INTRODUCTION

Disability and Family: An Overview of Major Themes and Perspectives

Disability has been a universal human experience right from the dawn of history. The term connotes a limitation in the functions and activities performed by individuals as members of society, thereby circumscribing their participation in the socio-cultural, political and economic life of their communities.

‘Disability’ is not a homogeneous category. It encompasses different kinds of bodily variations, physical impairments, sensory difficulties or deficits, mental and learning impairments which may be either congenital or acquired. Authors have engaged with the term ‘disability’ in a variety of ways. It has been viewed as a marker of disease (ICD-10), of physical deficiencies, malformations and malfunctions (WHO, 2002), or alterations to kinship expectations and domestic duties (Ingstad, 1995). Disability has been conceptualized in terms of circumscribed economic and productive roles (Stiker, 1999; Foucault, 1967) or in terms of community responses and obligations (Ingstad, 1995; Goffman, 1963).

As the term denotes a lack or deficiency, whether mental, physical or sensory, it has by and large been defined in medical terms. Yet, in all societies, the experience of disability is mediated by socio-cultural understandings that give meaning to impairments and affect the experiences of disabled people in various socio-historical contexts. Disability activists and scholars have long questioned exclusively medical definitions and have instead emphasized the social and cultural interpretations that define power relations between the ‘able’ and disabled which result in the disabled being stigmatized and relegated to the margins of social existence.
This thesis aims to focus on ‘autism’, a life-long developmental disability that profoundly impacts the social, communicative and imaginative capacities of an individual. Specifically, it aims to undertake a sociological study of families of children diagnosed with autism and various issues that confront them in everyday life and with respect to their future.

Autism emerged as a distinct diagnostic label with the publication of the Austrian psychiatrist Leo Kanner’s paper *Autistic disturbances of affective contact* published in 1943. Based upon clinical reports of eleven children encountered by Kanner in his practice, the paper pinpointed an outstanding, pathognomonic, fundamental disorder common to them all, namely, their “inability to relate themselves in the ordinary way to people and situations from the beginning of life” (1943: 242, Kanner’s italics).

Just a year after the publication of Kanner’s paper, another Austrian, Hans Asperger, independently published a dissertation concerning “autistic psychopathology” in childhood. The four children he studied were, unlike Kanner’s patients, highly intelligent and verbal. Yet, they too were socially impaired and often mercilessly teased and bullied by their peers. ‘Asperger’s Disorder’ is the diagnostic term that is given to mildly autistic, high functioning children.

Autism was also known as ‘childhood schizophrenia’, a misleading term, as, unlike schizophrenics, autistic individuals did not appear to have hallucinations or delusions. Kanner believed that autism was an innate disorder present since birth; unlike

---

1 The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Revised (DSM-IV-TR) of the American Psychiatric Association Defines autism as follows: “Pervasive Developmental Disorders (also called Autism Spectrum Disorders) are characterized by severe and pervasive impairment in several areas of development, reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities... [They include] Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, Pervasive Developmental Disorder Not otherwise Specified... These disorders are evident in the first years of life and are often associated with some degree of Mental Retardation.”
schizophrenics, autistic children did not ‘withdraw’ from the world; rather, they were unable to participate in it, in the first place.

Half a century of research has now established that autism is not a mental illness but a developmental disorder, characterized by a neurological impairment. Autism affects an individual’s “theory of mind” or ability to perceive the mental states of others and orient behaviours accordingly. Baron-Cohen (1997) has used the term “mind blindness” to describe this deficit. Jordan (1997) identifies the absence of a theory of mind, failure in inter-relatedness, failure to establish an “experiencing self” and executive function deficit (inability to plan, monitor and direct activities and achieving goals by flexible means) as some of the fundamental difficulties of autism. Wing (1988) identifies a triad of impairments in the areas of socialization, communication and imagination as sufficient and necessary to capture much of the behaviour found to be specific and universal to autism. It has also been established that autism is a spectrum disorder whose manifestations vary from severely withdrawn, non-verbal children who seem to shun human contact to extremely talkative yet naive individuals who often behave very inappropriately in social situations. A highly able, professionally successful American autistic woman, Temple Grandin described herself as “an anthropologist on Mars” to Oliver Sacks (1995). This accurately summarizes the plight of the autistic individual who lives in a social world whose rules he or she is scarcely able to comprehend.

In India, as in many other countries, knowledge and awareness about autism amongst medical and mental health professionals as well as the lay public is limited. Obtaining a diagnosis is difficult as few medical professionals are conversant with its symptoms.

---

2 We have used the term ‘autism’ throughout this work to connote ‘Autism Spectrum Disorders’.
and diagnostic criteria, as research by Daley and Sigman (2002) and Daley (2004) revealed.

Yet, WHO estimates indicate that 1.7 million individuals in India alone may be afflicted with autism. This is by all accounts an enormous figure. Autistic individuals have generally been regarded either as mentally retarded or mad. Their bizarre and perseverative behaviours and the high incidence of epilepsy amongst them is also seen as a symptom of possession by malevolent spirits.

Research on the developmental disorders within a cross cultural context and in non-western countries has received limited attention. It is felt that a disorder like autism which profoundly impacts social functioning, would be an interesting area for sociological study, particularly in the context of family functioning. The research aims at drawing on family narratives as a means to understanding the experience of living with a child with a complex and misunderstood disability like autism.

In order to contextualize the aims and objectives of the research, a discussion of the major themes and perspectives informing research on disability and the family will be taken up.

Scholarship within disability studies and other disciplines has theorized disability in various ways. We begin with a discussion of the medical and the social models of disability, which are well developed theoretical models from which numerous scholars, activists and practitioners have developed a body of literature and disability related practices.

Before we examine these models, a word on terminologies is in order. Under the WHO framework, the unspecified concept of disability has been replaced by three
differentiated conditions, viz., **impairment**, **disability** and **handicap**. Impairment denotes damage or loss of physiological, psychological or anatomical function or structure, eg. limb deformities, loss of sight or hearing, epileptic seizures etc. Disability is specified as a term that reflects functional limitations in performing day-to-day activities that are considered age and gender appropriate. It denotes the interrelationship between the impairment and the environment that impacts individual functioning, eg. communication disabilities, locomotor disabilities, cognitive disabilities etc. Handicap refers to the loss or limitation experienced by individuals with impairments and disabilities to take part in the life of the community and to perform their social roles within the society. The WHO developed the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) in 1980, and the *International Classification of Functioning, Disability and Health* in 2001.

However we may question whether these three overlapping notions are analytically separable; whether it is possible or indeed desirable to create a divide between the 'impaired body' and relegate it to the domain of bio-medicine on the one hand, and speak of disability and handicap in socio-cultural and political terms on the other. We shall come back to this point after elaborating the key features of both models.

**The Medical Model of Disability**

The medical model is the historical consequence of the tremendous advances in bio-medicine in the western world and the opening up of the human body to the medicalized gaze. The growth of the concept of 'normalcy' which prescribes certain standards of performance or functioning of body and mind, resulted in deviations or differences being pathologized and being labelled as abnormal or disabling. A range of physical, sensory and mental conditions came under the medical scanner. Disability, as
per this model, is viewed as a negative variation from the physical norm that impairs the functional capacities of the disabled person. Physical, sensory or cognitive disabilities are explained in terms of biological or physiological deficits and their medical etiology. Disabled people are seen as those whose bodies do not work, or who look different, act differently or who cannot do productive work (Shakespeare, 1996).

