Care, Contention and Family:
An Anthropological Inquiry on Autism

A THESIS SUBMITTED DURING 2022 TO THE UNIVERSITY OF HYDERABAD IN
PARTIAL FULFILMENT OF THE AWARD OF

Doctor of Philosophy in Anthropology

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DECLARATION

I, Mr. Sandeep K, hereby declare that this thesis entitled “Care, Contention and Family: An Anthropological Inquiry on Autism”, submitted by me under the guidance and supervision of Prof. B. V. Sharma is a bonafide research work. I also declare that it has not been submitted previously in part or in full to this University or any other University or Institution for the award of any degree or diploma.

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CERTIFICATE

This is to certify that the thesis entitled ‘Care, Contention and Family: An Anthropological Inquiry of Autism’, submitted by Mr. Sandeep K bearing registration number 15SAPH06 in partial fulfilment of the requirements for award of Doctor of Philosophy in the School of Social Sciences is a bonafide work carried out by him under my supervision and guidance.

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1. International Journal of Research Culture Society (ISBN/ISSN Number ISSN: 2456-6683). Chapter of dissertation where this publication appears Chapter 3.

and

has made presentation in the following conferences:

1. Indian Anthropology Congress- 2019- Pune (National)
2. Fifth National Conference on Disability, Accessibility, Inclusion and Wellbeing Mumbai (National)
3. Indian Anthropology Congress- 2022- Hyderabad (National)

Further, the student has passed the following courses towards fulfilment of coursework requirement for Ph.D./ was exempted from doing coursework (recommended by Doctoral Committee) on the basis of the following courses passed during his M.Phil. Program and the M.Phil. Degree was awarded:

Course Code	**Name of the Course**	**Credits**	**Pass/Fail**
1. ANTH 501	Tools and Techniques of Anthropological Research	6	Pass
2. ANTH 505	Economic Anthropology	6	Pass
3. ANTH 512	Background Paper (Physical Anthropology)	6	Pass
4. ANTH 513	Dissertation/Filed study and Project work	15	Pass
5. ANTH 514	Viva- Voce	3	Pass

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ACKNOWLEDGEMENT

Research is a process. It gives new experiences and knowledge to humanity and academia. It also allows us to renovate and modify ourselves in world perspective. The time I have gone through with the research given me such an opportunity to turn a mirror on myself. The interactions and relationships in these times helped to enrich my social life and identity. Therefore, I believe the time I have spent with the research is significant in life.

My thesis is a product of individual and collective efforts. At this moment, I have to express my gratitude to many people who have given their time and effort to reach the destination. First of all, I would like to thank my supervisor, Prof. B. V. Sharma, for giving me valuable instructions at all stages of the research. He has helped me to find ways to overcome the hurdles I faced at various stages in this journey. It would not have been possible without his immense support and thought- provoking input.

The insightful comments from Doctoral Committee members, Dr. C. Nagalakshmi (Department of Sociology) and Dr. K. Suneetha Rani (Centre for Women's Studies), have enriched my research. I am grateful to them for their satisfactory answers and suggestions to my queries.

I am thankful to the faculties in the department of Anthropology, R. Sivaprasad (Rtd.), Prof. N. Sudhakar Rao (Rtd.), Prof. P. Venkata Rao (Rtd.), Prof. Romesh Singh, Dr. George Tharakan C, Dr. T. Appa Rao, Dr. Alok Kumar Pandey and Mr. Sheikh Abdul Munaf for their valuable suggestions during my pre-field seminar and pre-submission seminar. I am also thankful to the non-teaching staff (former and present) in the department, Mr. Kanakayya, Mr. Jangayya, Mr. Ananthayya, Mr. D. V. Sekhar, Mr. Adi Narayana, Mr. Mohan, and Mr. Ashok for their remarkable services. I am grateful to the staff of IGM Library and University administration for their services. I also thankful to the University sanitation workers for maintaining a healthy surrounding for us. This study has been completed with financial support from UGC's JRF. Thanks to UGC for that.

I would also like to thank Prof. Vineetha Menon, Prof. S Gregory, Dr. Rajani Ramachandran (Department of Psychology, University of Calicut) for their suggestions.

Thanks to Dr. Jennifer C Sarratt, Dr. Subhangi Vaidya, and Dr. P. Bindu for sending their theses, books and articles on my request. I also thankful to the scholars who sent their research works through academic websites like ‘Academia’ and ‘Research Gate’.

Discussion with colleagues and friends inside and outside the department helped me to fulfil the work. This space is not enough to give all their names, however, some names cannot be omitted. Dr. Anil Gopi, Dr. Simpul Behra, Dr. M. Mahalakshmi, Dr. Anagha Ajith, Ganesh M, Pavan Kumar, Sravanthi, Gopika J, Archana Shanta, Anoosha, Hirock Barua, Vinod, Sonia A M, Dr. K. P. Manojan, Anoop Blathur, Anuranj Blathur, Jasna Jayaraj, Nimita K. P, Irfan Habib R. T, Safna M, Greeshma Gauri Gopinath, Jensi Lizy Johnson, Vaisakh, Vijila P, Riyas Beeran, Agaja P, Ansad C, Vimal P, Nidhin, Vineetha Balakrishnan, Nishar Mohammad, Vipula Padinjattil, Krishnakumar (Kiki), Dr. S. K. Sashikumar, Dr. V. K Sasikumar, Madhu Narayanan, Mahesh M, Dr. Suma Vishnudas, Dr. Nisar Kannankara, Tamanna Raza, Ameya M. R, Ajith Kunjunni, Mubashira, Suchitra Priyadarshini and many are remembered at this moment.

One of the factors that motivated me to take up the research topic was my sister Chandini K, a mother of an autistic girl Anashwara (Ponnu). She has given new energy to my research by enquiring about the various aspects and developments of the study. Along with this, the support of my father Chandu V, mother Baby B, sister Ranjini K, and my life partner Smrithi P. V who have helped me accomplish the aim.

I would like to express my gratitude to the family members, doctors and teachers who have participated in this study by providing the necessary information. Thank you for spending time for answering my queries and sharing lived experiences with me even in the busy schedule of caregiving.

Thank you all once again…

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CHAPTER- 1

INTRODUCTION

As individuals progress as social beings, members with different physical or mental conditions are expected in all societies. Each society responds to such conditions of its members in different ways according to its respective cultural context. The differential responses that are deeply rooted in the cultures of communities to certain physical and mental conditions continue to be a significant area of research in the discipline of anthropology. The current research is an anthropological inquiry into a mental condition, 'autism' in the state of Kerala. Before presenting the details and major academic works on autism, the anthropological involvement so far in the areas of human conditions, disability, and major theoretical discussions related to it are first provided below to serve as the background of this research.

Anthropology, Culture, and Human Condition

One of the fundamental goals of anthropology is to understand and theorize human conditions and behavioural patterns in different cultures. Anthropologists conducted remarkable ethnographic works in this regard (see Prichard, 1937, 1940; Frazer, 1890; Rivers, 1906, 1919; Mead, 1928; Benedict, 1946). 'Culture and personality' school of thought, which has given remarkable contributions to the academia, emerged during the engagement with the human condition at the beginning of the twentieth century. Proponents of this school argue that human mental conditions and behavioural patterns are deeply related to the socio-cultural context they are living. This school of thought has dealt with how people's behaviour in a community is linked to the cultural characteristics of that community. Scholars described human behaviours based on the concepts of 'configuration of culture' (Benedict, 1934; 1946), 'national character' (Mead, 1928; 1953), 'basic personality structures' (Kardiner& Linton, 1939; Kardiner, 1945), and 'model personality' (Dubois, 1944). Although not part of the personality school, similar studies were conducted in various socio- cultural contexts. The collaborative works of Hanks& Hanks (1948) conceptualized human conditions in a similar way. They explored the dimensions of personality and social psychological mechanisms among the lowland Thai people. Lucien Hanks talked about the psychological aspects of the people, and Jane Hanks focused on the people's character and the socialization process of children. Through the studies among Native American, Asian, Pacific, and African peoples, they have also revealed the role of social factors in determining the status of people with disabilities.

Observations regarding the concepts 'normal' and 'abnormal' (Benedict, 1934) are important in the discussions of human behaviour. Discussions on this categorization have helped academia to create a better understanding of mental health and illness. She conducted a study among the Shasth tribe of California. According to the study, the community does not consider 'epilepsy' a disease but sees it as a way to shamanic power. The people's 'different' behaviour, have regarded even extreme psychic manifestations not only as normal and desirable but even as characteristic of highly valued and gifted individuals' (1934: 60). By analysing this, Benedict opined that the idea of 'normal' and 'abnormal' are not a universally existing category but are culturally embedded. behaviours considered 'normal' or 'abnormal' in one culture may not have the same definition in another. But the definition will be related to the behaviour envisioned and demanded by the respective cultural context. Douglas (1966) described behaviours that did not conform to social norms as 'anomaly'. In some cultures, 'anomaly' define social order and are often considered challenging and polluting, and dangerous.

'Ability' and 'disability' are two concepts that anthropology has discussed for the past few decades. An anthropological perspective, these concepts do not have the same definitions universally, but it may vary according to differences in cultural context. In many non-Western communities, 'ability' is measured through an individual's capacity in productive engagement with their community. In the cultural context of Uganda, one's 'ability 'is found through the persons' engagement with the social realm through the family and neighbourhood (Whyte, 1998). However, if a member of that community has difficulty doing what the community demands, they are considered 'disabled'. Similar to this, in the Masai community, the ability is determined based on the practical competencies of the members of that community. The degree of their disability is determined by the extent to which individuals can perform everyday duties. In this cultural context, people with physical differences are not considered 'disabled' but 'normal' (Talle, 1995). Devlieger (1995) states that among Songye of Zaire, people with physical disabilities have been interpreted as 'superhuman', 'ambiguously human', or 'inhuman'. According to Nicolaisen (1995), among Punan Bah of Sarawak, personhood is measured based on social identity and family obligation rather than individual ability. The Inuit people of Greenland measured the intellectual ability of a member of the community through the person's capacity to hunt and fish and contribute to the community economy (Nuttal, 1998).

In medieval Europe, people with intellectual disabilities were considered less than human. They were considered as demon-possessed (Judge, 1987). But in some other contexts, they were protected in the churches with the consideration of ‘holy innocents’ or 'sacred fools'. Such people were considered close to God (Jenkins, 1998). Foucault (1967) says 'abnormal people' were treated as tainted. Therefore, they were taken into isolation as part of social control. Zola (1982) argues that people with disabilities are subject to invalidation and infantry licensing in society. He said, “Being different means being less” (p. 235-237). According to Scheper-Hughes (1992), "The sickly, wasted, or congenitally deformed infant challenges the tentative and fragile symbolic boundaries between human and non-human, natural and supernatural, normal and abominable" (p: 375). Conceptions of disability from a materialist point of view are significant (Finkelstein, 1980& Oliver, 1990, cited in Thomas, 2002). They talked about the relationship between disability and capitalist relations of production. During industrial capitalism, as wage labour became deeply associated with big industry, people with disabilities began to be excluded from direct involvement in economic activities. In a system that requires more production in less time, those unable to produce such results are expelled. Making such conclusions, Thomas (2002) says, "disability is not a transhistorical, ubiquitous, social phenomenon, but is bound up with social relationships at specific historical junctures. This enables us to move beyond simplistic ideas about disability being a type of always occurring 'restricted activity'; disability is located spatially, temporally, and economically" (p. 47).

Further expansion of biomedical knowledge, mental conditions, and behavioural patterns have been defined clinically and have become known under various labels. Similarly, therapeutic mechanisms have been developed to alleviate such conditions. However, anthropology seeks to understand disability, known by various biomedical labels, based on particular socio-cultural backgrounds. In this way, Klotz (2003) cited in Reid-Cunningham (2009:100) conceptualized disability as a "complex social, cultural, and biomedical phenomenon".

Anthropological interventions in disability became more specific as part of the Disability Rights Movement that emerged in Western countries in the 1960s. Mainly the movement was led by people with physical impairments who face discrimination from the public. Therefore, the movement demands disabled-friendly public spaces to ensure accessibility. The movement focused on questioning the concepts of normality and abnormality, ability and able-bodiedness, difference and deficit, health and illness, strength and weakness, dependence, independence, and inter-dependence. The movement sought to redefine the concept of disability through interventions in public education, politics, and law. It also addressed the issues of stigma, isolation, and dependence that arose as part of the disability. It also tried to ensure their social engagement and liberation by overcoming the social and physical limitations they face due to their physical or mental differences (Scotch, 1989). Despite the diversity of physical conditions, the social movement united people with disabilities under a common shelter. This movement viewed that people with disabilities face common difficulties irrespective of the nature of disabilities. In this way, disability has been conceptualized as a single category similar to gender, race, and ethnicity concerning oppression.

Anthropologists made an identifiable presence in the Disability Right Movement from its advent onwards. It opened a new room for disability research in the discipline of anthropology. Apart from the ethnographic documentation of disabling conditions, anthropologists became activists and immersed in the issues of disabled people. The scholars engaged in action research later developed action and applied anthropological careers (e.g., Tax, 1964). Along with the movement, they advocated for enacting social policy for social inclusion and equality and challenged the negation of the personhood of people with disabilities. The influence of the movement can be clearly seen in the approaches of academic researchers at that time and in the proposals that studies have put forward.

Incorporating the ideas of the disability rights movement, one of the most important studies was related to mental retardation (Edgerton, 1963, 1967, 1970, 1984, 1993). Edgerton described the condition as "mentally handicapped". He argued that the existence of the handicapped condition is related to competency and incompetency, as seen in a particular social-cultural background. He argues that the intellectual efficiency of an individual is determined by the efficiency of human interaction in matters related to economic and social behaviour, sexual mores, attitudes towards the property, and face-to-face encounters and relationships. Edgerton documented and analysed the perception of the people with 'mental retardation' who are coming out of mental institutions. He explained that people who are institutionalized go through the stages of mortification and aggregation. In addition, he suggested the collaborative interception of social and biomedical scientists to solve issues related to mental retardation, which is influenced by the environment. Similarly, Angrosino (1998) conducted another remarkable study related to mental retardation. To bring out the voices of those people, he explored their personalities, habits, and daily life. There have also been significant studies on the mental condition 'schizophrenia' (Estroff, 1993; 1989; 1984; 1985). He explored the relationships between psychiatric consumer/ survivor/ ex-patient identity formation, social constructions of emotional difference, and public policy. Based on this study, she elaborately talked about human suffering and the role of anthropology in humanitarian interventions. Nakamura (2010) explored the lives of people with schizophrenia in Japan. Her works unveil the experiences of those who were diagnosed with schizophrenia and came out of a psychiatric institution, and lived in a Bethel house. She also explored the potential of visual anthropology to intervene in the field of disability. Moreover, she has also engaged in the discussion of disability, sexuality, and social movements.

In addition to studies focusing on mental conditions, there have also been studies focusing on physical differences. Ablon (1981; 1984; 1988; 1992; 1999) work on 'dwarfism' comes under this category. Contrary to the notion that the origin of disability can be caused by individuals' physical or mental problems, the study discussed the role of social factors in making the disabling conditions. She focused on the economic, political, or structural factors that shape the experiences of those labelled with these conditions. Ablon used the concept of 'stigma' (Goffman, 1963) to explain the role of such social factors. According to Ablon, 'stigma' is caused by family attitudes, educational environments, the medical establishment, public opinion, media representations, cultural beliefs, and interpersonal social interactions. She also elaborated on the exclusionary social atmosphere faced by people having physical and cognitive differences. In their ethnographic account, Ablon was interested in incorporating the narratives of informants as such. She also explored the benefits of disability-related studies to bring change on a practical level. Ablon's studies have transformed medical anthropological studies of disability conditions from the disease framework to an ethnographic approach. Some other studies in this model are worth mentioning, for example, impaired hearing (Groce 1985), deaf (Nakamura, 2006). A study marks the life of a woman with a congenital amputee condition (Frank, 2000), particularly noteworthy. She conducted a phenomenological study from an anthropological perspective. The study was a cultural biography of a young woman in a congenital amputee state who had been in contact for 20 years. Therefore, in this study, Frank adopted information gathering from an emic perspective of getting to know the subject more closely. Jackson (1992), and Greenhalgh (2001), study on chronic pain and personal experience also deserve to be cited in this context.

Auto-ethnographic accounts made remarkable contributions to the disability literature in anthropology. Murphy's (2001) celebrated book, *'The Body Silent'*, is an example. He narrated his own experiences with the bodily condition quadriplegia. He portrayed his life condition with quadriplegia as a 'liminal space' (Gennep, 1909; Turner, 1967). He explored his journey from a 'normal' and 'healthy' person to a 'disability.' Elaboration of the experiences from a reflexive angle also comes from the parents of people with disabilities. Landsman (2009) theorized 'personhood' and 'motherhood' in the background of her experience as a mother of a child with cerebral palsy.

Anthropologists in the meantime have made attempts for terminological clarification of the disability. The depth of one's disability is determined based on what one can do for the survival of oneself and of others, and participation in the process of social production

(Kasnitz & Shuttleworth, 1999). These scholars have given some terminological clarification related to 'handicap', 'impairment', and 'disability'. They say, “Individuals are impaired if they experience (or are perceived to experience) physiological or behavioural statuses or processes which are socially identified as problems, illnesses, conditions, disorders, syndromes, or other similarly negatively valued differences, distinctions, or characteristics which might have an ethnomedical diagnostic category or label. Societies may or may not perceive impairments as a result of functional limitations. These functional limitations may or may not be disabling dependent on culture and situational criteria, including stigma and power. Disability exists when people experience discrimination based on perceived functional limitations. A disability may or may not be a handicap or handicapping, dependent on the management of societal discrimination and internalized oppression, particularly infantilization and paternalism, and on cultural and situational views of cause and cure and of fate and fault. People usually perceive disabilities and handicaps as enduring whereas illnesses are not necessarily perceived as enduring” (p.4).

