Autistic disorder with its difficult and bewildering behavioural expression, threatens cultural conventions regarding child-rearing practices and developmental expectations. It dramatically displays the process observed in severe psychiatric disorders, whereby everyday, taken for granted experience is shattered when confronted with such an unexpected "natural" reality. As it impacts social, communicative and emotional functioning (Wing, 1988) it is only around the second year of their child’s life that some of the parents’ recruited for this study became aware that there was something odd and unusual about the child. We examine their narratives about those early years.

Analysis of illness narratives uncovers the conflicts that a particular illness evokes in a society and indicates moral and political processes that operate within that community (Lewis-Fernandez and Kleinman, 1995). Simultaneously, these narratives also expose coping efforts aimed at maintaining the affected person’s acceptance within these moral worlds (Shaked, 2005). Narrative analysis takes as its object of investigation the story itself (Riessman, 1993) and assumes that referring to the structure of the story and its focus in different points reveals rich worlds of meaning.

The narratives produced below reveal how the notion of ‘normalcy’ is slowly and surely subverted by behaviours that seem initially easy to explain away but over time, coalesce to form a pattern that defies common sense explanation. They unpack the dawning realization of families that something is ‘wrong’ with the child, and chronicle the search to find explanations. These ‘explanatory models’ (Kleinman, 1980) include both the bio-medical as well as the religious and cultural. They cover the difficult and
painful task of ‘emotion management’ (Hochschild, 2001) and coming to terms with the reality of having a child with a life-long mental disability. We also examine how families factor in the disability of the child in their daily functioning and make adjustments in their life-scripts so as to enable them to come to terms with the reality of their child’s disability and get on with their lives.

2.1 SYMPTOM RECOGNITION: RECOGNISING ATYPICAL DEVELOPMENT

What is it about a child that gives pause to consider that it might not be ‘normal’? Built into this question is a cultural understanding of what constitutes ‘normal development’. In her study of symptom recognition amongst families of autistic children in India Daley (2004) found that the symptom that elicited most concern was lack of social relatedness, a finding corroborated in this study. Volkmar (1987) notes how the social behaviour of young autistic children is remarkable because of the sharp contrast between it and the demanding, omnipresent sociability of non-autistic toddlers and pre-school children. He also brings out the contrast between the relative lack of concern shown by many autistic children over social encounters and the intense interest displayed by the same children over trivial aspects of the physical environment.

One mother recalled, with the benefit of hindsight, how her child appeared quite indifferent to his regularly developing older brother. “One day at the bus stop, I was waiting for Tinku (the elder child)... another mother was there with her toddler also... I saw the way that child got excited when she saw her brother... She smiled and babbled... but my kid?.. He just didn’t seem to care that Tinku was back...” Parents reported feeling uneasy and confused about their child’s apparent obliviousness to the world and people around them, their disconcerting way of looking “through” people, indifference to the absence of the mother, lack of interest in other children and adults.
Delayed speech was another area of concern. Parents were concerned not only with the inability of the child to speak, but the apparent inability to understand and respond to spoken language and non-verbal cues like nodding and shaking of the hand or head. One of the parents recalled a visit to her sister-in-law’s home. “Her child was the same age as mine (2 years) but that is where the comparison ended. I was shocked at the things she could do... her mother said *darwaza band karo* (close the door) and she actually went and closed it! I also saw how she was nodding and shaking her head. *ishaaron se baat kar rahi thi*.. (making gestures). but this fellow? (her son). *Ye to patthar ki tarah tha*... (he was as unresponsive as a stone). Something just clicked in my head.. but then I tried to convince myself *ki ladkiyan jaldi seekhti hai* (girls understand quicker).” Some parents recall that this aloof and idiosyncratic behaviour was sometimes attributed to the child’s innate “brilliance”; one mother recalled a shopkeeper calling her quiet, pre-occupied, aloof baby “Professor-saheb”.

Parents also recalled strange behaviours like sudden, inexplicable display of fear, aversion to certain sounds and sights that elicited screaming, running and hiding behaviour (aeroplanes, fire-crackers, whistle of the pressure cooker, etc). These reactions were attributed to the child’s extreme sensitivity. One mother reported how terrified her child became when he was placed on a grassy lawn. Another child would hide in fear at the sight the logo of “Zee Cinema” on the T.V. screen; yet another had an aversion to the sound of his care-giver’s voice. He had to be ‘de-sensitised’ by exposing him to the taped sound of the voice for slowly increasing periods daily until he finally got used to it. Deafness was a possibility some parents considered, but they also report how the child who could apparently not ‘hear’ its own name from close quarters would rush to the T.V. set at the sound of a favourite commercial, or
unerringly pick out the rustle of a toffee-wrapper in a pocket. Parents also recalled their confusion at the lack of responsiveness of the child to his or her own name.

“Dirty habits”, eg. picking up food from the dustbin or street, eating faeces or mucus, unawareness of a sense of danger, eg. drinking cleaning fluids in the toilet, running onto a busy street, hiding under cars etc. were also reported, but ‘explained away’ by remarking that all children did these things anyway. The narratives abound with instances of children running way from a gathering only to be found fiddling with the hub-caps of a car in a distant car park or exploring some piece of machinery in an unsafe construction pit. One child who ran away from his own birthday party at the age of two was discovered in the middle of a road in one of South Delhi’s busiest markets, staring at his reflection in a puddle, oblivious to the commotion around him.

Mothers in particular earned disapproval from neighbours and relatives when the child behaved thus. One mother recalls her mother-in-law saying, “..bacche ko jaanwar bana diya!” (she has made this child into an animal) when he picked up food from the dustbin and stuffed it in his mouth. Gray (1993) found that parents with autistic children feel stigmatized in public situations like the market or mall and that parents of younger or more severely disabled children felt more stigmatized, a finding that was corroborated by the present study.

Bad parenting practices were cited by other family members as the reasons for the child’s odd behaviour. One behaviour that elicited great concern was tantrum throwing upon being thwarted, and episodes of intense distress resulting in non-stop screaming and crying. These outbursts were sometimes accompanied by self-injurious behaviour like head-banging, slapping and hitting the face, biting hands, even drawing blood. The child would be unable to communicate the cause of his/her distress and these episodes
took a heavy toll of the family physically and emotionally. One of the men said "I can take anything, anything... but when he used to hit himself and hurt himself like that it would just tear me apart... to see how much he was suffering and not even being able to understand what he felt, what he wanted... I felt a complete failure as a father."

Viewed in isolation, none of the individual behaviours described above are particularly remarkable or alarming; taken together, as a pattern they assume a different shape. They indicate the fundamental social deficits characteristic of autistic disorder; the innate deficits that Leo Kanner was able to co-relate and identify as a distinct syndrome despite the differing abilities and characteristics of his patients. The families' narratives of the early years of their children's development unfold a slowly dawning realisation that these odd behaviours and episodes were a cause of concern, that something, clearly, was "wrong" with the child. However, it was difficult to pinpoint exactly what was "wrong", as most of these children were doing many of the other things that parents look forward to; they were walking, running playing with toys (albeit in an idiosyncratic way, i.e. spinning wheels of toy cars, arranging blocks in stacks, preoccupation with parts of objects), exploring their environment. Within the sample, only two children had delayed physical milestones: a case of Rett's disorder and another with Cerebral Palsy in addition to autism. The absence of any physical stigmata and the unusually attractive appearance of some of these children did not mark them as impaired or "abnormal". Their strange ways were described as zidd (obstinacy), ajeeb strange, abhi samajh nahi hai (lack of maturity) or, as earlier mentioned, extraordinary intelligence. But, as the behaviour increased and became difficult to "excuse" or "condone" (because the child was expected to learn self-control) the word paagal (mad) or 'mental' began to be used by other people to describe the child. A young mother narrated her experiences when her non-verbal, aloof three year old was
admitted to a nearby play school in the hope that it would enhance his social skills and provoke speech: “The teacher told me he would just run to the terrace and spend the whole time there… he wasn’t shy or scared like some of the other children.. he was in a world of his own… One day she told me ‘I think there is something wrong with his head.. he has a mental problem’. I was so hurt, I withdrew him (from school) that very same day.”

Social disapproval was encountered when the child snatched sweets or toys from a younger child, threw a tantrum in public or engaged in self-stimulatory behaviour like rocking, spinning, finger-flicking, etc. Behaviours such as these and also uncontrolled laughing or crying for no apparent reason fit the rubric of *paagalpan* or madness. Many parents indeed began to fear that their child was mentally ill or insane.

The experiences quoted above reflect the experiences of families whose children’s development was atypical from the start. Six families in the sample also recounted that their children were apparently developed normally for the first 2½ to 3 years, but then started to regressing. One of the girls in the sample, as reported by her mother, appeared quite normal. By the age of 2 she was following her elder brother around the house, repeating all that he said, and entertaining the family with songs and nursery rhymes. On her second day at play school (when she was 3) her teacher told the parents that she was “different” from the other children; she did not respond to her name or play with other children.

