SUMMARY AND CONCLUSIONS

The thesis aimed to explore the manner in which a group of families living in Delhi negotiated with autism, the neuro-developmental disorder that afflicted their children. We described and to analysed the manner in which they understood this complex disability, attended to the special needs of the autistic child and prepared themselves for the prospect of life-long care and an uncertain future. Concurrently, they carried on with the other activities and responsibilities that domestic life entails, including earning a living, taking care of the physical and psychological needs of other children, aging parents other family members, conjugal life, maintaining familial and friendship networks, professional obligations, etc. In other words, our description and analysis of disability management on the part of the family is embedded within the dailyness and routines of domestic life.

The aims and objectives outlined at the outset comprised certain research concerns in the light of which data in the subsequent chapters were presented. The first of these research concerns referred to cultural conceptions of intellectual disability with special reference to autism.

Our findings indicate that there is growing awareness and information about Western bio-medical conceptions of child development, 'normalcy' and of developmental deviances. This growing awareness amongst young parents sits rather uneasily with more relaxed parenting styles of earlier generations, and 'folk wisdom' like boys being late talkers etc. We link this anxiety regarding 'normal development' with the skewed, inegalitarian educational system, the competition for scarce resources like 'good' and 'reputed' schools job prospects etc. and dwindling family supports. Under these
circumstances, we find that the ‘mind-body’ dualism, characteristic of Western culture and the emphasis on intellectual capacities and capabilities as the markers of ‘normal’ personhood is gaining salience. Conceptions of appropriate behaviour, the ability of interact with a variety of individuals within and outside the family, internalize social norms and expectations and display behaviour in concordance with these norms, are also prized qualities. In a culture where familism and respect for hierarchies has strong roots, the recent trends towards mobility co-exist with the need for conformity. The ‘law-breaking’ or rule defying aspects of autism thus make it a difficult condition to fathom and come to terms with. The reported impairments in ‘theory of mind’, of autistic persons, i.e. their inability to infer another person’s internal dispositions, beliefs, knowledge and desires, impacts upon their ability to function appropriately in society. This deficit not just sets them apart, but places the family, the primary agency of socialization, the site where rules of interaction are first learnt, under immense stress and confusion.

How then do families make sense of their child’s disability? Through their narratives, we culled certain metaphors or images that represent their understandings of the disability. These include the conceptualization of autism as curse, as a product of ‘karma’, an enigma that is hard to explain, understand and predict, a state of permanent childhood and therefore also a sign of divinity. These metaphors clearly indicate the difficulties families face in dealing with the child’s symptoms, the conflation of some of these symptoms with supernatural states which have cultural referents in the form of ascetics, mendicants and renouncers who eschew the carapace of normal social living and travel both without and within, abandoning pretence, appearances and shame, i.e. the maya-jaal of the world. The innocence and unworldliness of childhood also provides a positive image with which to view these children. They are frequently
referred to as *seedha* (simple) *bhola* (innocent) and their lack of self-control, impulsiveness, stubbornness and volatility is couched in these terms. At the same time, there is the realization that permanent childhood implies incompetent or failed adulthood and incomplete personhood, freezing these individuals in the liminal zone so evocatively described by Murphy (1990), questioning their very humanity.

The conceptualization of the disability in mystical terms appears to be in contradiction to the search for medical remedies and cures. This search draws families out of their secure worlds and motivates them to take bold and brave decisions for the child’s future. The case study of the young couple, who forsook the security of the joint household and relocated to an expensive, confusing, anonymous metropolis so that they could access therapy for their child, is a dramatic example. It indicates the belief that ‘expertise’ in the fields of medicine, education, rehabilitation etc. is a valued resource to be sought even if it conflicts with larger family interests and commitments. At the same time, making such difficult choices (e.g. the interests of the child versus the care of aged parents) causes much psychological distress and guilt.

The conceptualization of the condition as ‘curse’ indicates quite clearly the difficulties faced both by the child and the family. These difficulties stem from both, the embodied reality of the disability - the sensory and perceptual difficulties faced by the child, the abnormal responses to certain stimuli, the frustration of being unable to communicate wants and feelings – as well as the handicapping responses of society, like rejection, ridicule, stigma, reluctance to grant social spaces etc. The fear in the minds of the parents, namely, ‘what will happen to the child after us?’ is the thread that runs through all the narratives and links the micro aspects of the study, viz., ‘personal troubles’, with
macro and structural realities, viz., 'public issues', specifically the role of community, civil society and state.

The second research concern pertained to *identification of the disability, help-seeking behaviour and the process of arriving at diagnosis*. We noted that the salient symptom reported by families was the child's lack of social relatedness. The apparent inability to pick up social cues, the tendency towards aloofness, withdrawal and sometimes, active rejection of social overtures, the absence of speech, the apparent inability to understand even simple commands, lack of responsiveness to one's name and other similar symptoms which breach the 'taken-for-grantedness' of a young child's sociability, worried families. The symptoms that elicited great concern were self-injurious and other disruptive behaviours, behaviours which upset normal functioning of the family and caused stress, confusion and fear.