Anthropologists have made numerous self-critical observations about the shortcomings of anthropological intervention in relation to disability. One is that medical anthropology earlier rarely approached human physical and mental health experiences outside of the concepts of 'health', 'disease', 'illness, and 'healing' (Ingstad& Whyte, 1995; Shuttleworth& Kasnitz, 2004). This approach limited the discipline to discuss the human condition in relation to person-centreed, pathological, aetiology, and treatment rather than from a social and cultural point of view. Based on this recognition, arguments have been raised about the need to shift from the traditional clinical perspective of medical anthropology to family and communities perspective and conduction of the studies based on the phenomenological approach and personhood (Whyte& Ingstad, 1995). The second criticism is that anthropological engagements are acritical and hold a hyperrelativist perspective. But such self-criticism helped anthropology to intervene more effectively in the field of disability. As a reflection of this kind of self-criticism, numerous studies have been on impairment-disability since the end of the last century (see Ingstad& Whyte, 1995; Holzer, Vreede& Weigt, 1999; Hubert, 2000). Further, anthropologists can focus on issues such as violence, trauma, ethics, social suffocation, oppression, and inequality that may be part of the disability.

Anthropology and Disability Studies

The discipline of disability studies has played a significant role in making self-criticism and further activating anthropological interventions. Disability studies have emerged as part of the academic backing of the Disability Rights Movement. Later it became a common platform for various disciplines that seek to contribute to the field of disability. Many concepts that disability studies have discussed, contributed in the wake of anthropological intervention in this area. Linton (1998) says, "Disability studies take for its subject matter not simply the variations that exist in human behaviour, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations. The field explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state. It is an interdisciplinary field based on a socio-political analysis of disability and informed both by the knowledge base and the methodologies used in the traditional liberal arts and by conceptualizations and approaches developed in areas of the new scholarship. Disability studies have emerged as a logical base for examination of the construction and function of "disability". These scholarly explorations and the initiatives undertaken by the disability rights movement have resulted in new paradigms used to understand disability as a social, political, and cultural phenomenon" (p: 2).

The 'social model' (Oliver, 1996) serves as an important tool in the study of 'disability' for disability studies and other disciplines. The model was developed in the 1970s by disability activists in the Union of the Physically Impaired Against Segregation (UPIAS) and gave a theoretical force for the right movement. The British social model of disability claims that disabled people are an oppressed social group. Similarly, North American theorists have defined disability based on the social, cultural, and political dimensions of disability (Hahn, 1985, 1988; Albrecht, 1992; Amundsen, 1992; Rioux et al., 1994; Davis, 1995; Wendell, 1996). Many scholars have used the potentiality of the social model not only in the field of activism but also in the field of academia (Finkelstein, 1980, 1981; Barnes, 1991; Oliver, 1990, 1996). The emergence of the 'social model' has made a paradigm shift in the approaches to disability through its criticisms against the 'medical model', which was popular in academics and policy levels before that. According to the medical model of understanding, disability is a 'personal tragedy'. It does not recognize the role of society in relation to the condition of disability. The medical model tried to objectify the condition of disability. But the social model criticized the pathologizing approach of the medical model and talked about the role of society and its decisions in creating disability. Furthermore, the model spotlighted the physical, social, economic, political, communication, and attitudinal barriers, which are intensifying difficulties and disabling experiences. Oliver (1996), one of the proponents of the social model, argued that the exclusionary approach of society against people with a disability concerning social contribution is the foundation of creating disabled experiences.

The social model of disability underwent many criticisms from postmodern theorists and critical disability scholars, which led the disability discourse to new terrain. Postmodern theorists critiqued the social model's binary conceptualization of impairment and disability. The model defined 'impairment' as an individual functional limitation and 'disability' as a socially generated system of discrimination. The post-modernists pointed out the inadequacy of the social model because of its negligence in addressing the subjective and body experiences of a person with disabilities (Shakespeare, 1994; Corker, 1998, 1999; Mitchell& Snyder, 1997; Linton, 1998; Thomson, 1997). They argued for the discussion of disability through the experiences of the person, because, subjective experiences are important because the intensities of the experiences are different depending on the nature of impairment and the socio-cultural context. They also talked about filling the gap between 'impairment' and 'disability' with the concept of 'embodiment' (Paterson& Hughes, 1997). Connell (2011) validated the criticisms of the social model by elaborating the idea of 'embodiment'. According to Connel, the recognition of bodily experiences is relevant to understand the power assertion on the body and the creation of disability. He says, "We need a concept, which I call social embodiment, to refer to the collective, reflexive process that embroils bodies in social dynamics, and social dynamics in bodies. When we speak of 'disability', we emphasize the first side of the social embodiment; the way bodies are participants in social dynamics; when we speak of 'impairment', we emphasize the second side, the way social dynamics affect bodies" (p. 1371). In addition to this, there are some other criticisms of the social model for not discussing the oppression faced by people with disability identities (Shakespeare, 1994) and for not having a sufficient theoretical basis (Flinekstein, 2001), and the silence of the social model for incorporating the intersectionality of gender, race, sexuality in the discussion (Fougeyrollas& Beauregard, 2001; Klotz, 2003; Battles& Manderson, 2008). In addition, Shuttleworth (2007) criticized the negligence of the sexuality of people with disabilities and says, "There is a wide range of issues related to disability and sexuality that deserve social and political attention, including sexual abuse, asexual and hypersexual media images of disabled people, disability and gender issues, sexual identity and orientation, interpersonal barriers, and sexual intimacy, the use of sex workers and sexual surrogates, facilitated sex, and barriers to sexual access for significantly disabled persons living in institutions and group homes" (p: 145). Further criticisms of disability studies and the social model come from the disregard for the life experiences of people with disabilities in the Global South and the understanding that the experiences of people with disabilities are the same worldwide (Meekosha, 2008). The criticisms of the social model from the Global North itself encouraged the focus of study on the Global South.

Disability in Global South

Global South countries are one of the major locations of the people who are living with different types of disability conditions. Paradoxically, disability is not well explored in these countries. Most studies on disability in the Global South countries have been conducted in a Western framework. In fact, Western concepts are uncritically applied in the Global South context. The Western approach has been problematized because of the incompatibility of the models to the different socio-cultural contexts and neglects the perceptions of people with disabilities in the global South. The scholars in the global South critiqued the Disability Rights Movement's projection of personhood with 'independent living' and 'autonomy' of the people with disabilities. The two concepts are the core ideas of the rights movement that originated in the American community. But, the theoretical and methodological exposure of anthropology in non-Western and local cultural settings, helped the discipline to problematize the 'independent living' perspective. It helps the discipline to realize that, Western-oriented perspectives regarding autonomy and independent living are irrelevant to the global South countries but these societies focus more on 'interdependent' and 'collective identity' and 'survival'. In fact, global South countries survive as part of the 'familial self' (Roland, 1988) identity rather than the independent self-identity. Therefore, it is a high time for an "intellectual decolonization" (Meekosha, 2008: 16) as well as "cultural juxtaposition" (Marcus& Fischer, 1986: 157) and addressing the geopolitical scenario. Meekhosha (2008) argued for the contextual shift by critiquing the hegemonic supremacy of Western scholarship, and she questioned the Western-centred legacies. She argues that 'social suffering' (Kleinman, 1995) and 'human suffering' (Kleinman et al., 1997) are more appropriate concepts that can be used when analyzing disability in the Global South. By recognizing these issues, anthropologists and disability studies scholars who focus on global South countries argued for locally informed models in the conceptualization of disability (Ingstad& Whyte, 1995; Holzer, Vreede& Weigt, 1999; Hubert, 2000).

Anthropology opens up a great deal of potential for Global South-oriented disability-related studies because its methodological capacity to engage with cross-cultural comparisons would help to explore the diverse perception and experiences of disability. By recognizing such potential of the discipline, several studies have been conducted focusing on countries in the Global South, such as Kenya, Uganda, Botswana, southern Somalia, Japan, China, Israel, and India. These studies placed significant emphasis on the perspectives and experiences of people with disabilities (Ingstad& Whyte, 1995). Studies from global south countries focused on the exploration of disability through social movements such as the women's movement, Dalit and anti-caste movement (Mehrotra, 2011, 2004a& b, 2006; Addlakha, 2013), humanity, personhood (Staples& Mehrota, 2016), social movement, state policies, eugenics, citizenship, human rights, and sociality (Ingstad& Whyte, 2007; Ginsburg& Rapp, 2018; Friedner, 2014, 2015; Pisani et al. 2016).

As part of the intensification of global South-centric disability studies, there have been many studies focusing on India in the last two- three decades. These include disability, gender and women's movement (Davar, 1999, 2001), law (Addlakha& Mandal, 2009), social exclusion (Dalal, 2002; Friedner, 2015; Klasing, 2007), gender and sexuality (Addlakha, 2007; Block, 2000; Chakravarti, 2015), rehabilitation (Ghai, 2001; Pfeiffer, 2003), disability and education (Battacharya, 2010; Das etal., 2013; Goodley, 2007) families of people with disabilities (Chakravarti, 2008; Devlieger& Addlakha, 2009 Vaidya, 2008, 2016). Ghai (2003) sought to highlight the issues faced by disabled women in the Indian women's movement and the concept of disability feminism. Grech& Soldatic (2016) problematized the conception of development in the cultural context of disability and poverty. The author analysed the role of poverty in intensifying the disability experiences. The poverty condition curtails the opportunities of pooling the resources to reduce the difficulties of disability. The scholars criticized the equalization of disability and poverty for conceptualizing development. Global South theorists critically approach the definition of 'development' from the disability perspective. They argue for incorporating the disability perspective in the conceptualization of development.

The ethnographic method acquired a prominent space in the exploration of living experiences of people with disabilities and their families among the social science disciplines (Vaidya, 2008; Sarret, 2015; Nayar& Mehrotra, 2015). In similar way, Das& Addlakha (2001) conceptualized disability in the background of the 'kinship model'. The authors presented the ethnographic account through the association with the Panjabi family and the hospitalized female psychiatric patients. They explored the domestic spaces to conceptualize the impairment and disability.

In addition to studying kinship and family, 'caregiving' was an important area of scholarship in the global South. Chakravathi (2018) did an ethnographic study among the families of children with Cerebral Palsy in Delhi. She argued that different social factors make caregiving a burden for families. She especially pointed out the dearth of medical knowledge and availability of health and skill development training services as the factors which affect the quality of life. The lack of resources in developing the potentiality of disabled persons is also an ingredient of the making of the burden. Along with postulating the context of the burden of caregiving on families, she talked about the gender division of caregiving. She states caregiving involves social, economic, and emotional aspects. Moreover, de-institutionalization, withdrawal of the state from the health and welfare sector, and the limitations of biomedical approach caring fall upon family and women. By asserting the political economy is the influential factor intensifying the suffering of the people and the perceptions of disability, she has suggested a detailed exploration of the relationship between the state, society, and family in the context of disability. Addlakha (2020) explored the complexities of care for people with disabilities in the neoliberal Indian context. The study conceptualizes care in the context of disability and poverty. She argues that the social and cultural shift destabilize the family structures. By looking at the 'care complex' (Addlakha, 2020: 53), which includes the care receiver, caregiver, and the social context of the actors, it is asserted that the family is the main location of the management of disability. Further, the socio-cultural background determines the well-being of the disabled and the intensity of the caregiving.

Scholars in anthropology focusing on the global South region acknowledged the lack of a model of conceptualizing disability. Much of the anthropological works relayed upon a limited number of theoretical perspectives, including 'liminality' and 'stigma'. Therefore, scholars understood the need for the new model. As part of this, critical disability scholars have come with different models such as 'policy development model', 'socio-political model', and 'cultural context model' also known as socio- cultural model (Kasnitz, 2001; Shuttleworth, 2000; Kasnitz& Shuttleworth, 2001). The core idea of these models is to understand the disability experiences by addressing the power relations and eliminating the oppression experienced by people with disabilities. The 'socio-cultural model' seeks to entangle impairment and disability from the biomedical meanings and helps to discuss the oppression that people experience in terms of any physical or cognitive, or behaivoural differences (Shuttleworth, 2004; Shuttleworth& Kasnitz, 2004, 2006).

In addition to intensifying the intervention of anthropologists in disability, important discussions are taking place on the collaborative engagement of anthropology and disability studies. Along with anthropologists, disability studies scholars are also interested in such engagement. The element of power relation, which has a common theme from the critical understandings of both disciplines, opens up a way for collaborative interventions in addressing disability experiences. Anthropologists suggest collaborative works will benefit both disciplines theoretically and methodologically (Shuttleworth& Kasnitz, 2001). They proposed the goals for the mutual engagement of the anthropology and disability studies, such as “1) to further the understanding of the lives of disabled persons cross-culturally; 2) to improve the quality of life for disabled persons, and 3) to promote a mutual engagement and collaboration in research and curriculum development by anthropologists and other scholars looking at disability” (p. 27).

Disability and Family: A Case of Autism

The affairs of a person with a disability are mainly managed in the context of their family. In this way, family members become part of the lives of those who are disabled in every way. Autism[1] is a neurodevelopmental condition that has become widely heard in recent years. Earlier, the clinical interventions approached autism as a 'mental disorder'. In an article, '*Autistic Disturbances of Affective Contact'* child psychiatrist Kanner described autism as "the outstanding pathognomonic fundamental disorder of the children's inability to relate themselves in an ordinary way to people and situations from the beginning of life" (Kanner, 1943: 242). Kanner was the first person to observe and define the condition and call attention from the medical and academic communities. He used the term 'extreme autistic loneliness' to define the characteristic features of these children. Simultaneously Asperger (1944), an Austrian paediatrician, described the behaviour of a group of boys who were facing challenges in social interaction and denoted them as "little professors" due to their skills and interest in discussing subjects in detail. Therefore, the person shows autistic features with evident skills, usually known as Asperger Syndrome. Later, following these initial works, several studies on autism has come from the biomedical and psychological perspectives. As already mentioned, in biomedical perspectives, autism has been defined as a neurodevelopmental disorder that affects an individual in social behaviour and communication and termed the condition as Autism Spectrum Disorder (ASD). After the advent of autism rights movements, the terminology has been changed to Autism Spectrum Condition (ASC).

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[1] Diagnostic and Statistical Manual- V- 2013 has defined autism is the deficits in social emotional reciprocity; deficits in nonverbal communicative behaviours used for social interaction; deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures. Deficits in developing and maintaining relationships, appropriate to developmental level. Stereotyped or repetitive speech, motor movements, or use of objects. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behaviour, or excessive resistance to change. Highly restricted, fixated interests that are abnormal in intensity or focus. Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of environment.

Bio-medical perspectives has showed the interest in exploring the symptoms, aetiology, prevalence, genetics, heterogeneity, and development of autism (Amaral et al., 2008; Striano& Reed, 2009; Volkmar etal., 2005). Further, many theories were put forwarded from the psychological perspective to describe the etiological stories and that took a prominent place, for instance, Theory of Mind (Baron-Cohen, 2000), Weak Central Coherence and Executive Dysfunction (Happe, 2005), Triad of Impairments (Wing, 1997), Refrigerator mother (Bettelheim, 1967), Absence of mirror neurons (Rizzolatti et al., 2009), etc;.

Now, autism studies are an emergent area of research in the social science disciplines. The social science intervention on autism opened up a new path in the exploration of the condition of autism. The disciplines such as anthropology, sociology, and disability studies explored the social and cultural perspectives of autism through ethnographic accounts, personal, family, and community/ social group experiences, social interactions, and narrative accounts (Vaidya, 2008; Bagatell, 2007, 2010; Grinker, 2007, 2010; Ochs& Solomon 2004; Sarret, 2015). Those disciplines categorized autism in several ways. Anthropologists who engaged in disability studies presented autism as a psychosocial condition, intellectual disability (Vaidya, 2008; Sarret, 2015) and cognitive disability (Rapp& Ginsburg, 2018). Moreover, autism is also approached as a 'subculture' (Solomon, 2010).

Anthropological contribution to autism is said to be in three ways. One, the discipline is critiquing the biomedical approaches, which often ignore the individual social and cultural environments in the creation of the experiences of autism. Two, anthropological studies approach autism from a cross-cultural perspective (Sarrett, 2014; Grinker, 2015).

Three, the capability of anthropology in documenting and analysing the lived experiences of person with autism[2] and their families with its sound ethnographic methodology. Hacking (2000) argues that autism is not simply situated and created by genetic and neurological differences but is socially constructed by environments. In a study among Korean families, Grinker (2015) argues that biological descriptions are insufficient to understand the role of local socio-cultural context and the lived experiences of autism. He argues that the perceptions of behavioural differences are deeply related to their socio-cultural context. According to Grinker, the term 'autism' is not prevalent in Korean communities. The mothers of the children do not accept that their children have autism. But the children expressing autistic behaviour are usually represented as 'border children'. Here, we can see a dominance of local cultural knowledge on psychiatric knowledge.