Another little girl whose early development was reported to be ‘normal’ by her family members, appeared to regress after a prolonged fever at age 3. She seemed to “turn into a robot”, losing interest in play and communicating; staring fixedly for hours at the
T.V. screen. Initially attributing these symptoms to weakness caused by fever, the family soon became concerned as her 'lost' abilities showed no signs of returning.

What is interesting is that in both these cases, the children already had regularly developing siblings. Hence their family members were quite well versed in normal developmental milestones and could possibly have 'picked up' signs of atypical development had they presented themselves earlier. In the first case, for example, the mother still cannot understand how she failed to notice the signs that the school teacher saw immediately. Having discussed some of the signs and symptoms recognized by families as being odd or aberrant in the development of their children, we turn now to discussing the help-seeking behaviours resorted to by these families.

**Recognition of the Problem and Help-seeking**

Writing about help seeking behaviour in the context of illness and disability, Mechanic (1978) talks about social selection of symptoms, wherein attention is paid to the characteristics of individuals and groups that make them different in one way or the other. One of the most consistent findings in illness literature is that persons are likely to take action for symptoms that disrupt usual functioning. Drawing from the "health belief" model proposed by Zola; Mechanic (1978) identifies the following determinants affecting response to illness/disability.

1. **The visibility, recognizability and perceptual salience of deviant signs and symptoms:** With respect to the early symptoms of autism, viz. delay in language acquisition, lack of social relatedness and emotional reciprocity identified above, parents found it hard to conceptualise them as symptoms of a medical or clinical condition. More often than not these symptoms were viewed as reflective of 'bad' parenting; the anonymity of urban existence and absence of a 'family-like
atmosphere'; the absence of extended kin and frequent, intimate interaction with grand parents, aunts, uncles and cousins. Certain symptoms like a child’s withdrawn, aloof behaviour were not viewed as ‘symptoms’ at all, rather, as expressions of his/her unique character. Parallels were often drawn with other members of the extended family or earlier generations who were ‘late developers’ but turned out to be unusually talented or gifted. Given the relative absence of awareness of autism as a disorder, the perceptual salience of signs and symptoms was not very significant.

2. **Estimate of present and future probabilities of danger:** As mentioned above, families had difficulty in conceptualizing the odd behaviours of their children as symptoms of a disorder; hence they were not in a position to accurately assess the probabilities of danger. Unlike physical or family or anomalies, they were not thought of as sources of potential harm to the child.

3. **The extent to which symptoms disrupt family, work etc:** Families resorted to help-seeking as a consequence of the disruptiveness of their child’s symptoms. As described earlier, some of the behaviours displayed by the autistic children, notably self-injurious ones, cause immense distress and disturb family functioning. Parents narrated how they could never let the child out of their sight afraid that s/he might run away or hurt or harm herself/himself or others. Family outings, routine activities like shopping, visiting friends or relatives etc. became events fraught with difficulty due to the child’s symptoms. When it becomes clear to parents that these disruptive episodes are not the occasional tantrums thrown by every child but manifestations of something more serious, they resort to seeking help.
4. **Persistence, frequency of recurrence of symptoms:** Family narratives reveal the manner in which the symptoms of their child’s autism increased and intensified over the first few years of its life. By the age of four, all the children in the sample displayed behaviours that were decidedly different from the norm. As mentioned earlier, some families reported atypical developmental patterns from the outset while others reported regression after a period of comparatively normal development. However, even though the children were chronologically ready to enter school, it became obvious that they were lagging behind in the areas of communication and social development. The inability of the child to fit into the school set-up was often the trigger that prompted parents to seek help.

5. **The tolerance threshold of these exposed to symptoms:** As described above, tolerance threshold of families for symptoms such as head-banging, screaming and other self-injurious behaviours was low, as they took a heavy toll of the family’s physical and psychological reserves. Other symptoms such as delayed speech, although worrying were not viewed with as much concern; cultural beliefs about boys being late speakers, made many families gloss over this symptom. The belief that growing up in a nuclear family has an adverse impact on the sociability and responsiveness of the child also leads families to view social ‘disconnectedness’ more as the product of reduced opportunities for interaction rather than as a developmental deviance.

6. **Available knowledge, information, cultural assumptions:** The complexity and subtlety characterizing early symptoms of autism coupled with a lack of knowledge amongst both lay and professional people about the condition contributes greatly to early symptoms not being ‘picked up’ or ‘read’ by caregivers
and clinicians alike. Cultural assumptions about child development alluded to above also reinforce the non-recognition of symptoms. The narratives bring out how the mere suggestion that something was 'wrong' with the child lead to rejection, anger, hostility and other such denial responses in the family. "Aakhir voh baccha hi hai", (He is only a child after all) is used as the clinching argument to justify or rationalize the child’s oddities.

7. Basic needs that lead to denial, including the desire to ‘normalise’ the situation or keep it under control, sense of blame, guilt, shame etc: It is very difficult for parents to conceptualise their child’s difficulties as a potential ‘disorder’, much less a life-long one. The social stigma associated with mental disorders makes the prospect an abhorrent one for families. We have noted earlier how sharply parents reacted when it was hinted that their children may have some mental disorder, even to the extent of withdrawing them from their schools. The desire to ‘normalise’ the situation, to attempt to make the child ‘pass’ or ‘fit in’ was commonly observed. One mother admitted her small 4 year old to a playgroup meant for 2 and 3 year olds, wrongly giving his age as 3, so that he could ‘pass’. Families would invite over neighbourhood children and the children of domestic helpers to play with the child in an attempt to coax him/her out of the cocoon of self-absorption, and resort to various rationalizations to cover up their worries. As one mother said, “we were all fooling each other to be happy... we could see that things were not the way they should be.. but we would try to see the other side.. the child was playing with the remote control, he could drink from his own glass.. but still he was unable to utter a single word...” Mothers in particular narrated how they sometimes felt that there was something amiss, but then immediately felt guilty for thinking such thoughts. One mother who insisted on taking her child to
pediatricians and psychologists was dubbed a “neurotic, over-demanding mother” who could only find fault with a child who was otherwise showing normal development. (He was eventually diagnosed with Asperger’s Syndrome at the age of six.) Her husband and parents refused to give credence to her fears; her husband remained ‘in denial’ for several years.

8. **Needs competing with illness responses**: Apart from the factors discussed above, families sometimes could not seek help due to other equally pressing needs, including the birth and care of other children, career related responsibilities, and, as we shall see in pt. no. 10, the logistic difficulties involved in seeking help.

9. **Competing possible interpretations that can be assigned to symptoms once they are recognized**: This point has been elaborated in other contexts. As we have stressed, the symptoms displayed by children were often seen as reflective of inadequate familial stimulation and support rather than innate deficits. We have mentioned earlier how autism frequently falls into the cracks between mental disability and mental illness as it impacts the core ‘human’ capacities of language, imagination and social functioning. It is far easier to see a child who will throw tantrums to obtain his favourite sweet as a ‘spoilt brat’ (a reflection of bad parenting) or in extreme cases, a ‘mentally disturbed’ individual rather than a person whose neurological development is aberrant. As a parent remarked, “...it is only when you see a child with autism that you realize how amazing it is the way children learn social behaviour so naturally.” Order and normalcy are revealed only when they are breached, and psychiatric and developmental disturbances are such breaches.
10. **Availability of treatment, proximity, psychological and monetary costs of taking action:** The narratives of the thirteen families in the sample who migrated to Delhi specifically for the sake of the child reveal the difficulties, they faced in finding diagnoses and guidance. Even within the metropolis, families reported the callous, casual attitude of some doctors and clinicians who dismissed the child as “hopeless” or a “gone case” or else subjected families to multiple referrals, tentative or inaccurate diagnoses and, above all, uncertainty. These points shall be examined in greater detail in the next section. We may also mention the monetary costs involved in doctors’ consultation fees, travel, and the difficulties in obtaining appointments, leave from work and the long hours waiting at hospitals and clinics with a child whose difficult behaviours become even harder to manage in an alien and sometimes disturbing environment like a hospital.

Unlike physical handicaps, cerebral palsy or mental retardation, the social and emotional deficits that characterise autism are not easily recognized as symptoms of a neurological condition, and often manifest themselves in ways that can be explained with recourse to other factors. Thus, a child’s aloofness could be attributed to his “nature”, his speechlessness to heredity (family lore about late speakers abounds in the narratives) tantrum throwing to over-indulgence. When these symptoms regularly pose a challenge to family functioning and create situations of acute social embarrassment, the need to “normalise” may be overcome by the need to seek help. Tolerance of socially inappropriate behaviours varies; violent or self-injurious behaviour is likely to elicit a greater response than aloofness, withdrawal or inability to mix with peers. When the family arrives at the painful acknowledgement that something is wrong that cannot simply be explained away, the search for an explanation or diagnosis acquires salience.
Recognition of a problem is the first step of the process; however diagnosis of autism continues to create much confusion in actual practice. Cohen and Volkman (1997) argue that there is no other developmental or psychiatric disorder of children for which such well-grounded and internationally accepted diagnostic criteria exist. The most commonly used diagnostic systems are the Diagnostic and Statistical Manual (DSM-IV; American Psychiatric Association) and International Classification of Diseases (ICD-10; World Health Organisation, 1992). However, as Daley (2004) points out, actual diagnosis requires not just familiarity with diagnostic categories but also a belief that the symptom is problematic. The next section deals with the complex process of obtaining an appropriate diagnosis.