The apprehension that the child was mad or a lunatic frightened and worried families. Their fears were not confined to the child's difficulties alone, but also to the taint or stigma the whole family would face. The belief in the inheritability of madness, its impact upon life-chances, marriage prospects, social status of the family as a whole, make disabilities like autism seem like a 'fate worse than death', a curse or punishment to be borne by the entire family. Once again, the co-existence of spiritual/religious thinking with a scientific, rational belief in modern medicine are observed. *Karma* seems to be the stock explanation and rationalization for the child's autism, and probably facilitates acceptance.

The notion of the child's autism as a breach, a rupture of order and regularity, was highlighted. The various factors, social, cultural, economic which comprised a 'health belief' model according to which families assessed their children's symptoms was
analysed. We traced the interface of the family with a medical system that views disability within a 'disease-cure' framework that has little meaning in the context of developmental disabilities like autism. At the same time, we noted the difficulties faced by medical professionals in accurately assessing child development and the ethical dilemmas of diagnosis and disclosure. The difficulties in obtaining an accurate diagnosis of autism given the lack of awareness and absence of diagnostic facilities were highlighted.

A significant finding that emerges is that the onus for identifying the child’s problem rests squarely on the family. As a result, only those families that have the material and educational wherewithal to consult a variety of specialists and sometimes travel long distances, can hope to secure an appropriate diagnosis. Due to the middle and upper middle-class profile of such families, the notion that autism is a Western disorder, the product of family fission and disengaged parenting, is further exacerbated. This has serious implications at the macro level, in terms of policy planning, welfare provisions, state sponsored intervention, etc., because it is thought that this is a rare disorder afflicting upper class elites who are quite capable of looking after themselves and their children. The middle-class bias of the sample recruited for the study reflects this reality, as does the difficulty faced by parent groups in impressing upon the government the need to officially 'recognise' the disability. It has been estimated that between 2 to 4 million individuals are likely to be affected in India, and the majority are probably undiagnosed and lacking any facilities for rehabilitation.

We explored the impact of the diagnosis upon the family especially the parents of the child. As an alternative to prescriptive and deterministic models of grieving and bereavement, we contextualized the grieving process and examined the manner in
which family members made allowances for and accommodated each other’s feelings so as to permit domestic life to go on as usual. Through the lens of gender, we noted the differential impact of the child’s diagnosis on mothers and fathers. We noted how couples sought comfort and solace from their own support structures; notably, mothers tended to derive much emotional and practical support from their own mothers and natal homes. The paternal grandparents tended to be rather more judgmental, particularly of the mother, and familial conflict and fission was observed in some cases. We noted the limited spaces available to fathers to discuss their worries and fears. Using the concept of ‘couple-work’, we uncovered the different strategies adopted by husbands and wives to make allowances for each other, accommodate each other, in order that the interests of the child may not be adversely impacted.

Moving to the impact of the disorder on family relationships, patterns of coping and care and factors promoting and impeding resilience, we noted that families find themselves isolated and pushed into a corner when confronted with a complex disability like autism. The child’s bizarre, sometimes disruptive behaviours make it socially awkward, embarrassing and difficult for contact to be sustained with kin and community. This results in mothers in particular becoming bound to the child and his/her routine, frequently having to give up careers, interests, hobbies, friends, etc. because of the ‘constant parenting’ they must perforce perform. The immense cultural weight given to the mother-child bond, the valourization of selfless ‘mother’s love’ and the expectations, internalized by mothers, that they must become ‘more than mothers’ was explored through their narratives, and the entrapping and empowering dimensions of ‘mothering ideology’. The case study of a young, highly qualified upper-middle class mother, revealed that the effect of mothering a severely disabled child was depleting and exhausting, forcing her into a shell, isolated from family, friends, the
world of work and social life. Her class and educational advantages were neutralized, she was trapped in a potentially hopeless situation. In the case of another young mother, migration to the metropolis in search of appropriate services for her child proved liberative; free of the restrictions of joint family living in a small town, she could explore what the metropolis had to offer both her child and herself and find her own 'voice'. We may conclude that educational and class backgrounds do not have any predictable correlation with coping and management of the child’s disability. Our data suggests that acceptance of the child’s disability and conceptualizing him/her as a complete person are the key to successful coping, rather than class factors.

Fathers’ experiences, the expectations of masculinity and ‘responsibility’, the conflicts that sometimes arose between their breadwinning and nurturing roles was also highlighted. We also discussed the role of competitive work environments and the emphasis on appearances and self-presentation in promoting attitudes that were intolerant of difference and deviance. The impaired body and impaired mind thus become markers of shame and stigma.