The condition of autism has recently attracted attention from scholars in the Indian context. Family, educational institutions, and hospitals are the major sites of these studies (Vaidya, 2008; Daley& Sigman, 2002; Daley, 2004; Sarrett, 2015). Vaidya (2008) explored the everyday experiences of families with autism in Urban India. She focused on the way of negotiation of families living with autistic children and the transformation of families through those negotiations. The major concern of the study was to portray the role of the family in the assertion of personhood. The study showed that the 'settings' where the family resides have played a major role in the lived experiences of the parents. Those are the families that migrated to the urban ecology to ensure better resources for the rehabilitation of the child. They were able to change their family structure and

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[2] In this thesis, researcher has used both the terms ‘person with autism’ and ‘autistic person’ to represent the participants with autistic features.

lifestyle for the betterment of the child. They were able to shift their residence and spent money for the betterment of the child as they belonged to the middle and upper economic background. The author indicates the place is an 'autism hub' where the hospital, educational facilities, and institutions that disseminate knowledge on autism are sufficient. Further, the study has looked the Action For Autism (AFA), an NGO, as a case to describe the sufficiency of the resource availability. However, the life experiences of families from other socio- cultural and economic backgrounds and who do not have a clear understanding of autism and have limited access to resources may differ.

Another scholar Sarrett (2015), did a comparative study of physical locations and the sites of autism such as homes, schools and hospitals and its effects on autism experiences in Kerala and Atlanta. She argues that there are two distinct approaches in the conceptualization of autism. On one side, it is recognized as a biomedical phenomenon that needs intensive training programs to rectify the issue. The other side recognizes it as a social construction and has social and cultural implications. These two poles are because of the individuals' or professionals' exposure to biomedical knowledge. She asserts that this distinction in approaches also leads to the creation of two types of homes, such as 'therapeutic' and 'custodial'. The therapeutic homes focus more on the betterment of the child through intensive familial training. These homes has become an extension of training institutions. Conversely, custodial homes primarily focus on physical and emotional needs and pay less attention to intervention in rehabilitative works. She adds that Atalanta homes are 'therapeutic', and Kerala homes are 'custodial' basically. She also noted that the difference in homes also reflects the 'parental acceptance' of the condition of the child. She argues that the scant rehabilitation opportunities in Kerala are the major reason for the early parental acceptance compared to Atlanta. Moreover, the 'less therapeutic' parents recognized that the situation would not change and continue throughout life. Here, parental acceptance is referred to as a negative connotation that discourages parents from trying to improve their children's lives. However, the lack of rehabilitation opportunities is the deciding factor of the parental experiences and approaches, some other reasons behind this need to be explored. The study did not address the elements of social organizations such as religion and the intersectionality such as caste, class, age, gender, and sexuality, which is very evident in the global South context. There is a need to study lived experiences in culturally diverse families due to differences in religion, caste, and class within a larger socio-cultural context.

Overview of the Present Study

Some trends can be seen when examining the involvement of the discipline of anthropology in the condition of 'disability'. It should be noted that the intervention of anthropology based on the category of disability is becoming more focused. At the same time, in contrast to the studies based on Western countries and Western concepts, there has been a recent increase in studies focusing on the global South countries. In order to conceptualize disability, these studies have highlighted the lived experience and perspectives of the peoples from Global South. Further, scholars in this study area have realized the need for interaction between anthropology and disability studies. Studies have focused on disability from the concepts of disease, illness, stigma, and liminality to areas such as caregiving, personhood, human rights, and policy. While disability-related interactions are thus active, studies are increasingly analysing the experience of physical disability and those who experience it. On the contrary, studies on psychosocial disability are relatively rare. Most studies on psychosocial disability have been based on conditions such as mental retardation and schizophrenia. Attempts to analyse a life-long condition called autism, which has recently become widely heard, and to document the experiences of caregivers who have experienced such conditions have rarely been made. The review of the studies related to autism has shown that there are no anthropological studies that analyse the condition among families from a rural, low-income backgrounds with diverse religious, racial, and caste backgrounds.

Aims and Objectives

The present study is an ethnographic inquiry among 36 families of children with autism living in rural and semi-urban areas in Northern Kerala. A major question to be addressed in the present study is: How is autism defined, understood, managed, and experienced in the family context? Along with this, many sub-questions, such as How are the child's distinctive behaviours identified? How do family members deal with doubts about a child's distinctive behaviour? How do family members approach autism? How does the caregiving process surrounding autistic individuals proceed in the family context? Why do caregivers face challenges in the care process? How do caregivers approach challenges? are also addressed. Based on these questions, the present study framed four objectives. The main objective of this study is to understand the disability situation of autism in an anthropological way. For this, the following objectives are formulated 1. To understand disability from an anthropological perspective through ethnography and by emphasizing autism. 2. To understand the nature (or modes of) of realization , help-seeking, and labelling of autism. 3. To understand the processes and methods that family members adopt to address the condition of autism by using non-familial means, and 4. To understand the processes and methods of addressing autism in familial settings.

Conceptual Framework

The framework of the present study is formulated by using concepts of interdisciplinary literature in the fields of anthropology and disability studies. The study has accommodated the critiques of the 'medical' and 'social model' of disability and taken the vantage point of the 'critical disability study' perspective, which deals with the role of both agency and structure in the conceptualization of disability. The present study relied upon the 'socio-cultural model' also known as 'social context model' (Kasnitz, 2001; Shuttleworth, 2000; Kasnitz& Shuttleworth, 2001), which encourages a shift from Western-centreed knowledge production to non-Western countries. Moreover, the perspective has acknowledged power relationships as an important factor in the conceptualization of disability.

The 'care ethics model' is relevant to understand familial caregiving for person with autism. The care ethics model of disability has talked about the webs of relationships and focuses on the care receiver and the caregiver (Tronto, 2011). According to Mahon& Robinson (2011), “A care ethics model of disability must be grounded within the emotional, practical and socio-political spheres of caring work and founded upon caring relations. These spheres cannot be separated and completely understood individually” p:178). Kleinman's concept, 'social suffering', is a strong tool to analyse the experiences of the family members who are the caregivers of person with autism. "Social suffering results from what political, economic, and institutional power does to people and, reciprocally, how these forms of power themselves influence responses to social problems" (Kleinman et al., 1996: 9). Moreover, the present study adopted the 'Explanatory Models' (Kleinman, 1987) to understand the familial construction of autism. The study also relied upon 'biosociality' (Rabinow, 1996) to understand the engagement of the family members in the social sphere.

Chapterization

The thesis is organized into six chapters. The first chapter, 'Introduction', discussed the major themes and debates in the discipline of anthropology regarding human conditions, especially disability. The chapter also dealt with the need for collaborative works of anthropology and disability studies. The chapter has discussed the major research gaps in the study of autism, family, and caregiving. Following the research questions, the chapter presented the major aims and objectives of the present study. The second chapter, 'Methodology', discussed the methodological approach adopted to address the research questions, aims, and objectives of the study. The chapter has presented the socio-cultural profile of the families, communities in the study setting, the participants' profile, and other methodological issues, including the selection procedure of the participants. The chapter has also portrayed an in-depth description of the fieldwork and data collection among the families of autistic persons. At last, the chapter discusses the procedure that have adopted for the data analysis and interpretation. The findings and analytical observations from the field data are presented in the third, fourth, and fifth chapters, respectively. The third chapter, 'Realization, Consultation and Labelling', presented the trajectories families went thorough from the realization of the child's distinctive behaviour and which leads to the labelling 'autism'. In between that, the event of professional consultation approaches to medical treatments also presented. The fourth chapter, 'Mobilization of institutional resources' discussed the therapy, training, and education, which are the options parents have taken for overcoming the child's condition. The fifth chapter, 'Dimensions of familial caregiving', discussed the caregiving duties of the parents of autistic persons, their challenges in caregiving, and their approaches to those challenges. The conclusion chapter gives a summary and arguments in the present study.

CHAPTER- 2

METHODOLOGY

This chapter discusses the methodology of present study and its philosophical context. The chapter is organized into four sections; the first part discusses the philosophical position of the present study, the second part describes the strategy of selecting respondents, the third part deals with the fieldwork process and data collection, and the fourth part is devoted to some details of data analysis. Observations based on my experiences during the fieldwork are also discussed in between the sections.

Philosophy of Research

The philosophical position on what constitutes social reality (Ontology) and the understanding of knowledge about social reality (Epistemology) determines the methodology and methods required for the unveiling of social realities. When examining the history of research philosophy, based on the perspectives on social reality, there are two main streams: the positivist and the interpretivist. However, from time-to-time various debates and updates have been taken place in these two streams. Positivism holds a naturalistic approach based on empiricism. It argues that knowledge can be found through scientific observation and methods. Researchers from positivist tradition believes, they can understand social realities by being objective, as if they were not part of social reality, without being influenced by where research is conducted. It seeks to find a general principle that can be applied anywhere in the world. The research work from this position relied mainly on quantitative data (Guillin, 2016). August Comte is one of the prominent figures of positivism.

Interpretivism is significant in the anti-positivist stream that has come to criticize positivism. Interpretivism argues that there is no single reality but multiple and constructed realities. This social construction takes place through a variety of interpretations. What is presented as reality about a social phenomenon is passed down from one person to another after several constructions with various interpretations. Similarly, the descriptions that come into the hands of a researcher go through many constructions and interpretations. This process does happen not in a vacuum, but culture and society play an important role (Sarantakos, 2005). In interpretivism, theory building happens mainly by collecting and analyzing the data qualitatively. The data would be the collection of people's words; that comes from their thoughts, behaviours, emotions, interactions, and images (Ryan et al., 2007). As opposed to the theory-oriented deductive approach in positivism (Uwe, 1988), the inductive approach is the basis of interpretivism. The much discussed 'Deep Play: A Note on the Balinese Cockfight' (Geertz, 1973) is a classic example of an interpretive approach. Moreover, this philosophical perspective is well utilized to theorizes the lived experience (Dilthey, 1996) and everyday life.

Rapid changes taking place in contemporary society are creating complexities in human relationships, perspectives, and lifestyles. Therefore, a qualitative approach is the best way to understand complex human experiences. Thus the above mentioned ontological and epistemological position shapes the methodology of the present study. Research on the human condition of disability based on qualitative data is scarce, especially through this philosophical position. Basically, the quantitative research approach has limitations in dealing with the social and cultural factors behind the experiences related to disability. In fact, the realities associated with the condition of disability can be best revealed through a qualitative approach. In addition, by exposing the socio-cultural background, the opinions of those being researched are emphasized. Validity related issues are also resolved through qualitative inquiry (Hartley& Muhit, 2003). People living with disabilities go through a number of intense experiences in their everyday life. The methodology of the discipline of anthropology helps us to understand disability holistically by living among the people, analysing their experiences, and exploring the social relations and the invisible social realities associated with the experiences. Adopting this approach makes it possible to capture the memories, experiences, perspectives, sorrows, joys, desires, and defences of the experienced in a subtle sense. Thus, qualitative approach helps to overcome the challenges and limitations that may be encountered when documenting human experiences.

Sampling Strategy

The study relied on qualitative data relating to the labelling of autism, treatment, education, training activities, and care provided by family members. Therefore, the data were collected primarily from the caregivers and the institutions associated with autism. Thus, the person with autism, their family members, teachers, therapists, doctors, and activists became respondents in the present study. Based on each person's identity and the area in which they are involved, they are categorized into the following:

One, the persons who were labelled as 'Autism' (Between the ages of three and 26 of both sexes); Two, Caregivers (close kin members consisting of fathers, mothers, grandparents, siblings, aunts and uncles). Although the interaction of each family member with children is different, all close kins are considered as primary caregivers. Data on daily care related to autism were collected from them; Three, health care providers (psychologists, therapists, and professionals who are working in various treatment systems). Documenting the data from these professionals helped to understand the available treatment systems related to autism and the involvement of health care providers in the care of autism; Four, Trainers (Those who are giving institutional training to children with autism in addition to therapy). The interviews with trainers helped to document the training activities and also their views related to it; Five, Teachers (teachers in regular schools where autistic children are studying). The experiences and perspectives in relation to inclusive education were collected from the teachers; Six, Activists (those who are working for the rights of person with disabilities and their families). By gathering information from activists, it was possible to understand the issues related to the rights of person with autism and the activities being carried out in the district.

Though the research focussed on 36 families with autistic children , the number of interviews was thus substantial (87 in total) in order to cover the different aspects of the study. Thus, the key informants numbered 36 mothers, 15 fathers, nine grandparents, besides 23 trainers, three doctors, one clinical psychologist, and one activist. The researcher has also seized many opportunities in the residences of the children, institutions which the children attended for treatment, training, or education for collection of data through direct observation.

Sampling Technique

The entire sampling process in the present study was done in two stages. During my preliminary fieldwork, an extensive survey is carried out to determine the total number of families with autistic children in the study area. I could find a list of families of children with autism (a total of 140) by visiting Samagra Sikhsha Abhiyan (SSA) office. This number 140 can be considered as a sample universe. However, since the present study is proposed to be primarily qualitative in nature and due to the time constraints, it is thought that it is not very useful to conduct any survey for quantitative data from all these 140 families or a sample of this group. Further, the SSA could not provide family contacts and primary details to consider any sample based on this information. Therefore, it was decided to select specific cases by visiting special schools and therapy/training centres in each area to collect basic information about the child and family. Based on the information thus obtained, respondents were selected for in-depth information through interviews and observation to fulfil research objectives.

The primary selection of families was made based on criteria such as geographical representation, the severity of the autistic condition, gender of the autistic, presence and absence of siblings, and socio-economic background of the families. By using this technique with a purpose, initially I approached ten families. After that, I analysed the data gathered from these ten families. After the preliminary analysis, I searched for more families to collect more data to reach data saturation. At one point, I could not find any new information from the cases. So, I realized that this was the stage of data saturation. According to Glaser& Strauss (1967), this technique of selection of the informants through data saturation is 'theoretical sampling'. It is more than just a sampling technique; but is used as a method of collecting data to lead to the construction of a theory by systematic induction (Glaser& Strauss, 1967). Through theoretical sampling, the focus is more on data than the selection of the informants. Therefore, theoretical sampling is used not prior to the study but during the study. Here, based on the information available in the study so far and the knowledge it imparts decides what the subsequent data collection should look like (Burgess, 1984; Strauss, 1991). Theoretical sampling is interconnected with data collection and serves to enable comparisons in time and place so as to discover variations in concepts and to integrate categories in terms of their properties and dimensions (Strauss& Corbin, 1998: 201). Although I interacted with a lot of families, data saturation was reached when 36 families were approached. It is 25.5 percent of the sample universe and is thought to be an appropriate figure to conduct qualitative research using extended case studies and life histories.

I would like to point out some issues associated with selecting children with autism. It is related to the contradictions in diagnosis which has been written in disability certificates and the actual labelling. Most of the children in this study have a disability certificate issued by the Medical Board. However, the information in the certificate was not the main criterion for selecting families for this study. Because the majority of children with autism are recorded in the certificate as 'Mental Illness', 'Mental Retardation', 'Cerebral Palsy', and 'Downs Syndrome'. This is so, especially on older certificates. There are two reasons behind this, first, children with distinct behaviours were considered mentally retarded at the time when knowledge of autism was not widespread. Second, Disability Certificates are primarily issued to ensure government assistance. Autism was not considered a disability to avail government benefits until the recent past. So, recording as 'autism' on a disability certificate would not help to avail of government assistance. Therefore, in cases where the doctors have assessed that the child has autistic behaviour, it was recorded as 'mental retardation'. Subsequent to the changes in the government policy, in the certificates issued recently, it is recorded as 'autism' or 'autism with mental retardation'. Because of this ambiguity, the sample for this study was drawn based on the opinion of the trainers and parents regarding the diagnosis of the illness. Although only two trainers in the district have specialized in autism, all those who have completed special education have reported that autism was in the syllabus during their studies. Thus, most trainers have an understanding of autism. In addition, they have acquired more knowledge related to autism from other sources. But, in some cases, parents and trainers differ as to whether the child is autistic or not. These differences in opinions are included in this study as data for analysis. Thus, though the researcher is aware of the diagnostic criteria put forward by the Diagnostic and Statistical Manual- V which has been published in 2013, no special assessment has been done to determine whether a child's behaviour is autism or not.

Socio-Demographic Profile

Family Profile

The selected families were distributed in 18 local self-governments in the Kasargod district. Except for one, all families have been living in the present locality for generations. A family that migrated from a neighbouring state settled in the present place a generation ago. Following the local government classification and population density, the place of their residence has been classified into rural and semi-urban. Thirty-one families lived in rural areas, while five families belonged to semi-urban areas. The families who participated in the study belonged to three different religions: 23 families were Hindus, 12 were Muslims, and one was Christian. When the family types were considered, 21 belonged to nuclear families, and 15 others belonged to extended nuclear families. Three couples have consanguineous marriage. The numerical composition of families revealed that they have a minimum of three members and a maximum of seven members. There are nine families, each with three and four members; eleven families with five members, and seven families with more than five members. Even though the nuclear families live in separate houses, they have settled near the localities where their kin members are living. Except for two, all the families reported are living in their own houses. When looking at the class profile, as per the income reported, 16 families came under the income level of less than Rs. 15000 per/ month, ten families fell under the income level, Rs. 15000 to 30000, and six families came under the income level 30000 to 50000 and four families fell under the income level above 50000.

Informants Profile

Autistic Person's Profile

Of the 36 autistic persons who constituted the sample, 25 are males, and 11 are females. The age of these children varied between three and 26 at the time of fieldwork.

Table No. 1- Age Profile

Age range (in years)	**Below 6**	**6-12**	**12-18**	**Above 18**
Numbers of autistic person	01	16	15	04

Considering the birth order, 11 are the only child of their parents, 13 of the children are first-born among their siblings, and 11 children constituted second or higher order births. In one case, the child has a 'regularly developing' twin sister.

