 
with parents. It enables the child to participate in the world of ‘normal’ childhood, to 
learn from regularly developing children within the nurturing environment of home and 
family. In turn, growing up with a sibling with autism presents unique challenges and 
experiences to regularly developing children.

Making Sense of the Sibling’s Disability

As earlier discussed, siblings generally become aware of their brother’s or sister’s 
difference without actually being ‘told’ or ‘explained’ in so many words. The following 
sibling account brings this out evocatively.

I was in the fifth standard when one of my friends told me about her 
little brother. “He is so cute! Especially when he calls me ‘didi’!” She 
said.

“Oh, I have a little brother too. He’s also very sweet! But he has not 
started talking yet.” I said.

“Really? Your brother must be very small then. Mine is only 18 months 
old.”
18 months? I quickly calculated – that would mean 1½ years. Jeetu was 2. Immediately I felt indignation. That was not fair! Why should her brother start talking earlier than mine? After reaching home I told my mother about it. She just gave me a worried look. Obviously, the thought that Jeetu should have started saying at least a few words by now had crossed her mind before.

The next couple of years are a haze to me. It mostly consisted of taking Jeetu from one hospital to another, one doctor to another. It was not a very pleasant experience for any of us. (Autism Network: Vol. 2 Issue 2, Aug. 2007: 5)

Tara, Chinky’s sister “knows” her brother is ajeeb-sa (strange) because he does not speak or do the things other boys his age do. Although he goes to school, his homework is of a much lower level than hers; he does not study History Geography or Science. Moreover, he is sometimes taken for “sessions” to the NGO where there are many children who are even more ajeeb than he is; who scream, bite and run around wildly unlike the gentle Chinky. Tara says she is glad her brother is not like them. She says his large buck teeth make it difficult for him to speak, and once he gets them corrected with braces, he will be fine. She feels sad that he does not like Diwali or birthday celebrations and prefers his own company most of the time. She has also heard her parents and grandparents talk about him with much concern and sorrow, and understands that he is the focus of much of their attention. She told me she sometimes cries in the night and prays “..God, aapne in baccho ko aise kyon banaya hai..?” (God, why have you made these children this way?)

Seema (13) and Vikas (11), the elder siblings of 10 year old Vinny are affectionate and protective of him. While Seema teaches her little brother the alphabet, names of animals, fruits, flowers etc., Vikas engages him in playing ‘bat-ball’ and his favourite ‘Beyblade’. They do not talk about Vinny to their peers; when questioned, they say that he goes to a special school because he does not speak properly. Initially, they believed that Vinny’s atypical development was because of his various illnesses as an infant, but
soon they realized he was “different”. Their parents became totally preoccupied with him. Their mother says they virtually brought themselves up (“apne aap pal gaye”); they realize that the family has pinned its hopes on them. They excel in studies and sport. Vikas’s gold medal in athletics hangs proudly on the wall of their cramped two-room Government quarter alongside Vinny’s “learning charts”. As their mother is busy with domestic chores and their father away at work all day, both children have devised ways and means of working with and playing with their autistic brother. Without ever being ‘told’ that the brother has autism, this brother-sister duo has understood their responsibilities towards him as well as their parents and have accommodated the disability in their own routines.

These children came to their own understanding of the sibling’s disability without interrogating their parents much. Such is not the case with six year old Swayam. He has been told that his older sister has ‘autism’, which, as per his understanding, is some sort of sickness due to which children do not speak or go to a ‘proper’ school. He often asks why she has got autism and not he, and criticizes his mother for not teaching her properly. He once asked, “aapko tummy me chat lagi”? (did your stomach get hurt when you were expecting?) He is probably too young to understand the life long nature of the condition, but hopes a miracle will happen and she will start speaking and doing well in school, just like Rohit in the film Koi Mil Gaya in which aliens from outer space cured the mentally retarded hero. Their mother reports that he worries about his sister and her future. “What will she be when she grows up?” “Will she start speaking soon?” are questions he constantly asks. The mother realizes that when he is a little older she will have to explain her daughter’s condition to him more fully, and rues that there are no sibling support groups where he can interact with others like him and find answers to his questions.
15 year old Rinki vividly recounts the difficult years when her parents were going from doctor to doctor to find out what was ‘wrong’ with her little brother. Particularly hard for her was their decision to relocate in Delhi for his sake, and the loss of her familiar surroundings, school and friends. She faced difficulties in adjusting to life in Delhi, learning Hindi, making new friends, coping with a different school curriculum. Seeing her brother much improved now, she feels happy. She wants to become a child psychiatrist and work with autistic children. She looks up material on autism on the Internet and is quite comfortable discussing her brother with her close friends and teachers at school.

As the above vignettes reveal, making sense of a sibling’s disability is an ongoing process influenced by age, gender, socio-economic status, presence or absence of family and peer support. Focusing upon lived experiences and everyday interactions makes the ongoing task of accommodating difference more vivid and brings into sharper focus the issues confronting urban families grappling with disability.

The ‘Burden of Competence’

We have mentioned how parents other family members and friends frequently speak of the need of such families to have at least one *samajhdar* or *accha* (able, normal) child. Siblings frequently bear the “burden of *samajhdari* irrespective of age or birth order. While older siblings are ‘naturally’ expected to assume care-taking responsibilities for younger siblings, in the case of disabled children, the younger sibling is also assigned the responsible role. The admonition “*voh chhota/chhoti hai*” (s/he is younger than you) is frequently used to make older siblings accommodate the little one. However, what do parents say about the “incompetent” sibling who is obviously older and larger? In the
previous section, we highlighted the experiences of younger siblings like Tara, Simi and Swayam, who have, at a very young age developed strongly protective feelings for their older siblings, and accept, quite matter of factly, their parents’ preoccupation with his/her special needs.

