CHAPTER - 1
METHODOLOGY AND FIELDWORK

This doctoral thesis is a qualitative, ethnographic study of twenty families having children diagnosed with autism living in Delhi. The aim of the study earlier outlined in Chapter-1, is to present a nuanced, detailed account of the everyday experiences of living with an autistic child. As autism impacts the faculties that are essential for social interaction and reciprocity viz., language, imagination and social skills, parenting and living with such a child is difficult and challenging. In the context of a social structure where conformity is emphasized and differences are often viewed with suspicion and hostility, there are limited social spaces available for such families and their children. At the same time, discourses pertaining to disability, and the responsibility of society and state towards its disabled citizens are gaining ground, largely on account of the global emphasis on human rights, and grass-roots activism and advocacy by voluntary agencies, self-help groups and associations of affected individuals.

The present study is an effort at illuminating an aspect of urban Indian life viz., the lives of families with children having a complex disability, and the way they harness personal, social and relational resources to cope with this difficult circumstance. As studies pertaining to intellectual disability and family within a sociological perspective are scarce, it was thought that the use of qualitative research methods was an appropriate strategy to conduct the study.

1.1 RATIONALE FOR A QUALITATIVE STUDY

Qualitative research is a tradition in social science that depends on watching people in their own territory and interacting with them on their own terms and language. It is based on the paradigm of social construction and interpretation. Essentially inductive in
nature, it uses flexible concepts and techniques. The processes of data collection, analysis and verification of theory occur concurrently and feed into each other. The qualitative research tradition owes much to the anthropological tradition, including the contributions of Malinowski, Radcliffe-Brown, Evans-Pritchard and their intellectual descendents who studied other cultures by immersing themselves in them through prolonged, intimate engagement over several years. The sociological tradition of the Chicago school, headed by Robert E. Park in the 1930s, pioneered studies which unpacked the diversity, heterogeneity and complexities of a conflict-ridden metropolis through 'participant observation'.

The qualitative research tradition is of particular relevance in the study of social relations in a plural world, where researchers encounter new, ever-changing social realities and contexts. Studying the subjective meanings of members in a setting and their everyday experiences and lived realities enables researchers to grapple with the complexities of contemporary living. Toulmin's (1990) programme for a way forward for philosophy and science in general emphasizes:

- Return to the oral, i.e. carrying out research through the use of language, narratives and communication.
- Return to the particular, i.e. to concentrate on specific, concrete problems which arise in specific situations rather than concentrating on abstract, universal questions.
- Return to the local, i.e. studying systems of knowledge, practices and experiences in their local context, instead of assuming and attempting to test their universal validity, and
- Return to the timely, i.e. locating problems and identifying solutions in their historical context and describing and explaining them accordingly.
Qualitative research methodology subscribes to all the four approaches outlined above. It is rooted in understanding lived experiences as expressed and articulated by people themselves. It aims at understanding the issues at hand without resorting to cosmic generalizations and it accounts for the socio-historical context of behaviour. It also takes into account the reflexivity of the researcher such that the whole research endeavour becomes a continuous process of constructing versions of reality.

According to Flick (1998), the essential elements of qualitative research are:

- Appropriateness of methods and theories: In qualitative research, methods are designed to be so open that they do justice to the complexity of the object under study, which in fact is the determining factor for choosing a method and not the other way round. Objects are studied in their complexity in day-to-day situations and not reduced to single variables. Exceptional situations and persons are frequently studied. The nature of the problem at hand suggests the method to be used for studying it. In other words, the problem selects the method, and not vice-versa. For example, a researcher studying mental illness may adopt a strategy of interviewing patients, their families and professionals responsible for their treatments. S/He may also elicit narratives from the subjects or undertake a case study of an institution treating the mentally ill where patients, their families and professionals are observed within an institutional setting.

- Perspectives of the participants and their diversity: Qualitative research is directed to uncovering the diverse meanings and implications of the issue to the various individuals affected by it or involved with it. Using the example of mental illness, some of the questions that may be addressed include the following: What is the subjective meaning of the illness for the patient and what is it for his or her
relatives? How do the various people involved deal with the illness in their actual lives? What has led to the outbreak of the illness in the patient’s life and what has made it a chronic problem? How have various institutions handled the illness and what has been their impact on the patient? As these questions demonstrate, qualitative research accounts for the diverse perspectives of patients, their families and professionals.

- Reflexivity of the researcher: Qualitative research methods take the researcher’s communication with the field and its members as an explicit part of knowledge production instead of excluding it as an intervening variable. The subjectivities of both the researcher and the researched are part of the research process. Researchers’ reflections on their observations in the field, their impressions, irritations, feelings and emotions all become data in their own right.

- Variety of approaches and methods: Qualitative research is not based on a single unified theoretical and methodological concept. It is rather characterized by various approaches. These include;

  a) symbolic interactionism, which uses the subjective viewpoints of individuals as a starting point;

  b) ethnomethodology, which studies the making of social reality through the process of interactions between people; and

  c) structuralist models, which seek to reconstruct the structures of the social field and the hidden or latent meaning of practices.

**Qualitative Methods and the Study of Disability**

Sally Hartley and Mohd. Muhit (2003) point out that research in the area of disability in majority world countries is generally scarce and has been dominated by quantitative studies focusing on either the prevalence of impairments, biomedical issues or the
efficacy of interventions in numerical terms. The social aspects of disability, viz., its social construction, the human rights approach etc. have been generally neglected. They stress the need to utilize qualitative methods to collect information which is culture specific and for researchers to act on the knowledge that the complexities of human behaviour, and its dynamic nature may be beyond the scope of quantitative methods.

They specifically recommend the use of qualitative research paradigms in situations wherein little is known, when target populations are vulnerable and when policy information is required.

• When little is known: Hartley and Muhit point out that disability research in majority world countries is still in its infancy. In fact, many individual countries do not have any research on particular topics in the disability field. Qualitative research methods can thus be used to initiate exploratory studies, as they do not require a predictive statement and questions raised are open and subject to improvisation and modification. In the context of the present study qualitative methods were thought to be appropriate as the study focuses on the experiences of families of children with a complex intellectual disability about which little is known in India. Accounts and observations of lived experiences and the day-to-day routine as well as critical events in the lives of families thus help the researcher to understand the manner in which disability is socially constructed and factored into daily living.

• When target populations are vulnerable: The authors cite their own work in Uganda and Bangladesh in which they examine coping patterns of families with disabled children which has had policy implications in terms of CBR initiatives and training. Their work in Bangladesh with visually impaired children explores the need for
service provisions for such children as perceived by the children themselves and their families. Use of qualitative methods provided the opportunity to listen and include the voices of the vulnerable population in programme planning. Similarly, it is hoped that the voices of parents and families of autistic children in the present study sensitise policy planners to the needs of such families; the provision of better diagnostic facilities, educational programmes, respite care and most significantly care for the children after the parents are no longer there.