2.2 THE PROCESS OF OBTAINING A DIAGNOSIS

The preceding pages have brought out the gradual unfolding of awareness amongst family members that the development of the child was not typical and there was clearly “something wrong”. Parents were often unable to exactly pin-point what they felt was wrong, because, in most of the cases, the child was achieving normal developmental mile-stones in motor functions and in some cases was also developing speech. At the same time, they reported an uneasy awareness of the child’s oddities which they sought to explain away as bachpana (immaturity, childishness).

Some of the narratives reveal “moments of truth” that strike parents and force them to confront that something is amiss. One parent described how his 2 year old son woke up from sleep one afternoon. “..The look on his face was absolutely blank.. It was like a stone… I knew then.. it just hit me..”
One of the respondents described his “moment of truth” which occurred on the 5th birthday party of his child. “We had invited all his classmates.. the boys were using *gaalis* (abusive words) .. it shocked me, of course, but I could see that their world was different from his... I remember one little girl.. when the balloon bursts and the toffees fall out… she was collecting them... stuffing her hands and pockets.. actually covering them so that non-one else could get them... (my son) just picked up one toffee and ate it standing there...”

“Diagnosis stories” told by parents reveal the oscillation between doubt and hope, the uncertainty of not knowing how bad things are because doctors and specialists themselves appear so unsure; and the shock, pain and disbelief when they receive the news that the child not just has a mental disability, but that there is no known cure.

**Multiple Referrals, Multiple Diagnoses**

Diagnosing psychiatric illnesses or mental disabilities in very young children is akin to aiming a bullet at a moving target, as childhood is a time of immense change and development. Clinicians have to draw a fine line between sensitizing families to any deficits or delays in the child’s development and delivering a definitive and difficult diagnosis which may break the spirit of the family and destroy their hopes altogether. However, as some of the narratives reveal, doctors were not always sensitive. Some of them gave the diagnosis “as though it was a death sentence”, as one parent remarked. A pediatrician at a leading Delhi hospital told the parents of a 4 year old girl, “She will never be able to do anything. Forget about sending her to a good school.”

A psychiatrist, diagnosing a child as schizophrenic told the shocked parents that it was a “hopeless case” and the boy may one day need to be sent to a mental asylum. Identifying Rett’s Disorder in a 4 year old child, the pediatrician at one of Delhi’s
largest public hospitals merely jotted down “probable Retts” on the case-paper. Later in the day, when the father checked the Internet, the import of the diagnosis struck him.

Most families reported that they had visited a number of doctors before obtaining diagnosis. Some of the common patterns were as follows: The general physician/family doctor who had usually seen the child since infancy would try to allay the family’s fears, giving them the ‘tried and tested’ explanations of late speakers being very intelligent, or blaming parents for not talking to the child enough or giving into its wishes too easily so that it became willful and ‘refused’ to speak. The family would usually go away reassured, but soon become discomfited or disturbed by the child’s behaviours (new ones or persistence of the earlier ones). They either returned to the doctor or sought another opinion, usually that of a paediatrician, psychiatrist or child psychologist (either private practitioners or at large hospitals). The most frequently visited hospitals were the All-India Institute of Medical Sciences, New Delhi and the National Institute of Mental Health and Neurosciences, Bangalore. 12 families in the sample had consulted at AIIMS and 5 at NIMHANS. The rest had consulted only private practitioners. Parents had mixed experiences with the specialist doctors. While 5 children received prompt diagnoses at the very first visit, the rest were given either very vague or tentative diagnoses. Some of the labels included ‘Probable Autism’, ‘Minimal Brain Dysfunction’, ‘Speech and Language Delay’, ‘Mental Retardation’ and in one case, ‘Childhood Schizophrenia’.

One of the children in the sample who has cerebral palsy and mental retardation in addition to autism, was receiving care at a special needs centre ever since his deficits were detected in infancy. However, his autism was recognized much later, when he was nearly six. Lata, mother of Anu (aged 12 at the time of the fieldwork) recalled with a
shudder the early years of uncertainty and confusion before the child was diagnosed with Asperger’s Syndrome. She would take him to one therapist and special educator after the other, barely giving him time to eat and change after school. He had daily academic interventions, occupational therapy and a weekly session with a special educator who pronounced that the child was not impaired but ‘gifted’! When he finally received a diagnosis, the confusing, often contradictory symptoms fell in place. She understood his ‘disconnectedness’, his social impairments and islands of great ability in certain spheres like mathematics. She bitterly regrets the stress and exhaustion her child had to face as a result of all this uncertainty.

Reflecting on the long and confusing process of obtaining a diagnosis for her son, another mother remarked, “therapists don’t want you to get a correct diagnosis because then they’ll lose money... its a racket, so that you can try this, try that... its a seller’s market nowadays.”

However, during a personal conversation, a doctor remarked on how difficult it was for medical professionals to give a ‘definitive’ diagnosis because of cultural and social factors. “If you say the child is mentally disabled, the parents may just give up... there are families, rich, educated ones who just put the child away for the rest of its life because he is disabled... there is so much stigma.” (Fieldnotes, September 2005)

Several clinicians took the ‘middle path’, viz., by providing a probable diagnosis and then referring the family to specialized centres like Action for Autism or Tamanna in Delhi for follow-up. However, it was the “lack of authoritativeness at the delivery counter” as one parent succinctly put it, that took a toll of the parents. In an attempt to preserve hope, doctors often gave uncertainty and unease. However, we may mention that diagnoses of autism have become more common at the present time than they were
a decade ago. Parents of older children in the sample had far greater difficulty in obtaining an autism diagnosis than those of the youngest children. The efforts of the NGO Action for Autism have been instrumental in this regard. In particular we may mention their efforts to sensitise paediatricians who are often the first specialists who interact with the child. The availability of the Internet and growing influence and reach of the mass media have also helped to spread awareness about the disorder.

We shall now discuss the impact of the diagnosis on the families.

2.3 IMPACT OF THE DIAGNOSIS

Writing about good and bad practice in diagnosis and disclosure Hollinrake (2005) writes that she has often been struck by how readily parents will discuss their recollections in later years, She takes this as an indicator of how alive the issues remain for them and how vivid their memories are of such a significant turning point in their lives. She critiques a professional culture which still predominantly embraces a medical model emphasizing cure and treatment; approaches that do not have anything to offer parents of disabled children, and the wider cultural views that marginalize disabled people which resonate in professional attitudes and approaches as well. She cites the work of Cunningham et al (1984); Quine and Rutter (1994) and Scope (1994) which demonstrates that the way in which parents are told the news about their child’s disability impacts their attitudes and ability to adapt to parenting a disabled child in the long run.

At this vulnerable time in their lives, families reported the need to find people who ‘understood’; who would not give them strange looks or point fingers of blame or ridicule. The narratives reveal that the moment of truth about the child’s condition is a liminal moment, a point when their inter-subjectivity and that of the world around them
just do not seem to fit, when self-esteem and self-worth plummet and the world is perceived as a hostile, unforgiving place where there is no room for the child, and by extension, the family.

In this context, we would do well to understand how respondents construed mental disability before the arrival of the child. All of them had seen or known some individual in the community or extended family with a mental disability, although in none of the families was a close relative (parent, sibling, paternal or maternal aunt, uncle or cousin) thus afflicted. The image of mental disability most of them reported was either that of a mentally retarded person or a mentally unstable or ill one. Even the most highly educated and qualified parents who knew about the various mental disabilities and disorders had not had the opportunity to interact closely with such a person. ‘Autism’ was a term that was unfamiliar to all the respondents; some had read about it in magazines (an interview of Merry Barua in a 1994 issue of India Today Magazine was cited by 3 mothers) or in text-books; two of them had seen the Hollywood film The Rain Man which depicted the story of an adult with autism. However none of them had an idea of what autism actually ‘looked like’, what its behavioural manifestations were, and how it was different from other disorders. The term ‘mentally disabled’ connoted a being who was dull, vacant, slow, with sluggish physical movements, drooling mouth and low intelligence. Some mentioned ‘slant eyes’, obviously referring to people with Down’s Syndrome. One mother informed that she could not believe her child was mentally disabled because he had such bright, intelligent eyes; he was so “chust” (active) and skilled in the use of mechanical and electronic devices. The stereotype of the ‘idiot’ who is sub-normal and deficient in abilities and skills appeared quite well-entrenched in the thinking of the respondents.
This stereotype contains strong elements of revulsion, fear and rejection; such a person is deemed ‘unfit’ to live in a world that values achievements, especially intellectual ones. This brings us back to the ‘invention of the feeble mind’ (Trent, 1994), wherein the mind-body dualism characteristic of Western thought has permeated the ideological make-up of the Indian middle class, and its emphasis on academic achievements as the key to social mobility and status.

