

## Chapter 2

# “There Is Something Wrong with My Child”: Encounter with Autism

**Abstract** This chapter examines, through parental narratives, symptom recognition, help-seeking and obtaining a diagnosis of autism. It discusses the processes of grieving and the road towards acceptance with special reference to the differential gendered responses of mothers and fathers. It discusses the explanatory models of disability that emerge from family accounts and through detailed case studies, examines how families deal with the disability in everyday life and construct the personhood of the child.

**Keywords** Symptom recognition • Help-seeking • Grieving • Explanatory models • Everyday life • Autism

This chapter chronicles the long and difficult process of symptom recognition, help-seeking and obtaining a diagnosis, drawn from the narratives of the families recruited for the study. Autism poses profound challenges to cultural conventions regarding child-rearing practices and developmental expectations. The everyday, taken-for-granted experience is shattered when confronted with such an unexpected reality. This chapter will take the reader through the family’s encounter with autism; from the time they first realize that ‘something is wrong with the child’ to the receipt of diagnosis and making sense of it.

It is usually around the second year of the child’s life that families start getting the nagging feeling that the developmental pathway of their child is unusual or abnormal. Finding a name or label that captures the essence of the problem often proves elusive and difficult. Frequently, the ‘problem’ itself is dismissed as being of no significance and it is assumed that in due course the child will become more like his or her typically developing peers and ‘normalize’. Families are subjected to conventional wisdom from relatives and friends; mothers, particularly working ones are cautioned about their faulty parenting. The decline of the joint family is bemoaned; contradictory information and faulty medical diagnosis add to their confusion and unease.

The narratives of symptom recognition, help-seeking and coming to terms with the diagnosis of their child’s autism form the core of this chapter (see Vaidya 2015).

The narratives bring home the feelings of shock, disbelief, helplessness and anger variously experienced by families and the manner in which they attempt to cope with this new and difficult reality. The chapter examines how families accommodate the reality of their child’s condition through everyday life and the daily routines and practices that lend stability and predictability to existence.<sup>1</sup>

The narratives that follow reveal the ‘discovery of autism’, as Desai et al (2012) term it; 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.

## 2.1 Symptom Recognition and Atypical Development<sup>2</sup>

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, mentioned in Chap. 1, Daley (2004) found that the symptom that elicited most concern was lack of ‘social relatedness’, a particular concern in a ‘socio-centric’ context like India where the child’s ability to interact appropriately with others was accorded high value by Indian parents. A study by Edwardraj et al. (2010) on parental perceptions of intellectual disabilities has also noted diverse frames of reference featuring sociocultural, spiritual, and biomedical components. The study by Desai et al. (2012) on families of children with autism in Goa deploys phenomenological methods to access the lived experiences of parents of children with autism, paying due attention to local context and cultural backgrounds. Their interviews with 12 parents of 10 children diagnosed with autism unpack how parents over time, gradually identify the presence of incongruent and atypical behaviours creeping into their interactions with their children which challenge their ideas and perceptions regarding parenting. Crying inconsolably, indifference to the presence of the mother, extreme agitation in public settings like restaurants, lack of interest in others, etc., are some of the disturbing symptoms reported by parents.

In an early text on diagnostic issues in autism, Volkmar (1987) had noted how the social behaviour of young autistic children was remarkable because of the sharp contrast between it and the demanding, omnipresent sociability of non-autistic toddlers and pre-school children. He also brought out the contrast between the

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<sup>1</sup>The device used in this and later chapters is explicating themes through case studies which highlight key issues and concerns. The participants in the study shared generously aspects of their experiences and highly personal and often painful recollections. Interviews were conducted in both Hindi and English depending upon the comfort level of the participants. All the quotes in Hindi used in the book have been translated into English by the author.

<sup>2</sup>Some of the discussions in this section may be found in Vaidya, 2015.

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. In other words, the world of ‘things’ appeared more interesting to them than the world of people.

With the benefit of hindsight, I recall how my autistic son would be extremely particular about the exact location and placement of household items and go into a frenzy if they were rearranged. He was, however, not particularly interested in the comings and goings of people in the house. In a similar vein, a mother narrated how her child appeared quite indifferent to his regularly developing sibling. One day at the bus stop, while waiting for her older child, she noticed another mother with her toddler. She saw the way the child got excited when she saw her brother, smiled and babbled. However, her own son just did not seem to care that his brother 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 and 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. A mother recounted how different her child was from other children when she compared him with another two year old child:

“I was shocked at the things she could do. Her mother said ‘shut the door’ and she actually went and shut it! I also saw how she was nodding and shaking her head, communicating with gestures. But this fellow? (gesturing to her son) He was as unresponsive as a stone. I tried to convince myself that girls learn quicker but I realized he was not normal”.

The notion that ‘boys are late speakers’ was frequently used to allay the parents’ fears; they would be compared with other late speakers in the family who eventually turned out to be highly talkative. “I was told that once he starts speaking you will wish that he would stop!” recounted a mother ruefully. Explanations like ‘the tongue does not move’ or as reported in Desai et al.’s study, *Jeep Zodh asaa* (Konkani for ‘the tongue is thick’) were also given to account for the difficulty in speech.

Parents also recalled strange behaviours like sudden, inexplicable displays of fear, aversion to certain sounds and sights that elicited screaming, running and hiding behaviour like aeroplanes, firecrackers, or the whistle of the pressure cooker. These reactions were attributed to the child’s extreme sensitivity. One mother reported how terrified her child became when he was placed on a lawn, probably on account of the unfamiliar sensation of grass. Another child would hide in fear at the sight of a particular logo of a TV channel on the screen. I also learnt about a child who had such an aversion to the sound of his mother’s voice that he had to be ‘de-sensitized’ by being exposed to the taped sound of the voice for slowly increasing periods daily until he finally became used to it.

Deafness was a possibility some parents considered, but they also narrated how the child who could apparently not ‘hear’ his own name from close quarters would rush to the TV set at the sound of a particular commercial, or unerringly catch the rustle of a toffee wrapper in a trouser pocket. Parents also recalled their confusion at the lack of responsiveness of the child to his or her own name. A mother recounted an occasion when her husband called out to the child repeatedly. He was nearly 2 years old but seemed utterly oblivious to the sound of his father’s voice or recognition of his own name. “Our eyes met for a few seconds and both of us in that instant seemed to register that something was ‘wrong’”, she said.