By uncovering aspects of experience that only become available as a result of prolonged contact and intimate engagement, qualitative methods can render the accounts of vulnerable populations in a more humanistic, vivid and sensitive way.

- When policy information is required: Hartley and Muhit assert that even though quantitative data has been extensively used to inform policy and planning of health and education services at all levels, it does not provide information about the variations within the target population and the extremes that are likely to exist. Socio-cultural contexts as determinants of health and educational status and the fact that political problems are socially constructed tends to be overlooked. They emphasise the interactive, iterative relationship between the development of policy and existing practice and the perceptions of stake-holders towards the implementation of policy relating to disabled people (ibid: 109).

In the context of the present study, we may emphasise the critical role played by families in the management and care of the intellectually disabled. However, welfare policies tend to be individual centric and thus overlook the role of the family as the ‘voice’ of the intellectually disabled. Policy initiatives thus need to focus on the family as a whole, for intellectual disability is not merely an affliction
experienced by the affected individual, but has a profound impact on the functioning of the entire family.

1.2 THE RESEARCH SITE: REFLECTIONS ON THE FIELD

There has as yet been no large-scale epidemiological study on the prevalence and manner of manifestation of autism in India. Awareness of the condition although gradually increasing on account of the work of non-governmental organizations and the impact of mass media is confined to select urban pockets. The metropolis of Delhi with its large public and private hospitals, and well developed and active NGO sector has become as it were, the ‘autism hub’ of India. The pioneering non-governmental organization ‘Action for Autism’ which was set up in 1991 through the efforts of a parent, Mrs. Merry Barua, is recognized in the medical as well as educational community as one of the few places in the country where affected children can obtain diagnoses, intervention and training programmes under one roof. The organization has played an important role in disseminating information about autism to the medical and lay public alike through its training programmes for parents and professionals, quarterly magazine (Autism Network) website and advocacy work. Indeed, the availability (howsoever limited) of diagnostic and other facilities in Delhi prompts many families from all over the country to come to Delhi to “show” their child and find answers to their questions about his/her developmental deviances.

My own association with the organization dates back to the year 2000, when my younger son received a diagnosis of autism. I have had the opportunity to interact with several families from various parts of the country over the years, and establish contacts which proved of great use in the study.
The endeavour to transform the nature and scope of my experiences from parent of an autistic child whose academic discipline happened to be Sociology, to those of a researcher in Sociology undertaking a study of families of autistic children, was a problematic one. While my child’s disability affected me personally and emotionally it also fascinated the social scientist in me. Much of what I had studied in the areas of child development, socialization, development of selfhood and identity seemed inadequate to explain the developmental path my child was talking. Merely finding a “name” for his condition was not enough; it was not an organic condition like diphtheria or polio which was caused by viruses or bacteria, nor was it a developmental disorder like mental retardation or ‘manda buddhi’ which was culturally recognizable and would have been received by family and community with sympathy. The behaviours displayed by my child and others like him, more closely resembled the category of ‘paagalpan’ or madness, a far more stigmatizing label. Calling it by an English name like ‘autism’ made it seem even more strange and alienating. The situation that families like mine found themselves in, vis-à-vis the community was a break-down of intersubjectivity. The situation was further compounded by the demands for conformity and rejection of difference by an elitist educational system and a competitive urban social milieu where children’s academic achievements and extra-curricular triumphs were the “trophies” displayed by middle-class parents in the quest for upward social mobility.

We have earlier discussed how the child’s autism can be conceptualized as a window through which to view processes of change in the urban middle class family. Popular journals, newspapers and T.V. features have been telling us that modern Indian families are changing in many ways; women are taking up careers, the ‘joint family’ is breaking down, elders are being neglected, the number of ‘latch-key children’ is growing. We
read reports of ‘high-achieving’ children exhorted by parents to excel in academics, sports and the arts; we see ‘reality shows’ and ‘talent hunts’ on television where children as young as four are made to sing, dance, act, laugh and cry on demand, with scant regard for their tender age and psychological vulnerability. We also see the valourization of the ‘old style’ joint family in films (Karan Johar’s cinema is a case in point) television-serials, (eg. Ekta Kapoor’s soap-operas) which have a large audience amongst the urban middle class. These depictions in popular culture apparently fuel the notion that the all encompassing, nurturing joint family has been rent asunder by the pervasive impact of modernization and the growth of individual aspirations.

A difficult circumstance like a child’s disability acts as a ‘critical event’ or a breach in the fabric of ‘normalcy’ challenging existing rules and regulations and bringing to light the weaknesses in the social fabric. It is in a sense a natural laboratory in which to view the changes supposedly taking place in the urban family. The choice of topic for this project was thus the outcome both of biographical factors and a keen interest in the changes taking place within families in a metropolis that I have been living in for most of my adult life. Twenty years ago, a child with a disability in a middle-class family would probably not have been brought out in public for fear of opprobrium and shame. Today, the categories of “slow learners”, “special children”, “learning disabilities” are increasingly becoming familiar in middle class circles. The term “inclusive education” is sometimes used by fashionable public schools to showcase their “progressive” leanings rather than as a thoughtful pedagogical strategy. At the same time, as earlier mentioned, competition for admission to ‘good’ schools is getting stiffer and children with average intelligence and talents are getting left far behind in the race to succeed. The situation of intellectually disabled persons is likely to become even more untenable. Delhi thus appeared to be an ideal place to conduct such a study.
It has a population of almost 1.4 billion (13850507 as per the 2001 census) with a sex ratio of 821 women per thousand men and a population density of 9294 persons per square km. As the political capital of India, it is home to the bureaucratic and government machinery, various ministries and departments. 6.24 lakh people are employed in the public sector, including Central Government, Government of Delhi, quasi-governmental and local bodies. 2.13 lakh individuals are employed in the private sector (figures for March 2003; Source: Dte of Social Welfare, Govt. of Delhi) Over the last two decades, it has emerged as a leading centre of the service sector, including the B.P.O. sector. People come here in search of educational opportunities, medical treatment, jobs and the social mobility denied them in small towns and villages.