The children participated in this study have a variety of 'abnormal' behaviours. Lack of social life is one of the significant features of them. Some children do not have speech. But they communicate mainly through different sounds. Though some others speak a few words, and their parents can only understand. Some people tend to repeat the words (echolalia) if we ask anything about them. Some people like to carry some objects most of the time. Almost all of them need the help of others to do everyday matters. Repetitive behaviours, hyperactive behaviour, epilepsy, and many sensory issues are some other features they often express. In middle of these behaviours, some children express some skills in certain areas.. For instance, a child has skills in mathematics and mechanics (assembling toys).

Nine autistic persons are getting therapies from the autism centre associated with an Upper Primary school under BRC[3]. Those nine children are also enrolled in regular schools, though they are irregular in attending the classes. Three persons are reported to

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[3] Block Resource Centres (BRCs) were established in each block of every district under SSA to conduct in-service teacher training and to provide academic support to teachers and schools on a regular basis as well as to help in community mobilization activities.

be regular attendees of regular school. Even though those children are weak in academic performance, they regularly attend school with other children. Five persons are getting training from BUDS[4]. At the time of fieldwork, three were getting training from a school for autism that was started by their parents and ten children are attending different special schools. They are receiving training along with other children diagnosed with Mental Retardation, Downs Syndrome, Cerebral Palsy, etc. Six autistic persons are spending most of their time at home.

Parents Profile

The mothers who were part of this study were between 28 and 49 years old. The data on the educational qualification of the mothers showed that 15 mothers have school-level education, and ten mothers completed their Pre- Degree Course or Plus Two. Seven mothers completed Graduation, three have earned Post Graduation, and one mother completed a technical education course. Even though many of the mothers are educated, the majority of them are not doing any paid work, but they are full-time home-makers. The mothers stated that they could not take up employment in view of their responsibility to take care of the child. Along with the household chores, two mothers are working in Govt. sector; of these two, one is a teacher, and the other is a lower division clerk. At the time of fieldwork, the latter one is on leave with a loss of pay for providing training to

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[4] Buds institution is a free education program for children with psychosocial disabilities who come from economically weaker families. Buds School is run by local self-governments in each area with the help of the Kudumbashree Mission. These are functioning as per the directions of the State Government. Buds Schools' main focus is on rehabilitation, training, and daycare. The purpose of opening the Buds is to provide accommodation to persons with disabilities above the age of 18 who are facing a lack of opportunities for institutional education.

her son. Three mothers are working in the private sector; two are school teachers, and one is a special school helper. The special school helper mother has been working in a school where her son has been studying for 11 years. One mother is self-employed, and she is doing tailoring at home. One mother resigned from her teaching job to take care of her 18-year-old daughter.

The ages of the fathers who were part of this study varied between 32 and 61years. Among them, 23 are educated up to SSLC or less than that. Four completed the Pre-Degree Course. Eight fathers completed their Graduation, and one acquired a Post Graduation degree. As far as occupation is concerned, most of them are daily wage labourers. Eight fathers are employed in Gulf counties, and two fathers are working in the Government sector outside of Kerala State. Among the fathers, one is working as a physician and two are unemployed.

In the category of daily wage labourers, seven are working in the nearby places; amongst them, five are Gulf returnees, two are drivers in hired vehicles, and one is doing painting works; he is also a Gulf returnee. In the category of the Government sector, one is working as a Grama Panchayath employee, one other is the Police, and the other is working in the army. Four respondents, including one gulf returnee, reported working in the private sector. In the private sector category, one father is a doctor running his clinic, another is a *Yatheenkhana* (orphanage) receiver, and another is an employee on the Devaswam board. In the category of self-employed, one is an astrologer, another one owns a vegetable shop with a partnership, another one started autorickshaw driving after return from the Gulf, one father is an electrician, and another one is engaged in welding works, another one is running ice cream parlour on partnership after return from Gulf.

The people residing in Gulf countries are goldsmiths, chefs, and tailors. One gulf returnee is not working anywhere.

Fieldwork and Data Collection

This section of the chapter describes the field the study, different stages and duration of the fieldwork, methods of data collection, and nature of the data collected.

Defining the 'Field'

Before describing the processes associated with fieldwork, it seems that the terminology of 'field' needs to be explained. The 'field' is meant here not just a geographical area with certain boundaries, but also as a concept. The form and content of the the field varies depends on the nature of the research and the questions raised by the researcher.

In the present study, the term field is intended to be defined not only in the sense of a particular geographical area but it is defined as 'places' and 'spaces' where many engagements take place. Therefore, this study attempts to mark the field as a space rather than a place. As such, there are many other fields within a geographical field.

The district of Kasaragod, situated in the Northern part of Kerala, has been selected as the geographical field for this study. It is a district bordering the state of Karnataka. The district was formed on 24 May 1984 by assembling the parts of the Kannur district in South and South Canara district from Karnataka. The district has a coastal, intertidal, and hilly region. The Northern part of the district, known as *Tulu Nadu*, means the place of Tulu speakers. The district has a peculiarity in linguistic diversity with seven languages:

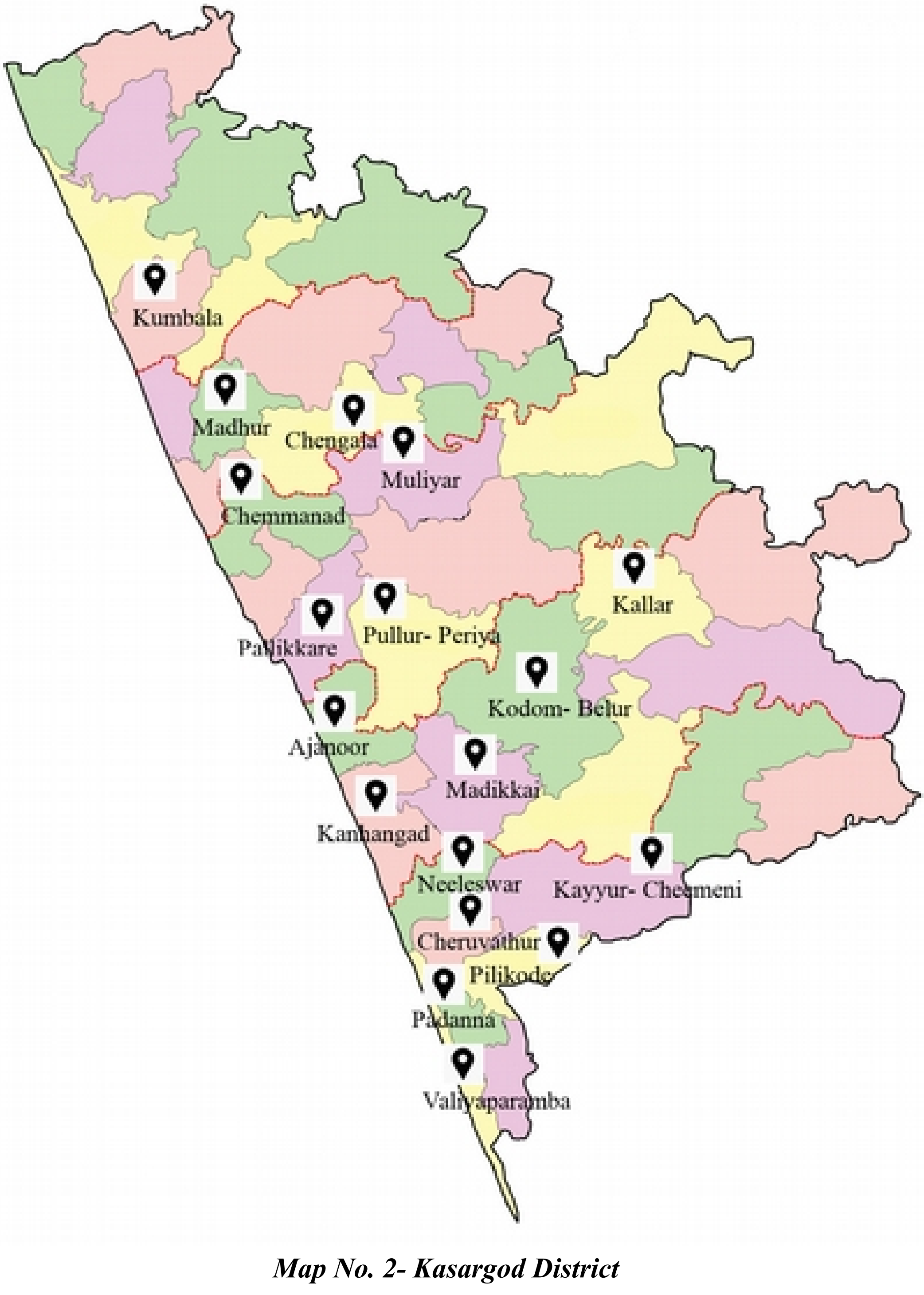
Malayalam, Kannada, Tulu, Marathi, Konkini, Byari, and Urdu. According to the 2011 census, the district has a population of 13,07,375, of which Hindus are 56.8%, Muslims are 37.2%, Christians are 6.7%, and Others constitute 0.3% (Census, 2011). Based on the economic, health, and educational attainments, the district is classified as 'backward' compared to other districts of Kerala. The economy in the district is largely based on traditional production sectors. Thus, the income for many families comes from agriculture, such as paddy cultivation, coconut, arecanut, plantain, etc. The economy in the Eastern part of the district is mainly rubber cultivation.

Field Selection Criteria

Kasargod district has been selected as the geographical field for this study based on certain criteria. Firstly, anthropological studies related to autism have not been conducted in this area. Secondly, Kasargod is viewed as one of the 'backward' districts of Kerala state, particularly in terms of the disability-friendly education and hospital facilities. Third, the knowledge of autism is expected to be scant among families and the general public. Fourth, the chosen field of study is the area where the researcher was born and brought up, it was thought it is much easier to grasp the experiences of the people and to understand the social realities. Although I have both the objective position of being a researcher and the subjective position of being a person living in relation to his culture, I am able to identify where the bias is likely to occur and where to approach both objectively and subjectively, and to take approaches accordingly. Being a native of Kasargod, it was easier to establish rapport with the informants. As a result, I have been able to approach families without any great challenges. Familiarity with the families facilitates the establishment of rapport. There were no linguistic or cultural barriers to me. Fifth, Kasargod is an area where the anti- Endosulfan struggle has been going on for the last several years. Studies have shown that the pesticide Endosulfan had been used to prevent tea mosquitoes in cashew plantations under government supervision, caused numerous mental and physical problems to the native people and ecology (Irshad& Joseph, 2015). The use of Endosulfan was banned a few years ago as a result of peoples' mass agitation. However, there are still ongoing campaigns to ensure rehabilitation for victims of Endosulfan and their families. There have been a number of struggles in recent times led by mothers of the victims. As a native, I recognize that this movement has accelerated discussions on 'disability'. Such agitations have raised many questions about the state's responsibility to the people. As part of rehabilitation efforts, education and treatment facilities have been introduced at the governmental and private levels. Although the topic of Endosulfan is not a major focus of this research, it is important that the study of disability be conducted in the area where agitation is taking place for the well-being of people with disability.

While Kasargod district was considered a field in the sense of a 'place', the 'family' was considered another field in the sense of 'space'. Family is a field that a child with autism as a family member spends most of their time. The family is the centre of many other fields. As a family member of an autistic person, my experiences often have to be considered as information. Thus, I have often had to transform myself into an informant while still a researcher. Moreover, the researcher's home and family members will be the field and the informants.

Map No. 1- Kerala State *(Kasargod district where study was conducted is marked)*



Map No. 2- Kasargod District

(The Local Self Governments where study was conducted is marked)

In addition to the family, the spaces where the person with autism and the people associated with them making interaction becomes a field. In this sense, educational institutions, hospitals, markets, religious institutions, restaurants, vehicles, social media, public spaces, and celebration occasions are also presented as the fields in this study.

Fieldwork Process

The extensive fieldwork lasted for about a year after a month-long primary field visit. The fieldwork was done in three phases. Although there are no gaps between these three phases, it is divided based on the progress and strategies of data collection. The details of the fieldwork process are given in the following section.

Table No. 2. Phases of Fieldwork and Data Collection

Phase	**Period**	**Work done**
Primary field visit	October- November 2016	Visited various institutions for the person with autism in different parts of Kerala
Phase 01	March- May 2018	Visited the educational institutions and collected the details of the persons with autism.
Phase 02	June- November 2018	Collected data from parents and family members of autistic children. Total 84 interviews were conducted.
Phase 03	December 2018- April 2019	Met new families and collected data to fill the gaps after preliminary analysis of data collected earlier.

Preliminary Field Visit

As part of the preliminary field visit from October to November 2016, general information on autism was collected by visiting educational institutions where persons with autism were enrolled in various parts of Kerala. According to the information obtained, a total of 140 autism cases are recorded in the Kasargod district. The information relating to the distribution of these cases in the district was used to design further research.

First Phase. The first phase of the fieldwork was conducted from March to May 2018. In this phase, the families of children with autism were selected. An effort was also made to spend time with the families who were already introduced during the preliminary field visit. It helped in establishing the necessary rapport for in-depth interviews.

The fieldwork was started by visiting the Samagra Shiksha Abhiyan (SSA) in the district headquarters. Information about educational institutions operating under SSA and the latest census data on autistic children was obtained from the SSA headquarters. The officials also suggested names of some other institutions which are not under SSA for additional information. As such, information on children with autism was not consolidated and documented in one place; it was collected after approaching many offices. Based on the information received from SSA, the Block Resource Centres in different parts of the district and one Autism centre under them were approached. In addition, three special schools and five BUDS were visited to collect information on children. A list of families, their addresses and phone numbers was prepared based on the information collected from all these places.

Owing to the misuse of information provided by the school authorities and the parents earlier by some students/ research staff of some institutions, and the parents' complaints regarding the questions that make difficulties, the officials were reluctant initially to provide any information without the written permissions.

Although I have made it clear to the informants that "I am a researcher", some have suspected that I am from some other special school. Some teachers at the training centres suspected I was collecting the information to start another school. Some other parents suspected I was a government official and came to take the census of autistic children. There have been incidents in some places where my visit has been viewed with great scepticism. One day when I was in BUDS talking with the director of that institution, one woman respondent suspected that the pen in my pocket was a camera.

Second Phase. In the second phase, from June to November 2018, I visited the families based on the information which was collected in the first phase. On some occasions, the help of child trainers was taken for introduction to family members. This strategy has opted on the understanding that the recommendation of trainers familiar with the parents would facilitate communication rather than contacting an unfamiliar researcher directly. It has helped to make acquaintance with the parents easier. On some occasions, I preferred introduction as "Chhaya's brother". Because, as a mother of an autistic girl, the parents were acquainted with my sister. The declaration that the researcher also belongs to a family of a person with autism reduced the strangeness between the family members and me. On some occasions, I requested my sister to accompany me for interviews with the parents who are friends of my sister. It was helpful for me to get better reception among the parents. In many cases, rapport with family members was achieved through multiple visits.

In this phase, families were informed about the objectives of the research. Attempts have been made for causal conversations with parents during the initial visits. In the days that followed, family members were met frequently, and in-depth interviews were conducted in phases. In addition, it was possible to collect data through participant observation in this phase. Substantial data on the events of realization of child difference, consultation, labelling, etc., were collected during this phase. Further, the perceptions of overcoming the condition and the familial caregiving experiences were explored during this phase.

During the fieldwork, some challenges were faced owing to my gender. Getting into the family environment, which is a private space, is often not an easy task. Even rapport-making visits were often not so easy. When I contacted a mother of a child for an appointment for an interview, she explicitly discouraged visiting home. I had been to that house twice before. The elderly woman of her family advised her not to meet me at home as the neighbours were asking them some embarrassing questions about my visit to the home. Considering such difficulties, meetings with this mother were held at the therapy centre.

Third Phase. The third phase of fieldwork was conducted from December 2018 to April 2019. In this phase of fieldwork, additional data were obtained to fill the gaps. In this phase, there was a slightly greater dependence on observation for data.

At this stage, I have experienced some dilemmas related to data collection owing to my profound closeness to my informants. During a series of home visits as part of the rapport establishment and data collection, one mother said, “*I treat you as my younger brother; you have to come to this house whenever you pass through this place”.* Although it made me happy to have a good rapport with them, the mother's comment made me feel guilty. I realized that though I wanted the participants to treat me as a researcher, they took an emotional approach and treated me like a brother. Therefore, it gave me the impression that I 'exploited their emotions' them for data collection.

Methods of Data Collection

Narratives and semi-structured interviews, participant and non-participant observation, and group discussion, which are prominent in the qualitative study, were used for the present study. All of these methods were used together rather than separately. There has been a combined use of these methods in data collection.

Narratives and Semi-structured Interviews. These are the major sources of primary data in this research. Interviews were designed like a conversation. This method was necessary to unveil their views on life experiences and the meanings they feel in it. Therefore the question types are open-ended. There was no strict structure adopted in asking questions. By conducting such interviews, participants are able to respond beyond certain boundaries (Burges, 1984). Depending on the comfort of the interviewee, I was trying to follow them in their own way. Charmaz (2006) says, in an in-depth interview, the objective is "to explore, not to interrogate" (p: 679). At the same time, the interviews focused on the areas that needed to be explored.

Although there were prepared questions on what the researcher should explore, the interviews were not focused solely on that. I have also carefully recorded what the participants shared about many matters outside my questions. I did not intervene to interrupt their descriptions during the interview because I wanted to hear what the informants had to say. At the same time, I kept my eyes and ears open for things that might lead to new questions from the informant's answers. Therefore, some interviews went on for a long time. The time taken for each interview ranged from 30 minutes to three hours. Interviews are conducted as per the convenience of the respondents.