“Dirty habits” like picking up food from the dustbin or street, smearing faeces or spit, unawareness of a sense of danger (drinking cleaning fluids in the toilet, running on to a busy street, hiding under cars, etc.) were also reported, but explained away by remarking that all children did these things anyway. I have personally experienced instances of a child running away oblivious to their surroundings; only to be found later by the frantic family fiddling with the hubcaps of a car in a distant car park or exploring a 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 Delhi’s busy markets, staring fixedly at his reflection in a puddle, apparently oblivious to the commotion around him.

Parents and mothers in particular earned disapproval from neighbours and relatives when the child behaved in a socially inappropriate manner; they were accused of spoiling or pampering as well as neglecting training the child in social skills. Gray (1993) found that parents with autistic children feel stigmatized in public situations like the market or mall and those parents of younger or more severely disabled children felt more stigmatized. While Indian society by and large tends to be tolerant of children (“*aakhir baccha hi hai*”! “after all s/he is only a child” is a commonly heard refrain), contemporary urban spaces like airports, malls, metro stations, restaurants, etc., are impersonal and lacking in warmth or a tolerant attitude towards difference. They can all be daunting to persons who find it difficult to understand social cues.

‘Unconventional’ or ‘disruptive’ behaviour is considered highly undesirable and parents with a ‘difficult’ or ‘unmanageable’ child face censure and embarrassment. In many cases parents were asked to leave shops or establishments (sometimes very rudely) because of their child’s unusual behaviour; one parent threatened to take legal action against an upscale club in the city when they requested him to take away his young son who was running around the dining hall making strange noises.

Bad parenting practices were often ascribed to these families. One particular behaviour that caused great stress and anxiety was when a child would throw a tantrum or display extreme reactions to seemingly trivial events. These outbursts were sometimes accompanied by self-injurious behaviour like headbanging, 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 respondents 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 made me feel a complete failure as a father”.

Viewed in isolation, none of the individual behaviours described above is particularly remarkable or alarming; taken together, as a pattern they assume a different dimension. They indicate the fundamental social deficits characteristic of autism, the innate difficulties which Leo Kanner (1943) first noted in his 11 young patients (see Chap. 1). Parental narratives of the early years of their children’s development unfold a slowly dawning realization 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 (spinning wheels of toy cars, arranging blocks in stacks, preoccupation with parts of objects) and exploring their environment.

Out of the 20 children in the present study, only two had delayed physical milestones. The absence of any physical stigmata and the unusually attractive appearance of some of these children did not mark them as impaired or ‘abnormal’. They were described as in Hindi as *ajeeb* (strange), *ziddi* (obstinate), *abhi samajh nahi hai* (lacks understanding/maturity) or paradoxically, having extraordinary intelligence. But, as the behaviour increased in intensity 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, socially immature 3-year old was admitted to a nearby play school in the hope that it would enhance his social skills and stimulate speech:

The teacher told me he would just run to the terrace and spend the whole time there. He was not shy or scared like some of the other children but 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 in lay or commonsensical constructions. 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. Some of the families in the study also recounted that their children apparently developed normally for the first 2 to 3 years, but then started to regress. One mother told how her daughter’s early development appeared quite normal. By the age of two she had started following her elder brother around the house, repeating what 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. The mother was in shock and blamed herself for not seeing that something was ‘wrong’ with the child, something that a stranger could catch immediately. Another child whose early development was reported to be ‘normal’ by the family members, appeared to regress after a prolonged fever at age 3. The child 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.

Writing about help-seeking behaviour in the context of illness and disability, David 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 which looks at the importance of socio-cultural factors and beliefs regarding health and sickness, Mechanic (1978, pp. 268–269) identifies ten determinants affecting response to illness/disability. I found this a useful framework with which to understand help-seeking behaviour in the context of autism.

**The visibility, recognizability and perceptual salience of deviant signs and symptoms** With respect to the early symptoms of autism, namely delay in language acquisition, lack of social relatedness and emotional reciprocity identified above, families found it hard to conceptualize them as symptoms of a medical or clinical condition. Rather, 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 grandparents, 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.

**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 to the child’s health or future. Unlike physical disabilities or disorders, they were not thought of as sources of potential harm to the child at least at the initial stages.

**The extent to which symptoms disrupt family, work, etc.** Families would resort to seeking medical or other help when their child’s symptoms started becoming disruptive or unmanageable. For instance, self-injurious behaviour or biting and hitting 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. There are instances of children with such intense self-injurious behaviours that they were made to wear a protective helmet and thick gloves or mitts to minimize the damage to their own persons.

**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 4, all the children in the sample displayed behaviours that were decidedly different from that of their age-mates and typically developing peers. 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 time of securing admission to school was often the turning point; parents realized that the developmental delays and peculiarities that they had hoped would go away by themselves were here to stay. I have written elsewhere about my difficulties in finding pre-school placements for my autistic toddler who displayed not the least interest in the letters of the alphabet nor the names of fruits and vegetables, but could correctly identify the make of every car he saw on the road, and covered the walls of our apartment with his favourite brand names! His idiosyncratic patterns of interest marked him as 'different', and later, 'abnormal' (Vaidya 2014).

**The tolerance threshold of those exposed to symptoms** As described above, tolerance threshold of families for symptoms such as headbanging, 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 such as boys being late speakers, etc., 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 the child's social 'dis-connectedness' more as the product of reduced opportunities for interaction rather than as a developmental delay.

**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 contributed greatly to early symptoms not being 'picked up' or 'read' by caregivers and clinicians alike. 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 woh baccha hi hai*" (s/he is only a child after all) is used as the clinching argument to justify or rationalize the child's difference.

**Basic needs that lead to denial** It is very difficult for parents to conceptualize 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 seen 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 'normalize' the situation, to attempt to make the child 'pass' or 'fit in' was commonly observed. One mother enrolled

her 4 year old to a playgroup meant for 2 and 3 year olds, wrongly giving his age as three so that he could ‘pass’ undetected as a child with disability. Families would invite 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 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 paediatricians and psychologists was dubbed ‘neurotic’ and ‘too demanding’; she was told to seek treatment for herself rather than burden her child with her high expectations. Her son appeared to be developing ‘normally’ but she was concerned about certain odd characteristics and traits which others in the family would not acknowledge. This heightened her sense of confusion and self-doubt. The child was eventually diagnosed with Asperger’s syndrome at the age of 6.