Therefore, to be told that their child was “one of them” (i.e., the intellectually disabled) came as a great shock to these middle-class and upper-class upwardly mobile and well-qualified families. As one of the mothers said, “...when I was pregnant, I had no idea whether it would be a boy or girl.. good in sports or good in art.. I was sure, though, that whatever else he would be, he would be beautiful and brilliant.” The realization of the disability meant the loss of the brilliant child that she and her husband had been expecting, and coming to terms with the fact that he would have to be taught step-by-step and with great patience the things that other children in their family and social circle did with such ease. Another mother reported how upset she felt when she took her son for a psychological evaluation for the first time. There were several other children there with mental disabilities and her reaction was, “My God! Is he one of them?”

The reactions of the family to the diagnosis must therefore be viewed keeping in mind the middle-class aspirational structure, the competitive educational system, the need to earn a living through one’s intellectual capacities and attainments, the dwindling away of traditional avenues of support and the absence of alternative structures to replace them (eg. Social security net, well-maintained and efficiently run homes for mentally disabled adults, etc.) While thoughts and worries about the future do eventually take
hold of families, their immediate reactions upon being told about the child’s condition range from denial, shock, anger, despair and disbelief.

Parents reported that the hardest thing for them to accept was the information that the disability was “incurable”, that no medicine, therapy or treatment could make the child “normal”. Prema, the mother of little Sakshi was told by the paediatrician “..ye autism hai... iska koi ilaaj nahi... aap ise accept kar lijiye..” (It is autism, and it is incurable. You must accept it). Prema was to spend the next few months just holding the child and weeping all day. They did not tell their relatives or friends. She started to compose herself when she heard her elder child phone up the father at work, “..Mummy Sakshi ko lekar roti rehti hai.. mai bahut pareshan hoon”. (I am very worried; Mummy just holds Sakshi and keeps weeping).

Some parents refused to accept the diagnosis; Vasu, father of 12 year old Krishna just walked out of the doctor’s office and refused to hear any more about it. “I refused to accept it.. that my child was a lesser mortal.. each of us is of a piece.. we all grow and develop in our own ways..”

Paradoxically, his wife confessed to a feeling of relief at being told the condition had a name. It was the uncertainty of not knowing what was wrong with him that had taken a toll of her patience.

In the case of families of children who had shown the regressive manifestation of autism, (i.e. whose symptoms had surfaced after a period of normal development) it was hard to accept that the child who had walked, talked and seemed so ‘normal’ was impaired for life. One mother said “..it was like a nightmare.. a cruel joke.. I have tapes
of her reciting rhymes.. I remember her first words.. to see such a child forgetting everything…” (she broke down at that point).

Hearing the words “your child can never recover” or variants thereof, was, according to all the parents interviewed, the greatest shock of their lives. The shock was followed by a period of intense grieving, sometimes for months and years at a stretch, before the task of re-organising, re-grouping and coming to terms with the news was undertaken. The factors that came into play at this point included their feelings of love and affection for the child, the support of family and friends, the need to protect other children (if any) from the crisis, belief in God or the supernatural and construal of their own roles as parents with a “special responsibility.” The following quotes exemplify the last point:

“I told myself, ‘God wanted you to have her, she was sent on earth specially for you.. crying won’t help.. you are so special that she will be safe in your hands”’. (Swati, 32, mother of 7 year old girl.)

“God sent him to us for a purpose. For many years we did not have a child… then God sent him to us.. part of God is there is my son… my destiny is with him..” (Deepak, 47, father of 12 year old boy)

“No cry-cry, sob-sob.. no blame-game.. it’s a part of life, you have to do it, go on with it… we worked hard, did our research, tried to do our best.” (Daisy, 45, mother of 12 year old boy)

**Grieving and Coming to Terms**

The psychological models used to understand the impact of a child’s disability derive from those concerning human reactions to bereavement and loss. They are based on the
notion that parents are grieving the loss of the normal child they were expecting. In these models, for example, those of Bowlby (1979) and Worden (1991), certain stages or phases of grief including tasks to be competed in each stage are proposed, which broadly cover the following:

- shock and numbness
- yearning and longing
- denial
- anger
- bargaining
- sadness and depression
- acceptance and re-organisation

These models have been criticized for being prescriptive and fostering judgements about what is normal and abnormal, denying individual difference in grieving process. New models emphasise the individual context of grief and social behavioural and spiritual dimensions as well as emotional and physical ones (Payne, 1999).

Olshansky (1962) developed the concept of ‘chronic sorrow’, later supported by Wickler et al (1981), which he applied to parents of disabled children, suggesting that the grieving process was ongoing and later life cycle transitions and events often serve as a reminder of the original loss and re-awaken the process of grieving. For example, watching the children of other family members and friends grow and develop normally serves to remind parents of the normal child they have lost. The difference between a three year old autistic child and a regularly developing age mate is not as marked as the difference between the same children at eight or ten years old. Chronic sorrow surfaced sharply during occasions when these differences became evident. One of the mothers, who is an avid reader, watches her friend’s children enjoying Harry Potter books and feels a sense of loss that she will never be able to enjoy reading and sharing books with her own son. A mother with two regularly developing siblings in addition to the autistic
one narrated how sad she felt that their worlds were so different. On family occasions, when the achievements of children are discussed and praised, some parents felt helpless and sad that they had “nothing to say”. The mother of a young adult with autism told me how her son had all the virtues a person could want, namely, simplicity, honesty, a hardworking and affectionate nature. Yet he was forced to remain on the fringes of society because of his disability, even though he had so many valuable gifts to contribute.

Seeing the worlds of other children in the family and neighbourhood becoming variegated and multidimensional while the autistic child remained “frozen” in childhood, was a source of constant and chronic grief.

The nature of the grieving process is also a gendered one. Even though both mothers and fathers reported intense emotions, mothers, due to their greater proximity with young children, took the news very hard. They reported intense grief, a sense of hopelessness and anger at God, fate or destiny, and also simultaneously, feelings of protectiveness, love and mamta (mother’s love). One mother said she finally understood that the reasons for her child’s behaviour were not willfulness or perversity, but something beyond his control. She felt great regret at the number of times she had slapped, pinched and screamed at the child earlier. “It’s not his fault... Can he help it if God has made him this way? .. But I’m his mother.. I shouldn’t have done all those mean things... God will never forgive me...” An exception to this pattern in the sample was a mother who withdrew from the child, expressing her inability to understand her. She busied herself with her household duties as the eldest daughter-in-law of a joint family. She has an extensive social network comprising her natal family where she often visits with her younger, regularly developing child. The responsibility for the care
of the autistic daughter is vested with an unmarried niece, who looks after the little girl “...as if she is my own child”. She has suspended her own plans of marriage because she believes that the mother is incapable of looking after the child.

The reactions of the fathers was no less intense in terms of grief and pain but sometimes manifested in flight. Some started spending long hours at work with the justification that they needed to provide for the child’s future. One or two resorted to staying out of the house for extended periods, and drowning their sorrows in drink. Few couples reported sharing their grief and seeking solace in each other; most said that each handled their grief in their own way, drawing on their own support systems, usually their natal kin or friend circle. Yet, they made allowances for each other, compensated for each other’s weaknesses so that the care of the child was not compromised. The following stories bring out the different ways in which parents responded to the disability and the “couple work” (Blumstein, 2001) i.e. speaking for each other, covering up each other’s lapses, presenting a ‘united front’ despite their innate differences that enabled them to slowly come to terms with it.

Case-1

Sindhu’s and Deepak’s son Chinky was diagnosed autistic at the age of five. The mother recalls days of intense loneliness and depression when she would weep silently in the bathroom and during her puja. Deepak was busy with his work staying out of the house for long hours and had started drinking heavily. She could not talk to him about the child without weeping, leading to emotional scenes that left both of them drained and uncommunicative. She became very sensitive to comments, however well-meaning, on Chinky’s condition, and highly protective of the child. She would pray fervently that he would start to talk and dream that it had actually happened. Waking
up, she would find him exactly the same. Her faith in God and the law of *Karma* helped her to deal with her pain. Her father explained, using a modern idiom. "It's like repaying a loan. The amount of E.M.I. will vary, but the loan has to repaid anyway."

She received much emotional support from her parents. However, their well-meaning advice on how to 'handle' the child would upset her, and one day she broke down and wept, "*Agar aap hi nahi samjhoge to mai kahan jaaoo?*" (If even you do not understand, where do I go?). As her awareness of autism and other disabilities increased through reading, she realised that Chinky's symptoms were milder than those of many other children. This gave her some relief. The birth of their second child (who is regularly developing) gave her confidence and she revelled in the 'normal' childhood of her daughter. Chinky himself started to show improvement with appropriate intervention, and with the arrival of his baby sister, his social skills also improved.

Through the long-drawn out procedure of referrals and diagnosis Deepak kept his fears about Chinky to himself. "..(I was) cut off from reality.. wanted to stay away from the scene.. Keep to myself... I took refuge in alcohol..." He would frequently lose his temper. Once, when Sindhu purchased some furnishings for the home, he flared up "..how can you do this when your child is this way..?" He experienced bouts of self-pity as he had struggled very hard throughout his life. Chinky was born after several years of marriage, and his disability appeared to be the last straw.