‘Normalising’ such impaired individuals is to be undertaken by medical and other specialists through the use of medical technologies. The underlying assumption is that of a universalized, uniform bio-medical body which is measurable; whose functions, capacities and limitations are generalizable over time and space. This denies the complexity and variability of the actual, lived disability experience and obscures the role of culture and society in giving meaning to these bodily states. Clinical definitions of disability also become administrative labels which control the access of disabled people to financial and other assistance. They also result in stigmatizing the labelled persons by suggesting a deviation from the norm.

The medical model was critiqued by disabled people themselves because of its inherent biological determinism and lack of emphasis on the lived experience of disabled people. It denies the social experiences of stigma, exclusion, dependency and discrimination that are experienced by disabled people (Lonsdale 1990, Marks 1999, Shakespeare 1996,). As such by focusing exclusively on the medical dimensions of difference, this model bypasses the role of oppressive environments and socio-political realities in creating and perpetuating disability.

The Social Model of Disability

The social model of disability arose as both a critique of the medical model as well as a challenge to exclusion, marginalisation and stigma. It first arose within the U.K. and
the U.S.A. in the 1970s and 1980s and was soon adopted by other disability communities. It is built on the premise that disability is not the outcome of bodily pathology but is socially produced by systematic patterns of exclusions that inhere in society. (Barnes and Mercer, 1997; Hughes and Paterson, 1997). The social model of disability has turned attention away from a preoccupation with people’s impairments, and instead focused on the ways in which disability is created through the social, economic, political, cultural, relational and psychological exclusion of people with impairments. Disability is thus imposed upon people with impairments through restrictions ranging from individual prejudice to institutional discrimination; inaccessible buildings to unusable transport systems; segregated education to excluding work arrangements (Oliver, 1990, 1996). Goodley and Lawthom (2006) describe disablement (the exclusion of people with impairments) as a form of apartheid of the 21st century. In the U.K., the birthplace of the social model, it took until 1995 for disabled people to receive some form of legislative protection through the Disability Discrimination Act. Despite legislative measures, disabled people are still facing life on the margins of society. Disability is thus, clearly a political phenomenon as well.

While this model has served as an effective tool in bringing about structural changes in the developed countries where it originated (through citizenship rights, anti-discrimination legislation, provision of better services, employment, education and access etc) it has been critiqued on grounds of sidelining the subjective, bodily experiences of disabled people (Turner, 2001; Tregaskis, 2002). By focusing on the social and political domains alone, the physical and psychological pain of impairment is denied, thus creating a separation between the body and culture, impairments and disability. By privileging interventions that focus upon social and political action, this framework in fact concedes the body to medicine (Hughes and Paterson, 1997). The
notion of impairment itself is not an unproblematic one. “When we speak of, label,
react to, deal with, joke about, medicalise, professionalise, rehabilitate, drug, treat,
think of or relate to ‘impairment’ then we reveal its fundamentally social nature”
(Goodley and Lawthom, 2006: 3)

The social model of disability thus brings with it a social model of impairment. The
body-society dualism inherent in the model also confounds the problem of identity
politics (Hughes and Paterson, 1997). In its politics, the social model denies the body as
a location of disability and the disabled identity as an embodied one. Recent analyses
have emphasized the role of the body in the construction, interpretation and experience
of disability. Turner (2001) highlights how the youthful and powerful body has
increasingly become a sign of social worth in contemporary societies and a principle
theme in the Giddensian notion of ‘self as a project’. (Giddens, 1991) Zola’s (1991)
influential lecture on “bringing bodies back in” spurred an emerging critical literature
on disability in which the notions of disability, handicap and impairment are now hotly
contested. The ‘sociology of the body’ perspective in the study of disability will be
referred to elsewhere in this chapter. Having situated the ‘body-society’ debates in
disability studies through the above brief examination of the medical and social models
of disability, we now focus upon some major sociological and anthropological
approaches to the understanding of disability.

Disability and Stigma

Erving Goffman’s (1963) sociological analysis of stigma is regarded as foundational in
theorizing disability. His application and elaboration of a symbolic interactionist
framework for understanding stigma laid the conceptual ground for many other social
scientists. Symbolic interactionism views human beings as pragmatic yet reflexive
actors who perceive and subsequently act upon the symbolic meanings of other actors and actions. Focusing on the interaction between the disabled and non-disabled Goffman observed that a major aspect of the disability experience is the constant struggle to avert the devaluation caused by being classified as 'less than normal' at best, and 'less than human' at worst. The stigmatized individual may “pass” as socially acceptable by employing strategies such as proving competence, using humour, disguising difference, etc., in other words, minimizing the social discreditation that stigma causes. If stigma cannot be successfully ‘managed’, then the individual is cast away to the margins of society and often internalizes the ‘spoiled’, stigmatized identity.

Goffman described in detail the manner in which publicly noted deviance is highlighted in society. eg., a noticeably impaired individual may be subjected to insensitive questions or comments, curious stares and denied the privacy that ‘normal’ people are generally accorded in public. They may also be granted a certain superficial acceptance provided they understand and stay within the limits of social tolerance. At worst, they may also be denied a status as ‘persons’, and thought incapable of sharing the same feelings, ideas, responsibilities and goals as ‘normal’ people.

Goffman also devoted much attention to the dilemma of the “discreditable” persons with a non-visible stigma that could potentially be discovered, contrasting then with the “discredited”, i.e. persons with an obvious stigma. Goffman theorized that while the central social demand of visible stigma is management of the tension of encounters, in the case of hidden stigma, it was management of information about oneself to avoid discreditation. This is an insight that has immense relevance not merely at the level of the disabled individual, but also in terms of how families manage information or represent their disabled children to the world to avoid discreditation. As examples from
the fieldwork on which the present study is based will show, families adopt a variety of interactional strategies, vocabularies and routines to construct their child as a ‘person’, a member of society whose existence must be acknowledged and respected.

Fred Davis (1961), one of Goffman’s contemporaries, studied strategic behaviours adopted by disabled persons to disavow deviance. He interviewed adults whose impairments included limb abnormalities, blindness and facial disfigurements, asking how they handled social relationships affected by the social attitudes towards disability. On the basis of their responses, he presented a three stage model of deviance disavowal.

In the first stage, *fictional acceptance*, non-disabled persons superficially treat the disabled persons as equals, much like the poor relation at the wedding party; “sufficient that he is here, he should not expect to dance with the bride” (ibid: 127). The process may end at this stage itself. If, however, it does proceed, the disabled individuals may then start revealing more information about themselves, their activities, and attempt to build bridges that will enable the non-disabled persons to identify in terms of shared interests and perspectives. This stage he termed *breaking through*. If breaking through succeeds, *institutionalization of the normalized relationship* takes place. The work of this stage is to expose the non-disabled person to gain a perspective into the disability experience and learn to relate to the disabled persons as though he or she were non-disabled – a goal Davis presumed is desirable to most disabled persons.

Both Goffman and Davis stressed the positive aspects of ‘normalization’ attempts of the disabled, to make their way and find their place in a society which devalues disability. Courting the non-disabled for acceptance is thus regarded as a more adaptive strategy than refusing to toe the line. Goffman (1963) argued that individuals who reject “normal” culture and prefer to forge alliances with other stigmatized
persons, fall prey to the very tendency to categorize that they so strenuously objected to, further exacerbating their social disconnectedness.