In the case of older, regularly developing siblings care-taking responsibilities almost assume the form of surrogate parenting, as in the case of Kavya and Divya whose story was narrated in an earlier chapter. The regularly developing sister performs all the chores an adult would; from feeding to changing soiled clothes to carrying the little sister around in her arms. Having an older sister is comparable to having a second mother. At the same time, families with regularly developing daughters were beset by the worry that eventually, their girls would go to their “own homes” (i.e., marital homes) and would not be able to maintain their strong, nurturant ties with the autistic sibling. The following extract from my field notes brings out this point:

Rajinder wondered who would look after Divya in future. “Kavya will go to her own home after marriage.” Pinky interjected, “why do you think this way?.. Don’t you think that she will look after her?.. Brothers act according to the wishes of ‘bhabhi’ (sister-in-law), but a sister always has feelings for her sister.. Rajinder glared at her and told her “..be practical. You know how the world is. This is not about feelings.”

(Field notes February 2006)

Sindhu and Deepak also share these fears; they do not think that Tara would be able to assume responsibility for Chinky after marriage, even if she wants to. Sindhu was cynical about “men’s nature”; she did not believe that a man could be “large-hearted” enough to accept the responsibility of looking after his wife’s disabled sibling. On the other hand, Rinki’s mother said that they depended entirely upon their daughter to take care of her brother. Rinki says she will not marry and wants to become a psychiatrist. Her mother says, “she has sacrificed a lot.. She has no social life.. We don’t go out, I
don't send her alone anywhere... no parties, no school trips, nothing... who will drop and pick her? We are busy the whole time with him (the autistic son)"

While sisters were viewed as reliable, loving and nurturing, the presence of a regularly developing brother (especially an older one) was seen as the autistic child's ticket to security in an uncertain and rapidly changing world. The parent of a regularly developing son along with an autistic one, was frequently told that she need not worry as much about the little one's future as he had a big brother to take care of him. When I suggested that perhaps the boy may not want to take the responsibility, I was refuted. "Is this England or America? Of course he will take care. Even if he is not there in person, he will ensure that his brother at least gets two square meals..." It would appear from the above discussion that Vinny had clearly hit the jackpot in the sibling department! While his sister assisted with his care, his brother was expected to assume the guardianship responsibility in the future.

Despite the natural and matter of fact way with which regular siblings took on additional responsibilities and expectation, they also underwent stress, irritation and frustration.

Swayam complains of being bored because his sister will not play with him. He greets the visits of his cousins with such joy and enthusiasm, that his mother says she feels tempted to adopt a child just so that he can have a playmate. His sister's odd behaviours inhibit him from inviting his friends home. One child was so frightened that he had to literally be cajoled to enter the house; the disabled daughter was sent to her room and the stereo put on so that she would not disturb them. Assuming that he would be more accepting of disabled children, one child was made to sit with two physically challenged children in class. He came home in tears. "Ghar me bhi disabled baccha.."
school me bhi ... mujhe nahi rehna disabled bacchon ke saath..” (A disabled child at home and at school.. I don’t want to be with disabled children any more!)

Siblings were frequently irritated when the autistic child disturbed them while they were studying or doing homework; one mother narrated how her son would often burst into tears when his sister scribbled all over his neatly written notebooks. Realising her need to mimic her brother’s activities, the mother taught her to sit down with the boy and practice her alphabets or colouring, thereby creating a space for both children to spend time together. Some siblings also found the computer a useful aid for interacting with the autistic child; its predictability and logical instructions are ideally suited to the cognitive styles of autistic children. Most of the children in the sample displayed considerable skill in computer use; their brothers and sisters now have a zone of equality within which they can relate with their autistic sibling.

Children would often feel embarrassed at the behaviours of the autistic siblings particularly in front of their peers or schoolmates. Some children preferred to maintain a discreet silence about their sibling; unwilling to disclose or discuss the disability. While most of the children were comfortable with the autistic sibling within the confines of the house, they found it difficult to engage them in outdoor activities and play. The complex rules of social give and take that regularly developing children internalize so effortlessly are difficult for the autistic child to comprehend or follow, sometimes leading to adverse comments by peers. “Your brother/sister is mad!” is a comment siblings regularly heard. The tendency of some autistic children to run off without any awareness of danger also places a burden on the regular sibling.
During the course of a wedding reception, a little boy with autism ran away without anyone noticing. People found him a while later almost a kilometre away from the venue, running pell-mell down a busy thoroughfare. His elder brother who had been entrusted the job of keeping an eye on him wept inconsolably during the ordeal and refused to be comforted by the assembled relatives and guests. He still blames himself for what he sees as his negligence. Their mother feels very guilty that she made such a young child take up such a responsibility. “It was not his fault, but if something had happened to Chhotu (the little one). he would have blamed himself all his life... it would have damaged him so badly psychologically...”

Adolescence is a difficult period and the need to “fit in” is particularly acute. As a result, adolescents may experience embarrassment at the autistic sibling’s appearance or behaviour. It is also during this period that the implications of the sibling’s autism become clearer; they may come to resent their care-giving responsibilities and worry about the future. One of the adolescent brothers in the sample feels very depressed about his sister, reports their mother. The girl started menstruating some months ago and the mother no longer leaves her alone at home with him. While her body has matured, her behaviour is still that of a very small child and this makes him very upset and disturbed. He is probably beginning to comprehend the complexity and delicacy of the stage of life into which she has entered and feels both fear and shame.

Adolescence is also a period when some children become the autistic child’s advocate and develop their own views about difference. We have earlier mentioned Rinki’s desire to obtain and share information about her brother’s condition. We may also cite the example of 13 year old Nitish, brother of a young adult with autism. With the help
and support of his teachers, Nitish arranged an exhibition of his brother’s art work in his school, and even addressed the assembly about autism.

In the write-up by a sibling referred to earlier, the girl describes her personal journey with her beloved little brother; her gradual acceptance of Sujit for the lovable child that he is. Even though she never spoke about him at school, she is now proud to acknowledge him.