Our analysis of the stories of fathers who typify the ‘disengaged breadwinner’ and ‘involved nurturer’ reveal the different ways in which fathers conceptualise and enact their roles. While, in the case of the former, it leads to a withdrawal from the life of the child and a single-minded focus on providing money and material goods, in the latter, there was a conscious endeavour to participate in childcare and share the child’s world, even at the cost of professional advancement and material gains.

The impact of the child’s autism on the marital relationship we noted, strengthened the marital bond through a common suffering and a shared concern for the best interests of the child in some cases, and lead to complete divergence of goals and interests in
others. The consistent pattern that emerged was that couples felt compelled to maintain intact the family unit for the sake of the child, even in the face of irreconcilable differences. At the structural level, we see the reinforcement of family values and the assertion of the primacy of the family in coping with a circumstance like disability. At the same time, parents' concern for their children over and above other relationships, the willingness to take difficult decisions like migrating and setting up independent conjugal units, reflects a child-centric trend in urban families. Adult identities are also contingent upon parenting performances. Decision making about children is also done by the conjugal unit, sometimes in contradiction, even defiance of elders and other authority figures. Thus, while there is nostalgia for the 'lost' joint or extended family and the support it is supposed to give, the conjugal unit has become critical.

The belief that 'only the family can look after the child' also translated into the way sibling bonds were conceptualized. Siblings too, became 'more than brothers' or 'more than sisters'; they were friends, care-takers, surrogate parents, future guardians, irrespective of gender or birth order.

Parents were cautiously optimistic that their regularly developing children would take the responsibility for the autistic sibling when they were no more; here too, gender played an important role. While sisters were seen as surrogate mothers, the prospect of their going away to their 'own' (i.e. conjugal) homes was also in the minds of the parents. Brothers were seen as the prospective guardians, the inheritors, as it were, of parental responsibility. Yet, citing their own experiences with their brothers and bhabhis mothers expressed apprehension about whether the autistic child would be 'tolerated' in the future. The views of the sisters were also indicative of the importance
of sibling bonds; the teenage girls interviewed were emphatic that they would care for their disabled siblings and one said she would even forego marriage. The notion of girls as *paraya dhan* is undergoing rapid transformation and their contributions to the natal homes increasingly recognized.

The experiences and feelings of grandparents reflected the generational change in the conception of intellectual disabilities and brought out the politics of family life particularly with regard to the vexed question of 'who is to blame?' The issues of maternal responsibility, decline of 'family-like atmosphere' and the pressure of urban lifestyles, were seen by some as the reason for the child’s difficulties. This aptly brought out the difficulty experienced by the family in conceptualizing the child’s behaviour as a neurological disorder, rather than evidence of poor upbringing. Here too, the differences in attitudes of paternal and maternal grandparents was evident. While the mother’s natal family tended to focus on the ‘misfortune’ of their daughter and render her emotional and physical support, the patrifocal family tended to view the child’s disability as evidence of maternal failure or poor parenting. The importance of the mother’s natal family as sources of support in situations of crisis or difficulty particularly in urban contexts is an area worth exploring.

In our discussions of coping behaviour, we examined task-oriented, emotion-oriented and avoidance-oriented styles of coping and found that those parents who adopted a task-oriented approach, tended to fare better. They focused on solutions, on changing the stress-inducing situation or problem, rather than indulging in self-blame and guilt or avoiding coming to terms with the problem. We also examined the concept of resilience, which refers to the ability to cope with a life filled with difficulty, or the ability to deal positively with adversity and stress. Drawing on the work of Booth and
Booth (1998) we identified certain ‘protective factors’ which enabled people in adverse circumstances to cope better. These included personal protective factors which helped to empower the individual with a sense of self-worth and the confidence to meet life’s challenges. Sociability, responsiveness to others, maintaining close relationships and feelings of responsibility for the family, especially the disabled person, participation in voluntary activities and having outside interests are some of the abilities that promote resilience, as our narratives corroborated.

Protective mechanisms within the family that promoted resilience according to Booth and Booth included warmth and mutuality, stability and security, which include having a large supportive extended family, financial security and living in the same household as parents or other relatives. As discussed earlier, our data showed that families were willing to risk sacrificing this potential source of security in order to access medical and therapeutic facilities for their children. In the absence of such security in the context of life in the metropolis, the third set of factors, viz., protective social supports, becomes critical. Supportive relationships with friends and neighbours, institutional support from agencies like the school, health centre etc., participation and involvement in community activities, sharing joys and sorrows, all mitigate the loneliness of urban existence, especially when it is coupled with the prospect of life-long care of a disabled child.