Narrative interviews were conducted with family members such as the fathers, mothers, grandparents, and siblings. Most of these interviews were conducted at home. At the same time, therapy centres are also suited for such interviews with mothers. During the therapy, mothers usually waited outside the centre and accepted to be interviewed. In addition, several interviews have been conducted in public places like markets, beaches, and public occasions that family members visited. Some interviews were conducted with family members individually and others with many family members together. In this way, it was possible to know personal and collective opinions.

After the conversation regarding the social background of the family being interviewed, I moved on to the issues related to autism and caregiving. The interview focused on child-related issues, contexts, events, choices of treatment, educational and training activities, and daily life. As expected in the case of open in-depth interviews, the answers provided by the participants often lead the researcher to pose new questions that were not listed in the interview guide. Thus the participants also took a major part in the research rather than just as respondents.

In some of the interviews, the mothers and other family members spoke in a very descriptive manner and touched on many areas with a single question, but in some other interviews, the informants gave very short answers to the questions. So I had to encourage them to talk more. Thus, the Informants' responses influenced the length of the interview and sometimes the nature of the interviews too.

I had experienced many strange situations during the interviews as the interview brought back many memories that the mothers did not like to remember. Sometimes they cried while sharing their experiences.

Interviews with trainers, teachers, doctors, and activists were semi-structured in nature. Interviews with them have been conducted in premise of educational institutions and hospitals. These interviews focused on their perspectives on autism, their perceptions of parental attitudes, and treatment and training systems.

The researcher approaches a field and participants to get a closer look at a topic and to find answers to the questions related to it. The 'researcher/ interviewer' who is asking the questions and the 'interviewee' who is the person answering them are the two elements often expected in an interview. Sometimes these understanding are irrelevant to the field of knowledge dealing with human subjects. The distinction between researcher and researched will become more fluid because the interview happens after the rapport establishment. Therefore, there is a change in the situation where the researcher is the one who asks the questions, and the one sitting on the other side is the one who answers. Sometimes the interviewee becomes the interviewer, and the interviewer becomes the interviewee. Therefore, the researcher has to face questions from the person sitting on the other side. In such cases, there is a situation where the person who was the questioner up to one stage of the interview is then subjected to the question. The interview process, which may seem unilinear in the beginning, will turn out to be a multi-dimensional process. During the data collection, the researcher faced many questions from participants regarding my research, and my social background. The main question was about the expected benefits of the research to autistic children and their families.

As a person who has seen many children with autism, many mothers have asked to compare their child with other children. They have often asked had I seen any other child like their child?. Many people inquired about the chances of establishing a school for children with autism near their places.

Participant and Non-participant Observation. Observation is a data collection method that is significant in anthropological research. It is classified into two types in relation to its nature, participant and non-participant observation.

Non- participant observation is the act of observing and documenting the informants and their activities and their surrounding. Due to language and communication problems, children with autism were unable to participate in interviews. But I found plenty of opportunities to record their activities through observation. Interactions of children and their parents at home and surroundings, educational institutions, hospitals, and on festive occasions, as well as activities performed by autistic children, were observed. In addition, the place of the house, and the arrangement and storage of goods and articles inside the house, could be recorded through observation. In this way, it was possible to know the presence t or absence of materials for the educational activities of the autistic at home.

During the interviews, the informants' approach, modulation of their voices, and facial expressions to the questions were constantly observed. Such observations helped to understand many emotions that informants may not express in words. The approach of the guests and their family members during the interview was also observed. By observing the pictures and posters on the walls of the houses, it was possible to identify the political and religious views of the family members. Similarly, the observation of general information displayed in hospitals about autism helped to understand the treatment modalities' approach to autism. Monitoring the activities of special schools and regular schools and the interaction between teachers and students where autistic children are studying helped me to identify how such institutions embrace the condition of autism.

Through numerous discussions on participant observation in the academic field, researchers have been able to better implement this method from a humanitarian perspective. It is an important method of data collection in many social science disciplines other than anthropology too. Malinowski (1922), the proponent of participant observation, states that the advantage of participant observation is that it helps to “grasp the native point of view, his relationship to life, to realize his vision of his world" (p:19). I could participate in a variety of activities of respondents in their home environment and in markets, schools, and hospitals. I was able to work with the parents in the inaugural function of a school for autism which was started by the parents. I participated in purchasing materials for the school, preparing school-related notices, preparing and distributing inaugural event notices, placing banners in public places, decorating the school, and welcoming attendees to the inaugural event. I was able to attend the birthday celebration of an autistic child held at the school where the child was studying. Also, I had the opportunity to attend the wedding occasion of an uncle of a child with autism. Mothers of other children with autism also attended the occasion. I participated in a medical camp that was organized to exchange educational equipment for children with autism. The camp was organized at the Autism centre under the supervision of local self-government. Many mothers and children attended the camp. Sitting next to the consultation desk, I could observe the doctor's assessment of the children and instructions they had given, and the interaction between the doctors and parents. Thus, observation as a participant in events involving children and parents further enhanced the data collection for this study.

Group Discussions. Group discussions were held during the 'waiting time' at the therapy centre, medical camps, and the opening of an autism school. There were no specific criteria was adopted in participation of the group discussion because all mothers were able to share their perspectives on care. In some cases, the mothers sat together for conversation as usual without any instructions, and I moderated their conversation. In the group discussions, I explored their child's behaviour, family attitudes towards it, and experiences of going out into public spaces with children. Four to six people participated in these group discussions.

Social Media. Social media platforms were also used for the data collection. I have regularly followed the Facebook posts of parents of autistic children and the Facebook pages that are handled by parents. Through this, it was possible to understand the interactions of parents on the social platform, know their attitudes on various issues, and collect up-to-date information about autism. I also followed the statuses posted by parents on WhatsApp.

Data Documentation

A variety of approaches to data documentation have been adopted as part of this study. Interviews were mainly recorded using a mobile voice recorder because it was the best way to accurately document the information provided by the informants. In addition to recording, I kept a diary to scribe the idea that seemed striking. At the same time, when it came to matters that needed to be clarified during the conversation, they were recorded in the diary and were then asked for clarification. In addition, the ideas and questions that came to my mind during the journey to the field and from the field were recorded in the 'note' on the mobile phone. After returning from the field, I transcribed the recorded interviews and developed the field notes. The recorded interviews were manually transcribed verbatim. The recorded voices and notes were transcribed directly to the laptop and sometimes to paper. The interviews were conducted in Malayalam, and the transcription was done in Malayalam and English.

Data Analysis

Qualitative data analysis involves the interpretation of the informants' experiences and perspectives which have been expressed through words and movements and documented through observations in a particular socio-cultural context. The researcher obtained a variety of essential data through interviews, narratives, observations, and group discussions. This section intends to describe the process of analysis of qualitative data collected through employing these techniques.

No specific rules have been adopted \for conducting qualitative data analysis. However, the information was analysed largely by following the guidelines and recommendations related to thematic analysis. The thematic analysis seeks to transform information into a variety of themes and identify patterns and relationships between them. There are several stages in thematic analysis. The following section describes those stages. It has already been pointed out that data analysis took place during fieldwork. Analysis at that time was used to understand the nature of the data and to select more participants. It is done through the 'constant comparison' of the data that was available initially and the data made available later. This comparison showed whether the information available at a later stage is consistent with or different from the information previously obtained. Constant comparison was felt essential for the defragmentation of data and for making an elaborate scheme of categories and themes.

Another phase of the data analysis began shortly after the completion of fieldwork. It was a somewhat systematic analysis process. The data is highlighted and coded based on the meaning that the interviews contained. The process of dividing data into conceptual categories was followed. Codes (Miles& Huberman, 1994), also known as categories (Glaser& Strauss, 1967), labels (Dey, 1993), segments (Tesch, 1990), thematic units (Krippendorf, 1980), concepts (Corbin& Strauss, 2008) were sorted out. The coding of data was done manually (This process is also known as open coding Strauss and Corbin, 1998) and initial coding (Charmaz, 2006). 'Codes' contain background information, informants' expressions, and opinions. Some codes are 'words' that contain the meaning of the data, while others are the 'exact words' of the informant. After the initial coding process, the codes were copied and stored in a 'code book'. After a detailed analysis of these codes, those that contain similar meanings are grouped into 'categories'. Each category was given a name according to the meaning it contained. After analyzing these categories, different themes were created by combining categories that have similar meanings. Each theme was given a different name based on the meanings it contained. The connections between these themes were later discovered, and the data extracts related to each theme were kept in a separate table. Different themes created in this way are presented in different chapters. Codes, categories, and themes that could not be integrated were stored in a separate file. Themes were discovered through an 'iterative' process, which is the inductive and deductive combinations (Dey, 1993). There was a preconceived notion of what kind of information to focus on. The literature review has given a similar impression. At the same time, I was careful to find new information in the field data that would enrich the information I was focusing on. This is how it is said to be an interactive process.

'Memos' are a running note during the research (Charmaz, 2006; Glazer, 1978; Strauss& Corbin, 1998). During the data collection and analysis, the researcher kept analytical memos that reflected many concepts and insights that came up in the study, as well as the analysis process and the coding. This is the step between coding and the first draft of the analysis (Charmaz, 2000: 517). These memos, which include concepts and insights, played an important role during the writing of the thesis.

Summary and Concluding Remarks

This chapter discussed the philosophical basis behind the present study and the methodological approach adopted. The sampling strategy adopted on such a philosophical basis and the fieldwork and its process are also discussed in this chapter. This chapter reveals the possibilities of such epistemological, ontological, and methodological approaches to contribute to a more nuanced and comprehensive inquiry into social experiences related to disability. It is hoped that such a methodological approach will make it possible to accurately understand the social context in which the study is conducted and to document in detail the involvement of family members and professionals in relation to disability. When dealing with sensitive issues such as disability, some limitations of traditional methodologies are often manifested. Therefore, a sincere attempt is made to unravel such limitations and adopt a flexible approach appropriate for such studies.

CHAPTER- 3

REALIZATION, CONSULTATION AND LABELLING

Meeting with medical care systems for the person with autism is a significant event in the caregiving trajectory. It is the moment when the family members realize the need for medical engagement to understand the condition. It is the place the family members receive the "naming and framing" (Brown, 1995) of the condition with the medical terms. It is when family members commence regular communication with the medical practitioners and think of alleviating the condition.

The present chapter discusses these different stages of events that lead to medical care. The sections of this chapter are prepared based on the family members' memories of different events such as realization, consultation, labelling, searching and practising treatment systems. In between these events, many preparatory events can be seen. It includes communicating and discussing the unusual development with close kin, analysis of paradoxes regarding the recognition of unusual development, and gathering opinions from other family members, friends, and colleagues on a selection of medical systems for consultation. It leads to shopping for diagnosis, dilemmas and tensions regarding treatment selection.

Realization Events

'Realizing' and 'reporting' of child's 'different' behaviour is the first phase of the caregiving trajectory. Parents and other family members are the primary actors in the realization and reporting of the unusual development. As a psychological condition, children never report their condition. In most cases, female members, especially mothers and grandmothers, are the first to identify. Because they are the ones who spend most of the time with the child. In this way, the parents simultaneously have objective and subjective positions in perceiving the illness experiences. They never experience the sufferer's feelings, but they report their experiences by observing them during the engagement with the children. In this way, parents are the second person who holds subjective experiences. In this regard, the reporting is mixed with subjective experiences and objective realities.

Due to the lack of previous experience, the early signs are not considered symptoms of autism or any other specific disease, but the parents realize that there are some issues with the child. Parents see such symptoms as the beginning of a child's current problems. It leads to medical consultation and labelling. The realization events vary between families. Parents shared different types of events that were considered the beginning of the present condition. Some parents shared single events, and some families shared multiple events of realization. In sequential order, 'unusual incidents at the time of birth', the 'unusual incidents after the birth,' 'delayed developmental milestones', and 'strange behaviours and activities' are the major events. These events are not exclusive to any family, but more or less, all these events are experienced by most families. The family members do recollect the first incident that they consider to have recognized as an 'unusual development'.

Unusual Incidents at Birth

In some cases, parents realize the 'problems' immediately or nearly after the child's birth. 'Complicated delivery' is one of the events the parents realized as the unusual event at the time of delivery. The parents widely used the phrases, 'the delivery was not normal', 'there were complications in pregnancy times', 'fluid dried', 'increased mother's blood pressure at the time of delivery', 'early birth', and 'low birth weight' to denote the problems. However, the parents did not confirm that the complication of birthing is the reason behind the child's 'abnormality'. Although there is no evidence that such events lead to autism, parents were greatly concerned about those events. When the child's birth was considered 'complicated delivery', suspicion about the child's normal growth arose. Those who have had such experiences felt the need for constant contact with the hospitals right after birth for 'medical care'. In the following paragraphs, the narratives of mothers who noticed the symptoms immediately after the birth are presented.

Disha is a 6.5 years old girl, and she is a twin sister of regularly developing child Divya. Most of the time, she is interested in staying inside the home by hearing songs. She has difficulties with movements. She shows discomfort whenever she is forced to come out of the room. Disha's mother remembers the issues that began at the time of birth. She recollected that she delivered the twins just after seventh and half months of pregnancy. She noticed little growth after the delivery during her stay in the hospital post-delivery.

In some other cases, the recognition of less than normal growth was realized within a couple of days after the parents left the hospital post-delivery. For example, in the case of Unais, a 15-year-old boy shows low physical strength compared to children of his age. His mother recalled that the child did not drink milk after the seventh day of birth. This was realized to be abnormal, and so the parents informed the doctor immediately. The doctor, however, informed them not to worry and that it would be fine in a few days. Then the parents tried some 'traditional' methods to tackle the issue. They gave *Zamzam*[5] water. But, these remedies did not help. In fact, the condition of the child gradually became worse. Moreover, the body turned to blue colour. The parents took the child to the hospital, where the delivery was conducted. They shifted to another hospital in the neighbouring district and consulted a paediatrician as they could not solve the child's problem at the local hospital.

In another case, the child's grandmother recollected the incidents at the hospital at the time of delivery. The boy does not have any issues with his physical strength but suffers from speech disorder and spends most of the time inside the home. The grandmother said that the delivery was normal, but the child did not cry, which is abnormal, and he did not take milk from his mother till the evening too. They reported these 'abnormalities' to the doctor. The doctor, however, did not acknowledge them as serious medical issues. After the BCG vaccination was given to the child, the colour turned blue, and the hands and legs became stiff. After the third day of birth, they moved from the hospital where the child was born to a speciality hospital in the neighbouring state. The child was admitted

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[5] A Holy water from Mekka the holiest place in Islam

for two months. Subsequently, too, they had to consult the doctors every week for the medical issues of the child.

In another case, Sumayya, a mother of a 13-year-old boy, reported that she noticed the 'abnormality' soon after the delivery as the child's head appeared very soft, like cotton. She also realized that the fluid in the uterus was 'abundant'. The doctor did not agree to any 'complications' reported by her. A few days later, she felt that the child's tongue was thick, and he suffered from fever and mucous more often.

The realization events happens at different places and at different times by different actors. In most cases, home is the primary site of realization. In some other cases, recognition of 'unusual incidents took place immediately after birth' in the hospitals where the child was born. In most cases, parents are the prominent actors of realization. The above narrations of the mothers reveal how the knowledge possessed by the mothers regarding a 'normal delivery' and 'normal childbirth' plays a crucial role in the realization of the child's 'abnormalities'.

Realization of Aberrations During the Initial Growth Phase Later to the Birth

Family members of some autistic children remembered the 'unusual events' that happened nearly after some months the birth. However, it is important to note that these were not taken as unusual then. This realization of such events as unusual occurred to them after the medical diagnosis of the illness in their wards. In most cases, the 'abnormality' realized was a co-morbid condition, particularly 'epilepsy'. For example, in the case of Safiya, a 11 years old autistic girl, her mother recalled that one day the daughter suddenly raised her hands in her sleep in the cradle. As she had no idea why this happened, she informed her mother first. She too, did not have a convincing answer to her question. In another case of Farhan, a 13 years old boy, he is diagnosed with hyperactivity and epilepsy along with autism. His mother, Fayath, remembered that at one and a half years old, the child suddenly fell unconscious. Subsequently, she also realized that he slept for less time than the other 'normal' children. She discussed these concerns of her with her friends but did not take them to be serious issues, then.

Unusual behaviours or bodily changes lead the parents to suspect any ill-health. In a case, Ushtha informed that she observed that her daughter (currently nine years old), when at the age of two years old, was keeping her eyes closed most of the time. The parents initially thought that it was because of dust. Then they observed that the body turned reddish, and scars appeared on it. After that, the child started to get fits, and later the fits became frequent. The mother now believes that these symptoms were the beginnings of the current medical issue the daughter.

Delayed Developmental Milestones

Delay in Physical Activities

Observing and reporting developmental milestones such as rolling over, crawling, sitting, standing, walking, smiling, and speaking is common in families that have children. The guests and neighbours who visit these families routinely enquire on these growth parameters. These enquiries turn out to be measures of the regular physical and psychological development of a child. Deviance from the expected behaviour and inability to achieve physical growth expected of a particular age leads to the conclusion that the *'child has some problem'*. The symptom recognition in the case of autistics usually happens in terms of these delayed developmental milestones. Norms and knowledge which is prevailing in society regarding the child's developmental pattern are crucial here. For example, in the case of Adwaith, a 10 years old boy, his mother Suramya memorizes the time when she realized her son had some issues. She compared the child with other children of the same age and recognized that he was not similar to other children. The child did not achieve neck strength at the age where other children could get it. Similarly, she noticed that her son could not 'roll over' even at the age when the other children of his age started crawling. At the age of one and a half years, suddenly, he became fatty, and his weight attained 16 kg. The child could not walk too.