In 2001, the city had 2416 primary, 715 middle and 1576 secondary schools; 131 colleges, including 5 medical and 8 engineering colleges; 5 Universities, 7 deemed Universities and one Open University. (www.delhieducation.net accessed on 3.12.07) As per data for 2003-04, there were a total of 563 hospitals in Delhi, including 496 private hospitals and 10 and 25 respectively under the jurisdiction of the Central Government and Government of Delhi. (Source: Dte of Social Welfare, Govt. of Delhi) The decade of the nineties saw a steady increase in Delhi’s population on account of migration, from 1.78 lakhs in 1991 to 2.41 lakhs in 2000, peaking at 2.59 lakhs in 1999. Delhi is also one of the bastions of India’s much discussed ‘middle class’, whose numbers were pegged at approximately 50 million by the American management firm McKinsey. In 2005 McKinsey defined the middle class as households with an annual disposable income of between USD 4,380 to 21,890, i.e. 13 million households or 50 million individuals. This burgeoning class purchased 1 million cars in 2006-07 and had 166 million mobile telephone subscriptions in March 2007 up by 68% from the previous year. (www.expressindia.com accessed on 3.12.07)
The proliferation of shopping malls carrying internationally branded merchandise, multiplex cinema halls, multi-cuisine restaurants, bars and ‘pubs’, so-called ‘Page 3’ parties and fashion shows, all point towards the growing spending power and conspicuous consumption of its middle and upper classes. Aspirational levels in this class have increased with the ready availability of consumer loans, credit cards and large pay slabs in the service sectors, including the B.P.O. sector.

Busy urban life-styles, the time spent commuting and the pressures at increasingly competitive work-places result in reduced interaction with relatives who may live in the same city, but may find it hard to make time for each other. Family get together are often restricted to special occasions like weddings or festivals like raksha bandhan where siblings and cousins are expected to meet. The help of relatives and extended kin in times of crisis, notably sickness, hospitalization etc. is solicited hesitantly due to the pressures on people’s time and the physical distances between homes. The family, as a site of nurture and support, of sharing and caring, is seemingly becoming confined to the nuclear unit comprising parents, children and grandparents who may be living with them. Siblings in separate households, aged parents living with other children or independently are not always available in times of crisis. Under these circumstances, how is disability managed by the family? To what limits can kin support be stretched? Are there emerging institutions or opportunities that ‘take over’ where the family has left off? What is the role of support groups and friendship circles in this context? The changes taking place among the urban professional classes, as outlined above, rarely attract sociological attention, perhaps because it is the very group to which sociologists belong, and therefore too close to home. Yet, it is felt that the study of this group is particularly interesting because it is precisely here that shifts and changes in social patterns may be clearly seen.
In this connection, Thapan (1998) refers to M.N. Srinivas's (1966) emphasis on the importance of the study of one's society as against that of other cultures, arguing that the process of rapid change taking place in all areas of Indian society needed to be examined in depth. The study of these ongoing social processes was for Srinivas the most important task for the social scientist. More recently Srinivas (1996: 657) has suggested a shift from the study of the "self-in the other" to "the self" itself. He argues that every life reflects the society in which it exists, and therefore, an anthropologist can consider his/her life as an ethnographic field and study it. Thapan (1998) interprets this as a need to understand oneself and thereby dismantle the self-other dichotomy prevalent in anthropological discourse, bringing into ethnography a perspective from within, based on self-understanding and reflexivity.

Due to my location as a parent of an autistic child and a member of the same social class that my respondents are drawn from, reflexivity plays an important part in the present study. It is my location as an "insider" that opened many doors to me; granting me access to intimate family narratives and active participation in the daily lives and activities of the respondents. Before elaborating upon this aspect further a description of the sample and criteria for its selection followed by a discussion of field methods is in place.

1.3 SAMPLING STRATEGY

The study is based on narrative interviews and participant observation conducted with twenty families over a 2 year period (June 2005 to June 2007). The unit of analysis was the family of the autistic child. Purposive sampling was undertaken to ensure that the families recruited displayed a range of characteristics, including the nature and severity of the child’s condition, gender of the child, presence or absence of siblings and socio-
economic status of the family. With respect to the last characteristic, the sample is an overwhelmingly middle and upper middle class one, with only two families falling in the income category of less than Rs.15,000 per month, 12 in the range of Rs.15,000 to 50,000 per month, and 6 families in the range of above Rs.50,000 per month. The middle class bias reflects the difficulty in obtaining appropriate diagnostic and rehabilitative facilities for children with autism. 19 families were Hindu, one Christian (Roman Catholic).

Access to the families was through snowballing and personal contacts. Contacts were mostly established through the mothers who introduced me to other mothers. My autistic son proved an effective "reference"; whenever I was introduced as "Vishu Ki Mummy", I was received with warmth and enthusiasm. Although I interacted with a large number of families, it was decided to restrict the sample size to twenty families in order not to sacrifice "depth" for "breadth" (Whyte, 1984: 226). Moreover, saturation of data was sought to be avoided.

My location as a parent of an autistic child worked in my favour. For one, I was not regarded as just a research scholar in search of a degree, rather as a co-sufferer. Many parents told me that they had been interviewed or surveyed before by researchers in psychology or special education, and they did cooperate in the interest of furthering knowledge. At the same time, they expressed the feeling that the researchers were only interested in them as data, not as persons. As one mother put it, "what do these young girls understand about what I'm going through? They ask their questions, fill their forms and go away... But you know how it is... you understand." This kind of acceptance and rapport with respondents in the field situation highlights the need for "insider" studies of disability and family. All the families I approached to participate in
the study readily agreed to do so. Whilst explaining to them the aims and objectives of the project, I made it clear that confidentiality would be respected and identities would be anonymised. Most of them did not appear to have serious reservations about these issues and told me I could ask them anything I wanted and even use their real names. Only one couple had concerns about what they termed “privacy issues” and expressed the desire to see what I had written about them and how I had represented their narratives. However, all names and personal details have been anonymised.

As mentioned earlier, it was through the mothers of the children that my “entry” into family experiences was mediated. In one case, it was the cousin of the child who was the primary care-giver and key informant in that family situation. In all detailed and frequent interviews were conducted with 19 mothers, 9 fathers and the cousin mentioned above. Siblings and grandparents, wherever available were also engaged in informal conversation.

As the study aims at understanding the day-to-day lived experiences of parenting and living with a child with autism, the unit of analysis was the family. Research questions were geared to take into account the dynamics of family life focusing on ‘activity settings’ and the social construction of disability through everyday shared routines.

i) Age and Characteristics of the Autistic Children

Using a purposive sampling strategy, families of twenty children diagnosed with one of the Autism Spectrum Disorders including one case each of Asperger’s Disorder¹ and

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¹ Asperger’s Disorder or Asperger Syndrome (AS) is one of the several Autism Spectrum Disorders characterized by difficulties in social interaction, restricted, stereotypical interests and activities. Individuals with AS usually do not have general delays in language and cognitive development, unlike other individuals on the Autism Spectrum.
Rett’s Syndrome was recruited for the study. Six of the children were girls and fourteen boys. At the time of the fieldwork, all the children in the sample were between the ages of 5 years and 12 years. It was thought that families of children within this age group were in a position to understand and articulate more clearly the concerns of raising such a child, as compared to parents of very young children who probably had recently received a diagnosis, and were thus grappling with shock and emotional distress. Moreover, autistic children in middle and late childhood quite clearly appear “different” from regularly developing peers as the socio-emotional developments that take place at this stage are very complex. The challenges of parenting, coming to terms with the reality that the child is markedly different, and arriving at a certain level of psychological and emotional stability make this category of parents sociologically interesting. It was decided to limit the upper end of the age group to thirteen years. It was felt that the issues pertaining to puberty, sexual maturation etc. that confront older children required detailed treatment and a separate study. However, one of the girls in the sample started menstruation during the course of the study. At the time of writing, two or three of the older boys had also started developing secondary sex characteristics (pubic hair, spurt in height, deepening voice etc.).