Although Deepak's difficult behaviour was a trial to Sindhu, she says she forgave him, because she believes that men are inherently weak and it is the women who have reserves of fortitude and self-sacrifice and are ultimately responsible for holding their families together. Chinky's problem made her determined to save her marriage at all costs, as she believed he needed the support of both parents.
Deepak’s gradual coming to terms, his “spiritual transformation”, as he puts it, occurred when he started “seeing God” in his child. He believes the child is his lucky mascot; his Vishnu Bhagwan, and the cause of his progress and prosperity.

Today, Deepak and Sindhu have reached a stage wherein the reality of their child’s condition has permeated every aspect of their life. They know that no ‘miracle’ is going to cure him, and they must accept the reality of his difference. Deepak now praises Sindhu’s ‘tolerance’ and ‘self-sacrifice’: she is quietly satisfied that her husband is at last becoming ‘domesticated’. They are united in the need to keep the family together at least for the sake of the child. Their different styles of coping (tragic hero versus self-sacrificing woman) are mutually complementary. Their construction of each other in these terms has helped to maintain the equilibrium in their relationship, and helped them to come to terms with Chinky’s disability.

Case-2

In the years leading up to 12 year old Anurag’s diagnosis, his mother, Lata became prone to fits of anger, storms of weeping, and the symptoms of a clinical depression. She would sometimes lose control and slap or shout at Anu (as he is affectionately known) if he forgot something, did not follow instructions or threw tantrums. She would live in fear that he would forget his way, be kidnapped, get lost in a crowd, accident or disaster. Things became so bad that her husband Kartik forced her to see a psychiatrist who put her on medication. Her symptoms of depression reduced significantly, thus helping her cope better. The fact that over time Anu has settled and is making good progress at school and socially helped to ease her fears somewhat. But she still is a “worry machine”, as Kartik describes her. She says,
".. I’m a pessimist ... always believe the worst will happen.. I worry about school.. social issues, will he get married, our finances... everything..." Their parents and relatives although very supportive, could not understand what was “wrong”. They said that the child was merely shy and withdrawn and would eventually blossom.

Kartik, as a counterfoil to Lata’s nervousness, was calm, and confident, much to the chagrin of his wife, who thought he was unfeeling and indifferent. Lata’s reactions to Anu’s oddities were violent and extreme, therefore Kartik deliberately worked on creating an environment wherein the child would not feel “threatened by her demands”.

"..She’d fly off the handle.. I’d be soothing her.. comforting Anu.. you could hear her screaming three buildings away.. I’d take Anu out for 4-5 hours.. Let her cool off..”

".. I went from being in denial for a very long time.. the way Lata was reacting.. forced me to go the other way... I wanted to believe what a lot of people were doing.. that he’d develop eventually...”

At the same time, he admits that had it not been for Lata’s insistence, her refusal to be cowed down by the label ‘neurotic mother, they would probably not have been able to find out Anu’s problem and that would have caused him far greater problems subsequently, especially during adolescence. Both Lata and Kartik have brilliant academic backgrounds. They admit to a feeling of sadness that their child is not like them. Kartik says he always thought of himself as a learner, someone who could pick up things easily and naturally. It was a big blow to realise that Anu needed to be taught things very slowly and patiently, that he was not a “natural” at most things. Both are determined to help him “pass” in society. His difficulty is kept a secret, and only recently have they come to terms sufficiently with it to talk about it.
Lata's fears for her child and her anxious desire for him to be like everyone else, "not stick out like a sore thumb", are offset by Kartik's calm good humour and confidence, enabling them to face the disability and move ahead with their life as a family.

**Discussion**

The above cases bring out how grieving and acceptance are not just personal or individual experiences, but are also experienced in response to and in conjunction with the feelings of other members of the family. We note how the two sets of spouses, while experiencing their own burden of grief and pain at their child's disability, also made allowances for and accommodated each other's responses. While Deepak and Sindhu enact the traditional "tragic hero" and "long suffering heroine" script, Lata and Kartik play the modern urban couple, i.e. the high-achieving, 'neurotic' wife and the urban "new-male" who is comfortable with his nurturant, 'feminine' side. The 'couple-work' they perform ensures that the family as a unit is not threatened.

It comes as no surprise that Deepak and Sindhu had an arranged marriage, that Deepak is the sole breadwinner and Sindhu has 'sacrificed' plans for a career because she feels her duties lie with her children particularly the disabled one. Lata and Kartik who studied and worked together, had a self-choice or 'love' marriage. They juggled their work schedules to ensure that their child got sufficient care. In fact, Kartik opted to do freelance work from home during Anu's difficult early years, when Lata was going through a mental health crisis.

What is common to both families are their strenuous efforts to enable their children to "pass". Although Chinky is more impaired, his mother is very particular about his dress, appearance and public behaviour. Anu's parents ensure that he attends parties, sleep-overs and outings with his peers at the public school he attends and work hard at
ensuring that he does not get left out or left behind. The acute grief and pain has given way to a determination to make their children ‘fit in’ and opened a path for action.

The following section engages with the complexity of the disorder and attempts made by families to make sense of it.

2.4 MAKING SENSE OF THE DISABILITY: EXPLANATORY MODELS OF AUTISM

A disease is more than a biological event; it has cultural underpinnings and meanings as well. Susan Sontag’s (1989) well-known work on “illness metaphors” highlights how every disease has certain associated myths, ideologies and metaphors (either positive or negative) which may change over time and may sometimes be based on incomplete knowledge. These illness metaphors may have a powerful impact on both, the patient and the caregiver. Metaphors regarding causality also have an impact upon the provision of care; i.e. maladies believed to be the result of divine wrath are allowed to take their own course, or treated by supernatural means, like placating spirits, exorcism etc.

In her analysis of illness metaphors pertaining to cancer and AIDS, Sontag shows how cancer is conflated with warfare and AIDS with indulgence, delinquency and perversity. Kleinman’s (1980) “disease explanatory models” similarly reveal how people make attempts to perceive and attribute meanings to various diseases, infer signs and symptoms and grade diseases e.g., leprosy is construed as danger and defilement of ‘inferior races’ due to its preponderance in tropical countries which were the victims of colonization (Gussow, 1989; cited in Bharat, 2000) AIDS is seen in terms of the metaphors of death, punishment, crime, war, otherness, horror and villainy (Gilmore and Somerville, 1994).
Shalini Bharat’s (2000) study of the perception of AIDS in low income communities in Mumbai highlights how members come to view AIDS as an alien disease, brought into India by morally degenerate foreigners. As it is thought to be ‘picked up’ by engaging in shameful, promiscuous acts, often with prostitutes, it is also viewed as an ‘invited’ disease and God’s punishment for sinful conduct. It is also seen as a disease of ‘others’; contagious and polluting, associated with uncertainty and decay that isolates people from the community. Such metaphors indicate why the sufferers of the disease, and, by extension, their families, are ostracized and denied even their basic human rights.

We may discuss mental disability and mental illness in this context. The two are often conflated, in popular perception, such that the term paagal (mad, crazy) and its regional variants are used as catch-all terms to cover mental retardation and other intellectual disabilities as well as insanity or mental illnesses of various kinds. A paagal individual is held to be incompetent, erratic, hot-tempered, indulging in unpredictable, and ‘crazy’ behaviour as well as one who is slow to understand or respond. The latter, more “benign” category of persons, as discussed in the Introduction, often go under rubrics like bhola or bawla, seedha or the technical term manda buddhi (mentally retarded, literally, ‘of slow intellect’). Underlying these conceptions is the notion of ‘lack of control’; neither is the individual able enough to exercise control over his/her thoughts and behaviour, nor is family and society able to ‘tame’ or control adequately the affected individual. However, while such ‘unregulated’ individuals were assigned some sort of space within the traditional, pre-modern communities, (eg., the wandering ascetic, the renunciate or mendicant, ‘the village idiot’ etc.), the demands of urban existence permit them no such culturally sanctioned space. Mental disabilities and illnesses are, like AIDS, highly stigmatizing, even though the agency for blame is not laid at the affected individual’s door.
However, the family is often blamed for the individual’s condition. Because the causality of the condition is unknown and it is usually incurable, it has a ‘sinister’ attribute and is viewed as ‘punishment’ or the product of past *Karma*. Because of beliefs in its heritability often backed by science, the existence of such an individual in the family has a negative impact on the marriage chances of other relatives. Thus, mental illnesses and disabilities are construed as punishment, incurable, dangerous, heritable and beyond the pale of social control, as the literature reviewed earlier has brought out. More positive images include childlike innocence, evolved spirituality and access to the divine. We now attempt to analyse the way families recruited for the study attempted to make sense of their child’s autism and the metaphors frequently used by them in the course of our interactions.