**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 later, the logistic difficulties involved in seeking help.

**Possible competing interpretations that can be assigned to symptoms once they are recognized** This point has been elaborated upon earlier. As we have stressed, the symptoms displayed by children were often seen as reflective of inadequate familial stimulation and support rather than innate deficits or difficulties. Autism frequently falls into the cracks between cognitive 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 with a developmental disorder. 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.

**Availability of treatment, proximity, psychological and monetary costs of taking action** The narratives of the families who migrated from small towns to the big cities specifically for the sake of the child reveal the difficulties they faced in finding diagnoses and guidance. They 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. The doctors’ consultation fees, travel, 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 take a heavy toll.



To sum up, the social and emotional difficulties that characterize autism are not easily recognized as symptoms of a ‘disorder’ 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, 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 normalize 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. Desai et al. (2012) similarly identify the various phases through which families they interviewed passed through on their road to the discovery of autism. The first phase is one of celebration and social cohesion, in which a child is welcomed into the family. In the second phase, parents begin to notice certain oddities and incongruities in the child’s behaviour, but these are seen as temporary disturbances, falling within the ambit of ordinary childhood behaviour. The third phase is when there is a qualitative change in how families perceive these behaviours, particularly in social situations, and also receive feedback from others. This leads parents to the fourth phase in which it becomes clear to them that the child’s difficulties are likely to affect the pattern of life and the child’s future place in the social world.

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 Volkmar (1997) argue that there is no other developmental or psychiatric disorder of children for which such well-grounded and internationally accepted diagnostic criteria exists. 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 arriving at a diagnosis.

## 2.2 Diagnosis Stories: Seeking Answers

The earlier section brought out the gradual unfolding of awareness amongst family members that the development of the child was not typical and there was “something wrong”. Parents were often unable to exactly pinpoint what it was, as in most of the cases, the child was achieving normal developmental milestones 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” or epiphanies that strike parents and force them to confront the fact that something is amiss. One parent describing such a moment narrated, “He had just woken up from his afternoon nap. The look on his face was absolutely blank. It was like a stone. I knew then. It just hit me.”

The father of a child later diagnosed with Asperger's syndrome described his "moment of truth" on the child's fifth birthday party when he realized how different his child was from his peers in terms of social behaviour and self-awareness:

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 burst and the toffees fell out of it, 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 disability, but that there is no known cure. 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 paediatrician 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. In one case, the specialist at a leading public hospital merely jotted down the diagnosis on the case paper and did not explain anything to the parents. Later in the day, when the father checked the Internet in his office, the real import of the diagnosis struck him.

Most families reported that they visited several doctors and other specialists before they obtained a diagnosis. A common pattern could be seen in this process. The general physician/family doctor who attended to 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 wilful 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 appointments with specialists like paediatricians, psychiatrists or child psychologists at hospitals or in private clinics. Parents had mixed experiences with the specialist doctors. While five children in my study 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 intellectual disability in addition to autism, was receiving care at a special needs centre ever since his medical problems were detected in infancy. However, the autism was recognized much later, when he was nearly six.

The mother of a young boy diagnosed with Asperger's Disorder recalled with a shudder the early years of uncertainty and confusion before the child was diagnosed. 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. It's a racket, so that you can try this, try that. It's a seller's market nowadays." However, during a personal conversation, a doctor remarked how difficult it was for medical professionals to give a definitive diagnosis because of cultural and social factors. "If you say the child has a disability the parents may just give up. There are families, rich, educated ones who just put the child away for the rest of his life because he is disabled. There is so much stigma."

In the absence of services and facilities a diagnosis by itself was seen to cause more harm than good. Some clinicians took the 'middle path', viz., by providing a tentative diagnosis and then referring the family to organizations or centres dealing with disabilities for follow-up. In an attempt to preserve hope, doctors often gave uncertainty and unease; a "lack of authoritativeness at the delivery counter" as one parent succinctly put it.

However, as I have earlier discussed in Chap. 1, diagnoses of autism have become more common at the present time. 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 NGOs like Action for Autism and Tamanna, to name just two in Delhi, have been instrumental in this regard. The availability of the Internet and growing influence and reach of the mass media have also helped to spread awareness about the condition. Preliminary findings from a longitudinal study of awareness levels amongst paediatricians by Daley and Barua (2010), analysing data gathered over a decade, indicates that paediatricians today are more aware of autism than in the past and have more experience of it in their practice. This is an important finding, because paediatricians play a critical role in identification and early intervention in childhood disabilities the Indian context.

### 2.3 Dealing with Diagnosis: From Despair to ‘Acceptance’

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.

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 (see Quine and Rutter 1994; Cunningham 1994). 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 intersubjectivity 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 it is interesting to see how respondents construed disability before the arrival of the child. Even though none of them reported the existence of a mentally disabled person in their immediate families, they had all seen or known some such individual in the community or extended family. ‘Autism’ was a term that was unfamiliar to all the respondents; some had read about it in magazines or in text books; a few of them had seen the Hollywood film *The Rain Man* (1988) in which Dustin Hoffman’s award winning performance as an autistic man Raymond Babbitt had become a sort of template for what autism ‘looked like’, at least in the West.

However, none of them had an idea of what autism actually was like; what its behavioural manifestations were, and how it was different from other disorders or conditions. The term ‘mentally disabled’ according to some respondents 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 disabled because he had such bright, intelligent eyes; he was so active (*chust*) 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 those values achievements, especially intellectual ones.

Individualism and mind-body dualism characteristic of western thought has permeated the ideological makeup 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 or developmentally disabled) came as a great shock to these upwardly mobile and well-qualified middle-class and upper-class 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 various disabilities and her reaction was, "My God! Is he one of them?"

The reactions of the family to the diagnosis reflected the anxieties induced by 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. 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'. A parent quoted the paediatrician: "This is autism and it has no cure. You simply have to accept it." She would 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 older child phone up the father at work and say, "I am very worried. Mummy just holds Sakshi and keeps crying and crying".

Some parents refused to accept the diagnosis; Vasu, father of Krishna just walked out of the doctor's office and refused to hear any more about it. "I refused to accept that my child was a lesser mortal. Each of us is of a piece, we all grow and develop in our own ways". Interestingly, his wife expressed a feeling of relief at being told the condition had a name and that there were others who also had it. It was the uncertainty of not knowing what was wrong with him that had taken a toll on her patience.