Offering a more complex and nuanced understanding of stigma, Robert Scott (1969) analysed disability as a social role. His powerful work, *The Making of Blind Men* (1969) exposed how the blind are conditioned to become dependent and compliant because these are the attitudes expected of them by service professionals who hold the key to the powerful blind services system. Unlike Goffman and Davis, Scott (1969) also described several forms of resistance put up by blind people who rejected the subservient and docile role they were expected to perform. Inevitably though, these attempts result in the blind person alienating himself/herself from other people. In this connection, we may recall the motion picture *The Scent of a Woman* in which the blind ex-serviceman, portrayed by Al Pacino defies all attempts by society to restrain him and make him enact the docile role of a blind man. He resists all attempts to 'tame' him, and proclaims his defiance by dancing in a ball-room and test-driving a sports car!

Gill (2001: 357) describes the theoretical frameworks advanced by Goffman, Davis and Scott as "blunt, plain-speaking theories", that focus on the handicapping responses of society towards difference. They confront head-on the devalued status of the disabled within the community and the way in which non-disabled society actively colludes in pushing the 'others' to the margins of social existence. Although disability theory became more nuanced and sophisticated in the following years, these early works retained their resonance and power. The idea that the relations between disabled and non-disabled persons are marked by strain, disconnection and misunderstanding has been the basis of much empirical work by a whole generation of scholars.
Empirical studies by Elizabeth Hastings (1981), Emry and Wiseman (1987), Fox and Giles (1996), Albrecht and DeVlieger (1999) indicate that non-disabled people generally view the disabled as depressed, unstable, dependent and frightened, leading a lower quality of life than the non-disabled and are unwilling to interact with them as a result of these prejudices (cited in Gill, 2001).

In this context, we may mention the differing experiences of disability of those born disabled and those who acquire it later in life. For the latter, disability is a profound disruption of the life-script and often impacts intimate relationships and friendships, including family relationships. (Murphy, 1990; Toombs, 1995)

**Disability and the Theory of Liminality**

The disabled anthropologist Robert Murphy's (1990) eloquent autobiographical account of his disability experience in the book *The Body Silent* is part of a tradition of experiential accounts produced by disabled writers. Gill (2001) cites the works of Browne, Connors and Stern (1985); Campling (1981); Carillo, Corbett and Lewis (1982); Duffy (1981); and Zola (1982) which follow this tradition. Murphy linked the social experience of disability to the anthropological concept of 'liminality'. Drawing on Arnold Van Gennep and Victor Turner’s use of liminality as a term to describe the "betwixt and between" status of initiates during rituals, Murphy argued that people with disabilities experience a similar ambiguous and socially removed state (ibid: 131). However, unlike the initiates who are ultimately transformed and enter into their new social roles, the disabled remain permanently frozen on the threshold of, and sometimes outside, the formal social system. Caught in a transitional stage between isolation and social emergence, they exist in a social limbo, in the twilight zones of social indefiniteness. They are, in a sense sociologically dead and therefore considered
socially dangerous (Murphy et al, 1988). The pervasive exclusion from ordinary life and denial of full humanity aptly characterizes the social experience of disabled people which is, in his evocative words, “the antiphony of everyday life.” (Murphy, 1990 :135)

Autism is a condition that seems to match quite uncannily the “betwixt and between” threshold described by Murphy. While many autistic individuals bear no trace of physical stigmata and appear as normal as anyone else their odd behaviours and social and communication difficulties mark them as clearly impaired. This observation is particularly apt in the case of high functioning individuals with autism who often “pass”, in the Goffmanian sense, yet are frequently regarded as peculiar, odd and eccentric. They cannot quite be classified as “mad” but are often treated with derision and condescension, or the butt of jokes. Mehrotra and Vaidya (forthcoming) highlight the ambiguous position of intellectually disabled adults in rural Haryana and Delhi and the denial of a competent adult identity to such individuals. Men are either feminized or infantilized on account of their inability to adopt the dominating discourses of ‘manhood’, and women considered unworthy of discharging their roles as wives and mothers.

Murphy (1990) concluded that the acquisition of a disability leads to the loss of familiar social roles and the ascription of a negative identity such as that of a dependent, lesser human in need of society’s charity, in other words, a social burden. Phillips (1993), Karp (1999) and Olkin (1999), among others, affirm the stereo-typing of disabled individuals as needy, child like, suffering and weak, no matter how capable they may actually be (cited in Gill, 2001).
Disability and Embodiment

As mentioned earlier in the chapter, the study of disability as an embodied experience has gained currency in social science discourse. Turner (2001) attempts to locate disability using a "sociology of the body" that combines the phenomenology of the "lived body", along with the Foucauldian tradition that examines external social and political structures that regulate, produce and govern bodies and populations.

A good example of the phenomenological approach is Wendy Seymour’s (1998) work, which reflects on how individuals manage personal roles and social relationships through the management of their bodies. Through her fieldwork with individuals who have suffered from paralysis due to spinal injury, Seymour discusses the way in which everyday tasks such as washing, grooming, eating, etc. engage embodied individuals in the production and reproduction of their bodies. The body is made meaningful in a phenomenological and social sense through social categories like appearance, routines, sexuality, intimacy, sport and embarrassment. Seymour assesses the reflexive project of making, unmaking and remaking one’s embodiment through everyday tasks associated with these social categories.

The Foucauldian approach has been summarized as the study of "governmentality" (Rose 1989:5). The concept refers to the development of systems of social regulation that exert control over populations. In the context of disability Foucault’s critical writings can be extended to demonstrate how social and political structures and institutions operate in the production, regulation and governance of bodies and disabled bodies in particular. The process of rehabilitation is aimed at regulating and discursively producing the rehabilitated person through the orchestration of various medical and social practices (Turner, 2001). In a thoughtful analysis of the widely
reported case of mass hysterectomies performed on women of a state-run home for the mentally retarded in Pune in February 1994, Rajeswari Sundar Rajan (2005) locates the issues confronting institutionalized women against the anxieties produced by their unregulated sexuality. The arguments given by ‘experts’ in favour of conducting the procedure dwelt upon the risks of unwanted pregnancy and the nuisance value and ‘dirtiness’ of the menstrual cycle. “..institutions offer protection to women (from the world ‘outside’ as the familial ‘home’ does) because women are vulnerable; and they offer protection (to society) from women because of the threat, nuisance, or danger they represent.” (2005: 142)

The hysterectomies therefore ‘tamed’ or ‘disciplined’ the sexuality of these women in its more visible manifestations, viz., the ‘pollution’ of monthly bleeding and the ‘danger’ of unwanted pregnancy. Regarding the Foucauldian view that institutions are regulatory by their very constitution, Sundar Rajan (2005: 142-3) suggests that vulnerable Indian women “..caught in the travails of a rapidly changing society are desperately in need of the services of institutions like shelters, short-stay homes, hostels, old age homes, and vocational training centres that only the state can provide..” This is a reality that theoreticians cannot ignore.

The medicalization of the body and the increasingly valourized role of bio-medicine in recent times has had a profound impact on the lives of disabled people around the world. By being labelled as a separate population on the basis of their impaired bodies or minds, their very right to life has been challenged. We need look no further than the recent advances in genetics which are seen as a potential source to iron out difference at the foetal stage itself, and eliminate life if it is thought to be non-normative or defective. Rabinow (1996) in his analyses of the ramifications of the Human Genome
Project predicts a shift from “sociobiology” to “biosociality”, that is, the remaking of nature through technique, such that ultimately nature will become artificial just as culture will become natural.