In a nutshell, families of children in this age group had the time to get over what Wolfensberger (1983) terms “novelty shock”. At the same time they were grappling with the issues of raising young children (the autistic child and his/her regularly developing siblings), ageing parents, workplace expectations and other pressures. The ages of the parents ranged between 30 and 47; this is an age group beset with domestic

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2 Rett’s Syndrome is a neurodevelopmental disorder found almost exclusively in females. It is classified as a ‘Pervasive Developmental Disorder’ by the DSM-IV. Its clinical features include deceleration of the rate of head growth, mouthing and wringing of hands. Symptoms which resemble autism include avoidance of eye contact, screaming fits, inconsolable crying, lack of social and emotional reciprocity, impaired communication and loss of speech.
and professional responsibilities. It is also a group vulnerable to physical and stress related ailments. Raising an autistic child is an exhausting business, as parental narratives revealed, and this took a toil on the physical and mental health of some parents. Parenting a disabled child was seen in the context of the wide variety and intensity of roles men and women in their 30s and 40s are expected to play in urban India.

The sample reflected considerable variety in the severity of the autistic child’s symptoms and behaviours. With the exception of the young boy who was diagnosed with Asperger’s syndrome, the rest of the children had limited verbal abilities. Some of them spoke a few words to indicate needs (e.g. “Maggi”, “Paani”, “de-do”, “Pepsi” etc.) addressed and greeted people when prompted, but rarely initiated conversation or expressed thoughts and feelings. One of the children had cerebral palsy along with autism and found it hard to perform even the simplest tasks, while another child was an expert ‘climber’ who could shoot up stairs, ladders and ledges with great dexterity, causing several anxious moments to her care-givers.

Some children had difficulty with fine motor coordination and hence could not do up buttons, laces, hold pens or pencils etc. while some were extremely dexterous with their hands and could do delicate embroidery and cross-stitch. One of the boys using “facilitated communication” could convey complex feelings and emotions (as reported by the mother), another was reported to be capable of solving difficult mathematical problems even though he could scarcely communicate for his needs. While some children appeared aloof and shunned contact, others appeared affectionate and receptive. A particularly poignant memory is of a child affected with Rett’s disorder
who perched in my lap throughout the duration of a field visit to her home, allowing me to feed her tid-bits, as she was unable to use her own hands for the purpose.

Two of the boys displayed particularly severe self-injurious behaviours including one child who hit himself hard on the face, rhythmically swinging his hands to-and-fro, until his face became black and blue. Tightly swaddling him in a sheet was the only way he could be stopped, but this solution was not always practicable. As has been mentioned earlier, autism is a spectrum disorder and no two individuals ‘present’ it in an identical manner. Despite the variety and variability of the behavioural manifestations, the core underlying deficits in language, imagination and social skills were clearly apparent in all the children and, as we shall discuss in the next chapter, it was their absence of “social relatedness” that first rang the alarm bells in their families.

The mean age upon receipt of diagnosis was 3.5 years; with the earliest diagnosis taking place at 2 years of age and the latest one at 6 years. All the children were in receipt of educational and therapeutic services. One child attended a mainstream classroom in a reputed public school, two attended ‘special’ classrooms in mainstream schools and the rest attended special schools for the mentally disabled. As this thesis is primarily concerned with family life, educational interventions will not be dealt with in detail, even though it is acknowledged that appropriate or inappropriate school placements and support play an important role in the way families handle the child’s disability.

ii) Family Composition: Migrants and Non-migrants

Of the 20 families in the sample, 13 are first generation Delhi-ites. The natal families of husband and/or wife are therefore geographically dispersed and contact with them is only intermittent. This has a significant impact on support networks within the family,
as we shall see. They migrated to Delhi for professional reasons and in ten cases, deliberately chose a Delhi posting or transfer on account of the child’s disability. Their households are nuclear. Of the 7 families who have been in Delhi for more than one generation, only two live in an extended set-up; the rest are nuclear. In one family, the husband’s elder brother, wife and their children live in the same building but on a separate floor, and the kitchens and financial arrangements are separate. One of the families has two young girls living with them doing the domestic chores and helping with the care of the child. The child’s parents insist that they are ‘family’; without their support it would be very hard for them to manage. Hired help and care-givers thus play an important role in urban households, particularly those under difficult circumstances or where women work outside the house. In another family, the unmarried chacha (father’s younger brother) plays a supportive role and helps to keep the child entertained. In one case, the care of the autistic child is entirely taken over by an unmarried female cousin.

**Figure-1.1: Migrant Status & Family Composition**

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<th>Residing in Delhi for more than 1 generation</th>
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iii) Sibling Profile

Eleven families had regularly developing children along with the autistic child. 6 had younger siblings, 5 had elder ones; one child had both, a regularly developing older sister and older brother. The siblings included eight sisters and four brothers. Their ages ranged from four to seventeen years.
iv) Regional Profile

The families represented a wide regional mix. Nine hail from the Northern region of the country, three from the East, four from the South and one from the Western region. The remaining three families are “mixed”, i.e., the couples hail from different regions and/or different castes. These include an Oriya Brahmin and U.P. Bania, Tamil Brahmin and U.P. Bania, and a U.P. Rajput and Bihari Brahmin. These and 2 other same-region unions were “love” or self-choice marriages; the other 15 couples married in a conventional yet modern way, viz. after a meeting arranged by parents or relatives. The match was finalized with the consent of both prospective bride and groom. Of the “unconventional” marriages, all but one faced active familial disapproval or displeasure, more on account of the perceived lower socio-economic status of the boy’s family rather than caste or other ritual considerations. In fact, both parties were of the same caste. The other couples met each other in Universities or at the work place. Their marriages took place with the approval and “blessings” of their parents.
It was observed that the languages spoken at home were usually Hindi and English, in addition to the vernacular. This was an interesting finding particularly in the South Indian and Bengali families within the sample. The reason given by the family was that their child (who was linguistically impaired to begin with) would need to understand these two languages if he/she was to live and study in Delhi. Regularly developing children appeared more comfortable and conversant in these languages as well due to their experiences and interactions at school and with peers. Due to limited contact with grandparents and other kin, it was noted that the use of the native tongue at home was on the decline. In the ‘mixed marriage’ families, Hindi and English were the languages of choice. Most of the interviews were conducted in a mix of the two languages, and the hybrid “Hinglish” that is practically the *lingua franca* of middle class Delhi. It was observed that many of the words and phrases used at school and by the therapists were incorporated into the vocabularies of the non-English speaking families; eg. “Bacche Ke Saath Work Karna” (working with the child), “Usey changes Ke Liye prepare Karna” (preparing him/her for changes), “Uska schedule banana” (making his/her schedule), “uske challenging behaviours ab kaafi kam ho gaye hat” (his/her challenging behaviours have reduced quite a bit) etc.

v) Educational and Occupational Profile

Of the mothers in the sample, 8 had completed a post graduate degree (including a doctorate in management an MBA and a post graduate diploma in Mass Communications). 10 mothers were graduates including one engineer, one trained nurse and one a B.Ed trained teacher. One mother had studied upto class XII and one had studied upto middle school before dropping out.
Three of the mothers had completed Diplomas in Special Education, specializing in Autism (DSE-Autism) conducted by Action for Autism and Tamanna School, New Delhi.