**i) Autism as a curse**

Many parents believed their child was an accursed being, because of the difficulties she/he had to face on account of the complexity of the disorder. Self-injurious behaviours, in particular, elicited such a response. When a child slaps himself on the face until he is black and blue or bites his hand until he draws blood, or seems in great fear or distress for reasons that parents are unable to identify, a feeling of helplessness and impotence arises in parents. The father of a 12 year old boy, when asked if he ever got angry with his son, had this to say:

“*Hum kya naaraz honge?... Ye bechara to khud apni haalat se itna pareshaan hai... hum iske liye kuch nahi kar sake.*” (How can we get angry with him? Poor thing, he is in such distress anyway... We can do nothing for him) Parents were particularly concerned about who would ‘put up’ with these behaviours once they were gone.
“While we are here, he’ll be taken care of.. but after us, I have no idea.. I suppose he’ll have to go to an institution..” (Smita, mother of 12 year old boy)

“..I feel so scared.. suppose he hits me and kills me.. he’ll be locked up.. people will hit him, ill treat him..” (Priti, mother of 10 year old boy)

“While I am there, let anyone dare to look at her in a ‘bad’ way.. but when I am gone, who will protect her?” (Kavita, mother of 10 year old girl)

The condition is a ‘curse’ not just for the child, but the whole family. 10 year old Soham exhibits very difficult behaviours including screaming, tantrums, self-injurious behaviours and extreme rigidity (eg. it is very difficult to get him to take a new road to school, deviate from his routine even slightly or adjust to unexpected events like a guest visiting). His mother said that their life had become “hell”. Although she was a qualified engineer, she was confined within the four walls of her home with a child whose difficulties she could not understand or control. Her husband is at work all day, her relatives live outside Delhi, she has no friends and is ashamed and embarrassed to take Soham out anywhere. “Uska hamare oopar itna control hai.. koi zindagi nahi hai hamari.” (We are totally controlled by him.. we have no life of our own.

The belief that these children would be dependent upon the ‘mercy’ of others and the belief that they would most likely not be able to experience adult love, companionship, sexuality and parenthood, reinforced the notion of the disability as a “curse”.

ii) Autism as karma

To what, then, do families attribute this ‘curse’? The overwhelming answer was *Karma*. One mother put it thus:
"Apne kapaal par likha hota hai.. dil pe patthar rakh kar ise sweekar karo.." (Its 'written an one’s forehead' (destiny).. Accept it stoically).

Even the highly Westernized, English speaking, cosmopolitan couples in the sample ultimately attributed causality to 'fate'. They had reflected in detail over their diets, medications and every activity they could recall during pregnancy; one mother speculated that it was perhaps extreme stress that 'caused it', another invoked her hypertension; however, both agreed that these were not sufficient causes.

One of the mothers recounted that she had been blamed by her parents in-law for violating meat eating taboos shortly after delivery. One of the fathers blamed himself for getting his child discharged early from the hospital even though the baby had been placed under observation in the ICU. At the same time, he also blamed doctors for not preventing him from doing so.

When 10 year old Vinny’s mother realized she was expecting him, she wanted to have an abortion as she already had two (regularly developing) children. But her relatives urged her to go ahead with the pregnancy and have a tubectomy after the delivery. She wryly says, "Hamein kya pata tha ki ye akele chhe bacchon ke barabar hoga?" (Little did we know that he would be the equivalent of six children!) It was sheer fate, she says that the child was born to them.

Searches for explanation regarding the causality of the condition were frequently undertaken by parents in the early years of grappling with the disability, but most of them said they eventually gave up thinking about the "why?" and focused on "what now?" The only Roman Catholic family in the sample expressed their belief in the "will of God", but stressed on the need for acceptance and working hard with the child. They
believe that their child’s acquisition of speech at the age of five was the result of the prayers of their family, friends and well-wishers, including the domestic helper who worked in their home for thirty years. Although not a church-goer himself, John, the father, taught his son to say “Thank you God”. They thus combine a belief in divine intervention along with human agency.

We have described earlier how some parents viewed the destiny of their child as inextricably entwined with theirs, as in the case of the father who called his child Vishnu-bhagwan and believed that he was the bringer of good luck and prosperity.

One mother told me that she thanked God for giving her the child, as she was educated, well-off and accepting and could therefore give her a better quality of life than many other families. Another confided how she had terminated two pregnancies before she conceived the autistic child and therefore went ahead with the pregnancy. “He had to come into this world, somehow”, she says.

iii) Autism as an enigma

We have repeatedly highlighted that the complexity and range of symptoms characteristic of the condition and its apparent unpredictability, make it hard for families to comprehend it and deal with it. To adequately ‘understand’ a behaviour, one must trace it backwards, i.e. identify the core issue that causes it. For example, a six year old child throwing a tantrum whilst getting a hair-cut could be behaving that way because the snipping sound of scissors close to his ears is aggravating his sensory issues. The strangeness of the barber’s chair, the cape wrapped around him or the unfamiliar articles all around may further aggravate his fear and discomfort. By preparing the child well in advance for the visit, simulating the experience at home, telling him what to expect etc., the experience can be made less traumatic. However,
undertaking such an elaborate exercise for what appears a routine, mundane activity often frustrates and exhausts families. Strategising and planning on a daily basis is not easy, nor is success always guaranteed.

Moreover, it is difficult for families to predict exactly how their child will respond; sometimes, when they least expect it, the child is compliant at other times s/he may have difficulty. A mother reported how the sight of blood makes her child very fearful, hence a visit to the doctor for cuts and scratches is upsetting for him. However, when he went to the dentist to get braces fitted, he complied with all the instructions and created no fuss. (We may mention that a visit to the dentist is one that is dreaded by parents of even the best behaved regularly developing children!)

Vasu, the father of 12 year old Krishna exclaimed, “...he can swim, ride a horse but cannot cross the street on his own... he has been toilet trained for years, but suddenly one day he will wet his pants... sometimes you just throw up your hands in the air and ask why...”

Perhaps it is the fact that autism impacts the core human faculties of language, social interaction and imagination that makes it such an enigma. The absence of physical stigmata in most of the children, their very “normal” physical appearance, made their deficits even harder to understand and explain. Even in the case of highly able and verbal children on the autism spectrum, parents reported that they could never assume that the child was “normal”, and that the core deficits that characterize the disorder could well manifest at any time. Parents reported feeling helpless and frustrated at such times.
Narrating her experiences with her son who was apt to run away as a small child, a mother told of how she still could not fully “trust” him not to display such behaviour at any time. “These days, I don’t have to hold his hand all the time.. he walks along with me very nicely. But sometimes, if I let my guard slip, he can just dash off somewhere like he used to. I still have to be on red alert wherever I take him out.”

The variability of symptoms over time also puzzled families. Children would apparently grow out of certain behaviours which were soon replaced by an equally baffling set. Often, such behaviours were taxing and stressful for the rest of the family. Some children would take a fascination to a particular string of words, a tune or television jingle and compulsively repeat it for days together, sometimes at the most inappropriate moments. One child took a fancy to an HIV-AIDS sensitization advertisement regularly broadcast on radio and T.V. He would repeat it verbatim everywhere, leading to much amusement and sometimes acute embarrassment. As the above accounts reveal, autism is viewed as an enigma that is hard to understand and to deal with.

iv) Autism as permanent childhood

A recurrent theme in parents’ accounts about their autistic children is that of innocence, absence of manipulativeness or guile. They described their children as seedha, (simple) man-mauji (free spirited), capable of unconditional love. The term ye samajhdaar nahi hai (S/he lacks the capacity to comprehend/understand) was frequently used to describe them. It may be noted that samajhdaari has both positive and negative connotations; on the positive side it refers to social competence, the ability to function autonomously and control impulses. On the flip side, it may refer to worldliness and cunning. Regularly developing children, some parents said, would soon become materialistic and worldly,
and “extract” what they could from their ageing parents. Media reports about ill-treatment of elders, family feuds in the neighbourhood and anecdotes about brothers willing to destroy each other for property and money were often invoked. The much publicized feud between the industrialists Anil and Mukesh Ambani often came up in conversations. Rationalising the disability thus made parents view their child in a more positive light i.e. as individuals who were free from the maya-jaal (web of illusion) and deceit of the adult world. One parent wryly remarked that her son enjoyed Raja yoga; he lived the life of a prince, unworried by the cares of life and was attended to devotedly by his parents and younger sibling! A father remarked, jokingly, that the first time he was grateful for his child’s autism was when he saw colleagues going through the nerve-wracking process of securing admission for their children in “good” public schools! On a more serious note, he added. “his autism is his gift, not his failing.. its the flag that I carry and I am proud of it.”