In the case of families of children whose symptoms had reportedly surfaced after a period of normal development it was hard to accept that the child who had walked, talked and seemed "normal" was in fact autistic and would be so all his 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 could not speak any more and broke down at that point).

Hearing the words, “your child can never recover” or “he/she will always need your care” 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 reorganizing, regrouping 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 revisiting their own roles as parents with a “special responsibility”, as the following quotes from respondents highlight.

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.

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.

No cry-cry, sob-sob, no blame-game... It is a part of life, you have to do it, go on with it. We worked hard, did our research, tried to do our best.

The psychological models used to understand the impact of a child’s disability on the family 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. Certain stages or phases of grief are identified. By working through each of these phases, the process of grieving finally finds resolution and individuals then move on with their lives. The stages of grief include shock and numbness, yearning and longing, denial, anger, bargaining, sadness and depression and finally the stage of acceptance and reorganization (Bowlby 1979; Worden 1991 cited in Vaidya, 2015).

These models have been criticized for being prescriptive and fostering judgements about what is normal and abnormal, denying individual difference in the grieving process. Olshansky (1962) developed the concept of ‘chronic sorrow’, 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 reawaken 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 3-year-old autistic child and a regularly developing age mate is not as marked as the difference between the same children at 8 or 10 years old. Chronic sorrow surfaced sharply during occasions when these differences became evident.

One of the mothers, who is an avid reader, observing her friend’s children enjoying Harry Potter books, felt a sense of loss that she would not be able to discuss her favourite authors in the same way with her own child. Another narrated how sad she felt that the worlds of her regularly developing child and the child with autism 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 would be regarded as a marginal figure because of his disability, even though he had so many valuable gifts to contribute to the community and society. Seeing the worlds of other children in the family and neighbourhood becoming variegated and multidimensional while the autistic child remained at a particular developmental level and with a restricted social life was a source of constant and chronic grief.

The nature of the grieving process is 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 wilfulness or perversity, but something beyond his control. She felt great regret at the number of times she had scolded or spanked the child earlier. "It's not his fault. Can he help it if God has made him this way? But I'm his mother and I shouldn't have done all those mean things. God will never forgive me". A dramatically different response was that of 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 had an extensive social network comprising her natal family whom she often visited with her younger, regularly developing child. The responsibility for the care of the autistic daughter was vested with an unmarried female relative who lived with them and who looked after the little girl "as if she is my own child".

The reactions of the fathers were 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 parents and siblings or friendship 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 case studies bring out the different ways in which parents responded to the disability and the "couple work" (Blumstein 2001) they performed; speaking for each other, covering up each other's lapses, presenting a united front despite their differences, enabling them to slowly come to terms with their child's disability and their own responses to it. The case studies that follow will highlight some of these themes and concerns. The first of these has earlier been discussed in Vaidya (2015).

## 2.4 Case Studies

### Chintu’s Parents

Smriti and Deepak’s son Chintu 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 *pūja* (ritual prayer). Deepak was busy with his work staying out of the house for long hours. 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 Chintu’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 religious faith and belief in 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. [equated monthly instalments] 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 make her defensive and upset. As her awareness of autism and other disabilities increased through reading, she realized that Chintu’s symptoms were milder than those of many other children. This gave her some relief.

The birth of their second child (a non-disabled one) gave her confidence and she found a sense of fulfilment. Chintu started to show improvement with appropriate intervention, and with the arrival of the new baby, his social skills also improved.

Through the long-drawn-out procedure of referrals and diagnosis Deepak kept his fears to himself. “(I was) cut off from reality and wanted to stay away from the scene.... I kept to myself and took refuge in alcohol” He became very touchy and irritable and experienced bouts of self-pity for the bad hand of cards he believed fate had dealt him. Although Deepak’s difficult behaviour was a trial to Smriti, she says she forgave him, because she believed that men were inherently weak.

However, she also believed that women have reserves of fortitude and self-sacrifice and are ultimately responsible for holding their families together. Chintu’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 and the cause of his progress and prosperity. Today, Deepak and Smriti 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 praises Smriti’s “tolerance and self-sacrifice”; she is quietly satisfied that her husband has calmed down. They are united in the need to keep the family together at least for the sake of the child. Their styles of coping are gendered and 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 Chintu's disability.

### **Anurag's Parents**

In the years leading up to her son Anurag's diagnosis, his mother Lata became prone to fits of anger, storms of weeping, and acute depression. She would sometimes lose control and shout at Anurag if he forgot something, did not follow instructions or threw tantrums. She would live in fear that he would lose his way, be kidnapped, get lost in a crowd, have accident or some other disaster.

Once she sought help and counselling for herself, her symptoms of depression reduced significantly and she started to cope better. Over time, Anurag settled and made good progress at school and amongst his peers and this helped to ease her fears somewhat.

But she still remained a "worry machine", as her husband Kartik described her. She said, "I'm a pessimist and 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 believed that the child was merely shy and withdrawn and would eventually blossom. Kartik, as a counterfoil to Lata's nervousness, was calm and unflappable much to the chagrin of his wife, who thought he was unfeeling and indifferent.

Lata's reactions to Anurag's oddities were very negative, 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 him. You could hear her screaming three buildings away. I would take him out for 4-5 hours and let her cool off.

I went from being in denial for a very long time.... The way she (Lata) was reacting forced me to go the other way. I wanted to believe what a lot of people were saying, that he would develop eventually.

At the same time, he admitted that had it not been for Lata's insistence, her refusal to be cowed down by the label 'neurotic mother', they would probably have not made such strenuous attempts to identify and name Anurag's difficulty. He believed that this would have caused him far greater problems subsequently, especially during adolescence.

Both Lata and Kartik had brilliant academic backgrounds. They admitted feeling disappointed that their child had so many difficulties. Kartik said he always thought of himself as a learner, someone who could pick up things easily and naturally. It was a big blow to realize that Anurag needed to be taught things very slowly and patiently, that he was not a "natural" at most things. Both were determined to help him pass in society. His difficulty was kept a secret, and only recently had 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", were offset by Kartik's calm good humour and confidence, enabling them to face the disability and move ahead with their life as a family.