The above review has traced some of the important perspectives on disability which emphasise how “normal” society constructs those with impairments as deficient, damaged, even less than human, and seeks to regulate non-normative populations deemed to be in need of normalization. These perspectives also illuminate the experiences of disabled individuals to adapt, accommodate and sometimes challenge and confront these dominant discourses.

Klotz (2003) points out that while the experiences, aspirations and perceptions of the physically disabled may somewhat match those of the “able-bodied”, the intellectually disabled often experience the world in entirely different ways. While the mildly intellectually disabled may desire to follow the social norms, expectations and goals pursued by “normals”, profoundly intellectually disabled persons are rarely able or indeed willing to participate in “normal” social activities like work or recreation. Indeed they are scarcely aware of or bothered by their own difference to others and continue to behave according to their own unique patterns which are often reflective of a very different intellectual and creative process as well as a different way of being in the world.

Klotz (2003: 23) aptly observes:

The theoretical and methodological tools that are required to understand and engage with these life worlds, however, are not those generally used by disability theorists. The focus on labels, constructs, structures and meanings, useful though these are for understanding the impact of socio-cultural practices and attitudes, does not allow us to actually enter into intellectually disabled people’s worlds and relate to them as people who are already fully human and encultured beings. Long term
ethnographic engagement holds out rich possibilities for forging relationships with the lived experiences of the intellectually disabled. In the following section, we review the contributions of selected social anthropologists and sociologists in grappling with the interplay between culture and intellectual disability.

**Intellectual Disability and Culture**

Ruth Benedict’s paper *Anthropology and the Abnormal*, published in the *Journal of General Psychiatry* in 1934 opened up the notion of ‘abnormality’ as a cultural construct. Comparing American Indian and Siberian cultural attitudes towards epilepsy, Benedict observed that the trance like states that accompanied epileptic seizures were honoured and valued as they were similar to those displayed by spiritual mediums. However, western cultures perceive epilepsy as a pathology, as something to be hidden from society. Normality and abnormality, concluded Benedict, are culturally and morally defined and thus based upon culturally variable definitions of appropriate behaviour and social roles.

One of the first anthropologists who attempted to understand the experiences of intellectually disabled people from their own perspective was Robert Edgerton, whose best known work is *The Cloak of Competence: Stigma in the lives of the Mentally Retarded* (1967). In this account of de-institutionalised people with mild mental retardation, Edgerton brought out the social and personal concerns of his informants and how they coped with life on “the outs” (i.e. outside the institution). To cope successfully, they invented biographies, accumulated personal belongings and made attempts to deny their history of institutionalization and the label of disability and incompetence. However Edgerton did not attempt to analyse the core issue of why cognition and intelligence are considered so fundamental to Western notions of personhood and human identity. Despite this limitation, he opened up the domain of intellectual disability to ethnographic study, stressing the importance of long-term,
intimate contact with research subjects and the use of interview and narrative based techniques.

The role of cultural meanings and subjective moral judgments in understanding intellectual disability was also explored by Robert Bogdan and Steven Taylor in their book *Inside Out: The Social Experience of Mental Retardation* (1982) Bogdan and Taylor link the concept of mental retardation with the complex demands of modern industrialized society. Rather than being an "objective condition", mental retardation is viewed as social construction, dependent upon social and cultural concepts. They thus challenge the validity of mental retardation as a meaningful category at all. Their theoretical approach draws upon Berger and Luckman's (1984) theory of social constructionism and therefore they focus upon the meanings attributed to difference, in particular through the perspective of those who are not disabled.

Klotz (2003: 12) argues that interpretations that only take socio-cultural structures and constructions into account disregard the fact that "intellectual disability is an ontological reality that makes a real difference to one's experience of being in the world. Researchers who adopt a constructivist perspective ignore the real implications of difference as both productive of the socio-cultural world and the product of it." The category of mental retardation has become a highly contested one. Similar debates have taken place in the context of autism.

Although the cluster of symptoms we call "autism" received a name fairly recently, there are several cultures in the world that do not have a name for autism nor see the symptoms associated with it as pathological. Some researchers assert that autism is an illness of modern civilization and is therefore primarily found in economically advanced countries characterized by high geographical and economic mobility, along
with the preponderance of the nuclear family (Sanua, 1984). Such assertions raise fundamental questions about the cultural relativity of psychiatric conditions. Berry et al's (1992) cross-cultural framework of psychopathology classification suggests that psychiatric conditions can be identified as culturally relative, universal or absolute. The "refrigerator mother" theory propagated by Bettelheim (1967) which blamed the autistic child's condition on disengaged and 'cold' mothers, usually well-educated and qualified, implicitly suggests economic relativity. This further fuels assertions about autism being a Western malaise, a product of a specific kind of culture.

At the other extreme, disorders that are invariant across cultures are most likely to have an organic etiology. (Berry et al, 1992). Current research seems to suggest overwhelmingly that autism is a neurodevelopmental disorder and that there is remarkable consistency in its symptoms across cultures. Cohen and Volkmar (1997: 947) write, "there is no other developmental or psychiatric disorder of children (or, perhaps, of persons of any age) for which such well-grounded and internationally accepted diagnostic criteria exist". Daley (2002) suggests that the safest option in the absence of adequate cross-cultural data is the adoption of the middle position, which sees autism as a universal disorder, which occurs in some form in all cultures. At the same time, cultural influences play a major role in its expression and course. She supports this position by turning to the evidence of national parent organizations in such diverse countries of the world as Namibia, Uruguay, Malaysia and Serbia, where a constellation of behaviours has been identified that fit those of the disorder known as

---

3 "Refrigerator Mother", an unfortunate phrase coined by Leo Kanner came to be associated with the work on Bruno Bettelheim (1967). Bettelheim suggested that autism was caused by bad mothering. Their cold, detached behaviour caused the pathology to manifest and therefore these children needed to be taken away from their 'frozen' environments so that they could receive warmth and nurturance by 'experts' like himself.
autism. The same point may be made in the Indian context where the diagnostic category of autism is gradually gaining currency.

**Disability and Personhood**

The work of David Goode (1980) and John Gleason (1989) inserted a corrective into the almost exclusively constructivist analyses of intellectual disabilities and the impact of social policies, stigma and labelling. Both authors engaged with the lived experiences and interactions of people with profound intellectual disabilities through prolonged ethnographic engagement aimed at uncovering the meaningfulness of their behaviour and mode of being in the world. Goode’s interactional encounters with Chris, a deaf, blind and retarded girl, whose world he attempted to enter by mimicking and attempting to understand her behaviours, are a path breaking endeavour in understanding disability from the inside-out.

Gleason’s book *Special Education in Context: An Ethnographic Study of Persons with Developmental Disabilities* (1989) is an account of five years of fieldwork, observing the interactions of a group of inmates at a residential school for physically and mentally challenged children in North America. Gleason argued that dominant therapeutic and special education practices aim at transforming the apparently aberrant and meaningless behaviour and interactions of profoundly disabled individuals. He discovered that the seemingly random, meaningless behaviours of Thomas and Daniel, two multiply disabled boys was in fact meaningful and intentional when viewed in context. The work of Goode and Gleason acknowledges the essential humanness of intellectually disabled people and the meaningfulness and intentionality of their behavioural expressions. Parental narratives in the present study reveal how hard it was for parents to understand their children’s behaviours according to their own perceptions of what was normative.
However, when they developed the capacities to “read” their children’s behaviours and interpret them appropriately, due to their prolonged and intimate engagement, they realized the meaningfulness of their sometimes incomprehensible behaviour. They began acknowledging their child’s agency, his ‘personhood’.