In another case, Meena, a 7 years old girl, her mother Chintha said that they expected their daughter to attain some maturity at the age of two or three months and start responding to their interaction with her. But this did not happen even when she attained six months of age. She started to sit several months later. At that time, the child was also observed to be shaking her head a little frequently. Therefore, they doubted her development. In another case of Subhash, a 21 years old young boy, his mother informed, *"Children should look at us when they are two or three months old. However, our son did not do that. He was not smiling when we showed something like a flower and all. Not could not suck milk from his mother's breast".*

Delay in Speech

Development of speech is an important milestone in children growth. Among the developmental milestones, development of speech is important. As reported by family members, the early developmental milestones were proper for many autistic children. But the reduction in the speech was noticed over the years. Amira remembered that, in the case of her child, the speech was there up to the age of three when she was attending Anganwadi[6]. But then they noticed a gradual reduction. They believed that her speech would improve when she started to mingle with the other children in the Anganwadi. Then, Amira noticed that compared to other children, the child is slow in her reactions and activities. It was also realized that she does not have urinary bladder control. When the mother reported this to the Anganwadi teachers, they said, 'she will be fine later'. Another mother, Shonima, a mother of a 14-year-old boy, also recalled similar events. Even after attaining two and half years of age, her son could not start to speak, though he pronounced some words. His activities were much slower, and toileting was not perfect.

Strange Behaviours and Activities

Some 'strange behaviour' and 'activities' are another event of realization among many families. It is challenging for the parents to recognize the symptoms when the children do not show any significant problems. If the child does not show any other developmental issues, the autistic behaviour is usually recognized only after two or three years. Most parents shared, 'earlier times the child was normal', spoken many words, and 'activities were normal'. The difficulties of recognizing a child's different behaviour before the age of two or three and the regular physical development accelerate the 'normal history' in parents' memory. Parents show difficulties in acceptance due to the 'normal history' of the child. The earlier 'normal' and later 'abnormal' behaviour makes the parents worry more.

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[6] A pre-schooling institution under Integrated Child Development Scheme (ICDS). It is also a part of public health care system.

Comparing the child's autistic behaviour to his normal behaviour earlier, a mother stated that *"it is like two children"*. Parents confirm 'normal' behaviour by recalling that children could learn and sing songs and play games that are embedded in the culture. The decision for professional consultation is also very tough after convincing the other family members initially that the 'strange behaviours' if any, are 'normal'.

The realization events that have been described by the parents are also different as each child exhibits different types of behaviour. Some families identified their children's problems by evaluating unmanageable temper tantrums and hyperactivity. Some other families recognized strangeness in their child's engagement with family members. Some families recognized the behaviour by observing the child's play closely. If the child does not show any other developmental issues, the autistic behaviour is usually recognized only after the age of two or three years. But for families who have some prior knowledge of autism, the child's behavioural differences may become apparent a little earlier. For example, the father of a child, who is a general physician, said that at the age of one and a half years, he had doubted whether his son was autistic? Because at that time, the child did not allow the parents to cut nails and hair. The father noticed the child was interested in only the red-coloured toy cars. He did not allow his parents to give him food but took himself. The child's babbling stopped at one and a half, but he pointed out what he needed. The child's mother also remembers his reactions while listening to certain sounds and songs. He would cry in fear while listening to certain songs or run away when the mixer grinder with loud noise was turned on. In this case, the parents could identify even minute behavioural differences in the child. In some other cases, the parents noticed strange behaviour by recognizing the child's attachment and reaction to certain objects and sounds. For instance, a 12 years old boy named Naveen often smiles when hearing the sounds of falling, breaking objects, and combing hair. He often picks up women's hair and smells it. Instead of rolling the toy vehicle on the ground, he would sit on it and try to roll. When he was hungry, he could not communicate it with other people; instead, he was crying. He did not know the names of the food items he was consuming. When children show such behaviours, parents often arrive at certain conclusions. In this case, the parents assumed that the child's peculiar behaviour was due to the fact that he had not started interacting with other children through school, and there were no other children at home to spend time with him. Therefore, parents hoped that the child would change his behaviour after his admission to a school. Some other parents noticed a difference in their child's behaviour by observing and comparing their activities with other children in the classroom. A child had been sent to the *Anganwadi* as he had not started to speak even after age two. Parents hoped that mingling with other children would encourage him to speak. By evaluating his engagement with other children, in addition to speech delay, parents realized the child's behavioural issues. He was also lagging behind in acquiring general knowledge. In another case, parents said the child was always concentrating only on a few specific activities. Whenever they let him play, he would collect leaves or stones from the surroundings and arrange them in a particular order. He had no interest in playing with toys or interacting with other children. Differences in the behaviour of children were generally recognized by the parents, but in some cases, it was done by the doctors. For example, in the case of Ashish, a eight years old boy, the problem was identified when the child was three years old. Once when the child was taken to a doctor for treatment of a fever he was suffering from, the doctor observed the child's behaviour and told him that he had some behavioural problems. Although he exhibited behaviours such as 'covering the ears' and' head banging' at home, his parents did not feel that there was anything wrong with it. But they considered it as 'normal' behaviour.

Compared to any other modes, the realization through behavioural patterns is most challenging. This is because the behaviours that children express are diverse. This leads to the difficulty for parents to easily and accurately evaluate such behaviours of their children. The peculiarities of certain behaviour can only be identified by careful observation. Therefore, initially, many behaviours were generally not understood as a clinical condition. Moreover, there was also difficulty in convincing the relatives regarding the medical consultation and treating it as a clinical condition.

Existing 'local' and 'scientific' knowledge of children's normal development plays a crucial role in realization events. There are many instances in which local knowledge is confirmed along with scientific knowledge. In this way, knowledge does not work in a dualistic way of local or scientific, but it works together. There is a strong belief that after a 'normal delivery', the baby should cry or breastfeed, and such behaviours are considered 'normal'. But things that happen differently from that are often considered 'abnormal' conditions.

Although the symptoms of autism are often recognized based on the difficulties in the child's social interaction, as suggested by Daley (2004), the present context shows that parents consider birth issues and developmental milestones to be symptoms. Although various realization events are mentioned here, realizations do not end with a single event in a family. They face many other events after one event. Further realization events can be seen in the case of children with birth issues. In children with birth problems,

problems with fits and developmental delays can be seen later in life. Those who have had realization through behavioural issues have had fewer events. This is because behavioural issues are the only problem for such children.

Reporting and Consultation

'Realization events' lead parents to find the details of the condition they have found in the child and some course of action to overcome it. As a primary step, family members discuss amongst themselves realizations of differences and the need for professional advice. But it is rare to report a child's condition or to discuss medical consultation with other relatives or neighbours. Parents try to keep their assumptions about the child's problems in the circle of close kin. Existing social stigma regarding psychological issues leads the parents to take such decisions. Therefore, only family members and medical professionals are involved at this stage. It is through such sharing that they reinforce the doubts they have. Differences can be seen within the family and between families in accepting realization. Similar to the realization events, in most cases, mothers take the initiative for medical consultation. One family member identifying and reporting the realization is normally accepted by everyone else in the family. But sometimes, not everyone in the family agrees with such doubts. When a mother reports something as unnatural behaviour, other family members will consider it not an issue that requires special consideration but something usual. When a mother says that there is a problem in the child's behaviour, it is often not accepted by fathers. They do not want the child to be labelled with any type of mental illness. But mothers are a little more practical in this regard. They can overcome such type of thought more easily than fathers. Therefore, mothers have to expend more energy on convincing their close kin to seek professional help. Therefore, minor conflicts between the family members are common. Along with the conflicts between parents, in rare cases, conflicts can also be seen between the mother and the grandparents. For example, in the case of Naveen, after understanding the child's behavioural issues, his mother asked other family members to consult a doctor. But no one else in the family listened to her voice. She remembers her husband and mother arguing with her. They said to her, *"You do not make it by saying like that; he has no problem. He does not have any problem with consulting a psychiatrist*." But, respecting the opinion of a family friend, they took the child to a doctor several days later. The mother says that the husband would still not have agreed to medical consultation if the friend had not suggested the professional opinion. The conflicts reflect the higher engagement of the mothers in the child's development and the less understanding and engagement of the fathers. Mothers get many chances for minute observation regarding the child's development. But due to the lack of such intimate interactions with children, fathers usually consider the behaviour as usual.

This kind of disagreement among the child's parents is nearly absent in the cases of symptom recognition due to birth issues, delay in development or any other physical condition. There are two reasons for such differences of opinion when it comes to behaviour-related issues. One of them is the stigma that exists in society regarding mental disability, and the second is parents' conviction that behavioural disorders are unlikely if the child had no problems at birth and if the physical growth and development of the child are 'normal'. Some cultural elements exist in relation to children's behavioural development that leads to considering abnormalities as normal. For example, even when the delay in speech is recognized by the parents and others, adult members argue that 'some children do not speak until the age of four, but they will learn to speak quite easily after that age'. Such judgments force parents to wait without consulting anyone. Similarly, adults often refer to children's inarticulate speech as '*konju*'[7]. They do not understand that it is a clinical condition. Such comments come not only from family members but also from neighbours and friends. The differences of opinion within the family often lead to delays in getting help. However, compromises between family members regarding the child's condition make consultation much easier. Moreover, they would think that the child's behaviour and communication skills would be rectified after enrolling in the school.

Parents approach either practitioners of biomedical systems or religious healers for an initial consultation. Most families consider biomedicine as it is easily available and acceptable to people. Biomedicine is also known here as English Medicine. Biomedical pharmacies are known as English drug shops. Biomedical hospitals, clinics and pharmacies are widespread, regardless of rural or urban areas.

When it comes to issues of child development, parents often consult a reputable paediatrician in their area. Even though many paediatricians are available in the area, there will be some paediatricians that everyone prefers. Therefore, the names of paediatricians mentioned by many families were often common. While some are from within the district, others are practising outside the district. This first consultation with a paediatrician becomes the entry point for parents and children into the medical system.

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[7] A colloquial term used by native people to refer to children who exhibit vague speech.

Generally, parents continue their consultation with paediatricians up to the age of twelve years. But in cases of autistic children, paediatricians are considered to be the appropriate specialists to discuss any health issue of the child, even after they attain adulthood. Parents refer to paediatricians as someone who know everything about a child from an early age. Whatever happens to the child, the parents will do it as directed by the paediatrician.

The first medical consultation and the physician's evaluations play a major role in parents' decision-making for subsequent treatment regimens. In many cases, there have been instances where parents' concerns about their children have not been taken into account during their first meeting with a doctor. In some cases, when parents approach a doctor in connection with developmental delay, the doctor will send them back saying 'it would be fine later'. In such cases, parents have to wait to find the child's further developmental or behavioural issues. In a case, the mother said, when they consulted a doctor in the ninth month because of the child's delay in developmental milestones, the doctor said, 'what the child should have to do in the ninth month? Are you expecting he should beat you?' The doctor told them it would be okay to grow up. Contrary to what the physician said, the mother observed that her child's growth has slowed down over the years. In another case of Krishi, an 18 years old young boy, at one and a half, parents approached the doctor in response to the father's suspicion that the child had autism. They discussed it with his pediatric doctor friends. But the doctors felt that the child was fine, he was smart, and that everything would be all right by the time he was four. After two or three months, they went to the same doctor. At that time, he recommended consulting a doctor in the neighbouring district. During the consultation, the child tried to arrange the chairs in that room in a line. By observing these activities, the doctor told the child is autistic. The possibility of multiple assessments of the child's condition is revealed here.

As it involves suggestions for follow-up, medical consultation does not end with a single visit to the doctor. The first consultation is followed by several consultations with the same or different doctors. Therefore, in addition to approaching a paediatrician, there are rare cases where a psychologist, child psychiatrist, orthopaedist and head specialist are approached based on the conditions of the child. If a paediatrician fails to assess the child's issues perfectly, they often will advise parents for further consultation with a neurologist or child psychiatrist. In many cases, subsequent consultations, as prescribed by a doctor, often took place in the neighbouring state or district. Due to the lack of good hospitals in the district, people in the district generally resorted to consultations with specialists in the medical college located in the neighbouring state. Therefore, over the years, they cultivated cordial relationships with the hospital staff in the neighbouring state, and it remained a preferred medical institution even after the establishment of a teaching hospital in the neighbouring district of the same state. The follow-up consultation with the same doctor happens because of two reasons. One is that parents often consult a doctor for an issue of the child at a time when they need a consultation on some other issue. Two, if the child does not show any improvement, they may approach the same doctor again. Consultation with another doctor is considered because of two reasons. One, if the child develops any other type of health problem; Two, multiple consultations may happen because of the recommendations for the same by the first doctor. In some cases, when the parents felt no improvement in the condition, they seek out other doctors. In spite of a consultation with a different health provider, the parents often try to stay in touch with the paediatrician they consulted first. Interestingly, apart from the biomedical consultation, religious healers also have been consulted. It will be discussed in detail in the section on treatment options.

Professionals' Initial Reporting

After assessing the child's behaviour, professionals report the assessment to the parents in various ways. They often report by using terms such as 'less intelligence', 'mental retardation', 'behavioural issues', 'reduced brain growth', 'nerve problem', 'not be like other children', 'child with low Intelligence Quotient (IQ) level', 'not suitable to excel in academics', and 'child with no proper blood circulation'. At the same time, doctors inform the parents about autism by linking a child's mental development and age. For example, a doctor told the parents, 'he is not similar to all other children. Even if he is ten years old, you may expect the mental ability of five years child'. In another case, after the assessment, a psychiatrist informed the parents, 'the child's brain nerve is vibrating, so the child behaves like this'. A doctor informed the mother, 'the child does not seem to be able to excel in regular academics because the child's IQ level is low'. Another doctor reported that the strange behaviour arose because there was no proper blood circulation to the brain nerve of the child. In order to convince the parents of the child's condition, the doctors try to give explanations in a way that the parents can understand. Therefore, they explain it through certain explanations that are 'popular'. Physicians intend to communicate with parents during the first assessment to reveal how different the child is from a 'normal' condition.

Labelling

The labelling of autism happens after multiple consultations with medical professionals. It is part of the biomedical treatment system and, as such, is the task of the doctors, therapists and other health professionals. With the exception of cases where overt behavioural deviations have been realized by the family members, parents traverse a long way prior to the labelling of autism. It is considered only after careful scrutiny of all other events of realization over a period of time. Meanwhile, various assumptions are made during their encounters with alternate medical systems. It is only when behavioural problems begin to manifest in the child that professionals and parents realize that the child's problem is related to intellectual development. Until then, they continue to focus on speech impediments, developmental milestone issues, and physical development. Realization sometimes occurs at the time of childbirth, but actual labelling of the condition as autism occurs around the age of five or six when the child consistently shows behavioural differences. In one case, a child was labelled autism at the age of eight, though the realization of some deviant condition was made in the eighth month itself when a delay in development was noticed. But in many other cases where behavioural problems were present, autism was labelled at three or four years old. Autism labelling at this age is possible only when the child exhibits clear deviant behavioural patterns. Although various behavioural differences can be identified, it can also be labelled as mental retardation, learning disability, or epilepsy before the autism labelling.

In the cases of older children, labelling was often done through an advanced consultation outside the district rather than from a local medical facility. In addition to hospitals, in recent times, labelling is taking place in therapy centres, special schools,

schools for autism, medical camps, and Anganwadis. The professionals behind the diagnosis in these institutions are usually doctors, therapists, or trainers. Among the doctors, child psychiatrists, neurologists, and in rare cases, paediatricians are responsible for labelling the condition as autism.

'Autism features', '*pure autism'*, '*fully autism'*, and '*pakka autism'* are the names parents and professionals repeatedly use to denote the condition. Parents categorized autism based on the nature of behavioural patterns and co-morbid conditions. These notations can be equated with the categorization of mild, moderate, and severe autistic behaviour. To represent the mild condition, they often say 'autism features'. These phrases reflect parents' concerns about co-morbid conditions such as epilepsy and hyperactivity rather than autism. Parents usually prefer to say the child has 'autism features' rather than 'autism'. Because the phrase 'autistic features' is thought to have less stigma than the word 'autism'. In some cases, mothers do not agree that their child has autism but more or less agree children have the features of autism. Similar to this, some parents are not interested in saying 'the child has autism' but say, 'not fully autism' or 'behavioural' issues. This indicates that many parents are reluctant to accept the labelling 'autism' that has clinical connotations.