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. 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 Smriti exemplify the culturally recognizable roles of the long-suffering wife who, through love and sacrifice tames the errant husband, Lata and Kartik are the new, metropolitan urban couple—the high-achieving, highly qualified, and successful wife and the ‘new male’ who is also comfortable with his nurturant, ‘feminine’ side.

The ‘couple-work’ they perform ensures that the family as a unit is not threatened. Deepak and Smriti had a traditional arranged marriage; Deepak is the sole breadwinner while Smriti ‘sacrificed’ plans for a career because she felt that her duties lay 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 and that they were also able to respond to each other’s needs.

What was common to both families was their strenuous effort to enable their children to receive social acceptance. Although Chintu had significant difficulties, his mother was very particular about his dress, appearance and public behaviour. Anurag’s parents ensured that he attended parties, sleepovers and excursions with his peers and worked hard at ensuring that he did not get left out or left behind.

The acute grief and pain gave way to a determination to make their children ‘fit in’ and opened a path for action. The process of grieving and coming to terms with a reality is part and parcel of meaning-making and attempting to create order out of a potentially chaotic situation. Families are engaged in the task of trying to make sense of their child’s condition beyond just biomedical labels and categories. The following section brings home this aspect of their experience.

## 2.5 Making Sense of the Disability: Cultural Models of Disability

Within medical anthropology, ‘explanatory models’ (EMs) and ‘illness narratives’ have been extensively used to capture the personal, cultural and social dimensions of various diseases, disorders and disabilities and how these are understood and dealt with in an everyday context. Illness narratives are the narratives of sick people and/or those who care for them about the illness and its impact upon their lives and relationships. These can take the form of oral, informal, daily conversations or more formal written narratives, or “pathographies” (Hydén 2007).

The medical sociologist Arthur Frank’s influential book *The Wounded Storyteller* (1995) tells the story of his encounter with and recovery from cancer. Frank views an illness narrative as an interactive experience, through which the ill

person can find other persons (patients, caregivers, medical professionals) to interact with, using the illness as a primary focal point for those interactions. How family and friends react to an illness affects the stories a patient tells herself and others. Severe or chronic illness-related events present patients and their family members with a physically and socially changed reality (Costello n.d.).

The growing interest in illness narratives in recent times is of a piece with the tendency of individuals in late modernity to highlight their very particular experiences of suffering (Frank 1995 cited by Hydén 2007). The disability narrative of Robert Murphy (1990) has already been referred to in Chap. 1. There has been a slew of family narratives about autism over the years particularly by mothers who, it may be recalled, were the prime targets for their children's difficulties, as per the 'refrigerator mother' theory discussed in Chap. 1.

One of the earliest and best known of these was Clara Claiborne Park's book *The Seige* (1967) published in the same year as Bettelheim's book *The Empty Fortress*. Park wrote in moving detail of her experiences raising Elly (a pseudonym for her autistic daughter), and her rejection of the pernicious theory that held her to be responsible for her child's condition. She narrates her attempts to penetrate the wall of silence that surrounds Elly and enter her world. Through music and song, drawing and play, Park humanizes her child; acknowledges her as a complete (if different) human being. Merry Barua's (2007) narrative of recognition, acceptance and celebration of the lessons taught to her by her autistic son Neeraj, is a good example from India. Skinner and Weisner (2007) explain the significance of cultural models, or the underlying assumptions held by members of a society about various aspects of the world, including health, disability and healing. These 'interpretative frameworks' act as templates that people use to make sense of their experiences, and to modify their environment.

In their process of meaning-making, parents draw on cultural models of disability and of normative child development, along with other cultural resources, to build understandings of their child's delays and modify them as their experiences and need for information changes (p. 304).

While some families may be satisfied by the medical explanations given by their doctors, others may contest or modify it in consonance with their own belief systems and lived experiences. In this context, Arthur Kleinman's (1980) work on 'explanatory models' has been extremely influential in understanding lay constructs or explanations for a disability or illness. EMs give researchers insights into how affected individuals actually experience the condition; including its causes, effects and amelioration. EMs are used in both clinical settings and in ethnographic research as a way to access information about the affliction from the perspective of the sufferer.

Family narratives of conditions like autism have proved a rich resource for understanding how childhood disability impacts the family. Gray's (1995, 2001) research with Australian families of children with autism, for example, draws upon parental constructions of their child's autism and the role they play in creating coherence out of the disordering effects of autism on family life. Shaked (2005) and Shaked and Bilu (2006) in their analyses of the narratives of mothers of children

with autism from the ultraorthodox Jewish Israeli community, discuss how these mothers act as mediators between their child and the community, challenging their child’s exclusion and attempting to reinclude the child in the community. Mothers draw upon both biomedical and cultural/religious frames to make sense of the reality and deploy the moral and religious theme of suffering to come to terms with their plight. A similar trajectory was also noticed with the mothers in this study.

Explanatory models of autism are particularly intriguing, as Sarrett (2015) points out, because there is no known cause, and therefore parents and caregivers can draw upon those explanations that most appeal to or suit them. For instance, the caretaker explanatory models in Kerala revealed that caretakers prefer biological explanations like illness and injury that are believed to cause the autism rather than genetic ones that imply the stigma of ‘bad blood’. Indeed, the stigma of mental illness and disorders as being the product of tainted blood or ‘bad genes’ (usually the mother’s) is a theme that figures in the accounts in the present work as well.

Grinker and Cho’s (2013) discussion on the ‘border children’ socially constructed by South Korean mothers mentioned in Chap. 1 is another apt example of how diagnostic categories are contested and reframed.

As has been mentioned before, diseases and disorders are not just organic or biological but are surrounded by meanings and myths that may vary across cultures and historical periods. In this context, Susan Sontag’s (1989) well known work on the ‘metaphors’ of diseases, like cancer and AIDS, reveals the powerful impact of these metaphors on both the sufferer and the caregiver as well as on systems of care. For instance, 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 associated with homosexuality and drug use.

Metaphors also 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).

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.

Cohen’s (1999) exploration of old age, senility and dementia in India suggests that old age is, in fact as much a social construction, as an objective material fact, and that the ‘new’ problems of old age actually reflect and are a metaphor for the moral decay of the family and the nation under conditions of modernity.