Last year, when I went to my new college my new friends asked me if I had any siblings, I replied, “Yes, I have a brother. His name is Sujit but I call him Jeetu. He is 12 years old and he is autistic. But he is the most adorable and most loving brother you will ever find. (Autism Network, Vol. 2, Issue 2, August 2007: 6)

Supporting Siblings

A crucial factor impacting the manner in which siblings relate to each other is the attitude of the rest of the family, particularly the parents, to the child’s disability. Whether parents display pity, irritation, disgust and anger or empathy, acceptance and respect towards the disabled child, is critical in shaping sibling attitudes. (Dunn, 1984)

Bringing up a child with a disability, particularly one as complex as autism does take a toll of the family’s physical, financial and emotional resources, often leaving them with little time or energy to devote to the regularly developing sibling. Some of the cases highlighted earlier reflect this. There may also be unrealistic expectations for the regular sibling to ‘compensate’ for the deficiencies of the disabled one. The regular child is sometimes expected to become a ‘super-achiever’, mitigating the ‘failure’ of the parents in producing a ‘defective’ child, restoring the status and prestige of the family. My observations of the “mom sessions” at the NGO referred to in the previous chapter, corroborate this. I noted the pride with which mothers showed off the
achievements of their regular children. They even described their pranks and naughtiness as prized virtues.

My conversations with parents and siblings indicated that while siblings understood their parents' compulsions for giving the disabled child more attention, they did miss doing things as a family, viz., going out for a meal together, attending parties and functions, visiting relatives, having friends over, going out for movies etc. Observing their peers doing such things with their families made some of them feel sad. Not being able to celebrate Diwali with fireworks because it scares the sibling, or not inviting friends over because of the sibling's odd behaviour are difficult things for children to accept with resignation.

The narratives abound with stories of birthday celebrations ruined by a child's screaming tantrums, parties or outings spent running around looking out for the autistic child, school functions where only one parent or neither could attend, embarrassing scenes at the homes of friends and relatives. Siblings felt anger, hurt, resentment, and indignation on such occasions, especially when the autistic child's unacceptable behaviour was not punished or dealt with severely as they would have been dealt with under similar circumstances.

Some of the siblings expressed resentment at being forced to share toys, snacks, sweets etc. with a child who found it difficult if not impossible to share his or her own things, as a result of the social deficits that characterize the condition. One brother aptly remarked, "Everything I have is his, and everything he has is also his!"
The 'burden of competence' placed upon the shoulders of these children required them to display a level of maturity, self-reliance, patience and self-control well beyond their years. In the case of girls, in particular, it demanded the internalisation of the nurturing role. Brothers, particularly older ones, were expected to internalize guardianship roles. With the support system and social possibilities of the extended family in decline, sibling relationships have become even more critical. Just as parents are expected to be 'more than parents' for their disabled children, siblings are also expected to be teachers, friends, protectors, care-takers and role models, irrespective of the age order or gender. Both, the non-availability of family support networks and the inherent deficits of autism mitigate against autistic children obtaining satisfying relationships and friendships outside the constricted circle of the nuclear family. After parents, siblings are often the only persons an autistic child can call upon for care, support and companionship.

In this context it becomes important for siblings to have access to networks outside the ambit of family and kin where they can receive counselling and support. Unfortunately, such avenues are as yet not readily available. None of the siblings in the sample were members of any such network or support group which catered exclusively to their needs.

The NGO can play a critical role in this regard. Action for Autism actively encourages the participation of 'normal' siblings and friends in the various events and activities conducted at the Centre. Thus, the Annual Day function has 'normal' children participating along with the autistic ones on the stage. Many siblings actually did not get stage exposure even in their 'regular' schools, so the opportunity to dress up, sing, dance and show off their talents is welcomed. During the few days of school break
which mark the transition between academic sessions, some siblings accompany the autistic child to the Centre and participate in class activities. Similarly, picnics, concerts, summer camps and the annual ‘Walk for Autism’ see a good sibling turn out. A particular favourite is the Christmas Party, complete with Santa Claus, who has gifts for the siblings as well. These occasions enable the children to let down their guard and enjoy themselves. They observe that there are other children who bang their heads, flap their hands, rock and spin and make strange noises, so they do not have to feel self-conscious about their own autistic sibling. They receive much affection and attention from staff, teachers and other parents. They also get the opportunity to meet other regularly developing siblings like themselves and discuss issues of common concern.

These occasions also provide outlets for parents and children to have fun together, without the fear of public opprobrium and embarrassment. As discussed earlier, regular siblings long to go out and celebrate or have fun together as a family without feeling stressed or embarrassed by the autistic child’s difficult behaviour.

They learn, at an early age how to do without many things that their peers at school or in the neighbourhood take for granted. While they experience anger and frustration as some of the examples given show, on the whole, they accept the situation calmly and naturally. This is not to say that they are miniature martyrs. Rather, the autistic child’s ‘condition’ is a given, inseparable from its being. Unlike parents who experienced a sense of the loss of a normal child, siblings were born into or socialised into a situation where the disabled sibling was basically a brother or sister first, rather than an autistic person. In this context we may cite the representation of the normal sister in the recent film *Black* (directed by Sanjay Leela Bhansali). She is shown to respond with resentment to her parents’ perceived partiality towards the disabled sister and feels
jealous of her sibling. The Western conception of ‘sibling rivalry’ that this image evokes was not found to be very salient in the families in this study. Positive relationships between normal and disabled siblings have also been reported in the work of Raizada and Sharma (2003) and Saxena and Sharma (2000). How they would respond to the future prospect of care-giving or guardianship during adulthood remains to be seen and a longitudinal study needs to be carried out to assess the same.

4.2 GRANDPARENTS' EXPERIENCES

While discussing the reaction of grandparents to the child’s autism, it is important to consider their dual roles, viz., as parents of the mother or father of the child and as grandparents of the child. Most of the mothers interviewed spoke of the support and sustenance they received from their own parents, notably, their mothers. Maternal grandmothers grieved for the loss of their daughters’ “normal” motherhood and the day-to-day struggles they faced, as well as for the child. Mothers-in-law, on the other hand, seemed to participate in the ‘blame game’, attributing the child’s difficulties to faulty mothering, mothers’ careers, inability to train and socialise their children correctly. This perception of the empathetic mother and hostile mother-in-law is fairly typical of the patriarchal values of the culture. We have earlier highlighted this point in our discussion of the over-determined conception of mamta as seen in the narrative of an elderly woman whose paternal grand child has a learning disability. (Chaudhary and Bhargava, 2006a)

While daughters could depend upon their mothers for sympathy, understanding and assistance, their contact was circumscribed by geographical distance, especially in the cases of the families who had migrated to Delhi. In the case of those whose mothers lived within the same city, interactions were limited by the notion of the daughter’s
‘otherness’ vis-à-vis her natal home. Brothers and sisters-in-law, with whom the parents lived, thus became the gate-keepers to the daughter’s access to her parents. Moreover, the child’s difficult behaviours made it embarrassing and painful for the mothers to visit their natal homes or siblings’ homes regularly.