Only five of the mothers held paid employment. One of them worked ‘freelance’ from home. One mother, trained in special education worked part-time as a special educator in a public school (not the one that her child was attending). Only 3 held full-time ‘nine to five’ jobs; two as government servants and one in a Management Institute. Of the 15 mothers not in paid employment, four had held jobs before the birth of the children, but could not resume their careers on account of their children’s disability. One of these “stay-at-home mothers” conducts art-and-craft classes for neighbourhood children during summer vacations in order to supplement the family income and for her personal satisfaction. One of the mothers who is financially not well-off, completed a beautician’s course, but due to her child’s odd behaviour, found it difficult and embarrassing to attend to clients in his presence.

**Fig.-1.4: Educational and Occupational Profile of Mothers**

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<th>a) Educational Qualifications</th>
<th>b) Employment</th>
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<td>1. 12th and below</td>
<td>1. Not in paid employment</td>
</tr>
<tr>
<td>2. Graduate</td>
<td>2. Self-employed/part-time</td>
</tr>
<tr>
<td>3. Post-Graduate</td>
<td>3. Full-time</td>
</tr>
<tr>
<td>4. Special Training in Disability</td>
<td>a. Govt./pub. Sector</td>
</tr>
<tr>
<td></td>
<td>b. Pvt. Sector</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>
Of the fathers, 3 have professional degrees (1 doctor, 2 engineers); 9 are post graduates; 6 graduates and 2 studied upto Class XII. The occupational profile includes seven Government servants, including two highly ranked officers, one Lower Division Clerk and the rest placed on the middle rungs. One of them is a doctor in the Armed Services and nine work in private companies in posts ranging from middle-level executives to Senior Manager and C.E.Os. Three pursue their own businesses; two high turnover family run businesses and one selling crockery in weekly ‘haats’ in Delhi. Fifteen of the men are the sole earners in the family including the two at the lowest end of the educational and occupational spectrum viz. the low ranking Government servant and the man with the crockery business.

**Fig.-1.5: Educational and Occupational Profile of Fathers**

<table>
<thead>
<tr>
<th>a) Educational Qualifications</th>
<th>b) Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 12th and below</td>
<td>1. Not in paid employment</td>
</tr>
<tr>
<td>2. Graduate</td>
<td>2. Self-employed/part-time</td>
</tr>
<tr>
<td>3. Post-Graduate</td>
<td>3. Full-time</td>
</tr>
<tr>
<td>4. Special Training in Disability</td>
<td>a. Govt./pub. Sector</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>b. Pvt. Sector</th>
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<tr>
<td></td>
<td>Total</td>
</tr>
<tr>
<td></td>
<td>20</td>
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</table>

![vi)

**vi) Class Profile**

In terms of income, the families can be categorized as follows:

**Fig.-1.6: Monthly Income of the Family**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1. Below 15,000 PM</td>
<td>2</td>
</tr>
<tr>
<td>2. 15,000 PM to 25,000 PM</td>
<td>5</td>
</tr>
<tr>
<td>3. 25,000 PM to 50,000 PM</td>
<td>7</td>
</tr>
<tr>
<td>4. Above 50,000 PM</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>
Of the 20 families, only 7 lived in their own residences or reported that they owned property in Delhi; the rest either lived in leased or rented private residences or in Government quarters. This may be explained on account of the fact that more than half of these families are first generation migrants to the city, and are not sure whether they plan to spend their old age there. Some couples, who shifted to Delhi to access services for their child and who are living in rented flats, expressed their desire to purchase property and permanently settle in Delhi; however, escalating real-estate prices along with the need to save for their child's future made them hesitant to take on housing loans or credit. Interestingly, a number of families (including three in the sample) have rented homes in a housing cluster in the vicinity of Action for Autism, thereby inaugurating a nascent “autism community”. One of the mothers joked that perhaps the presence of so many autistic children in the neighbourhood might bring property values down!

As the class profile delineated earlier suggests, the majority of the families in the sample have access to household conveniences and appliances that are the *sine qua non* of urban life including vehicles (14 families have one or more cars, 6 have scooters). All but four families have hired domestic helpers for household chores. A look at the educational institutions attended by the regular children in the family reveals that nearly all the siblings attend well-renowned public schools. In one of the families where the sole earner is a lower division clerk, the regularly developing son and daughter study at a *Navodaya* school and also go for private tuitions. They are both doing very well academically, much to the pride of their parents. Aspirational levels and the importance given to educational attainments is of a high order through the sample. This also reflects in the strenuous attempts made by these families to secure educational interventions for their autistic children. In fact, many expressed regret and unhappiness
that special schools did not focus much on "academics", but rather, functional and pre-vocational activities. Some parents told me their children knew reading, writing and mathematics but the school did not challenge their intelligence enough.

Thus we see that the 20 families although differing in composition, regional and linguistic backgrounds, display a fundamental similarity in terms of the growing child-centric orientation that is becoming part of urban culture. They display a willingness to uproot themselves, travel long distances, make immense sacrifices in order to improve the life-chances of their children. They emphasise medical interventions, timely achievement of developmental milestones, educational attainments and extra-curricular success. Childhood is construed as an enterprise, a work-in-progress and successful attainment of milestones is viewed as a measure of successful parenting. In a competitive urban milieu, conformity to norms is the key to success. The arrival of a developmentally disabled child alters the life-plan. However, the efforts to find treatment, cure, therapy, rehabilitation, medication, and the willingness to undergo hardship "for the sake of the child" are as strenuous, if not more so, than the efforts to "make" the future of the regularly developing ones.

The following section discusses the manner in which the fieldwork was conducted. Before dwelling on the methods used and the issues that came to the fore as a result, the feminist underpinning of the work is sought to be clarified. We do not imply that only the standpoint of the women in the sample was considered; undeniably, due to the fact that I am a woman, I was able to interact with other women more easily than with men. It may be noted that the thesis topic is not about 'mothers of autistic children' but rather, 'families of autistic children', thereby implying that the disability impacts the
family as a whole. While, in most cases, the primary informants were women, interviews with fathers also yielded rich data and insights.