What sorts of metaphors or explanatory models do mental disability and mental illness evoke? The two are often conflated, in popular perception. The Hindi word *paagal* (mad, crazy) and its regional variants are used as catch-all terms to cover mental retardation and other intellectual disabilities as well as madness 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, often go under rubrics like *bhola* or *bawla*, *seedha* (simple-minded) or the technical term *mandabuddhi* (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, hence the need for restrictive measures like confinement, chaining, etc., that are observed, often with tragic consequences, as in the Erwadi incident referred to earlier.

However, while ‘simple’ or feeble-minded individuals were assigned some sort of space within the traditional, pre-modern communities, the demands of urban existence do not permit them such a culturally sanctioned space. Writing of the meanings attributed to ‘madness’ and the medicalization of distress amongst women in a low income settlement in Delhi, Nayar (2015) notes that behaviours such as talking to oneself or laughing without reason, shouting and screaming in public, walking about aimlessly and restlessly and running out of the house, were attributed to supernatural causes and possession by spirits; ‘*upar ki hawa lagna*’ (being affected by the ‘air above’, i.e., supernatural causation) (p. 345).

Autism, though a ‘new’ diagnostic label is associated with certain behavioural characteristics that tally with local cultural conceptions of mental disorder or *paa-galpan* which make it extremely stigmatizing for the family to come to terms with. Family narratives in my study yielded some interesting metaphors that revealed the persistence of certain deep-seated cultural tropes even as families updated themselves with the latest scientific and medical developments in their attempts to find a cure.

## 2.6 Multiple Meanings of Autism

### Autism as a curse

Some 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 her hand until she 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 multiply disabled child when asked if he ever got angry or lost patience with the bouts of extreme behaviour displayed by his child had this to say “How can we possibly get angry with

him? Poor fellow, he is in such distress anyway. We can do nothing to ease his difficulty”. Parents were particularly concerned about who would handle these behaviours once they were gone. The following quotes highlight this point:

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.

I feel so scared! Suppose he hits me and kills me? He’ll be locked up; people will hit him, ill-treat him.

While I am there, I dare anyone to look at her in a ‘bad’ way, but when I am gone, who will protect her?

The condition is conceptualized as a ‘curse’ not just for the child, but the whole family, as in the case of Soham, a boy with autism, who was 10 years old at the time of the fieldwork. Soham sometimes had spells of screaming, tantrums, self-injurious behaviours like head-banging and also displayed extreme rigidity in his routine. It was very difficult to get him to take a new road to school or adjust to unexpected events like a guest visiting. His mother said that their life had become “hell”. Although she was a well-qualified professional before her marriage, the arrival of Soham confined her within the four walls of her home with a child whose difficulties she could not understand or control. Her husband was at work all day, her relatives lived outside Delhi, she had few friends and was reluctant and embarrassed to take Soham out anywhere. “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 that they would possibly not be able to experience adult love, companionship, sexual relationships and parenthood, reinforced the notion of the disability as a curse.

### **Autism as *Karma***

To what, then, do families attribute this ‘curse?’ The overwhelming answer was *karma*. One mother put it thus: It is ‘written on one’s forehead’ (*kapaal par likha hota hai*)—accept it stoically. Even the highly westernized, English speaking, cosmopolitan respondents 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 recalled 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 paediatric ICU. He also blamed doctors for not preventing him from taking the child home. In another case, a mother recounted that she wanted to have an abortion as she already had two typically developing children. But her relatives urged her to go ahead with the pregnancy and have a tubectomy after the delivery. She said ruefully, “How were

we to know that having him would be as difficult as bringing up six children?" It was sheer fate 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 Christian 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 believed 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 several years. Although not a churchgoer himself, the father taught his child to say "Thank you God".

They thus combined a belief in divine intervention along with human agency. Earlier, I discussed how some parents viewed the destiny of their child as inextricably entwined with theirs, as in the case of the man who believed that his son was the bringer of good luck and prosperity and was endowed with divine grace.

A 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. It would have been terrible, she said, if the child had been born in an impoverished and vulnerable home. Another confided that she had terminated an unwanted pregnancy earlier and did not want to go through the procedure when she conceived again. She therefore went ahead and had the baby. When he was diagnosed, she could not help wondering whether this was a 'punishment' to her for terminating the earlier pregnancy. But she convinced herself that it was nothing but destiny at work. "He had to come into this world, somehow", she said.

### **Autism as an Enigma**

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' behaviour, one must trace it backwards, i.e., identify the core issue that causes it. For example, a young child throwing a tantrum whilst getting a haircut could be behaving that way because the snipping sound of scissors close to his ears is deeply distressing. The strangeness of the hairdresser'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 at the hairdresser's, the experience can be made more predictable and comfortable. However, undertaking such an elaborate exercise for what appears a routine, mundane activity often frustrates and exhausts families. Strategizing 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. (Interestingly, a visit to the dentist is one that is dreaded by parents of even the best behaved typically developing children!) A parent 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 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 difficulties 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 condition had gone away and that the fundamental difficulties that characterize it could well manifest at any time. Whenever they relaxed or ‘let down their guard’ something would happen that would topple the applecart, shatter the illusion of ‘normalcy’.

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 am not careful 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. Sometimes, they had unintentionally comical consequences. 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. A child I knew took a fancy to an HIV-AIDS sensitization advertisement regularly broadcast on radio and TV. He would repeat it verbatim everywhere, leading to much amusement and sometimes acute embarrassment to those accompanying him. As the above accounts reveal, autism is viewed as an enigma that is hard to fathom and harder still to live with.

### **Autism as Permanent Childhood**

A recurrent theme in parents’ accounts about their autistic children was that of innocence, absence of cunning, 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.

*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 aging 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 cited.



The much publicized fallout between the industrialist brothers Anil and Mukesh Ambani that hit the headlines at the time of the fieldwork often came up in conversations. Rationalizing the disability thus made parents view their child in a more positive light, i.e., as individuals who were free from the web of illusion (*maayajaal*) and deception of the adult world.

One parent wryly remarked that her son enjoyed *raja yoga* (a kingly fate): he lived a carefree life free of the day-to-day worries of the ‘normal’ world; devotedly attended by his parents and 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-racking process of securing admission for their children in good public schools!

While this conception of other-worldly 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. This response is a typical one with respect to persons with developmental disabilities; families found it very difficult to accept that their children would have sexual and emotional needs like any other “normal” person and that some fulfilling outlet for these needs would have to be provided.