One of the mothers described how supportive her mother has always been. But over time, she like her daughter has become dispirited due to the grand child’s difficulties. She has given up eating meat and eggs, keeps fasts, no longer wears lipstick or brightly coloured dresses. Recently, she was diagnosed with breast cancer. She finds the chemotherapy unbearable but is going ahead with it bravely. Her daughter broke down and wept bitterly, “...if something happens to you, what will become of me? of all of us?”

Before she fell ill, she would visit her daughter at least twice a year and enthusiastically participate in the child’s routine, bringing him to school and helping with his daily care. Her daughter says she can scarcely imagine how she is going to face up to life if her mother dies prematurely.

Sindhu whose story was narrated in an earlier chapter, also relies greatly on her parents for emotional support. Her son loves to spend time with his Naana-Naani (maternal grand-parents). Deepak’s transfer to Delhi after several years seemed like the ideal opportunity for Sindhu to spend time with her parents.

Sindhu is especially close to her father. As the eldest child, she enjoyed a very special relationship with him and imbibed a love of philosophy and literature from him. During one of my visits to her home, I observed the affection and harmony between father and daughter. Chinky enjoys his Nana’s gentle, undemanding company. He takes his grandson for walks, watches T.V. and listens to music with him. When Chinky fell
asleep that afternoon, I observed how he gently massaged the sleeping child’s legs. However, the physical distance between her home and that of her parents makes it difficult for regular meetings. They can only come to her house when their son and daughter-in-law can find time off from their schedules as busy professionals and drive them across. They also feel responsible for their paternal grandson and cannot leave him alone as both his parents work. Sindhu regrets that she cannot avail more of their support simply because she is a daughter and therefore does not have the same ‘right’ over them as her brother.

The sense of being forcibly separated from those she holds most dear was voiced by another mother, who narrated how her husband and parents-in-law minimised her contacts with her natal home, and the blame ascribed to her mother for not taking proper care of her during her pregnancy. Her own pain, grief and confusion were not considered important, and she had to deal with it on her own, even though she missed her parents very much.

During his early difficult years of life, Aashu would have crying fits all night. Luckily his mother’s parents lived just a few streets away and she would often arrive at their doorstep in the middle of the night with her baby. Her mother would rock and comfort him all night while the exhausted young woman slept. The death of her father and the grandmother’s increased responsibilities towards her son and his children have lessened the frequency of their interaction. The daughter is careful not to breach the delicate Lakshman-Rekha between her own and her brother’s household. Her father-in-law who used to look after Aashu when she was out of the house, passed away recently. She thus feels very alone and the onus of Aashu’s care is now entirely upon her, without any options for respite.
Lata recounts how her son’s birth coincided with her father suffering a crippling stroke. Although her mother was under tremendous stress, she stood by her solidly, constantly exhorting her “just to love the child”; reminding her that he was much like she had been at that age and encouraging her to hope for the best and believe in him.

Their accounts of the support rendered by their parents reveal that the mother of the autistic child is viewed as a victim of misfortune or an innocent sufferer. Parents-in-law, as per the narratives, took a rather more critical view. Some mothers reported that they were criticized for being “too soft” or “too harsh”, neglectful or over-protective. The pre-diagnosis stage was particularly stressful. When they articulated their doubts about the child’s normalcy, they were snubbed; when their in-laws suspected that something was amiss, their family histories (heritable illnesses) were probed. One mother wryly remarked that despite her daughter being diagnosed eight years ago, her in-laws are still trying to pin the blame on her ‘bad genes’! She is willing to let that pass, but what angers her is the way they speak of the child in front of her regularly developing son, exhorting them to send her to a hostel because she would ‘disturb’ the sibling.

In another family, there was a serious rift when the paternal grandparents attributed the grand child’s condition to bad parenting practices. Happily, the grandparents have now come to terms with the disability and dote on the grandchild. They visit him twice a year and spend happy times together. During a field visit, I observed how Gayathri, the grand-mother, sings to her grandson, and talks to him constantly. He responds by sitting close to her, flicking his fingers on her face and nibbling her shoulder. When she conversed with me, the child became agitated and started flapping his hands. Gayathri was delighted at this exhibition of “jealousy”! He would sleep next to them at night and
did not appear to miss his parents who were out at work. Her son had earlier told me about his mother’s expertise with children; she had been a counsellor and advisor to parents and young people in their neighbourhood, and it hurt him deeply that even she was helpless when it came to his own child’s problems.

The complex reactions of grandparents to having a developmentally disabled grandchild are brought out in the following experts from a grandmother’s narrative published recently in *Autism Network* (Volume 2, Issue 1, April, 2007: 10-11).

Recalling the child’s early years and the slowly dawning realization of his oddities, she writes,

My grandson was a beautiful baby. By the time he was two years old, he had become a very spirited child – a busybody who would seldom sit down and play. He had a funny choice of objects to play with. He would hardly talk, but would address us very appropriately, like Mama, Baba, Dada or Didi.

BUT more often than not, he would not respond to us. My husband and I attributed this to the ‘moods’ of our Little Prince. But my daughter started getting worried about the situation. I saw no reason for concern. I blamed Dr. Spock and his child care manual for making young mothers unnecessarily ‘hyper’. After all had I not noticed that baby boys would quite often start talking a little late? After several visits to doctors and other professionals at the insistence of the child’s mother, a diagnosis of autism was given. Recounting their response, she continues,

The word meant nothing to us. We looked up the dictionary and became more confused. My daughter tried to explain to us what autism was. I remember asking her two questions. One, whether my grandson will be able to speak fluently the way we do, and two, whether he will make headway in the educational field. My daughter did not have any positive answer. The situation was very depressing. My otherwise lively daughter became very subdued.