1.4 FIELDWORK STRATEGY

In 1959, C. Wright Mills wrote that “the sociological imagination” enables us to grasp history and biography and the relations between the two within society. Sociologists have long worked with narratives of individual lives, but since the 1960’s, there has been a renewed interest in the uses of biographies, autobiographies and life histories in the social sciences, including sociology. This approach owes much to the feminist perspective that posed an important theoretical and methodological challenge to ‘conventional’ social science. One of the major challenges of feminist epistemology to mainstream social science has been its powerful critique of positivism and to underlying assumptions. The positivist tenet of value-free objectivity which encourages distance and non-involvement between researcher and researched and assumes that the researcher can objectively observe and interpret the life and meanings of his/her subjects, contrasts sharply with feminist research which has been described as “contextual, inclusive, experiential, involved, socially relevant... complete but not necessarily replicable, inclusive of emotions and events as experienced”. (Nielsen, 1990: 6)

Feminist scholars oriented towards qualitative fieldwork have often encouraged relationships between researcher and researched that are based on friendship, closeness and sharing of experience rather than hierarchical and potentially exploitative (see Haider, 1998). Many feminists have argued for an approach that focuses on process (Gorelik, 1991) and makes use of one’s intuition, emotions and viewpoints to enhance the research relationship and process. Through “intersubjectivity”, the researcher
compares her own work and experiences as a woman and shares it with her respondents, who then add their opinion (Duelli Klein, 1983). Thus the splitting of researcher and researched and subject and object is challenged.

The present study is informed by feminist epistemology and methodology as outlined above. The methods of data collection employed include in-depth, narrative interviews, observation and participant observation. The methods were not really separable and flowed into each other. The field methods were geared towards capturing in all its rich detail, the ebb and flow of daily life, the constant demands and challenges of parenting an autistic child.

i) Interviews

Basic information was noted down at the time of seeking consent for participation in the research. The primary data collection tool used was the narrative interview. Participants were encouraged to talk about all the aspects of their lives that they considered significant. The interviews ranged in length from one and a half hours to three hours, and were usually conducted at the homes of the respondents. A minimum of one and a maximum of six interviews were conducted with each respondent. Some interviews were also conducted in the reception area of the child’s school, where some mothers waited for the duration of the school day. Frequent telephone conversations with parents helped me to keep track of the various events and activities taking place in their families.

The interviews were unstructured in the sense that respondents were free to talk as much or as little as they liked about topics, revert back to earlier topics, introduce new topics or avoid certain topics altogether. The broad themes that were covered in all the interviews overlapped with the research questions raised earlier, viz., what was it about
their child that gave them pause to consider that it was not ‘normal’? What sort of help-seeking behaviour was resorted to? What were their experiences and feelings during the processes of symptom recognition and diagnosis? What were the explanatory models evoked to help them come to grips with the diagnosis of a life long disability? How did they help the afflicted child to cope with his/her daily activities and routine? What was the impact of the child’s disability on the lives of parents, siblings and other family members? How did neighbours and relatives react? What were their plans for the future? How did they visualize the child’s future when they were no longer there to take care of him/her?

The interviews were more in the nature of intimate, sometimes emotionally draining conversations. Hence a tape-recorder was not used. This was a difficult decision to take, for the introduction of a mechanical device might have resulted in the conversation becoming stilled or awkward. I jotted down key points on a note-pad, especially apt or pithy quotes and wrote up my field-notes as soon as I returned from the field-site. Moreover, as anyone who has interacted with autistic children would testify, a device like a tape-recorder is of particular fascination for some of these children; it would probably have been systematically taken apart by one of them! As has been mentioned earlier, the majority of the respondents were mothers. Most often, they were the primary care-givers and in the majority of the cases were the first to realize that the child’s development was atypical. In most of the cases it was they who took the lead in seeking various medical opinions and often coerced their spouses into taking the child to various hospitals and specialists. Post-diagnosis it was more often than not, the mother who had to assume the major responsibility for care. She became the care-giver, the therapist, playmate and protector all in one. This is not to deny the role that fathers played in the care and nurture of their children. However, it may be
safely asserted that in the majority of the cases, the mothers engaged with their children and assumed responsibility to a greater degree than did the fathers; an observation that is equally valid in the case of regularly developing children.

**Talking with the Mothers**

My interviews with mothers proved to be occasions for sharing and articulating thoughts and feelings not just about their autistic children but also about their own childhoods, marital relationships, relationships with parents and in-laws, regular children, neighbours and friends. They discussed their hopes and fears, the strategies they employed for balancing the demands of their multiple roles, workplace issues, sexual issues and family dynamics. The interviews were dialogic; they also wanted to know about my child and how I lead my life. In particular, they were curious about my experiences as a single parent, and how I coped with the loss of my spouse. One of my respondents told me with tears in her eyes that she spent a sleepless night thinking about me. I was not viewed as just a researcher, but also as a mother who faced the same issues as they did. One of the mothers told me “...I can never say ‘no’ to you... Whenever I think my sorrow is so great, I always look at you... We are in the same boat.”

Whenever I felt that a question was intrusive or too personal, I would apologise. However, in most cases the mothers would respond very positively; they rarely took umbrage and sometimes revealed disconcerting things. For example, some of them frankly expressed a desire for the early death of their child. It is unlikely that this sort of disclosure would have been made to a researcher who was not “in the same boat”.
Some of the mothers told me that speaking to me was like a catharsis; "man bahut halka hua" (feeling unburdened). One of them said that she had not been able to talk so frankly before for fear of being misunderstood or regarded as a "bad mother". Some of them told me no one took interest in their day-to-day problems. "Koi nahi poochta.. Kisi ke paas time nahi hai." (Nobody has the time to enquire how I am) said one; "Aapka-hamara ek jaisa dard hai, isliye aap samajhte ho" (Both of us share the same sorrow, that is why you understand) said another. When I expressed thanks for their participation and support, I was touched that many of them actually thanked me back for spending time with them and listening to their stories.

**Talking with the Fathers**

My experiences in interviewing mothers were characterized by warmth, intimacy and sharing, as detailed above. Before embarking on my first interview with a father, I was a little wary. My conversations with his wife suggested that he was not given to sharing his thoughts and feelings about his autistic son. I was told that he had agreed to speak to me because he felt I was "worse off" (i.e., a single parent) and therefore he felt it his duty to oblige me. He expressed these very thoughts at the start of our interview conducted in his office chamber (after office hours). Within a few minutes though it was as if a dam had burst; he talked with intensity about his unhappy childhood, ambivalent feelings for his child, the grief and disbelief about his child's disability and his fears about the future. Two hours later, he had smoked his way through eight cigarettes and was practically in tears. I had not 'asked' him a single question other than the opening "..so tell me something about your early life.." I listened quietly, only nodding and making responses like "I see", and "uh-huh". He told me that it was the first time he had spoken of his child so frankly. "To tell (my wife) would only hurt her.. she'll start to cry.. and then I'll join her.. what is the point? ..." He said he felt
unburdened, because he believed I was a non-judgemental yet empathetic third person; he did not have to pretend to be strong and in control.