They found it difficult to conceptualize their children as future 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 aged, experienced ill health and the final destination, death. Some parents very frankly said that they hoped their children would not outlive them. One of the mothers said that she prayed every day for her child to live “only up to 25–30”. Another said she wanted her child to die just a day before her, so that she could depart peacefully from the world. Needless to say, these disclosures were very painful and discomfiting to me given my own identity as the parent of an autistic child.

### **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 the 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 conceptualize 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 idiosyncratic, sometimes asocial behaviour makes it possible to conceptualize these children as *sadhu-babas* (renouncers, mendicants) or lost spirits fulfilling their destiny, or karma. Grinker (2007) writes about how Lord Shiva was used by some mothers interviewed by him as a metaphor to describe their children’s behaviour—he too was aloof, had peculiar habits, bad hygiene and no friends! Analogies were also drawn with the Sufi whirling dervishes because many of these children would stimulate themselves by spinning round and round.

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. The social and educational profiles of the respondents who were by and large middle and upper-middle-class professionals and their impression of the interviewer as an ‘educated parent’ engaged in academic research may have resulted in feelings of awkwardness and a reluctance to admit to superstition and ‘irrational’ beliefs.

Other studies (Daley 2004; Grinker 2007) indicate that families did resort to a variety of folk remedies and faith healers, however, the sample I studied did not give such feedback. The unambiguous message that came through was that even though their children might be a cause of stress and worry, they 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’.

### **2.6.1 Discussion: Contradictory Constructions of a Complex Condition**

The metaphors culled from the narratives appeared contradictory; e.g., ‘curse’ versus ‘divine blessing’; ‘innocence’ versus ‘incompetence’; but in their very contradictions, they exemplified the complexity of the condition and the cultural underpinnings of disability. They also brought 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 were not viewed as an aggregate of deficits or a ‘condition’ to be dealt with, rather, they were loved and valued members of a family.

Parents 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, a 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 unconditional attachment. 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”.

It was 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 contrast. Perhaps framing of the more disturbing and difficult aspects of the disorder in biomedical terms made it easier to deal with emotionally; at the same time, characteristics of the condition like extreme social naiveté and absence of cunning and guile were valorized and projected as fast-disappearing virtues in a materialistic and opportunistic (*matlabi*) world. Perhaps this enabled families to appreciate the child as a human being worthy of a special quality of love and care above and beyond that required by 'normal' people.

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.

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'. In the following section I present accounts of everyday life of two families in an attempt to tease out how the disability is accommodated and fitted into the day-to-day routines that constitute the bedrock of family life.

## 2.7 Autism and Everyday Life: Accounts of Family Routines

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, p. 160). The characteristics most frequently associated with 'everyday life' according to Featherstone (1992) are an emphasis on what happens every day, i.e., the routine, repetitive, mundane experiences of the ordinary world which are untouched by great events and the extraordinary. The everyday is regarded as the sphere of reproduction and maintenance, and is marked by an emphasis on the present; "a non-reflexive sense of immersion in the immediacy of current experiences and activities" (p. 161). There is 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" (p. 161). The ordinary practices of day-to-day living have the capacity to challenge dominant understandings and discourses.

Applying this understanding to the domain of disability and family life, it is through everyday life that the view of disability as a medical anomaly, misfortune or tragedy is reframed and reconfigured. Families learn to engage with and value their children for what they are rather than what they were expected to be. By focusing on lived experiences, the everyday lifeworld, we reconceptualize intellectual disability as one of the many ways of being in the world. We pay attention to the way that families construct the personhood and humanity of their child through shared routines and "immersion in the immediacy of current experiences and activities" (Featherstone 1992, p. 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. The individual is socialized into a particular identity and set of behaviours which are imposed from the outside by others who do not share their embodiment. Intellectual disability/learning difficulty as a category "systematically albeit implicitly, impeaches the personhood of its members" (1998, p. 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 lens of normalcy, the family provides or withdraws opportunities for the optimal growth and development of the child's potential.

The following accounts of the everyday routines of two families, were elicited through their narratives and my fieldwork observations. As has been discussed earlier, family accounts of daily routine reveal multiple strands of culture and the social construction of roles, responsibilities and obligations. They also highlight the political and historical processes and institutional arrangements which impact the manner in which families live in the urban moment. The first family, that of Divya, was a middle-class, double income, two child nuclear family residing in a government colony in Delhi. The second, that of Aashu, was a lower-middle-class family living in a cramped tenement in one of the 'urban villages' on the city's border.

### ***2.7.1 Divya and Her Family: Sharing Roles and Responsibilities***

Divya, a beautiful little girl was 5 years old at the time of the fieldwork. She was diagnosed when she was two-and-a-half years old. She was hyperactive, non-verbal and needed assistance with most self-help tasks. She had difficulties in bowel and bladder control and eating independently. She preferred to be by herself and enjoyed looking out of the balcony at the world going by. If her needs were not met, she would cry inconsolably and it became difficult to calm her. She would get very agitated in crowded places. She attended a special needs centre about 10 km away from her home. Her mother, Pinky, and her father, Rajinder, worked in white-collar jobs in government departments. Her elder typically developing sibling, Kavya, a bright, active girl of 9, was studying in Class IV at a public school nearby at the time of the fieldwork. The family's day began at 5.30 a.m. Divya would frequently wet the bed and Rajinder's first task was to change the sheets and Divya's soiled clothing. He would assist her with her breakfast. One of the parents would get busy in the kitchen preparing breakfast and packing all their lunch boxes, while the other got both the girls ready for school. (They took turns with these chores.) By 7.30 a.m., the girls would leave for school. The parents would then get ready and leave for office. Kavya was usually home by 2 p.m. and Divya by 3 p.m. Kavya would take her lunch and receive her little sister at the bus stop. As Divya had lunch at school, she did not need to be fed in the afternoons. Kavya would help Divya change her soiled clothing and attend to her needs. They would watch TV and relax together. Kavya phoned up their mother from time to time to assure her they were all right. The parents would return home in the late evening after office work and spend the evening doing domestic chores and shopping. Kavya would run off to play with her big group of neighbourhood friends and later sit down with one of her parents to study and complete her homework. The other 'free' parent would take Divya outdoors for some fresh air.