The notions of humanness, personhood and competence as they manifest across cultures are critical in understanding the cultural meanings ascribed to intellectual disability. (Jenkins, 1998; Ingstad and Whyte, 1995). In the following section we briefly examine these notions both in a historical and cross-cultural context.

In Western cultures, personhood is defined in individualistic terms, which emphasise success. These are usually associated with the attributes of productivity, intelligence and literacy. However, cultures which emphasise sociality above individualism tend to value attributes like interdependence, relatedness and affiliation. (Jenkins, 1998; Devlieger, 1998; Nuttall, 1998; Whyte, 1998). Let us examine how these differing conceptions of personhood reflect in cross-cultural understandings of intellectual disability and ‘difference’.

**Western conception of Intellectual Disabilities**

Stainton (1998) suggests that a distinctive and consistent characteristic associated with intellectual disability is the phenomenon of ‘otherness’. The notion that a defect of the human mind can be equated with sub-human species is found in the natural philosophy and social and ethical writings of both Plato and Aristotle. People with intellectual disabilities were considered less than human, even possessed by the devil, according to the religious beliefs of the Christian era (Judge, 1987). In other contexts, such people were protected by the Church as ‘holy innocents’ or ‘sacred fools’; their intellectual deficits interpreted as sign of spiritual grace and simple state of nature that were closer
to God than the corruption and immorality of culture (Jenkins, 1998). The Foucauldian interpretation of classification, confinement and control of those considered mad, and symbolic interactionist and labelling perspectives on the construction of deviance aptly demonstrate the ‘invention of the feeble mind’ (Trent, 1994).

The Enlightenment brought with it a phase of institutionalization of the intellectually disabled, prodded by the Eugenics movement and what Parmenter (2001) calls the ‘reification of intelligence’, the effects of which affect disability policy worldwide, even in the present time.

The ‘normalization principle’ articulated by the Swedish scholar Bengt Nirje (1992) which aimed at the provision of conditions of everyday living as close as possible to the regular life-ways of the community to the disabled, is viewed by Paramenter (2001) as one of the most significant events of the last century in the context of life-changes for persons with intellectual disabilities. In North America, Wolfensberger’s (1972) formulation emphasized the need for intellectually disabled persons to adopt the cultural norms of their community by minimising their differences so that they could pass undetected in society. The normalization principle and its offshoots set into motion a paradigm shift from institutionalization to community based rehabilitation programmes, special education and intervention.

A related intellectual and technological development of utmost salience is the rapid growth of the neurosciences and new research into the preventability of intellectual disabilities. The discovery of the Fragile X Syndrome\(^4\) represents a major advance in

---

\(^4\)The Fragile ‘X’ syndrome is a genetic disorder caused by the mutation of a particular gene on the ‘X’ chromosome. Symptoms include physical characteristics like elongated face, large or protuberant ears, flat feet and large testicles in men. Behavioural characteristics include atypical social development, speech delays, etc. Persons with Fragile ‘X’ in family histories are advised to seek genetic counselling to assess the likelihood of occurrence in their children.
understanding the inherited causes of intellectual disability. The work of Rabinow (1996) in this regard has been cited earlier.

In conjunction with the discourses of normalization the human rights approach stressed the importance of the inalienable right of the intellectually disabled individual to the same dignity as fellow human beings. (Oliver, 1990). This has found expression in several proclamations of the UNO and pro-disabled legislation in many countries including India. The rights approach, contends Reinders (1999) can only work in the context of caring practices, and “without people who have sufficient moral character to care, rights can do little to sustain the mentally disabled and their families. People can be forced to comply, but they cannot be forced to care.” (cited in Parmenter, 2001: 286)

Cultural constructs about the otherness of intellectually disabled persons find a reflection in special education programmes. Armstrong (2003), Leicester (1999), Thomas and Loxley (2001) and Tomlinson (1982) highlight the power relationship between professionals and experts on the one hand and impaired individuals and their families on the other, wherein the “voices” of the disabled are simply not heard and categories are created by State and society in order to manage difference. Meeting the individual’s “special needs” thus absolves society of creating an environment that is inclusive and accepting of difference, and deflects the blame, as it were, on the affected individual and family. Pippa Murray (2006) makes the point that the “psychological reality” and internal experiences of disabled people is denied; they are seen more as cardboard cut-outs rather than real individuals. This mitigates against ‘inclusion’ in the real sense of the term. They are still seen as the ‘other’ and their humanity remains unacknowledged, as the following passage reveals:
The undisguised disregard for his emotional well-being (Murray’s disabled son) stood in stark contrast to the value nominally placed on that of his non-disabled sister. On more than one occasion I was told that her well-being would be threatened by his presence in the same school. As a matter of fact, this disparity of concern was not only unjust, but inaccurate: my daughter was forever sad that her brother could not be there with her. Contrary to the perceptions of a disabling world, she suffered from his absence. (2006: 37-38)

Conceptions of Intellectual Disability in Non-Western Societies

Unlike the practices of labelling, segregation and institutionalization observed in the West, the socio-cultural milieus in non-western societies including India tended to absorb the intellectually disabled within the circle of family and social networks creating spaces for them to function according to their capacities. Patrik Devlieger (1998) argues that amongst the Shona and Songye peoples of south-eastern Africa, personhood is defined as the ability to interact with others within broader social contexts. Physical or mental deficiencies are viewed as the result of “wronged relationships” with nature, relatives, ancestors and God, and witchcraft is employed to restore “relational embeddedness”. Thus, it is flawed relationships that are sought to be restored, rather than individual ailments or maladies. This is in sharp contrast to the western bio-medical model.

Susan Reynolds Whyte (1998) in her ethnographic work amongst the Nyole people of Uganda demonstrates how the notion of ‘competence’ is linked with the way the individual conducted himself/herself in the social sphere, in the context of family and neighbourhood relations. At the same time, kin relatedness is the primary means of defining personhood, thus ensuring that all persons have a place in society irrespective of their individual attributes and skills.
Nuttall (1998) highlights how the Inuits of Greenland defined the ability to hunt and fish in a subsistence economy as competence, rather than the ability to read or write. For the Inuit, a person consists of body, soul and name. Full personhood is a consequence of being named and thus incorporated in a wider social network. The Danish educational system, which removes those designated as mentally disabled from their family and environment and places them in special schools, has had a disastrous impact on the culture by denying these individuals their place in society and the opportunity to learn cultural practices.

Lin and Lin (1980) in their study of responses of Chinese families to mental handicap, cite the concern for the well-being of family members which underlies the long-standing Chinese tradition of interfamilial coping with stress, including the stress of mental illness and disability.

In the Indian context, the Hindu worldview on disability as articulated in scriptures can be explained through the karma theory, wherein illness or disability in this life are a consequence of past misdeeds. This also works against efforts to ameliorate or improve the life-conditions of those so afflicted. Srivastava (2002) writes that Indians pay less attention to mental rather than physical illness. Sen (1992) in her study of mentally retarded children in rural India corroborates this. Disabilities are regarded as the outcomes of cosmic factors and, in the absence of techniques to resolve them, are to be accepted in a spirit of resignation (Dalal et al, 2000; Dube, 1990). Miles (1995) discusses the conceptualization of disability in Eastern religions including Hinduism, and highlights how disablement is viewed as result of misdeeds in previous incarnations. Mehrotra (2004) in her ethnographic work in rural Haryana, mentions that the categories used to describe the intellectually disabled are “bhola” or “bawla”
(naïve, innocent). They are assigned household chores and their reduced mental capacities are viewed as disabilities if coupled with any kind of physical impairment. Thus the mere fact of being mentally ‘defective’ is not stigmatizing in itself in the context of agrarian/pastoral societies.