It is common for autism to be referred to as 'mental retardation'. This is validated by the disability certificates issued to children. Medical certificates of many children state 'autism with mental retardation' or 'mental retardation'. Such labelling is done because of two reasons. One is that autism has recently been included in the category of disability by the government. Therefore, government financial assistance for children with autism was not available until recently. Therefore, even if the child is diagnosed as autistic, regardless of the nature of the diagnosis, the certificate will state that it is a 'mental retardation' that falls into the disability category. It was only after autism was included in the disability category that it began to be listed on the disability certificate. Another reason for understanding childhood behaviours as mental retardation is a lack of accurate understanding of autism. It is recorded as mental retardation without any further investigation. Professionals' knowledge and understanding about the child's condition also influence its labelling. Therefore, the labelling also changes depending on the perception of the professionals. A trainer said the assessment and examination process depends on how mothers report the conditions. For example, if the mothers simply report that the 'child does not speak', the doctor will conclude it as 'mental retardation'. If mothers inform that the child was not speaking from childhood onward and was also late to walk and all, the doctor may conclude that the child has 'milestone delay' with 'mental retardation'. For example, in the case of Anand, an eight years old boy, the doctor assessed the child's condition as 'mild to moderate autism'. But in another hospital, the doctor did not agree with this labelling of 'autism'. But they labelled it as 'Attention Deficit Hyperactivity Disorder' (ADHD). In this case, even though the child received multiple labelling, the mother agreed that the child has autism. Because she does not believe ADHD children show behaviours such as hand flapping, interest in a particular colour, places, greenery, etc. In her understanding, he exhibits autistic behaviour. Another reason given by parents for such multiple labelling on the part of professionals is that doctors often draw some conclusions based on parental observations and descriptions. The more accurate the parent's observations, the more accurate the doctor's conclusions will be. Therefore, it can be seen that the labelling of the condition as autism is also related to the understanding of the parents. Suppose the parents do not know or do not observe the children closely; there is a chance of multiple labelling. As a behavioural condition, labelling needs thorough observation. According to trainers, observing for a minimum of one hour is necessary to identify an autistic child. There is a high chance of inaccurate labelling as the doctors do not give sufficient time for detailed assessments. Insufficient knowledge of professionals on the diagnostic criteria is also a reason for multiple labelling. Some doctors believe that a child's speech impairment is a feature of autism, while others think autistic children can have speech ability. For example, in the case of Amith, a 14 years old boy, he was assessed as autistic at a school, but in another assessment, by a doctor, the earlier assessment disagreed. The grandmother recalls the doctor's words, *'if autism, the child can pronounce at least one word, that is the symptom. But he is not pronouncing anything'.* If the child has multiple issues such as fits, speech delay, and hyperactivity, it takes more time the labelling autism. In a nutshell, the parent's explanation of the child's behaviour, professional knowledge, and the unique behaviour of the child are the factors for multiple labelling.

'Labelling' is not an end of the trajectory but is the beginning of another phase. Further constructions of the condition are done in this phase by the parents. They try to cross-check the label of autism on their own, as well as with the help of other professionals. Different visions on labelling and its relevance and irrelevance will come into the picture in this phase. Some parents fully accept the label of autism, but others do not. There may be evaluations on the part of some parents who disagree with the doctor's assessment. Such assessments are mainly made by parents of young children. For example, a mother says, *"Psychologist told me that the child has 'mental retardation'. But we can say autism* *because she shows symptoms related to autism".* Parents' knowledge of autism and their daily life experiences with the child helps them to make such authoritative assessments. This reveals that parents are not just passive recipients of professional knowledge. There are differing opinions among parents regarding the relevance of labelling. Some of the parents shared that it is relevant to label the condition, but some other parents felt that labelling is a futile exercise. They feel all conditions are the same, so there is no need for categorization. They do not feel any benefits of any precise labelling of the condition.

The above descriptions reveal that 'autism' exists because a diagnostic category exists. Otherwise, it is just a behavioural difference. The biomedical system creates diagnostic criteria; it defines and labels many human behavioural patterns. Such diagnostic criteria make up the label of autism. Therefore, autism may have been present before the formation of the diagnostic criteria and may have been known by many other names. The spread of biomedical knowledge has made the name autism known in most societies. The narratives of the family members also reveal that autism has not yet begun to be labelled as an accurate clinical category. The labelling does not appear to have a definite uniformity. Sometimes doctors do not label autism, but parents understand the child's behaviour and call it autism. As such, parents do not seem to give much importance to labelling.

Treatment Options

Following the medical consultations, the discussions on the treatment needed to address the child's problem take priority. The first dilemma faced is whether or not the medication is necessary. Decisions on these dilemmas are made based on the nature of the child's condition. Even before getting the label of autism, parents may start medical treatment. It is mainly given for hyperactivity and epilepsy. Once the label of autism is received, there will be inquiries about more appropriate medical treatment for it. When it comes to treatment, families rely not only on biomedicine and religious healing but also on systems such as Ayurveda and Homoeopathy.

The different opinions among family members and between families can be seen regarding treatment options. Some members of the family, especially parents, may be interested in biomedicine. But some elderly members advise choosing Ayurveda and not biomedicine. One of the reasons for such advice is concerns about the side effects of biomedicine. A grandmother validates her arguments by describing some of her past experiences. She says, *"Medical treatment may not change this condition. In the past, children like this survived. At some point, they will improve. There are children in this area who start talking after eleven. I think his problem started after consuming medicines. We have been giving him medicine since he was three years. After taking it, he fell unconscious several times, and the doctor said that epilepsy had begun to come out".* Additionally, previous experiences with the benefits of traditional medicine prompt adults to advise to prefer traditional systems of medicine. These disagreements between family members can sometimes slow down the treatment process.

During these initial discussions on treatment, parents often realize that there is no 'cure' for autism. Such conviction is generally based on discussions with professionals working in the field and information from other parents conducting further inquiries about autism. The parents are informed that there is no medicine to cure autism, and it can only be 'managed' by controlling the co-morbid conditions. Some biomedical physicians call for the cessation of all other psychiatric medications that parents have been giving to their children, except for epilepsy. Most parents follow such advice from doctors. This is why some parents do not want to continue medicine 'unnecessarily'. After such realization regarding medical treatment, parents give medications to children mainly to control epilepsy and hyperactivity. For example, in the case of Safiya, she has been taking medicine for hyperactivity for the past four years. But later, her parents stopped this on the advice of a doctor. Her mother's thoughts regarding medication have changed over time. New knowledge regarding autism has led to significant changes in her perception. Moreover, the mother takes a critical approach to parents who are searching for and practising different types of medical treatments for autism. However, some parents have never approached for any medical treatment to cure autism. They believe in the futility of using biomedicine. Therefore, they confirmed with doctors regarding the effectiveness of medications from the time of initial realization onward. It is this recognition that motivates parents to consider other treatment options. Although the biomedical system does not prescribe any medication for autism, Ayurveda and Homoeopathy claim to have a cure for autism. The treatment they prescribe is not directly related to autism but to 'improving intelligence'. Ayurveda and Homeopathy practitioners, too, prefer the allopathic terminology of autism to the medical conditions presented by the parents.

In the study area, there is a Homoeopathy doctor who is famous for his research on autism. In recent times many other Homoeopathy doctors too started claiming specialization for autism. With the help of clinical psychologists, many treatment programs that address autism are being implemented in Homoeopathic hospitals.

According to doctors, parents turn to Homoeopathy for the treatment of autism when they are about six years old on average.

Parents who are reluctant to accept the labelling from biomedicine often approach Ayurvedic medicine as another option. Although there are no specific treatments for autism in Ayurveda, there are treatment modalities for addressing neurotic problems. In Ayurveda, the first step in the treatment of autism is to maintain a proper digestive system so that the the medicines given to the child become effective. Then the child is given medication for problems related to his behaviour. Although parents use a variety of treatment modalities, there are no definite timelines or criteria for such a transition from one treatment system to another. There is usually a period of overlap with treatment from more than one medical system. Resort to treatment from multiple treatment options is felt necessary to address the issues of autism, epilepsy, hyperactivity, children's sexuality issues and menstrual pain.

But after the realization of the pros and cons of different treatment options, parents come to the decision to continue or abandon such treatment modalities. One mother confessed that ignorance about autism prompted them to make the decision to try different types of medical treatments. Thus, the parents' search for a treatment option begins to decrease as more knowledge about autism becomes available. For example, in the case of Anand, his parents gave him Homeopathic medicine to manage autistic behaviour for two years. Later they realized that there is no possibility of major change even if it is continued for some more years. The mother confessed that before choosing Homoeopathy, they did not have a clear idea of what autism was. Therefore, they initially sought Homoeopathic treatment. They searched for more appropriate treatment in several places in the meanwhile. It took years to accept the child's condition and to realize that there is no cure. Thus, many parents opt out of their initial treatment under a specific medical system when they do not find any improvement in their child's condition. In the case of choice of Ayurvedic medicines, parents may stop even early if the children are reluctant to use such medicines or due to the difficulty of making the medicines at home.

'Religious healing' is another treatment option that comes along with the treatment mentioned above modalities. Some families approach religious healers as the first option when they begin to realize problems with their child's development. After that, only they approach the biomedical providers. Such families often keep in touch with the religious healing system even when they shift to the biomedical treatment system. Muslim families from Sunni tradition usually consult and receive treatment from male traditional healers known as *'Thangal'* or *'Usthad'.* These religious specialists are very respected personalities in that area. Their home serves as a centre for the Muslim community in an area. Mosques and the *Thangal's* house usually surround the Muslim houses. People in that area consult and gather opinions on health, business, and other issues. The people of the area narrated many success stories after following the *Thangal's* instructions. The natives consider these religious specialists as the guardians of an area. Irfana talked s about her consultation with *Usthad* and the treatment she received from him for her child's development. She revealed that when they went to *Usthad*, he gave honey after mantra and Holy water. He also gave holy water in a bottle after reciting hymns and asked to administer it to the child on an empty stomach. Though the parents believe that not all problems can be solved 100 per cent, they also feel that it would be great if such treatment systems could provide some relief. Such consultation helps them to get suggestions related to follow-up treatment. Healers from Islamic tradition do not view the birth of the child as a bad luck in the family. But they perceive the condition as a blessing of God. Thus it is considered that God will rectify the problem of the child. Similar to this understanding, while parents see autism as a life-threatening event through experience, many want to believe it is a test of God. Many maintain the belief that God had sent that child to their family to take care of. Thus, they think they have to follow God and provide the best facilities to the child as possible. Parents are thus led by the impression that God is with them and that they are not alone. Therefore, they do not fully agree to consider this condition of the child as a challenge to their family. Such comments reflect how families mentally prepare to accept autism. Families following the Hindu religion also approach religious healers for healing and follow their recommendations. For example, in the case of Ankita, an 18 years old young girl, her mother Reena approached a religious healer to find the religious explanations for the child's condition and remedial actions for it. The healer tied talismans to resist evils. To alleviate the issues described by the Astrologer, the mother offered many religious offerings for the daughter. Along with that, each month, she does *Pooja* and gets sacred food. The mother said she had seen many positive changes in the child since then.

At one point during these religious healing attempts, some families felt utterly disappointed. Such families reported fundamental changes in their religious outlook. For example, in a case, the grandmother said they had been to all the famous temples with their child. However, the child's problems were not resolved as they had expected. Such an experience lead to a decline in their beliefs. So, they have not been to any sacred centres in the last year. They stopped visiting the temples. She now lost interest to call on God any more. She said she is despaired.

Despite the argument that globalization produces cultural homogeneity, it is essential to understand that local differences in the treatment systems are embedded in the culture. The decision-making relating to the choice of medical options for consultation and further treatment is not similar in all families but depends on the socio-cultural contexts. The difference can be seen between cultures and within a culture. "Knowledge, availability and convenience" (Suchman, 1965: 115) concerning the medical options play a crucial role in this process. It is clear from the narratives given above that different treatment modalities work in the same culture at the same time. In one socio-cultural context, people relayed simultaneously on different treatment systems. In some other contexts, parents tried to use the three available systems at different times. Thus, as observed earlier by Fabrega and Manning (1979), "the constellation of beliefs, knowledge, practices, personnel, and facilities and resources that structure and pattern the way members of a socio-cultural group obtain care and treatment of illness" (p: 41).

Differential Perceptions of Causes of Autism

Until recently, autism was not a popular term. But, today, the word autism and related issues are an important topic of discussion in the social sphere. Although people do not have a deep knowledge of autism, there is some understanding about it in the general public. Media plays a vital role in the recent popularization of the word autism. The musical reality show, which was aired on a private television channel, has thus made autism a familiar word in the mainstream. Many parents who were part of this study said that they first heard the word autism through that reality show. One of the contestants in that reality show was an autistic young boy. He usually comes to the floor with his mother. He needs his mother's presence while singing the song. Many mothers shared that they expected their child to have similar skills to the boy in that reality show. They thought it was manageable, but in real life, they realized the difficulties in management. Parents began to recognize more and more issues due to autism at the later stages. Parents also heard about autism through magazines and newspaper reports. Recently, many articles on the life experiences of parents of autistic children, especially mothers, have been published in women's magazines and health magazines. Even though parents became familiar with autism from many sources, they begin to learn more about it only after their children have developed the condition. Many parents have said that the experience of autism was very different from what they had previously thought.

Parents pay attention to the causes of autism in the early stages of labelling but then do not pursue it as an important goal. The scientific community has not yet provided definitive answers to the causes of autism. The scientific community puts forward a variety of theories, assumptions and conclusions related to causes. The causes put forward in one period are ignored in another period. The lack of definite explanations for the causes opens possibilities for several assumptions. In most cases, parents do not show interest in discussing related to the causes. They often say 'we do not know'. However, they do have their assumptions about the causes of the disease in their child. The following section describes the parents' assumptions about the causes of their child's disease.

Some have found causes related to medical events. They believed that autism might have been caused due to maternal problems during pregnancy or difficulty in birthing. On the other hand, some parents shared that the child did not speak after the vaccination and the that the child's behaviour changed after the onset of epilepsy. Some previous assumptions that vaccination could cause autism to reinforce such suspicions of parents. One mother suspected the child became autistic due to the side effects of the medicine she consumed to treat fever during her pregnancy. Some mothers thought that the increase in blood pressure and mental tensions they had experienced during pregnancy affected the growth of the child. Parents further thought that such conditions could have been avoided if the doctors had preferred C-section or if their husband had been there during the delivery. Such assumptions about causes are presented in conjunction with realization events. Although the descriptions of the causes of autism to their child did not directly hint at the genetic factors, the suspicion of such genetic factors is generally discussed. Cross cousins' marriage is a common practice in the studied area. Some of the couples who are part of this study are married in this way. Therefore, some parents thought that this 'inbreeding' was the cause of the child's illness. The question parents often hear from doctors is whether or not they are married to close relatives. It is for this fear of genetic factors many of them expressed fear about another child. They fear that the next child too may suffer from a similar condition.

Some parents believe that falls that occur at a child's early age may have caused autism. A father explained that his son fell down from his aunt's hand in the tenth month, and during that time, his head hit on the floor and bulged. Parents assume that autism may have resulted due to that incident.

Those who could not find any biological cause shared some others relating to the environment, food consumption or their social circumstances. One of such causes is the use of pesticides, especially Endosulfan. Some areas of the district have been identified as Endosulfan-affected areas. Some of the children in this study are included in the list of Endosulfan- affected persons.

Some other parents believed that such conditions in children are the result of the disintegration of the joint family system. They thought that the social environment in the nuclear family system did not provide the opportunity for the children to interact intensively with other family members, which could cause behavioural shortcomings.

Some mothers said that their husbands believed that autism was caused by the child was not breastfed enough, soon after the delivery but later. It is reported by the women that their husbands continue to blame them for this.

Parents say that some theories have been developed about the causes by those who have settled in the city. One such theory is that autism is due to living within the four walls of the room without much contact with the outside world. Such assumptions were made by relatives of the child living in rural areas.

Some parents think that autism was caused by some supernatural agents. For instance, it was put forth that their failure to fulfil the vows promised in the name of children was the reason. Some others attributed it to the attack of evil spirits on the timing of the child's birth. A few only felt that it is due to the sins they may have committed unintentionally or intentionally.

Parental descriptions of causation can be categorized as biological, social, or supernatural. The first two reasons are based on the knowledge available to parents in the professional field. The third is personal assumptions based on one's beliefs. Different forms of these three causes can be found more or less in every family.

Discussion

The perception and approaches related to a human condition vary from person to person and society to society. The distinctive approaches do not happen in a vacuum, but decisive socio-cultural factors are bound to be behind these distinctions. (Fabrega, 1971a; 1971b). When it comes to the condition of 'autism', it can be seen that many socio-cultural factors influence the events that occur in the families living with it. Those factors are uncovered during the caregiving process for autistic people. The similarities and differences in the experiences thus bring to light the subtleties of society. Factors such as child behaviour, the social background of families, and resource availability create many similarities and differences in this process. When it comes to each parent's choices regarding medical treatment, it is determined based on the child's problems and how the parents perceive them. First is the inability of parents to manage the autistic child's behaviour, mainly due to hyperactivity and epilepsy. Second is the situation where the expected result from the training is not obtained. Third, an approach that understands autism as a mental problem and accordingly cures is attempted through medication. Lack of understanding about autism and suggestions from friends become fertile ground for this.

The realization of the labelling trajectory has been conceptualized as "illness behaviour" (Mechanic& Volkart, 1961) reflects the perception, evaluation, and actions against the symptom experienced by a person. The encounter with medical care happens through several stages (Suchman, 1965), which deals with the "seeking, finding and carrying out of medical care" (p:114). Based on the sequence, Suchman (1965) has put forward five stages that lead to medical care. Suchman, of course, has not discussed the influence of institutional and structural factors on illness behaviour. But Anderson& Adey (1978) have expanded Suchman's model to include population characteristics, enabling factories, need factors, health system characteristics, and environmental factories.

'Symptom recognition stage', 'assumption of the sick role stage', and 'medical care contact stage' are relevant here in the process of medical care. In the symptom recognition stage, one can recognize that something wrong is happening at a physical or cognitive level. The accumulation of information regarding the symptoms usually happens in the second stage. It usually happens through lay referrals. The 'legitimization' of the condition and 'labelling' happens in the third stage. The labelling of the condition as autism occurs after going through certain stages, realization, consultation, and labelling. Parents and family members are the persons who experiencing autism, other than the person showing autistic behaviour. The parents and the family members recognize the symptoms; they are the people who accumulate the knowledge regarding the condition, they are the people seeking medical care to understand the condition, and they are the people receiving the naming and labelling. The labelling ensures the existence of a condition and its legitimization (Brown, 1995). It considers a "politics of definition" (Conrad& Schneider, 1992, pp. 22) where many actors participate in many disputes as they occur. Labelling is a way to understand the perceptions regarding health, illness and medical systems in a particular socio-cultural context. Parents are the 'experts'

(Avdi et al., 2000; Belief, 2003) and 'authorities' concerning understanding the child's condition. Parents' reporting of the realization of atypical development to the professional influences the compartmentalization of the labelling (Larson, 1998; Landsman, 2003). Therefore, the parent's role is inevitable in labelling. In this way, labelling can be viewed as an "active interpretative work" (Arksey& Sloper, 1999: 484).