The following excerpts capture the conflicting feelings experienced by grandparents in difficult situations such as these:
Some parents may think that, after all, being just a grandmother it is easy for her to take the matter that way. But being a grandmother is also not very easy. My grandson, my daughter and my son-in-law are equally precious to me. When my daughter works hard, my grandson improves. When my son-in-law comes back home after a hard day's work, his son wants to interact with him – thus the boy's communication improves. But the other two (that is the parents) are overworked. In the reverse situation, when they are less focused the boy may show signs of regression. So what am I supposed to do? Whose side do I take? It is like falling on a double-edged sword – one can get hurt from either side.

At times I have heard from parents of children with special needs that their parents do not approve of the special ways the children are handled. Grandparents think that mothers are too strict. Pampering is a very natural propensity of any grandparent. May be that is their way of dealing with the situation, trying to make-believe that everything is okay.

She clearly brings out the gap in the understanding of developmental disabilities between her own generation and that of her daughter and advocates a liberal and open approach for other grandparents.

In my opinion, so far as autism is concerned it is better, for us the grandparents, to listen to our children. They certainly know more about the subject and are aware of the new methods that will help our grandchildren.

In the present scenario, I have adopted a few means that have helped me. I would like to share those with other grandparents. I make it a point to interact with other families who are in a similar situation. I feel that I am understood better, and that I can reciprocate better in these interactions. I have also attended a few workshops discussing subjects like teaching self help skills, behaviour modification, and so on. These workshops help me to understand and follow what my daughter does to handle different challenging situations.

I often wonder how these mothers manage to handle these not so easy situations so well. I feel that they deserve all the encouragement possible from their extended families and friends.

The most important fact I have realized is, that my grandson would not have been more dear to me had he been someone else and not him. He is precious to me just the way he is. It feels wonderful, to hear our boy calling me ‘Didi’, whenever he interacts with me. No one else can take his place in my heart.
The key points that emerge from the grandmother’s narrative are

- the difficulty in construing odd behaviours as symptoms of a medical/psychological condition, and viewing them as part of the child’s personality or nature (note the use of the terms “spirited”, “busybody”, “moods of our Little Prince” and the oft heard explanation of boys talking late);

- rejection of western notions of parenting and child development (note the blame on Dr. Spock’s manual and ‘hyper’ young mothers);

- the emphasis on speech and progress in the “educational field” as the markers of normalcy and competence;

- concerns for one’s own child sometimes conflicting with those for the grandchild (“whose side do I take? Its like falling on a double-edged sword”);

- the wisdom gained through personal experience falling short of ‘modern’ knowledge: “They (our children) certainly know more about the subject and are aware of new methods that will help our grandchildren”;

- coping strategies, (viz. interacting with other families, attending workshops etc.);

- belief in the intrinsic worth and humanity of the child, notwithstanding his impairments.

The first four responses are most often experienced and voiced, as our narratives reveal.

Conceding that the child has a developmental problem, and that there exists a body of specialised knowledge and expertise about the condition, is difficult for most people. Parents disclosed that they felt frustrated trying to explain to their own parents that their child was in need of treatment and therapy, and that the condition would not simply
improve with time. The fact that despite intervention, the child was not “improving” or “getting cured”, was seen by some grandparents as proof that the diagnosis itself was flawed and there were other reasons for the child’s peculiarities. Folk remedies like tying of amulets, maintenance of fasts, consultation with astrologers were sometimes suggested by grandparents. Even if parents resisted these suggestions, the “lack of improvement” was cited as proof of super-natural causation.

In the case of higher-functioning children, grandparents found it hard to fathom what was “wrong”. “If the child is speaking, reading, writing, counting, then what is the need to send him to this school for mad children?” Labelling a child autistic, as per this view, is a convenient way for parents to make excuses for having brought up an unruly and indisciplined child. In this regard, the experiences of the teachers and therapists at AFA was also a mixed one. While some grandparents laud their work and express appreciation that efforts are being made with the child, others dismiss their work. A senior therapist told me how the maternal grandparents of a particular child warmly embraced her and complimented her upon being an ideal role-model and support for their daughter. However, the paternal grandparents (highly educated, retired civil servants) told her that there was nothing ‘wrong’ with their grandson; he was merely moody and would outgrow his oddities. The therapist said that they seemed unable to digest that a child of their social class could possibly have a developmental disability.

Grinker (2007) narrates the story of a young mother from Kumaon whose in-laws believed that her son’s difficulty was a consequence of divine retribution for their failure to perform sacrifices to the family deity. Much against their wishes she brought him to Delhi where he was placed in a program for autistic children. They are upset that she listened to the autism centre rather than the priests. He also quotes an Indian child
psychiatrist’s opinion that “grandparents routinely subvert the therapeutic process” (2007: 215). While this view appears extreme and was not corroborated by the present study, it may safely be asserted that grandparents in the present sample resisted the labelling of the child at an early age and were less anxious about delayed developmental milestones than their children.

The fact that developmental disabilities are now becoming a part of public discourse and being seen as ‘conditions’ for which therapy and rehabilitation are available runs counter to the ‘misfortune’ or ‘personal tragedy’ model of disability that is still the dominant one for the older generation who tend to view disability through the lens of personal and familial tragedy. Coming to terms with the grandchild’s difficulties presents a challenge, more so when it is constructed in a discourse that is unfamiliar and confusing.

4.3 INTERACTION WITH THE EXTENDED KIN NETWORK

With regard to their own siblings, the parents’ accounts suggested that sisters were, on the whole, more caring and supportive. At the same time, married sisters found it difficult to devote much time to their sibling in distress, even though they talked regularly on the telephone.

Brothers, while caring, tended to be ‘non-involved’. One of the mothers narrated her deep sense of hurt that her brother, a medical doctor, refused to get “too involved” with the child. Another woman roundly castigated her “insensitive” sister-in-law and “passive” brother for making life so uncomfortable for their aged parents that they shifted back to their native place. The sister feels that they have alienated her from her parents at a time when she most needs them. However, one young mother informed that her siblings, a sister and a brother, were her greatest source of support, far more than
her husband who kept away from the house and child as much as possible. Her siblings plied her with literature on autism, visited and spent time with her as much as they could. Without their support, she says, she might even have committed suicide.

Once again, we observe the impact of busy urban life styles interacting with views about the ‘otherness’ of the married daughter. Simultaneously, Western influenced views about ‘non-involvement’, privacy and the emphasis on the conjugal bond, mitigate against adult siblings actively and intimately engaging with each other, especially in issues pertaining to child-rearing.