While such innocence freezes these children in “permanent childhood” it also denies them the opportunity to lead a “complete” life. Parents expressed anguish that their children may not be able to have friends, fall in love, have a sex-life, marry and set up a family. They found it difficult to conceptualise their children as potential adults, as adulthood implied competence, assumption of responsibilities towards family, participation in the world of work (particularly for males) and autonomous functioning. They worried about their capacity to look after adult autistic children as they would also face the problems of old age and imminent death.
As a result, some parents very frankly said that they hoped their children would not outlive them. One mother said that she prayed everyday for her child to live “only upto 25-30”. Another said she wanted her child to die just one day before her, so that she could depart peacefully from the world.

v) Autism as a sign of divinity

The innocence and absence of guile that parents attribute to their autistic children is sometimes conceptualized in mystical terms. Their appearance of self-absorption, the ‘far away’ look in their eyes, the impression of being in a world of their own, and the physical beauty some of them are endowed with, makes it easy to conceptualise them as ‘divine’ or ‘spiritual’ beings. The cultural space sanctioned to ascetics to withdraw from the world and the high degree of tolerance towards their bizarre, sometimes asocial behaviour makes it possible to conceptualise these children as sadhu-babas (renouncers, mendicants) or lost spirits fulfilling their destiny or karma. Lord Shiva was used by some mothers as a metaphor; he too was aloof, had peculiar habits, bad hygiene and no friends! (Grinker, 2007). Analogies were drawn with the Sufi whirling dervishes because many of these children loved to spin around.

When we consider some of the more disturbing behavioural manifestations of autism, we are tempted to ask if families also view their children as possessed by malevolent spirits, and whether they have tried folk remedies or supernatural ones to exorcise them. Not a single respondent in the study replied in the affirmative. This is possibly because the interviewer was regarded as an “enlightened parent” who, they surmised, would react negatively to such information. Even when I readily admitted that I had been tempted to try such remedies for my son, they dismissed it by saying that we were all educated people and should not become victims of superstition. The unambiguous
message that came through was that even though their children might be a cause of stress and worry, they were “educated parents” who would not resort to superstition or magic. The children were deeply loved and sometimes even revered. The corruptibility of *samajhdaari* was held in sharp contrast to their unimpeachable ‘purity’.

**Discussion**

The metaphors culled from the narratives appear contradictory; eg. ‘curse’ versus ‘divine blessing’; ‘innocence’ versus ‘incompetence’; but in their very contradictions, they exemplify the complexity of the disorder and the cultural underpinnings of mental disability. They also bring out the ongoing attempts by affected families to make sense of and come to terms with the circumstance of bringing up an autistic child. Despite the severity of their handicaps, children are not viewed as an aggregate of deficits or a ‘condition’ to be dealt with, rather, they are loved and valued members of a family. It is worthwhile, in this context to refer to Trawick’s (1990) understanding of love (*anpu*) as a guiding force underlying kinship. Parents in the present study spoke at length about the love they felt for their autistic children and its qualitative difference with their love for the regularly developing ones. The feelings for the autistic child had elements of pity, chronic sorrow, greater sense of responsibility, a strong sense of protectiveness, resentment and irritation, frequent frustration followed by guilt, fear for the future and a sense of unconditionality. This complicated mix of feelings reflected in their understandings of the disorder.

It is also interesting to note that over a period of time, families started to view the autism as intrinsic to the personality and identity of the child, rather than as a thing apart, an inconvenient impediment that would not go away. When asked to imagine their child “cured”, parents of the older children in the sample said that it was very hard
to imagine, as the children would not be “themselves”, but somebody else. One of the
siblings expressed this sentiment perfectly: “It would be great if he was normal.. but he
would not have been my brother. I’d like to have a normal brother… but I also want
this one.”

I found it difficult to accept at face value that the families had not taken recourse to
some kind of faith-healing, magical remedies, supernatural intervention, etc., because
these are so deeply ingrained into our cultural matrix. Their conceptualizations of the
disorder in mystical rather than medical terms coupled with their insistence on medical
interventions made for an interesting contradiction. Perhaps conceptualization of the
more disturbing and difficult aspects of the disorder in bio-medical terms made it easier
to deal with emotionally; at the same time, characteristics of the condition like extreme
social naivete were valourised and projected as fast-disappearing virtues in changing
world. Perhaps this enabled families to appreciate the child as a human being worthy of
love and care.

The ‘encounter’ with autism narrated by families is an ongoing process of adjustment,
understanding and rewriting of life-scripts. It involves a shattering of received notions
of normalcy, redefinition of parental roles and responsibilities, grieving for the ‘lost’,
normal child while loving and accepting the one that has been given to them. It
involves questioning, negotiating and sometimes challenging and overthrowing
conventional norms and expectations about childhood and parenting. Grinker (2007)
cites the case of an Indian mother filming an act of masturbation and showing it to her
teenage son, so that he would learn how to alleviate his sexual tension. This may appear
bizarre and aberrant parental behaviour, but in this context, the author says it is a
perfectly understandable and deeply compassionate act. Perhaps the following quote best illustrates the issues brought out thus far in this chapter:

“Celebrate with me. Rejoice in who he is and who he will become, but forgive me, if, from time to time, I shed a tear for who he might have been.”


2.5 AUTISM AND EVERYDAY LIFE

From where do the complex and contradictory conceptions of the disability arise? They are the products of daily living with the autistic individual; the routines of feeding, toileting, bathing, dressing, play and leisure, rest and teaching. Families learn how to cope with the needs of their autistic member, and at the same time perform other routine and special family activities. The disability gets factored into daily functioning and cannot easily be separated from the other routines performed by the family. The ordinary, mundane, taken-for-granted experiences that constitute everyday life both encompass and weave themselves around the disability, such that it ceases to be a ‘disruption’ and blends into the ‘normal’ course of domestic life. Undoubtedly these families do suffer hardships on account of the child’s disability, but what is sociologically interesting is to study how these hardships and difficulties become part and parcel of the ‘everyday’.

The sociological concept of ‘everyday life’ has proved difficult to define because it is “...the life-world which provides the ultimate ground from which spring all our conceptualizations, definitions and narratives. At the same time... it appears to be a residual category into which can be jettisoned all the irritating bits and pieces which do not fit into orderly thought.” (Featherstone, 1992: 160). The characteristics most frequently associated with ‘everyday life’ according to Featherstone are as follows:
1) An emphasis on what happens everyday, i.e. the routine, repetitive, mundane experiences of the ordinary world which are untouched by great events and the extraordinary;

2) The everyday is regarded as the sphere of reproduction and maintenance, in which the basic activities that sustain the institutional realms are performed, largely by women;

3) An emphasis on the present; “a non-reflexive sense of immersion in the immediacy of current experiences and activities.” (ibid: 161)

4) A focus on the embodied sense of being together in spontaneous, common activities; “an emphasis upon common sensuality, being with others in frivolous, playful sociability”. (ibid: 161)

5) An emphasis upon heterogeneous knowledge wherein speech and multiple voices are valued above the linearity of writing.

Alfred Schutz (1962) refers to the everyday common sense world as the ‘paramount reality’, which can be distinguished from a series of ‘multiple realities’ or ‘finite provinces of meaning’. Habermas (1981) has elaborated a distinction between ‘system’ and ‘life-world’ in which the instrumental rationality of the politico-economic and administrative systems attempts to erode the emancipatory communicative potential of the everyday life-world. The everyday life-world refers to the background environment of competencies, practices and attitudes and the lived realm of informal, culturally grounded understandings and mutual assumptions. The ‘liberative’ aspect of the everyday is also discussed by Lefebvre (1971), and de Certeau (1984). These writers affirm the ordinary practices of everyday life and its capacity to utilize modes of syncretism to oppose transgress and subvert official dominant culture and technical rationality.

In the context of the present study, we argue that an emphasis on the everyday opens up the concept of disability and frees it from a medicalized understanding which focuses on ‘impairment’ and ‘cure’. That which is bio-medically ‘incurable’, as per this model, is thus doomed and hopeless. By focusing on lived experiences, the everyday life-
world, we re-conceptualise intellectual disability as one of the many ways of being in the world. By extension, families grappling with intellectual disability are not pathologized or seen as dysfunctional, rather, we pay attention to the way they construct the personhood, the humanity of their child (Bogdan and Taylor, 1998) through shared routines and “immersion in the immediacy of current experiences and activities”. (Featherstone, 1992: 161)

Writing about the labelling of people with intellectual disabilities, Charlotte Aull Davies (1998) remarks on the vast power differentials between the ‘labellers’ and the labelled. The former are usually adults and the latter children. This labelling initiates a process of socialization of the individual into a comprehensive social identity whose meanings and expected behaviours are constructed externally to the category of those who embody and exhibit them. Intellectual disability/learning difficulty as a category “systematically albeit implicitly, impeaches the personhood of its members.” (1998: 116)

While diagnosis and labelling in a sense robs the child of ‘agency’, the family becomes instrumental in defining the child’s personhood both to itself and to others in society. ‘Interpreting’ the child through the grid of normalcy, the family provides or withdraws opportunities for the optimal growth and development of the child’s potential. We now present accounts of the everyday routines of two families, elicited through their narratives and the researcher’s observations. Family accounts of daily routine reveal multiple strands of culture and the social construction of roles, responsibilities and obligations. They also bring to scrutiny political and historical processes and institutional arrangements which directly and indirectly impact the manner in which families live in the “urban moment”.

124
The first family, that of Divya, is a middle-class, double-income, two child nuclear family residing in a Government Colony in South Delhi. The second, that of Aashu, is a lower-middle class family living in a cramped tenement in one of the “urban villages” on the city’s southern border.