This interview set the pattern for what was to follow in the other interviews with the fathers. Of the nine men interviewed, all but one were known to me through their wives, i.e. I first made the acquaintance and struck up a relationship with the wives before being introduced to the husbands. In one case I knew the husband beforehand through common acquaintances. Interviewing him about his experiences thus did not pose difficulties. However, I had to persevere with his wife, who was initially rather cool and reserved. However, after a few sessions she opened up and contributed valuable inputs.

I had expected that my gender and single status would constrain my interactions with the fathers. As a single woman, there were bound to be certain ‘Lakshman Rekhas’ (limits) in place; I did not expect to discuss matters of an intimate or deeply personal nature. After initial moments of hesitation and reserve, I was surprised to find the fathers talking very freely. They discussed financial issues, the issues of stigma and shame, social acceptance, employment related issues, housing, legal provisions and adulthood issues. While mothers provided an entry into the ‘inner’ world of emotions, fathers acted as a window looking outwards, to the societal domain. (See Shaked, 2005 for a similar insight).

My location as a working person, the sole breadwinner of the family was akin to their situation (only 3 of the 9 men interviewed had working wives); they could discuss issues like tax planning, saving and insurance, legal provisions etc. with me. One of the important themes that emerged was the issue of ‘concealment versus disclosure’ at the workplace, with some of the fathers, particularly in the corporate sector expressing
anxiety about the child's disability (and consequent pre-occupation of the father) being 'used' by ambitious co-workers to get ahead in the corporate race. I was asked of my own workplace experiences, how I managed to 'keep my superiors happy' and the trade-offs between giving the child time and doing justice to the responsibilities at the workplace. I was, in a sense 'androgynised'; they saw me as "one of them". Even the encounter described earlier which started as a "favour" conferred to a "weak" female concluded on terms of equality, with the man talking with me rather than talking down to me. Peggy Golde's (1970) observation about women researchers being treated as androgynous or honorary males had a curious resonance in this context.

My interviews with the fathers made me realize sharply the paucity of outlets for them to discuss their worries and fears. While women do find spaces and opportunities to share their thoughts and feelings with other women (mothers, sisters, friends, neighbours), this kind of space is not culturally sanctioned to men. In particular, the competitive urban milieu precludes such intimacy with co-workers and even friends. As one man confided in me, he did not want to be seen as a 'failure' (implying that the disabled child was a marker of 'failed' manhood) and that by disclosing worries about the child's difficulties and fears for its future he would be exposing his weakness and would be 'taken advantage of.' With me they did not feel threatened.

Indeed, I was taken aback by some of the disclosures of a very personal nature made by one or two of them. This posed a major ethical dilemma for me; I was now in the uncomfortable position of hearing husbands and wives talking about each other and the difference between the ways they viewed each other and actually acted. I worked my way out of the situation by focusing pointedly on those disclosures that impacted their parenting ideologies and practices, rather than dwelling on their marital politics.
ii) Participant Observation

The narratives built up through long interviews yielded rich data about the way parents perceived their child’s disability, assessed their inter-personal relationships and devised strategies to cope with daily living. The interview data were strengthened and refined by observational data. Observation of families in daily activities like eating, playing, transporting the child to and from school, routine and special events at the NGO (eg. Parent-Teacher Meetings, Annual Day Functions, parties and celebrations etc.) enabled me to build up a more nuanced understanding of the way they constructed the identity of their child and portrayed it to society.

The ‘family visits’ I undertook yielded several insights into the processes of construction and portrayal of the child’s identity. I would usually spend the whole day with the family at their home, participating in their activities and interacting with all the family members and occasionally, the neighbours as well. Usually, these visits took place on weekends or holidays when all members were likely to be home. My sons (the elder, regularly developing and the younger, autistic) sometimes accompanied me. This made the situation more interesting, as it brought to the fore interactions between regular siblings, autistic siblings and parental attitudes and expectations towards both. I noted the affection with which my regularly developing son was welcomed wherever he went. The parents of an autistic boy of the same age as he, (an only child) told me how much they enjoyed talking to my son and having him respond to them. In particular, the father enjoyed discussing cars, computers and sports (i.e., “boyish” things) with him. I noted the unique modes of interaction between the autistic children as well; my autistic child would eagerly look forward to a visit, yet during the course of it would play alone in a corner minimally interacting with the other children. Upon going home, he would enthusiastically say, “X se milkar bahut mazaa aaya!” (I really
enjoyed meeting X). The family of ‘X’ would report virtually the same response from their child.

These visits also proved to be avenues of social interaction for the families. As several of my respondents told me, they missed entertaining friends and guests on account of their child’s difficulties and found making social visits awkward and embarrassing unless it was to the home of people who understood autism and made allowances for the child. As one father put it. “After slogging the whole week.. you want to go to a place where they are O.K. with a child doing potty in the middle of the room and spreading it on the walls..”

As mentioned earlier participant observation was also undertaken during the various events conducted at the NGO. Large group discussions in parent-teacher meetings brought into the open concerns and issues being faced by parents vis-à-vis the child and the organization. Some of the meetings were heated ones with parents venting their grievances and the representatives of the organization stating the limitations and problems they encountered. Celebrations and social functions arranged by the school were excellent occasions to observe families; eg. preparations for the Annual Day function, the rehearsals, the elaborate planning of costumes and make-up, the festival like atmosphere and loud cheering that accompanied every item, all were rich with meaning and significance. Similarly, the very popular Christmas party, where families, friends and well-wishers all come together to celebrate, revealed the families with their guards down unconcerned about “what will people say” and at ease in the company of other families like their own.
Fieldwork in the organization was carried out for the duration of one year (2005-2006). This included bi-weekly visits over a three month period (August to October, 2005) in which I interacted with parents, teachers and other functionaries and, as mentioned undertook participant observation in all the events conducted by it during the course of the academic session July, 2005 to May, 2006. I also studied back issues of the newsletter *Autism Network* brought out by A.F.A. The publication is a rich compendium, comprising common and unusual problems faced by families of autistic children, coping strategies based on personal experiences, cheerful, often amusing stories about the escapades of the children and research articles in the fields of psychology and special education.