Observing daily life and activities was the underlying and unifying research concern which reflected in the qualitative methodology employed. The fieldwork strategy which relied upon unstructured narrative interviews and participant observation, elicited data on everyday routines pertaining to feeding, dressing, recreation, commuting, shopping, schooling, in other words, the activities and practices that form the bedrock of domestic
life, in and through which families constructed the disability of the child and negotiated with it. We observed that families built up and modified their routines around those of the disabled child and, over time, the special efforts and adjustments they made became absorbed into the family routine. While their social activities reduced on account of the child’s difficulties, they sought to network with and derive support from other families like them, initiating the development of ‘a community of co-sufferers’.

Examining the interface between family and community with special reference to parent support organizations, it was noted that the interactions between families and the wider community were fraught with tensions; neighbours were, on the whole concerned but cautious, and strangers often reacted with curiosity, amusement or ridicule to odd behaviours exhibited by the child. While children with severe symptoms were regarded as deranged or mad, the mildly affected or high functioning ones managed to “pass”, usually with difficulty. Autistic children we noted are rarely welcome in regular schools and even mixed-disability settings because of their social deficits and odd behaviours. Teachers are inadequately trained to handle their unique difficulties and they are often seen as a disruption or disturbance in the order and routine of the classroom.

There is a growing awareness of developmental disabilities like autism and greater visibility of such individuals and their families in the public realm. The mass media and 24 hour television channels have had a role to play in making disability a ‘talking point’. The year 2007 alone has seen a slew of programmes on autism on both English and Hindi News Channels. The Hindi film Taare Zameen Par which sensitively captures the predicament of a dyslexic child and his family, has received much critical acclaim and commercial success. While these developments are indeed heartening, it
remains to be seen whether they will usher in any systemic changes in the way the needs of such children and their families are addressed. For families struggling to find answers to the big question, “what will happen to my child after me?” it is the family-support organization that offers a glimmer of hope. A case study of ‘Action for Autism’, a Delhi-based parent directed Non-Governmental Organisation was presented. We traced its genesis from the efforts of a handful of motivated parents to a multi-pronged and dynamic organization at the vanguard of autism rehabilitation and disability activism. Interestingly, the NGO is conceptualized by some families as a sort of extended family, and its leaders the figures of strength and solace that are called upon or consulted during crisis. This transfer of dependency has become problematic, now that the organization has expanded its activities and reach and is changing from a small, intimate group of parents to an organization staffed by experts and professionals.

At the same time, we observed that the role of NGOs is necessarily limited; ultimately, it is the state and society that has to own responsibility for its disadvantaged citizens, and must, in concert with other stake-holders, put in place systemic changes and safeguards. While the changes in legal frameworks covering the intellectually disabled are welcomed, their implementation and monitoring require commitment to welfare goals and the creation of a humane society.

In this context, we may recall Martha Nussbaum’s (1997) concept of ‘capacities’ essential for the cultivation of humanity which include (i) the ability to examine oneself and one’s traditions critically (ii) seeing beyond local group, region and country and recognizing that the world around us is “inescapably international” (1997: 10) and (iii) the development of a “narrative imagination”, or “the ability to think what it might be like to be in the shoes of a person different from oneself, to be an intelligent reader of
that person’s story, and to understand the emotions and wishes and desires that someone so placed might have” (ibid: 10-11).

Extending this idea, Parmenter (2001) urges the development of an ethical community wherein the interdependence of all individuals is a central feature. Reinders (1999) argues that the Western notion of viewing ‘dependence’ negatively as compromising the integrity of the individual, is untenable in the case of intellectually disabled. There is therefore a need to foster an ethical community in which primary support roles are taken up by family, friends and extended support networks rather than professionals. The ‘de-institutionalization’ of the intellectually disabled currently underway in the West is based on the premise that community care is better and cheaper than institutional care. Within the urban Indian context, we note that traditional patterns of support are disappearing and have yet to be replaced by viable alternatives. As our narratives highlight, parents look towards their ‘normal’ children for assuming guardianship roles, but simultaneously voice their apprehensions that this might not be viable. For parents who do not have other children, even this ray of hope does not exist. An option that is often discussed in the NGO is setting up of ‘group homes’, where young adults can live together, supervised from the outside by family and community workers. Such a model has been put in place in Western countries, however, it is monitored by long-standing systems of social security which are lacking in our country. Chaswal (2008) outlines a model for community care and support which emphasizes the use of local resources and persons in the neighbourhood and community who the child and family regularly interact with. Such a model is based upon the premise of interdependence and a shared humanity; the need to involve the community in the life of the child and the child in the life of the community. This will also help to check the tendency for families to migrate to selected towns and cities for rehabilitation and
facilitate the growth of family based community care and responsibility within local communities.

Will we tread the path taken and subsequently rejected by the Western world namely exclusion and incarceration? Or will an 'ethical community' amply supported by civil society and the welfare State reinterpret and revitalize traditional values of community care?

Only time will tell.