Although they said that they had no social life, they fulfilled social obligations like attending marriages and other family occasions. One of the parents would attend these gatherings with Kavya while the other stayed home with Divya, as large numbers of people and strange places upset her. Divya loved going for drives in their car. They arrived at this mode of self-sufficiency after much experimentation. They placed Divya in 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 remarked that their home had become a "training centre" for *ayahs* (caregivers)! Both their employers were aware of Divya's condition, hence obtaining leave and coming home early in case of emergencies was not a problem. Both carried mobile phones and there was a landline telephone at home. The neighbours were distant and rather indifferent; yet could be called upon in an emergency. Most of all, Kavya was very solicitous and affectionate with her little

sister; almost a surrogate parent. Their daily life was circumscribed by the clock, as, indeed is the life of most middle-class working couples. Their daily routine resembled that of any other family of their class; Divya’s special needs were taken care of by making a few adjustments, incorporating them into their routine.

### ***2.7.2 Aashu and His Family: Engagement and Inclusion***

Aashu a boy with autism and cerebral palsy was 11 years old at the time of the fieldwork. His well-formed face and sharp, well cut features were distinctive; he was tall for his age, very thin, with poor muscular tone, and his walk was stumbling and uncoordinated. His fine motor skills were poorly developed and he was unable to perform self-help tasks like feeding, bathing and toileting. He was non-verbal, uttering grunts and screeches and flapping his limbs uncontrollably every now and then. He would sometimes hit himself and scratch his own face until he drew blood. He attended a model school for children with autism. He was the only child of his parents, Anju, a homemaker, and Hari, a trader. Anju’s day would begin early, at 5 a.m. She would wash clothes, clean the house and prepare the morning meal. Aashu would wake up at 7.30 a.m., receive assistance in the toilet and be prepared for school by his mother. Hari would escort him to the school bus. Earlier, 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 was likely to fall off otherwise. The rest of the morning would be spent in household chores. Hari would pick up Aashu up at 12.30 p.m., feed him lunch and then leave for work. Aashu usually spent his afternoons at home watching TV (particularly, the commercials), and pottering around the house. In the evenings he would go with his mother to the busy local market to buy milk, fruit and vegetables. He enjoyed putting in the tokens in the slot at the milk booth and seeing the milk gush out. Anju would get busy with the evening chores, watch some TV and assist the child with his dinner. Hari usually returned by 11 p.m.

On his free day, his father would take him out to the market or to visit a relative, the temple or the *chabootra* (a dome-like monument) nearby. Aashu would wait for the *jhoolewala* (the man with the portable swings) and enjoy a turn on the swings. They rarely visited the local park since it was quite a long walk away. They visited relatives and attended family celebrations with Aashu, but took great care to prepare him in advance, so that he could deal with the new situation and sensory stimulation. Although their day revolved around the needs of this severely impaired child, they found time to do things together as a couple. They enjoyed shopping, visiting neighbours and relatives and attended all the meetings, talks and events organized by Aashu’s learning centre. Despite their limited economic means and restricted social opportunities they tried to lead as full a life as they could, including their child as far as possible in all their activities.

### 2.7.3 Discussion: Constructing Disability Through Everyday Practices

How is disability constructed and negotiated through these daily routines? Both families placed a good deal of emphasis on the school routine, ensuring that the child did not miss a day at school, sometimes sending them even if they had a mild fever or bad cold. In Divya's case it may be attributed to the parent's busy schedule, but Aashu's parents insisted on school attendance because his activities at school were planned and structured, his teachers understood and worked hard with him. They reported how their relatives and friends (even highly educated ones) failed to understand their need to send a child "like that" to school. ("*Jab baccha samajh-daar nahi, to school kyu jata hai?*") If the child is not capable, then why send him to school? Divya's parents were not convinced that their child actually learnt anything at school ("time-pass", said Rajinder) but at least it gave her somewhere to go; it occupied a large part of her day. Vacations were considered a nuisance because it meant finding some sort of engagement for both the children at home, availing of precious leave and rearranging schedules.

In terms of daily activities like feeding; bathing, dressing, toileting, etc., both children, as mentioned earlier had severe difficulties. Family routines were woven around the accomplishment of basic tasks. In the case of the family where both parents worked outside the home, domestic chores were equally shared, with the non-disabled sibling playing a critical role as well. However, it would be simplistic to view this as exploitation or abuse of the rights of a young child; Kavya was a bright, mischievous little girl with a large group of playmates who did very well in school and cared deeply about her little sister. She very naturally accepted her extraordinary responsibilities and discharged them with good cheer (Vaidya 2015).

Gender socialization of the girl child to be the 'surrogate mother' of younger siblings within the Indian cultural context and its implication for disability management in the domestic sphere will be discussed in a later chapter. Aashu, being an only child and with severe impairments, was the fulcrum around which the family revolved. The mother's continued presence at home and the father's flexible work hours made 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 demonstrated marked differences, which indicate the way they constructed their child's 'personhood'. Divya's parents kept her away from public view because her lack of bowel and bladder control and other challenging behaviours were a social embarrassment. As a middle class, north Indian family with another daughter, they were perhaps also worried about Kavya's marriage prospects being adversely affected by the presence of a disabled sibling. Rajinder informed that very few people outside the immediate family circle knew about Divya's disability. He preferred it that way because he did not like to explain it; it made him tense and the reality became harder to bear.

Aashu, on the other hand, accompanied his parents everywhere. His mother reported that he often got strange looks, people pointed and stared at him. She had many unpleasant exchanges with strangers because of their rude comments but that did not inhibit her. Whenever he threw tantrums in front of others, it upset the parents greatly, but they would try to tell Aashu that others would not like him if he displayed such behaviour.

The way families talk to and about their child reveals significant information about their construction of the child. 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. 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 didn't fall asleep, instead he wanted to play with his father! 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 made it difficult for anyone to imagine him capable of such social intelligence and deviousness. However, this incident exemplified the manner in which agency and personhood were attributed to him, despite his impairments.

As the above narratives suggest, coming to terms with a child's autism is a work in progress, an evolving process with numerous pitfalls 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 complexity of the condition and the barriers in both, the physical environment and social attitudes. Recognizing and respecting the humanity of an individual who seems so different and behaves so unusually may seem the right or politically correct 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 battle. While some families adapt to these circumstances positively, others may flounder, or crack under the strain. Chap. 3 examines parenting, both as ideology and practice. 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.

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