**Autism in a Cross-Cultural Context**

Given the wide range of cultures in which autism has been reported, there is little known about the disorder within a cross-cultural context. Daley (2002) remarks that the questions asked by disability researchers such as how mental and physical impairments are managed in different cultures and how identity is shaped by disability is as intriguing when asked of autism as of deafness or visual impairment. Similarly, questions regarding the social contexts and consequences of mental illness are as applicable to autism as to schizophrenia or depression. She speculates that autism has “fallen between the cracks of the disability literature and mental health fields, viewed by one as a problem akin to schizophrenia and by the other as more related to mental retardation.” (ibid: 532) We briefly review some of the research on autism in a cross-cultural perspective.

Anthropologists have explored folk concepts of conditions similar to autism. Ellenberger (1968, cited in Daley, 2002) wrote of the *Nit-Ku-bon* or ‘marvelous children’ in Senegal who had many traits observed in autism such as lack of social responsiveness and speech. Westermeyer (1979, cited in ibid) reported that rural Laotians use a category known as *Samqng Uan* to describe children who have developmental difficulties like delayed learning, lack of flexibility and adaptability and difficulty in getting on with others. Grinker (2007) cites publications pertaining to so called feral children, the most famous of which include ‘Wild Peter’ found in 1724 in
what is today’s Germany; Victor, the French boy whose story was depicted in Francois Truffant’s celebrated film *L’ Enfant sauvage*; Kamala and Amala, the two girls found together in a forest in India. It is now known that few or none of these children were actually wild or lived with animals, but were very likely autistic. Daley (2002) refers to the case report of Lane and Pillard (1978) describing their search for the ‘wild boy of Burundi’, a child reported to have lived in the jungle. Lane and Pillard’s research reveals that he had not been reared in the wild but rather appeared to fit the behavioural criteria for autism. It is significant to note that autistic behaviour is seen as non-human, animal like or wild behaviour.


Bilu and Goodman’s (1997) examination of autism and religion within the ultra-orthodox Israeli community explores how “facilitated communication” (FC), a procedure used by a non-verbal individual to communicate with the help of a facilitator has been adapted by this community to construct the identity of severely impaired
children in religious terms. Messages transmitted through autistic children using FC contain religious injunctions, eg. avoidance of sexual relations with menstruating women, to beware of the ‘evil tongue’ etc. However the perceived abuse of FC has been attacked by the wider community as exploitation of disabled children to push reactionary religious agendas.

Daley (2002) also cites the comparative studies of Lotter (1978) and Probst (1998). The former study was conducted in six African countries. The author concluded that autistic symptoms are less common in Africa rather than the U.K., and when detected, are primarily found in the upper classes. These findings can be explained by methodological factors. As the author himself discussed later, he obtained his sample from institutions for the mentally disabled, whereas African families do not normally send their handicapped children to schools or institutions. He also included indices of competence that were not quite culture appropriate, viz., eating with knife and fork, riding a tricycle, completing a form board etc.

The latter study by Probst (1998) cited in Daley (2002) dealt with parental understandings of child-health related issues in Brazil, Italy, Greece and Germany. He concluded that an important factor in parental adaptation to having an autistic child was a feeling of ‘coherence’. Parents needed to have expert information about the causes, course, prognosis and treatment of the condition. Community and state support, he felt would also contribute to the sense of coherence and positive adaptation. Intentionally exploratory in nature, the study is an important contribution towards unpacking cultural factors like health cognitions and examining their relationship to other processes in families with autistic children.
Mention may also be made of the handbook by Cohen and Volkmar (1997) which includes a chapter outlining international perspectives on autism covering China, Japan, Korea, Latin America and several European countries. It covers each geographic area in terms of history of the disorder, diagnosis, treatment, parent’s associations, national issues and research. The authors emphasize the nearly universal acceptance of the standard DSM-IV and ICD-10 classification systems and treatment approaches. However, as Daley (2002) points out, the information was probably obtained from clinicians and researchers using the western system of diagnosis and treatment, rather than the norm who were acquainted with the work of the authors and Western trends in autism research.

In the Indian context, we may cite the study of Tamara Daley (2004), *From Symptom recognition to diagnosis: children with autism in urban India*, based on interviews conducted with 95 Indian families in four cities – Bangalore, Chennai, Calcutta and New Delhi – which provides rich data on the process of initial symptom recognition, help-seeking and diagnosis of autism. The study examines how cultural factors shape the saliency of symptoms and how environmental, cultural and socio-economic factors impact upon the process of obtaining diagnosis. R. Richard Grinker, an American anthropologist, recently published a book entitled *Unstrange Minds: Remapping the World of Autism* (2007). Grinker traces the history of the disorder and also provides material from a number of cultural contexts including India, South Africa, and Korea, showing how the disorder is understood and dealt with cross-culturally. His work brings out how globalization, the expansion of Western bio-medicine and the easy availability of information through the Internet has made autism more recognizable as a diagnostic category across the world including India.
Grinker’s analysis of contemporary society in South Korea locates attitudes towards disabilities in the cultural context of *Ijil*, or ‘difference’. Unlike contemporary American society where ‘difference’ connotes ‘diversity’ (i.e., a positive connotation), in Korea, it has a negative connotation. *Ijil* is something to be overcome in a society that places a very high premium on sameness and homogeneity. Difference is unnatural, unwanted and thus, deliberately unrecognized. In Korea, children with autism are often diagnosed with ‘Reactive Attachment Disorder’ (RAD), sometimes pejoratively described as “lack of love”. In this Korean version of the “refrigerator mother” theory, the child’s disorder is blamed on the mother. It is believed that it can be ameliorated by giving love. An autism diagnosis, on the other hand, would impugn the family and damage marriage prospects of other family members because of its genetic and life-long nature.

Blaming the mother is also linked to the conservatism and resistance that accompanies rapid social change, which has become a feature of Korean society. Mothers are entering the workforce in large numbers, leaving their children with grandmothers and nannies. Psychologists and psychiatrists assert that they no longer know how to bond with their children, hence the escalation in language and social deficits. As in India, “...what happens to the child happens also to the mother, and therein lies her stigma. If he is socially disabled, she is as well.” (ibid: 243)

To understand the predicament of the autistic child and his/her family, the intense pressures of the Korean educational system or “education fever” (ibid: 246) must be accounted for. The obsession with education reflects the desire of the huge Korean middle class to achieve prestige and status through the educational attainments of their children. A disabled child thus finds no place in a ruthlessly competitive, hierarchical
society. It is not surprising then that parents would rather devote time, energy and money to their able children rather than on a disabled one who will never be totally cured. "If the normal child fails to make it to the university, the parents will be criticized for having exerted so much effort on the child who never even had a chance to begin with." (ibid: 250) The parallels with the urban Indian situation are unmistakable.