1.5 DILEMMAS IN FIELDWORK

Situating dilemmas in fieldwork from a feminist location, Hale (1991) writes that they are as much ethical and personal as academic and political. Wolf (1996: 1) describes how “...they gnaw at our core, challenging our integrity, our work, at and times, the *raison d'etre* of our projects ..(they) revolve around power, often displaying contradictory, difficult and irreconciliable positions for the researcher”. As has been stated earlier, the present study subscribes to a feminist epistemology, particularly with regard to the attention paid to breaking down the “hierarchical and potentially exploitative relationship between researcher and researched.” (ibid: 4). Due to my location as a parent, reflexivity was an essential aspect of the research design. However, during the course of the research the roles of ‘researcher’ and ‘parent’ gradually came to be demarcated and separated.
i) The Issue of Power

According to Wolf (1996: 2), the central dilemma for contemporary feminists in fieldwork from which other contradictions derive, pertains to power and

* ..the unequal hierarchies or levels of control that are often maintained, perpetuated, created and re-created during and after field research. Power is discernible in three interrelated dimensions: (1) power differences stemming from different positionalities of the researcher and the researched (race, class, nationality, life chances, urban-rural backgrounds); (2) power exerted during the research process, such as defining the research relationship, unequal exchange, and exploitation; and (3) power exerted during the post fieldwork period – writing and representing.

My positionality as a parent of an autistic child was a critical factor in ensuring that the research relationship was a non-hierarchical meeting of ‘equals’. However, the issue of power was confronted during the phase of writing and representation. I had to exercise much caution in presenting the stories narrated to me by the interlocutors so that identities were kept confidential and intimate details about their lives were presented in a tactful manner. I had originally planned to present detailed case histories of individual families and weave around them the themes that had emerged from the fieldwork. However, this would have exposed the identities of the participants as the ‘autism community’ in Delhi is a small one. Moreover, as has earlier been mentioned. I had unwittingly become privy to confidences of a private nature and revealing these while elaborating a case could have caused family conflict or worse. I therefore had to change my strategy of representation by focusing on major themes and illustrating them with examples and snippets drawn from the lives of several families. By opting in this case, for “breadth” over “depth” in presentation, the dilemma of focusing the spotlight too searchingly on specific families was dealt with.
The more detailed case studies that are to be found in the chapters focus on specific situations or aspects of life with a disabled child, including the process of obtaining diagnosis and coming to terms with it, daily routines, parental coping etc.

In this context, Judith Stacey’s (1991) classic piece “Can there be a Feminist Ethnography?” is relevant. Stacy argues that the friendship that may develop between a feminist researcher and her subject could end up becoming more manipulative than traditional, positivist methods which had no pretensions of aiming at empathy or solidarity. Stacy felt she was using and betraying her informants by transforming the extremely private and intimate information revealed to her into data. I had to battle with similar feelings throughout the course of the study. The uneasy feeling that another person’s pain was the source of my academic advancement refused to go away. The only justification I could offer myself was that I too had experienced a similar pain. Exteriorising it, analyzing and putting it to scrutiny and making it available to others was part of my academic training. I had to convince myself, time and again, that the experiences of families with autistic children needed to be made available to scholarly and lay audiences, and that I was uniquely qualified to accomplish this task.

ii) Emotions and Fieldwork

The very theme of the study is deeply personal and emotive. For families to learn that their child is suffering from an incurable, life-long mental disability is traumatic, to put it mildly. In addition, several of the behaviours associated with autism are disruptive and bizarre and cause stress to families. As described earlier in the chapter, there was a good amount of variability in the symptoms displayed by the children. Some of them had behaviours that were so distressing, it left me disturbed and shaken. My own autistic child is fairly high functioning and verbal; sometimes he is considered to be a
normal, if hyperactive child by strangers. I am also the mother of a regularly
developing child. I experienced “survivor guilt” when I encountered families with
severely impaired children, especially when these were only children. I also
experienced feelings of annoyance and impatience with some respondents. I had to
restrain myself from giving unsolicited advice or passing judgements. Sometimes I
would get so weighed down by the burden of other people’s problems, I would
seriously consider giving up altogether.

Following the advice of Kleinman and Copp (1993), I acknowledged and recorded the
emotions accompanying the fieldwork in my fieldnotes. These acted as data in their
own right, helping me understand the reactions of others to families grappling with
disability. This also helped me to work through my own biases, prejudices and taken-
for granted assumptions, enabling me to appreciate the way culture interacting with
biography shapes responses and understandings of a difficult circumstance like a
child’s disability.

During the course of the fieldwork, some families went through severe trials and
tribulations; one of the mothers suffered a fall resulting in a serious head injury; one of
the grandmothers was diagnosed with cancer and underwent painful and debilitating
surgery and chemotherapy; a sibling was diagnosed with a potentially fatal disorder.
Naturally, these affected me deeply as well. At the same time, they also enabled me to
observe the impact of serious crises on families already battling with disability. I was
rather appalled at the manner in which I was able to study these events clinically; from
an involved, empathetic insider, I seemed to slide into the conventional, dispassionate
researcher role. I realized that the very dynamic of the research relationship had made
this transition possible; I did eventually manage to “rise above” my emotions in order
to represent my experiences. How this reflects on my human qualities is a different matter entirely.

iii) Continued Engagement with the field

The process of entry into the field, as discussed earlier, was the natural outcome of my own positionality. Access to informants, rapport building and soliciting cooperation were also smooth processes based on mutual feelings of trust and give-and-take. I had become a part of the field I was studying and therefore “leaving” it was a logical impossibility. I could not disengage completely from my informants; they were part and parcel of the social space I inhabited. I still encounter them in various situations and we discuss our children, their problems and progress, our families and various other aspects of our lives. While the frequency and intensity of our interactions (as compared to the fieldwork phase) reduced, I was able to continue to “fill in the blanks” in the data, share my thoughts with them, seek correctives or elaborations to my interpretations. In this sense, the practice of considering informants as “co-researchers”, as prescribed in phenomenological and feminist texts was followed. At the same time, I had to exercise caution and self-restraint in order to avoid getting “over-involved” with my participants. Also, the temptation to treat every interaction with them as a “research opportunity” had to be controlled. I had to remind myself on some occasions that I was to be “just a parent” and not an omnipresent researcher.

Overall, the fieldwork experience proved to be both exhilarating and exhausting. Exhilarating, because one felt that one was unlocking an aspect of social reality that had so far received scant attention in Sociology, and that there were stories that urgently needed to be told; exhausting, because of the toll it took on one’s physical and emotional energies. In terms of the impact it had on the participants, I was aware that
by recounting their experiences, they were reliving their pain. At the same time, I was encouraged by their comments that talking to me helped them to unburden themselves and feel that someone cared. The niggling feeling that I was using their pain to advance my research was mitigated by the belief that their issues needed to be brought into scholarly discourse, and that my positionality was ideally suited for this.

I also became aware of the liberative aspect of social science at the level of my own experience. By viewing biographical events through a sociological prism and attempting to understand how culture and society shape our emotions, our constructs and definitions of the situation, I learnt to view events in my own life and lives around me as part of the ‘bigger picture’ and began at last to understand how the personal is the political.