We have repeatedly mentioned the shrinking familial circles available to urban families. The compulsions of urban living limit interactions between members of the extended family to ‘special’ occasions like weddings and other such gatherings. The presence of the autistic child on such occasions is quite frequently a source of stress to the family as well as the child. Due to the sensory difficulties associated with the condition, noisy gatherings peopled with unfamiliar faces in strange settings like banquet halls, wedding pandals etc. can prove to be upsetting and unsettling for the child often triggering tantrums, crying, self-injurious and fleeing behaviours. Well-meaning relatives may try to show their affection to the child by kissing and cuddling, scarcely realising how distressing it can be to the child. The narratives reveal instances of how such gatherings became scenes of acute embarrassment and sometimes even dangerous ones. Terrified at the sight of bright lighting at a wedding a child once ran off into the parking lot and hid beneath a vehicle. Luckily he was found before a fatal accident could take place. Needless to say, the incident ruined the festive atmosphere. A husband recounted his wife’s acute discomfiture at family gatherings when the child would eat his meal and then put on his shoes, signalling that as far as he was concerned,
the evening was over. The mother would painstakingly make him say Namaste and greet every single person present. Failure to comply would upset her greatly. Family get-togethers thus became arenas of conflict. As a consequence of the difficulties described above, many families curtailed their interactions with relatives, and were in turn avoided by them.

One parent said "..on such occasions, what do we talk about? Everyone talks about their kids... how so-and-so’s son topped the exams... how someone is getting into I.I.T... what do we have to say? ..that he’s not creating a scene at school any more..? Its so painful, you know...”

The feeling of being shunned and avoided by relatives was strongly voiced by one of the fathers. “Koi nahi poochta hai, ji.. ki iska kya haal-chaal hai... rishtedaar to sirf ‘formality’ nibhaate hai..” (Nobody cares or asks how the child is faring. Relatives merely perform formalities). The parents of a severely impaired child say that although their relatives are kind and polite, they do not regard the child as a human being, but more like an animal that needs to be fed, cleaned and kept alive. Some of their better-educated relatives do not understand why he is being sent to a school and why his parents take such pains with him. They feel he should be sent to a residential institution, and they should go ahead and have another child. On the other hand some of their less educated and rather rustic relatives understand and support the decision to send him to a special school. “Voh uski bhasha samajhte hai, mehnat karte hai” (they understand his language, they take pains with him). This father is very particular about performing his social obligations towards his relatives, visiting during “dukh-sukh” (times of joy and sorrow) and keeping contacts alive, despite the lack of reciprocity from the other side. They also make it a point to take the child with them wherever they
go. By making him as visible as they possibly can, they hope to foster greater understanding and acceptance.

In a cultural setting where sociality is prized and competence defined in terms of an individual’s ability to understand and appropriately enact a multitude of social roles, the autistic child’s aloof, idiosyncratic behaviour, inappropriate social expression, awkward self-presentation and difficulties in apprehending what is permissible and what is ‘off-limits’ is viewed with embarrassment, disapproval and rejection. The child is sometimes viewed as an aggregate of inappropriate behaviours rather than as a complete human being. The undermining of the child’s personhood is sometimes hard for the family to see. It is also important to note that relatives who meet the child only infrequently tend to evaluate him/her in terms of present functioning, rather than the changes that have taken place over time. For example, a ten year old snatching sweets from a four year old cousin will be viewed and evaluated as such, rather than as a child who is now able enough to withstand being in a strange place for a period of a few hours. Relatives forget that the same child would probably have refused to enter an unfamiliar setting a few years ago. The positive changes that parents value and treasure are thus undercut by a comment like “Why haven’t you taught him any manners? See how he bullies the small kids!” Or, “what point is there sending him to this school?”

The sense of defective personhood of the child is also conveyed through pitying glances and words, well meaning advice to have more children, look for options for residential care, consult mystics and healers, alternative systems of medicine etc. A mother recalled an elderly aunt telling her, “Don’t worry, daughter, just as some people don’t have an arm or a leg, this child does not have a tongue.” She did not take offence at this remark. But when her jethaani (husband’s elder brother’s wife) delivered a baby
boy and expressed relief that at last there was a male to carry on the family name, she realised that her child was not regarded as complete human being even by close relatives. This upset and hurt her.

The experiences described above have been culled from the narratives of families whose interactions even with ‘close’ kin are limited due to the nuclear structure of the household and the fact that kin who live in the same city may live quite far away making frequent interaction difficult. One family in the sample was an extended one; that of Charu. It comprised her paternal grandparents, parents and younger sister, chacha-chachi (father’s younger brother and his wife) and their two children and Charu’s unmarried cousin, the daughter of the eldest son in the family, who, along with his wife, died several years ago. The following narrative uncovers the way in which the child’s disability is managed within the context of an extended family and the tensions and strife that characterise it.

Charu’s primary care-taker is her cousin Shalini. The following reconstruction of their family life is drawn from interviews with Shalini. The family lives in a middle-class colony that is dominated by Punjabis dislocated during Partition. The grandfather runs a grocery store and Charu’s father works as an accountant in a private firm. The younger uncle does some ‘business’. The women of the family do not have outside employment. Charu has a younger sister, Mehek, and the uncle and aunt have two children, both regularly developing. They have a common kitchen and household expenses are met by the income of the grandfather and the elder son. Chacha (Father’s younger brother) pays his children’s school fees and buys their clothes and personal articles, but does not contribute to the household expenses.
Despite the availability of a multitude of family members we find that the care of the disabled child is concentrated in the hands of the unmarried cousin with scant help or support from the others.

**Case Study: Charu’s family**

Charu is a 10 year old girl with autism. She speaks a few words like “Maggi” and “toffee”. She is hyperactive and apt to wonder off here and there. She is tall, slim yet strongly built, with curly cropped hair and a beautiful smile. She is the first child of Rani and Gurvinder. Shalini, her cousin, (father’s brother’s daughter) was a 19 year old college student when she was born, and the new baby was her “toy”. Shortly after Charu’s birth, Rani conceived again. It was a difficult pregnancy and she was advised bed rest. Charu’s care fell to Shalini, a responsibility she accepted joyfully. Although her motor milestones were normal, she had delayed speech, and by the age of three, her deficits became apparent. She was diagnosed autistic after almost a year of doctor’s visits during which she would be accompanied by her father and Shalini.