We can see that categories like "intellectually disabled", "learning difficulties" etc. are rapidly becoming areas of concern in contemporary Indian society. Urbanization, the dwindling of traditional support networks like the extended kin group and neighbourhood, the stress on formal educational attainments as the critical factors in charting out careers, in other words, the whole enterprise of social mobility engaged in by the urban middle classes, has resulted in the categorization as "incompetent" of those individuals whose mental limitations would otherwise have been contained within the ambit of the family and social networks. Beteille (1994) describes how the school has become a major institution for mediating the relationship between the family and the new occupational system, and how middle class parents take an active interest in helping the child with school work. The labelling of the intellectually disabled as socially incompetent has thus become a concomitant of changing notions of what constitutes competence in a rapidly changing world. (Jenkins, 1998). At the same time, local models regarding causality, traditional treatments and remedies and distinctive patterns of help seeking behaviour exist side by side as demonstrated by Kleinman (1980) in his extensive work in China, and other Asian countries.
Disability and the Family

Disability, whether physical, sensory or intellectual is not merely an individual phenomenon. It has a profound impact on relationships and social groups within which the individual is embedded, notably the family. The family is the key site within which the disability is managed. In the context of intellectual disabilities, the family very frequently has to act as the ‘voice’ of the disabled individual and the bridge between him/her and the wider community. Unlike the West which has had a history of institutionalization and segregation of the intellectually disabled, non-western societies like India tended to absorb and accommodate intellectually disabled members within the ambit of kin and community networks, as highlighted earlier. Das and Addlakha (2001) employing the concept of “external body-selves” make the point that the locus of disability or disfigurement is not just “in” the body of individual but rather “off” the body permeating family, kin and community.

Much of the western literature on family and disability since the 1960’s has focused on parental responses to the child’s disability. In consonance with the medical model, many scholars have viewed the impact of the disability on the family as pathological, thus supporting the prevailing practice of sending such children off to specialist institutions in order to “save” the rest of the family. This body of literature assumed that disability distorted the connection between child and parent in ways that were both intrinsic and harmful (Ferguson, 2001). Most descriptions of the “typical” parents of a disabled child spoke of the parent experiencing hostility, denial, grief, guilt and defense mechanisms of all types.
Bruno Bettelheim perhaps exemplified this psychoanalytical approach to viewing disability not just as an individual pathology but a family one. Bettelheim’s work *The Empty Fortress* (1967) specifically dealt with children with autism. His belief that cold, distant parenting practices trigger autistic behaviours gave credence to the “refrigerator mother” theory referred to earlier due to which an entire generation of western mothers castigated themselves as responsible for their child’s difficulties.

Psychoanalytical models came to be replaced by psychosocial approaches which highlighted the contextuality of emotions and their interplay with social and environmental circumstances. Olshansky’s (1962) classic description of “chronic sorrow” conceptualizes familial reactions to a child’s disability not as a neurotic response but rather a natural response to a difficult situation. Wolfensberger’s (1983) analysis of “novelty shock” focuses on the initial shock, confusion and bewilderment parents experience when they learn that the child is disabled. However, the crucial factor identified by Wolfensberger is the social communication of information and the responses of professionals and other family members. Limited financial resources, lack of appropriate services and insufficient support systems have been viewed as major stressors on the family system.

The growth of the Western disability movement in the 1970s and the disavowal of the medical model in favour of the social model resulted in a shift in focus from the emphasis on emotions, marital role disruption, social withdrawal etc. to issues like class, poverty, access and equity (Ferguson, 2001). The emphasis is no longer just on how families respond to disability, but also how society responds to such families, in terms of provision of appropriate services, access to them and opportunities to participate fully in the life of the community.
Social and historical forces influence the directions that family research takes. The passing of pro-disabled legislation, lobbying for rights, expansion of inclusive education and provision of medical and educational and support services for disabilities of every description has been a feature of Western societies over the past two decades, and thus the cohort of families being studied in the context of these services initiatives is quite different from the one studied by scholars subscribing to the earlier psychoanalytical approaches. Family research over the past three decades has moved away from family pathology to family adaptation, life course development and activity settings. However, in countries like India where disability has only recently gained a foot hold in public discourse, the earlier theoretical models of stigma, marginalization, family pathology etc. continue to be followed.

Within the broad domain of social psychology the adaptive family perspective (based on the ‘ABCX’ model of family crisis originally developed by Reuben Hill) engages with the “family crisis” (X) as an interactive outcome of A (an initial “stressor event”); B (a family’s resources for dealing with crisis); and C (how the family defines the stressor) (Ferguson 2001 : 385) McCubbin and Patterson (1983) discovered that some families actually adapt well to raising child with developmental disabilities; a state called “bonadaptation.” Patterson’s (1989) ‘family adjustment and adaptation response model’ is focused on the processes by which families restore the balance between demands and capabilities and minimize their experience of stress. Gupta and Singhal (2005), cite the work of Singer and Irvin (1989) and Singer et al (1999), who examined the positive impact of parent support groups on the coping capacities of families with disabled children. The present study also discusses the role of parent driven organizations in facilitating familial coping and building up a community of “co-sufferers”.

34
It may be noted that research pertaining to families with disabled children tended to focus on young children. The emergence of the life course and ‘family career’ perspective has opened up research with hitherto unseen families; older parents with disabled adult children, changes in family composition on account of death, departure of grown up children etc and the impact of long term care on family coping. (Ferguson, 2001) Hayden and Heller (1997) found higher levels of adaptation in a group of parents in their late fifties, suggesting that over time, parents experience reduced stress and greater adaptability rather than the “wear and tear” hypothesis which suggests the opposite.

Drawing on the theoretical lead of Bronfenbrenner’s (1979) social ecological approach to families, another rich research direction is in the field of ‘eco-cultural niches’ by Thomas Weisner, Roland Gallimore and their colleagues. This approach focuses on family routines and the activity settings of daily life, in an attempt to tease out the meanings of disability constructed by families in and through interaction with their children. It attempts to understand how families construct these shared activities and portray them to others. A mother’s account of a day in the life her family, for example, reveals multiple levels of culture and values. This approach fits in well with the ethnographic enterprise of looking for the small, seemingly insignificant details of everyday life that when fitted together reveal the larger picture of social structure, values and culture (Gallimore et al, 1993; Weisner, 1997).

The above overview on family research reflects the general trend in disability research, viz. a movement away from the individualized, medicalized model which pathologises both the individual and the family, towards a more nuanced understanding of the means by which families engage with society and culture in coping with a child’s disability.
The present study locates itself within this trend. The response of families to a child’s disability is not viewed merely in terms of stigma or prevailing societal attitudes but also in terms of the manner in which families draw on personal, social and cultural resources to construct understandings of the disability and accommodate it. We may say that families are involved in an anthropological enterprise; just as an anthropologist studies and tries to understand an alien culture and represent it to his own community, these families attempt to understand the unique mode of being and subjectivities of their children and represent them to the world.

**An Overview of the Present Study**

The review of literature and overview of discourses pertaining to disability, (especially intellectual disability) and family, reflect the following trends:

- A blurring of the ‘body-society’ dualism and recognition of embodiment and lived experience of disability;
- ‘insider’s perspectives’ on disability and family, in keeping with the reflexive and feminist turns in social science;
- a movement away from paradigms that pathologize the family of the disabled individual;
- a move away from institutionalization, an emphasis of human rights, community participation, and the dignity of disabled individuals and their families.

The present study is a qualitative, ethnographic engagement with twenty families having children diagnosed with autism living in Delhi.
Aims and Objectives

The study aims at

- Exploring the cultural conceptions of intellectual disability with special reference to autism in India.
- Chronicling the process of identification, help seeking behaviour and arrival at diagnosis.
- Examining the impact of the disorder on relationships within the family, the patterns of coping and care and factors promoting and impeding resilience within these families.
- Observing daily life and activities of the family with special reference to management of the disability.
- Examining the interface between family and community with special reference to the role of parent support organizations. A case study of such an organisation will be presented.