Case-3: Divya and her family

Divya is a beautiful little five year old girl. She was diagnosed when she was two and a half years old. She is hyperactive, non-verbal and needs assistance with most self-help tasks. She has poor bowel and bladder control and is unable to eat independently. She prefers to be by herself and enjoys looking out of the balcony at the world going by. If her needs are not met, she cries and it becomes difficult to calm her. She gets very agitated in crowded places. She attends a Special Needs Centre about 10 km. away from her home. Her mother, Pinky and her father, Rajinder work in clerical jobs in Government offices. Her elder regularly developing sibling, Kavya is a bright, active girl of 9, studying in Class IV at a public school nearby.

The family’s day begins at 5.30 a.m. Divya usually wets the bed and Rajinder’s first task is to change the sheets and Divya’s soiled clothing (Divya prefers to sleep with her father). He assists her in drinking her milk. One of the parents gets busy in the kitchen preparing breakfast and packing all their lunch boxes, while the other gets both the girls ready for school. (They take turns with these chores).

By 7.30 a.m., the girls go off to school. The parents then get ready and leave for office. Kavya is home by 2 p.m. and Divya by 3 p.m. Kavya takes her lunch from the hot-case and receives her little sister at the bus stop. As Divya eats lunch at school, she does not need to be fed. Kavya changes Divya’s clothing whenever she soils it and attends to her needs. They watch T.V. and relax together. Kavya phones up their mother from time to
time to assure her they are alright. By 5.15 p.m. Pinky is home. Rajinder is back by
6.15 p.m. The evenings are spent doing domestic chores and shopping. Kavya runs off
to play with her big group of neighbourhood friends and is back by 7 p.m. Either of the
parents then sits with her and helps her complete her homework. The other ‘free’ parent
takes Divya to the playground or the terrace for some fresh air. Although they say they
have no ‘social life’, they fulfill social obligations like attending marriages and other
family functions. One of the parents attends with Kavya while the other stays home
with Divya, as large gatherings upset her.

Divya loves going for drives, and they sometimes take her for one in their new family
car. They were, for the first time since her birth planning a train journey and were
excited and tense about it.

They have arrived at this mode of self-sufficiency after much experimentation. They
had admitted Divya into a crèche when she was younger, but were not satisfied with the
quality of care. They hired one domestic help after another, none stayed long. Rajinder
wryly remarks that their home had become a ‘training centre’ for ayahs (domestic
help)! Both their employers are aware of Divya’s condition, hence obtaining leave or
coming home early in case of emergencies is not a problem. Both carry cell-phones and
there is a land-line telephone at home. The neighbours are distant and rather indifferent;
yet can be called upon in an emergency. Most of all Kayya is very solicitous and
affectionate with her little sister; almost a surrogate parent. Their daily life is
circumscribed by the clock, as, indeed is the life of most middle-class working couples.
Their daily routine resembles that of any other family of their class; Divya’s special
needs are taken care of by making a few adjustments, incorporating them into their
routine.
Case-4: Aashu and his family

Aashu is an eleven year old boy with autism and cerebral palsy. He is tall for his age, very thin, with poor muscular tone. His walk is a stumbling gait; his fine motor skills poorly developed and he is unable to perform self-help tasks like feeding, bathing and toileting. He is non-verbal, utters grunts and screeches and flaps his limbs uncontrollably every now and then. He sometimes hits himself and scratches his own face until he draws blood. He has a well-formed face with sharp, chiselled features. He attends a model school for children with autism. He is the only child.

Aashu’s mother Anju is a homemaker and his father Hari is a trader in weekly markets (haats) in the city. Anju wakes up at 5.30 a.m. washes clothes, cleans the house and cooks the morning meal. Aashu is woken up at 7.30 a.m., taken to the toilet and prepared for school by his mother. Hari escorts him to the school van. Previously both parents would take him to school on their family scooter; he would sit wedged between the two as he could not control his twitching limbs and might have fallen off otherwise. The rest of the morning is devoted to household chores and relaxation. Hari picks Aashu up at 12.30 p.m., feeds him lunch and then leaves for work. Aashu spends his afternoons at home watching T.V. (the advertisements interest him), and potters around the house. In the evening he goes with his mother to the busy local market to buy milk, fruit and vegetables. He enjoys putting in the tokens in the slot at the Mother Dairy booth and seeing the milk gush out. They return home and Anju busies herself with the evening chores, watching T.V. and feeding him dinner. Hari returns at 11 p.m. and they retire for the night. On his free day, he takes him out to the market or to visit a relative, the temple or the chabootra nearby. Aashu waits for the jhoolwala and enjoys a turn on the swings. They rarely visit the local park since it is quite a walk away. They visit
relatives and attend functions with Aashu, but take care to ‘prepare’ him in advance, so that he can deal with the new situation.

Although their day revolves around the needs of this severely impaired child, they find time to do things together as a couple. They enjoy shopping, visiting neighbours and relatives. They make it a point to attend all the meetings, talks and functions organized by Aashu’s learning centre, even though many of these are conducted in English, with which they are not conversant. Despite their limited economic means and restricted social opportunities they try to lead as full a life as they can including their child as far as possible.

Discussion

How is disability ‘constructed’ through these daily routines? Both families lay a good deal of emphasis on the school routine, ensuring that the child does not miss a day at school, sometimes even sending them even if they have a mild fever or bad cold. In Kayya’s case it may be attributed to the parent’s busy schedule, but Aashu’s parents insist on school attendance because his activities at school are planned and structured, his teachers understand him and work hard with him. They report how their relatives and friends (even educated ones) do not understand their need to send a child “like that” to school. (“jab baccha samajhdar nahi, to school kyu jata hai?” i.e. If the child is not capable, then why send him to school?)

Divya’s parents are rather cynical about what goes on in her school (“time-pass”, says Rajinder) but at least it gives her somewhere to go, it occupies a large part of her day. Vacations are considered a nuisance because it means finding some sort of engagement for both the children at home, availing of precious leave and re-arranging schedules.
In terms of daily activities like feeding; bathing dressing, toileting etc. both children, as mentioned earlier have severe difficulties. Family routines are thus woven around the accomplishment of these tasks. In the case of the family where both parents work, domestic chores are equally shared with the regular sibling playing a critical role as well. However, it would be simplistic to view this as ‘exploitation’ or ‘abuse’; Kavya is a bright, mischievous little girl with a large group of playmates who does well in school and cares about her little sister. She has very naturally accepted her extraordinary responsibilities and discharges them with good cheer.

Aashu, being an only child and with severe impairments is the fulcrum around which the family revolves. The mother’s continued presence at home and the father’s unusual work hours make it relatively easier for them to manage his daily care as well as their own social obligations.

In terms of their interactions outside the confines of the nuclear households, both families demonstrate marked differences, which, as we shall see, indicate the way they construct their child’s ‘personhood’.

Divya’s parents keep her away from public view because her wetting habit and other behaviours are a social embarrassment. As a middle-class Punjabi family with another daughter, they are perhaps also worried about Kavya’s marriage prospects being hampered by the disabled sibling. Rajinder says that very few people know about Divya’s disability. He prefers it that way because he does not like to explain it; it makes him more tense and the reality becomes harder to bear, he says. Aashu accompanies his parents everywhere. Anju reports that he gets strange looks, people point and stare at him. She has had many fights with strangers because of their rude comments but that has not inhibited her. When he throws tantrums in front of others, it upsets the parents.
greatly, but they try to tell Aashu that others won’t like him if he displays such behaviour.

The way families talk to and about their child reveals significant information about the way they construct his/her personhood. One of the observations made during the fieldwork was that Divya’s parents particularly her father, spoke of her as if she had no thoughts or feelings of her own. When speaking of residential schools as a possible option, her father said “..what difference will it make to her?.. She doesn’t even know who her father or mother are..” Aashu’s parents, on the other hand, kept referring to his feelings, his likes, dislikes, his little acts of defiance. Recounting an episode when he took Aashu for a satsang (prayer meeting). Hari described how Aashu sat for a while, then got bored and pretended to yawn to catch his father’s attention. When he got him home, he stayed awake! He narrated this incident with much pride, delighted that Aashu displayed a ‘normal’ child’s behaviour of fooling the parents! It was a poignant and humbling moment because Aashu’s severe impairments make it difficult for one to imagine him capable of such social thought. However, it exemplifies the manner in which agency and personhood are attributed to him, despite his impairments.

As the above narratives suggest, coming to terms with a child’s autism is not a ‘once-off’ event, but an evolving process with numerous pit-falls as well as moments of joy and delight at the child’s achievements and accomplishments, These may be negligible if viewed through the lens of normalcy but considerable when one considers the severity and complexity of the condition. Recognising and respecting the humanity of an individual who seems so different and behaves so oddly may seem the humane thing to do, but is difficult to put into practice. It is through the nitty-gritty of daily life that families learn to appreciate the odds against which their children are battling. While
some families adapt to these circumstances positively, others may flounder, or break under the strain.

The next chapter examines parenting, both as practice and as ideology. By focusing on the way parents of autistic children conceptualize and enact their parental roles, we may gauge the impact of the disability on the family as a whole and examine the factors that promote or impede its resilience and 'staying power' under unusual and difficult circumstances.