The realisation that it was a life-long condition came as a great shock to the family. Gurvinder suffered from extreme depression and Rani withdrew from the child. Shalini, at 23 was now Charu’s surrogate mother and companion. She quit college and devoted herself to the care of the little girl.

Shalini reports that she hates the atmosphere at home. It is noisy, quarrelsome and disorganised. She is an orphan, her grandparents are old and frail. Rani refuses to take responsibility for her daughter and spends much of her time visiting her natal home. The younger brother and his wife resent Shalini’s involvement with Gurvinder’s children. They have instructed their own children to insult and slight their cousin at the slightest pretext. Shalini often loses her temper and slaps them, leading to fights. She
vents her anger and frustration onto her grandmother who listens listlessly and without response. Once or twice she even smacked Charu when she urinated in the neighbour’s house. The look of fear on the child’s face made her feel so guilty, she swore to herself she would never hit her again. She has fights with the neighbours who call Charu *paagal* and *bewakuf* (mad, stupid) because she is in the habit of throwing things into their terraces, collecting toothbrushes from their houses and urinating on the common staircase. When they slight the child, Rani shouts at them, but soon forgets and becomes friends again. Mehek is very attached to and protective of her elder sister, and will only do her homework if Shalini and Charu sit down with her. Rani resents the “hold” Shalini has over her regularly developing daughter.

Shalini is now 30. Thin and pale-skinned, she wears simple, old fashioned *salwar kameez*, and pulls back her curly hair in a severe pony-tail. She has lost touch with all her friends after leaving college, and misses her parents greatly. No-one in the family seems to be interested in arranging her marriage. She says, “I have stopped thinking about marriage.. what will happen to Charu then? I’d like to take her with me but I know that won’t be possible… if people in the family, if her own mother is not ready to do things for her, why will any outsider bother?”

She knows that as long as her grandparents are alive, she will be looked after and protected. But she is not sure about what the future holds for her. Will she be considered a burden? Or will she have to “earn her keep” by assuming continued responsibility for the disabled child? She does not know the answers.
Discussion

We observed in the previous chapter how the child's autism acts as a window through which tensions and power struggles operating within the family may be viewed. The daily tussles that characterise life in Charu's family centre around money, rights and responsibility. Chacha and Chachi, while reaping the benefits of the joint kitchen, guard their privacy zealously. They resent the involvement of their orphaned cousin with the elder brother's children and the position she enjoys in the family because of the responsibility she has been given. Charu's mother has handed over the onerous responsibility of caring for a disabled daughter to the conveniently single female relation. At the same time, she is jealous of her normally developing daughter's obvious attachment to her. Shalini, the orphaned unmarried, dependent daughter of the house whose grandparents have lost the energy and resolve to get her settled, finds herself caught in a double bind. On the one hand, her devotion and attachment to the most vulnerable member of the household, like her, a daughter of the house, on the other, her desire to lead a normal life and not be 'used' by her own relatives for their convenience.

Cases such as these highlight the sinister aspects of the much valourized extended family and, the exploitation of its vulnerable members, women and the disabled. At the same time, to discount the role of the extended family as a site for support and nurture would be misleading.

One of the families recruited for the study, that of Daisy, John and their son Vijay, report their strong attachment with their extended families in South India. Both have several siblings and are confident that their son will not lack for care in future. Daisy's mother and sisters run a school which is supported by the local parish and have a
deeply ingrained sense of community service. Daisy informs that they have “taken in” several destitute children in the community and is confident that her child will be looked after when needed. This reinforces the point made in the previous chapter about the role of social ‘protective factors’ in the form of community networks.

In an earlier chapter, we discussed the case of Dimple’s extended family and her father’s belief that they will look after her if needed. Her mother, though, expressed her reservations. One of the mothers stated “..I only do so much for her because I have given birth to her. I cannot expect anyone else to do the same. I would not have been able to do it for any other child, so how can I expect others...? (to do it)”

So who, then, will “do it”? None of the parents wanted to send their children to state-run institutions for the mentally disabled, because of their reputation for being “hell-holes” with poor facilities, over-worked staff and their reputation for corruption and inefficiency. Privately run residential facilities are few and very expensive. Siblings are the only hope, but parents are realistic that they might not want to take on the responsibility. It is against this backdrop that we examine the role of parent support organizations in the next chapter. Before we do so, a discussion of neighbourhood and community networks will be taken up.

4.3 FAMILY, NEIGHBOURHOOD AND COMMUNITY

The preceding chapters have touched upon the interface between families of disabled children and the community. We have highlighted the stigma associated with mental disability and the awkwardness and embarrassment caused by the odd behaviour of autistic children. Harvey Sacks (1970) describes how ‘doing being ordinary’ is an enterprise we constantly engage in, mostly unselfconsciously, in order that we may ‘fit in’ our surroundings, not ‘stick out like a sore thumb’, as a mother perceptively
remarked of her son. While family members and friends make allowances for the child’s disability, members of the community have no such compulsions.

We have cited parental accounts of curious glances, comments and sometimes outright hostility encountered by these children in public settings. While some parents have become so sensitive that they refuse to take their child to public places, others say they have stopped reacting and become immune to the stares and comments. Within urban settings where interaction with the extended family is limited, the role of neighbours becomes all the more important. However, media reports and anecdotal evidence suggests that the pressure of busy lifestyles and preference for privacy leads to situations wherein neighbours do not even know if the person living next door is alive or dead. Recent incidents in Delhi, widely reported by the media of mentally unstable adults dying of starvation and neglect, highlight the anonymity and isolation of urban life especially for vulnerable people like the aged, the sick and women.

At the same time, friendly and helpful neighbours can be a source of support and sustenance during times of crisis, as frequently reported by the families in the study. The presence of a developmentally disabled child usually elicits concern and sympathy, as the narratives reveal.