It would be in place to locate the study in the socio-historical context of structural and interactional transformations within the urban Indian family (which is the unit of analysis). These changes impact upon and shape child-rearing and socialization practices. Shah (1998) in his description of the new “cosmopolitan” class that has emerged in India in the past century highlights the fact that the ideology of individualism and the Western-style nuclear family has had the maximum impact on this class. Yet, at the same time, the extended family is resorted to for drawing support and strength in times of crisis. According to Sinha (1988), this leads to ambiguity in setting roles and expectations for the growing child. There are unstable and contradictory patterns of child-rearing which generate conflict and anxiety. Parents assume the main socializing role and external agencies like day-care centers, pre-

5 According to Beteille (1994), nuclear residence is on the rise in what he terms the ‘service class’ in urban India. Sharma (1986) and Vatuk (1972) observe that a branch of the joint family migrates to the city and resides there, acting as a buffer for other members of the joint family who may join them to pursue education or jobs.
schools and the peer group are also taking over the socialization role. Sinha points out that clear-cut and consistent role models are not available to the child.

Attitudes toward traditional methods of disciplining, toilet training schedules etc. have shown the impact of Western thinking, but traditional attitudes have not given over completely, resulting in the alternating of permissiveness and strictness which create anxiety and confusion. Joint family values of sharing, accommodativeness, mutual dependence and conformity are being superceded by the values of individualism, personal freedom, autonomy and self-determination. Accordingly, children are being socialized to adapt and adjust to the changing value system and ethos (Bharat, 1992).

Patel (2005: 31) makes the point that Indian sociology and social anthropology of the family has been “dodging the study of crises” which have challenged some of the principles of kinship and marriage in Indian society. There is a need to engage with the “existential messiness” that family life entails, to explore its everyday realities and “changing unchangeableness” (ibid: 21, 31). These reflect in parenting ideology and practice, in relationships between siblings, grandparents and other kin, and in the context of disability, the valourization of the family as the sole agency that can take up the ‘burden’ of life long care of the disabled member.

In families faced with the prospect of raising a disabled child, the contradictory pulls of preparing a child for autonomy so that s/he can function in an increasingly competitive world, along with the desire to protect and safeguard him/her from the world outside co-exist uneasily. In a disability like autism which is rarely accompanied by physical stigmata and in which the child often ‘looks’ very normal, the bizarre and abnormal behaviours are often attributed by kin and community to be the product of faulty
parenting or lack of parental affection and attention, a version of the "refrigerator mother" theory which has only lately been discredited in autism discourses in the West.

Cosmopolitan centres like New Delhi which is also the hub of Government and a burgeoning service and media sector witness the migration of young professionals who marry and set up nuclear households in the city, far away from their parents, siblings and kin. This sort of 'privatized' family life in which conjugal and parent-child bonds have gained primacy is characteristic of urban life. (Ramu, 2006) The absence of a 'family like atmosphere' is often cited by respondents as being a likely cause for developmental delays and anomalies in child development.

We may speculate that a child's disability is a window through which to observe other socio-cultural process at work. How a 'law-breaking' disorder such as this (Shaked 2005) is constructed and managed against the backdrop of a family system that is itself in a state of transformation and flux, is the central problematic of this work.

Autism in a sense provides a natural experiment wherein conceptions of 'normalcy', sociality and being-in-the-world are breached and turned on their heads. At a philosophical level, it forces us to confront the issues of selfhood and human-ness. The present study will focus on unravelling the everyday experiences of living with a child with autism. In doing so, it will attempt to hold up a mirror to understanding processes of change and new avenues of affiliation and association that are being explored in an expanding metropolis.
Conceptual Framework

The present study draws upon a variety of inter-disciplinary literature in the fields of disability studies, sociology of the family, urban sociology, medical anthropology, cross-cultural psychiatry, social psychology, human development and gender studies.

As earlier mentioned, it moves away from the medicalized view of disability which also extends to the family. Rather, it uses everyday life as a key concept with which to study the interplay between intellectual disability, family and community.

Broadly locating itself within a symbolic interactionist framework, the study uses several ‘sensitising concepts’ that enable an inductive understanding of social reality. The starting point for this study is the recognition that contemporary families are undergoing much change and flux. Sociological and anthropological theorizing on family has by and large been guided by structural-functional paradigms. In this study, we focus more on ‘doing’ family rather than ‘being’ family. Morgan’s (1996) work on family practices, shifts sociological analysis away from family as a structure to which individuals in some sense belong, towards understanding families as sets of activities which take on particular meanings, associated with family, at a given point in time. Such a conceptualization of family incorporates the fluidy, diversity and multifacetedness that characterizes contemporary families, by rooting our understanding of ‘doing family’ in the everyday and the routine. (Finch, 2007)

The Goffmanian concepts of discredited and discreditable identities, and Murphy’s concept of liminality enable a better understanding of a disorder like autism with its complex manifestations. In order to understand how families construe and come to terms with autism, we employ the concepts of explanatory model and illness metaphor.
The analysis of the impact of the child's disability on family life and the dynamics which operate in middle-class urban families under difficult circumstances, is the core concern of the study. This is informed by a feminist understanding and interpretation which takes as its focus the actual, intimate, emotional aspects of interpersonal relationships within the family. Feminist theorizing on parenting ideologies and practices, especially mothering, are referred to and sought to be reinterpreted in the light of the social reality in which this work is grounded. Through the social-psychological concepts of coping and resilience, we attempt to understand why some families fare better than others in coping with the child's disability.

We also discuss non-familial support in the form of friendship circles and family support organization which mediate between family, community and state. Anselm Strauss’s concept of social world is used in the context of emerging networks of like-minded and similarly placed families living within the urban moment, who network with each other, share information and experiences and utilize rapidly expanding communication technologies to do so.

Chapterisation

Chapter 1: Methodology and Fieldwork Strategy
This chapter explicates the rationale for conducting a qualitative study, and locates the study within its socio-historical context through a discussion of the field area. The criteria for sample selection, the range of characteristics observed in the sample and the methods of sample selection are clarified. The section on fieldwork strategy discusses in detail the manner in which long interviews and participant observation were conducted, and how the researcher’s positionality and politics influenced and was influenced by the research process. The academic and ethical dilemmas encountered during fieldwork are taken up in the final section.
Chapter-2: Encounter with Autism: Symptom Recognition, Diagnosis and Accommodation

This chapter deals with the processes of symptom recognition, help-seeking, diagnosis and disclosure of the child’s disability and family responses to the same. It analyses the way families ‘make sense’ of the disability through explanatory models and illness metaphors. It concludes with an examination of how disability is dealt with in the everyday routines of domestic life.

Chapter-3: Family Dynamics I: The Challenges of Parenting a Child with Autism

Chapter-4: Family Dynamics II: Shrinking Circles of Support

These chapters address family dynamics, the patterns of coping and care and the impact of the child’s autism on family functioning. Chapter 3 focuses on parenting ideology and practices and Chapter 4 with the impact of autism on relationships with siblings, grandparents and other kin. It concludes with an examination of the interface between family and community and the shrinking circles of kin support available to these families.

Chapter-5: Emerging Institutions, New Opportunities: NGO, Civil Society and State

This chapter links the issues and fears confronting these families with the growth of parent support organizations. It presents the case study of a Delhi based Non-Governmental Organisation, ‘Action for Autism’ (AFA). It discusses the responsibilities of State and civil society with respect to its disabled citizens and concludes with an examination of the legal provisions and entitlements that have been put in place for the intellectually disabled.

We conclude with a summary of key findings.