Not a single family reported that their neighbours displayed active hostility or rejection towards their child even though some of them reported that their neighbours were too preoccupied with their own concerns to bother much. In families where there were regularly developing siblings as well, the siblings reportedly received affection and attention from neighbours, and were often treated with special consideration.
In cases where children had severe difficulties, self-injurious behaviours, aggression, etc., neighbours preferred to keep a safe distance, even though they were usually solicitous when they met the parents alone. A mother reported apologising to the family living one floor below her, after her child spent the night screaming and throwing things on the floor. The neighbours told her not to worry about them and attend to her child instead. I encountered a very protective elderly landlord during the fieldwork. He checked my antecedents carefully before allowing me to ascend the steps and meet the family who lived there. The mother later told me that he was very protective of them, especially when her husband was out of town. His family was very fond of the child, and would take much interest in her progress.

One family preferred to pay an exorbitant rent they could ill afford for a flat in a South Delhi populated mainly by academics and journalists. As they expected, their child was treated warmly and affectionately, as there were already several disabled children in that colony.

While searching for an address in a rather confusingly numbered Government colony, I asked several Garhwali ladies basking on the charpais in the winter afternoon sun, where a certain ajeeb-sa-baccha lived. They despatched a little boy to show me the correct location. The concerned family, also Garhwali, informed that the child was seen as a community responsibility. He often drifted away from his home, but would be brought back by alert neighbours. Everyone looked out for him and ensured he was safe. His antics in the neighbourhood market were also tolerated by the shopkeepers.

In terms of the participation of the disabled child in neighbourhood activities, play and entertainment, a different picture emerges. Rarely are such children invited for birthday parties of peers in the neighbourhood, especially as they grow older; rarely are they
invited to participate in cultural programmes or common celebrations or to play outdoors or at home with other children. They are either accompanied by a family member or care-giver, on the infrequent occasion that they are actually invited somewhere. Sometimes, they go as ‘add-ons’ with their siblings, but rarely, if ever are they individually invited. This sort of ‘limited acceptance’ indicates that while neighbours are, on the whole sympathetic with the difficulties experienced by such families, they are reluctant to engage with the differences of the child, or involve themselves in understanding his or her mode of being. With prolonged contact, however, some of them come to an understanding and appreciation of the child’s unique personality and gifts, and value him or her as a person in their own right. One of the families reported how some of the neighbourhood children desisted from playing with noisy crackers on Diwali because it upset and frightened the autistic child so much. They were not requested to do so by the adults, it was a decision they made on their own, out of respect for the feelings of their friend.

It appears that awareness about developmental disabilities is growing in urban communities. The coverage of the mass media, proliferation of special schools, learning centres etc., access and availability of Internet and the growing visibility of such individuals in the community has contributed to this. Simultaneously, as we have earlier discussed, a competitive educational system, skyrocketing aspirations and the desire for ‘the good life’, have created a milieu where ‘achievement’, ‘smartness’ and ambition are the watch words. Difference acts as an impediment to achievement and hence it is sought to be eliminated or sidelined.
Interestingly enough, even amongst families of disabled children, distinctions are made based on ability. Thus, more verbal and more able autistic children are deemed ‘superior’; their abilities and achievements ‘flaunted’. The mother of a very able autistic boy at a special needs centre was often advised by other parents to send him to a mainstream school because he was “far above” his classmates; she pointed out that the positive changes seen in him were on account of appropriate teaching methods and acceptance from his teachers, and that in a regular classroom without adequate support he would have a very difficult time indeed. Another parent, whose child had severe impairments would frequently complain that no teacher or therapist would want to ‘touch’ her child; other parents would give her the cold-shoulder, make her feel small. Clearly, the dynamics of competition that obtain between families of regularly developing children in the metropolis also hold good for developmentally disabled ones. These outweigh class and status differentials. One often heard comments like the one below directed towards some extremely well to do families:

“What’s the use of having so much wealth if the child is so handicapped?” Some of the less well off families whose children were not so impaired considered themselves much better off. Similarly, the presence or absence of regularly developing siblings was a factor that played a major role in determining the family’s misfortune or good fortune.

School plays a critical role in shaping the child’s self-concept and empowering the family to help him/her fit better in the community. Seventeen children in the sample attended Special Needs Centres or schools where their difficulties were dealt with by trained professionals and where peers were also children with various kinds of disabilities.
Two children, who attended regular schools, were either accommodated in a special classroom or received some measure of integration, viz., having their special needs catered to by specialist teachers for part of the school day, and joining the ‘regular’ class for sports, library, music, activity periods, break-time, assembly etc. Only one child, diagnosed with Asperger’s syndrome, attended a mainstream classroom. He had a very difficult time “fitting in”, and changed two schools before settling down in a small, progressive school which laid much emphasis on co-curricular activities, ‘learning through doing’, and innovative teaching strategies.

Despite some parents being able to provide richer educational interventions in terms of integrated or semi-integrated schools, they were plagued by worries about the child’s future. While some autistic children fare very well in mixed settings in the lower grades their social deficits often cause immense difficulties in the middle and upper grades, which coincide with late childhood and adolescence. Teachers in special schools cite numerous cases of children who are “thrown out” of regular schools after the primary stage and have to be taken into special schools which offer them much less by way of stimulation and the company of peers. This can quite frequently be traumatic for both the child, who feels rejected for no fault of his own, and the family who see this ‘demotion’ as a personal failure.

This attitude reflects the ‘limited acceptance’ earlier discussed; disabled people are welcome if they abide by the rules, stay within the limits drawn by others; once they transgress these limits or cannot understand the rules, they are no longer welcome, much like the image of the poor relation at the wedding who cannot dance with the bride! (Davis, 1961)
‘Normal society’ and autism make strange bed-fellows. The former is based on mutual understanding of roles and expectations by actors and shared socio-cultural scripts. Autistic individuals lack precisely those very abilities, which enable this shared understanding to take place. Families of autistic people become the interpreters of these socio-cultural scripts; decoding them for their children and simultaneously ‘scripting’ their children for a world that does not understand them. We locate the emergence of the family driven NGO ‘Action for Autism’ against the backdrop of families struggling to understand and accept their children as well as struggling to find a place for them by society at large. Underpinning this quest is the ‘big question’, viz. ‘What will happen to my child when I am gone?’