Conclusion

The present chapter discusses realization events, consultation, labelling, and treatment that family members go through. The social context leading to the experiences related to the above process is also discussed. One thing that emerges from this is that labelling does not come through a uni-linear sequence of events and experiences but through a back-and-forth process. Medical consultation related to it begin after certain realization events have taken place. But then some other realization events take place, and further consultations are held as part of it. Even after labelling, various realization events and consultations take place. Moreover, realization events, consultation, and labelling can occur even after the treatment(s) are commenced. In this way, it should be understood that these processes are not linear in nature but multi-dimensional.

CHAPTER- 4

MOBILIZATION OF INSTITUTIONAL RESOURCES

The previous chapter discussed the family experiences in the realization of the child's behavioural differences, expert consultation, treatment options, and receiving the medical label of the condition. Once the family members receive the label of the condition of the child as 'autism' from the medical professionals, they necessarily turn their attention to exploring and mobilizing the available resources to mitigate the condition. In addition to the primary mechanism of medical treatment, parents adopt different supplementary therapies and educational and training facilities to cope with the condition. The present chapter presents the available therapies, training and educational facilities in the studied area and the parental perceptions and decision-making regarding that. The chapter is arranged into two sections; the first section deals with the mobilization of different institutional resources through therapies, training and education, parental perceptions of 'Special schooling' and 'inclusive schooling', which reflects the parents' understanding of autism, their expectation, and aims. The second section discusses the alternative methods, such as a parents-owned centre for autism and parental activism, which comes as part of the parents' lived experiences. This section also attempts to analyse the parental decision-making, choices, and the social forces behind various choices being opted by the parents to deal the autistic condition of their children.

Institutional Therapies

Along with medical treatment, institutional therapies are another way parents often approach. As noted in the previous chapter, many children show a delay in achieving developmental milestones and speech; therefore, different therapies are felt to be needed to 'strengthen' the child's 'weakness'. When the parents approach the doctors, regarding t the children's lack of speech, they often recommend speech therapy, and if they report a delay in developmental milestones, they recommend physiotherapy or occupational therapy. Since the issues related to a child's development are recognized at an early age, most parents commence such therapies too to their children very early. These days, younger children have greater access to a variety of therapy facilities than what was available to older children. These therapies are administered through hospitals or therapy centres which are affiliated with regular schools or government-owned mobile units. Although the therapy facilities have increased, their quality still remains an issue.

In the present study, all children with autism receive general therapies from their native places. However, it cannot be said that the therapy centres operating in their native places are functioning in a well-sophisticated manner with the required facilities. There are cases in which such institutions operate with minimal resources. The limitations are evident in terms of human resources as well as instrumental resources. However, in the absence of good therapy institutions in the native place, the local professionals usually suggest the parents approach the institutions which are situated outside the district or the state. But, due to the difficulties of going to therapy centres in distant places and the financial constraints of staying in a rented residence, many parents are unable to heed such advice. Therefore, most parents rely on local therapy centres.

Apart from the lack of sufficient material and experts in the local therapy centres, the non-adherence to the schedules by the parents is also a problem. The parents skip treatment for several weeks or even months. There are also many cases where the therapy is discontinued. The difficulties of transportation, the frequent illnesses of children, and the difficulty of finding attendants to accompany the child to therapy centres have led to irregularities and the cessation of therapy.

At therapy centres, children receive treatment for one session lasting about an hour for two days a week. Each child is given a particular time slot for therapy. To attend the therapy sessions, parents and children have to rely on private and public transport facilities. For those coming from faraway places, they have to rely on the train. But often, the inability to handle the child in public places discourages them to commute using the public transport systems.

A few parents approached and joined for therapy from certain institutions that offer residential facilities outside the district or even the state. Therefore, some children could get good therapies with sufficient resource facilities consistently. Along with the children, parents, especially mothers, have received training for giving therapies to the children at home. The idea behind this is to make parents a resource person. But at the time of the present study, no autistic child was consulting and receiving therapies from institutions with advanced facilities.

Parents are kept out during therapy in local therapy centres because the child would be impatient during therapy if the parents were present. Therefore, mothers often wait outside the centre till the therapy is over. In this way, therapy centres are often a place of union for mothers of children with autism. While the mothers wait outside the resource room, they talk about household matters, local affairs, jokes, and worries. Mothers shared that such unions are very much comfortable, and it is an opportunity for some mental relief for them. This opportunity of meeting other parents with similar issues to their children leads to healthy communication and dissemination of information amongst them. People from far away places usually bring their lunch/snacks and eat together. Moreover, therapy centres are also a place for different celebrations related to the child, like a birthday. During such occasions, the mothers arrange lunch or at least distribute sweets, and such activity brings closer ties amongst the families of the autistic children.

Parents hold different opinions regarding the efficiency of therapies that are available in their native places. Some parents have a reasonable opinion about the therapy, but some have opposing opinions. On a positive note, a grandmother of an autistic child said that, because of the lag in milestone achievements, the child was given physiotherapy on a daily basis at the nearest hospital. On the recommendation of the physiotherapist, they availed of oxygen therapy also for strengthening the spinal cord. The doctor initially convinced them that the child would stand on his own within three months. Therefore, they attended therapy every day as suggested by the doctor. After 85 days, the child was able to stand on his own. In some other cases, children who are unable to speak began to speak certain words after speech therapy. However, such therapies do not make remarkable changes in all children. So, parents also shared the opposite of the experiences mentioned above. Many of the parents are of the opinion that 'speech therapy' is useless. They did not notice any change in the child even though they had been given the therapies as advised. A mother said that even though her son was continuously given speech therapy for a year, there was no major change. They attended therapy every day. But day after day, therapists felt that it was fun giving him that training as no one could succeed in teaching him with any effectiveness. The narration of such an experience by a mother reveals that advice on specific therapies to manage the condition of autism is generally accepted in varying ways. Due to problems of resource constraints and the varying results that the therapies produce in children as well, institutional therapies are not opined to be either a complete or a final solution.

Education and Training

In addition to medical therapies, formal education and training are other resources that parents are making use of. The sources of information on training and education are the professionals whom the parents frequently visit. Professionals suggest education methods and also details of institutions that practice those methods. Parents often collect information not only from professionals such as doctors, trainers, and therapists but also from friends, colleagues, and other parents of children with autism. The government policies with the objectives of 'mainstreaming' the person with disabilities receive attention from the parents to approach the educational opportunities. The different programs such as Integrated Education for Disabled Children (IEDC), 1974 Persons with Disabilities Act (PwD Act), 1995 and monetary assistance accelerate the 'mainstreaming' process. The National Policy on Education (NPE), 1986 and the Programme of Action, 1992 talked about the necessity of integrating children with disabilities into the larger social world. The NPE (1986) recommends "to integrate the physically and mentally handicapped with the general community as equal partners, to prepare them for normal growth and to enable them to face life with courage and confidence". The Salamanca Statement and Framework for Action on Disable Education, 1994 developed the idea of education for all through inclusive education. The inclusion comprehends temporal, instructional, and social integration of the person with disabilities in regularly developing peers (Kauffman et al.,1975).

'Special education and 'inclusive education' are the two prominent systems of education which aim at the integration of children with disabilities. These education systems are executed through the institutions like Special schools, Buds, and regular schools. Although parents believe that training and education are necessary and are aware of the advantages of these education systems, differences can be seen in their preferences, perception, and selection of methods.

Special education

The idea of a 'special education' facility has been created for children with disabilities who are not able to take part in general educational opportunities. This schooling system ensures accommodation, curriculum, and equipment to overcome the hurdles of the person with disabilities to be a part of the social world. There are two types of institutions in the district for providing special education, namely Special schools and Buds. Autistic children in this study area are enrolled in five Special schools. Among them, four schools are situated in the studied district, and one is in a neighbouring district. Most Special schools operate in the private sector and are run by religious-based charity organizations. It reflects the 'charity model' which comes with the conceptualization of special schooling (Alur, 2002). Among the privately operated institutions, one Special school is run by Christian management, one by Muslim management, two schools are in the unaided private sector with specific private management, and another one is working under a charitable trust. The names of Special schools and Buds are fascinating. It aims to give a positive feeling. For instance, the names are *Thanal* (Shade), *Snehatheeram* (Love shore), *Santhwanam* (Solace), *Prathyasa* (Hope), *Pragathi* (Progress), *Karuna* (Mercy), *Theeram* (Shore), *Snehaveed* (House of love) etc.

The schools function from 10 am to 3.30 pm; on Monday to Friday. Usually, Special schools consist of one or two trainers and *Ayahs* (helpers) to take care of the children and one or two cooks to prepare meals for the children and the employers. Trainers in these schools are those who have completed Special education training. The training of children with Autism by those trained in general, special education should be seen as evidence that there is no significant specialization in autism training. Sometimes, drivers of the institute vehicle also take part in the 'care' of the children. Some of the families do experience difficulty to reach the pickup point of the buses as they live in rural areas. Such families have to migrate to the place where the bus service is available. Schools do not charge for training, but the parents must pay the vehicle rent. Apart from autism, children with mental retardation, Down's syndrome', learning disability', and cerebral palsy' attend these schools. Autistic children are given the same training as other categories of children. There are no particular teaching methods for autistic children. Even though Special schools do not prescribe any age limit for the selection of students, the children generally belong to the age group between 6 and 15 years. Training is based on the behaviour of the children and their 'strengths' and 'limitations'. Children with similar 'behaviours', 'capabilities' and 'difficulties' are trained together irrespective of age. They give training for toileting. Training is specially focused on children who have difficulty in eating independently. If children have attention problems, including reluctance to occupy designated seats, the trainers try to address these issues. Generally, the training in daily living skills is given priority to academic skills. Trainers say it is difficult to train and manage children with Autism. Therefore, children with Autism are not forced to do things. Intervention is often based on the interests of the children. In addition to training, Special schools also have a way of assessing children's progress. Some schools offer a variety of therapies in addition to training. Some schools offer training based on age, such as Pre-Primary, Primary, Secondary, Pre-Vocational and Vacational. In one Special school, the focus is on vocational training only. The students in this school engage in different activities such as dance and music and make different products such as artwork with coconut shells, embroidery, flower making on cloth etc. They also participate in exhibitions and sell their products. The trainers say it is an attempt to bring children who are confined to the home into the mainstream. In addition to training in the classroom, field trips are also conducted for entertainment. Some schools also offer home-based therapy for children who have difficulty to come to school.

Buds institutions are located in the twelve Grama Panchayats of the district. Of these, six have autistic children.. Although the origin and concept of Buds differs from that of Special schools, there are many similarities in the functioning of these institutions. Similar to Special schools, children labelled differently are attending Buds. These institutions operate with meagre infrastructural facilities. Only one Buds in the district operates with an excellent infrastructure and resource availability. It operates in a building constructed as part of the Endosulfan Rehabilitation Package. Most of the institutions are situated in rural and semi-urban areas. Like the Special school, Buds also provide institutional buses for picking up and dropping the children from homes. Although Buds is designed for people over the age of 18 years, most of Buds accommodate people below the age of 18 years. The authorities have taken this decision after a protest called by the parents of children below the age of 18 years. During the working hours, similar to the children in Special schools, children in Buds also spend time by playing, singing, eating, and sleeping. The classrooms are arranged based on the age of the children. But, in some institutions, all children sit together without age-based differentiation. These arrangements are dependent on the availability of infrastructural facilities.

Parents hold different perspectives and positions towards the idea and practice of Special schools and Buds. Some parents consider Special schools to be 'shelters' to take care of the children from morning to evening. Parents consider it a great relief to spend so much time in school. They find comfort in having a place for children to spend, rather than focusing on the child's syllabus, learning methods, what the children do at school, or the child's character improvement. While parents may not have high expectations of learning activities from a Special school, parents may find that playing and engaging with other children benefit their children. Because home environments are often fraught with dangers (discussed in detail in Chapter Five), parents find it difficult to manage their children's home environment. Therefore, going to school is considered big luck by some parents. They consider school to be a safe place. Though the school hours are from morning to evening, the child does not have to spend the whole time in school. If a child has any difficulty, the teacher may call the parents and send back the child to the home. However, parents say that relief is available for a while. This is because parents are relieved to be able to use this time to complete their homework and other chores. Some children's interest in going to such schools is also forcing parents to rely on Special schools. Some children are very much interested in many things they do in Special schools. For example, a nine years old girl named Shahina is interested in cutting papers to make designs, pasting pictures and sewing. She is very comfortable there because she does all that at school. The walls and dining table of Shahina's house are adorned with such works as she did.

Some parents prefer to stay in Special schools based on the improvements that the child will show. A mother says her child's temper tantrum decreased after he started going to Special school. The mother says that the attitude and work of the teachers in the Special school is the reason for such a positive result. In addition, many mothers say that going to school has improved their child's eating habits. Because of these improvements, mothers are of the opinion that Special school teachers are capable of managing such children. Parents say that Special school teachers treat their children with an emotional attachment that is different from the professional approach. This has helped to create some impression on mothers about special school teachers. Therefore, some parents see Special schools as a continuation of home care. Moreover, Special school teachers can be seen accepting to pay roles of the 'continuum of mothers'. This kind of approach by teachers brings many children closer to Special schools.

Some parents preferred to transfer their child from a regular school to a Special school, with the expectation that positive changes will come with joining a Special school. For example, Adil, while in regular school, often was wandering from place to place without sitting anywhere. He failed to show average performance in the study. His parents say that though he is currently nine years old, he still can not write the alphabet. His parents see his condition as a limitation of his admission to a regular school. Hence they say that going to regular school is like 'just going there'. Parents also share their concern that he may harm other children. Thus the parents generally believe that Special schools are the best option to promote intelligence at an early age.

The 'special care' received from Special schools leads some parents to keep closeness and distance from Special schools. Since the Special school system is designed to give special consideration to such children, parents feel that each child receives special consideration in such schools. They say the reason for receiving such special treatment is that all children in Special schools deserve special consideration. Therefore, teachers cannot avoid giving such consideration to the children. For example, teachers in Special schools are efficient in managing when children urinate or cause other difficulties. Special school teachers are skilled at providing such care. Parents say that children who need special care do not receive such care if they attend a regular school. The regular school system is not for such children. The school teachers also agree with that. The parents do realize the advantages of Special schools and the limitations of regular schools. Due to the lack of expertise in managing autistic children, the teachers in regular schools often adopt an approach that excludes such children from their attention. One mother argues that regular school teachers neglect the needs of the children with disabilities in the class because they need to pay attention to other children's learning. She highlighted the advantages of the special school where every child can be given more attention by teachers because all children are in the category of 'disabled'.

In addition to the care, parents' concern about their children's safety is also pushing parents to rely on Special schools rather than regular schools. Parents say that children in a Special school are much safer than in a regular school. For example, Aamna, a mother of an 18-year-old young boy, shares an incident she experienced in relation to security issues from the regular school. She said that one day the child left the school premises unnoticed into traffic. After that incident, the teachers informed the school authorities and parents about the difficulties of managing such children.

In some other cases, the 'normal' children of regular schools showed avoidance of the 'problem' children in those schools. Charulatha, a mother of 15 years old girl, shared an incident and the reason behind her decision to opt for a Buds by taking a break from regular school. When she approached a regular school to enrol her daughter, the school headmaster said that a 'trouble-making' child could not be admitted because the parents of other children would complain'. But the mother stuck on with her decision to enrol her daughter in that school, and she was even ready to sit with the child in the classroom to avoid other children being disturbed. She strongly believed that the condition of the child would improve when exposed to other children in the classroom. She continued with this for six months with her child by sitting in class. But she felt the other students were watching her without writing or reading. She found that this would not be good for those children. Moreover, the mother had to be at school from morning till evening. Without the mother, the daughter will not do anything on her own and will not even go to the toilet alone. Thus, when she came to know about Buds, she shifted her daughter to there. The embarrassment the parents feel at regular schools due to the child's behaviour is also a factor in opting for Special schools over regular schools. In a nutshell, 'care', 'security', and 'improvement' are the major parameters of the parents when making a decision on admission to a Special school.

Although parents prefer to rely on Special schools, some are not satisfied with the 'care' and 'security' provided by such schools. Therefore, they do not go to Special schools or even regular schools. For example, Shahul, a 11 years old boy was a student of Buds; he had not been to school for some time. He stays at home because of some bad experiences he had at school. Even though his mother is interested in sending him to a Special school, his mother says that the teachers at the school do not pay much attention to him and do not live up to their expectations. The mother has shared the incidents where he ate harmful substances such as pencils, dress materials etc., due to the negligence of the teachers. Later, his mother lodged a complaint with the school authorities in the wake of such incidents. However, the authorities said the child should not be brought to school thereafter. After that, there was no other option for her than to accompany the child to school every day. As she subsequently felt that the attitude of the school teachers was not good, she withdrew the child from the school.

Some trainers' disinterest to ensure the engagement of the children with autism in school activities along with the children with other disabilities lead the parents to detach from Special schools. In the case of Anna, an 18-year-old girl, her mother Chaaya shares the approaches of the Special school trainers to the children by describing an incident that happened during a school festival. She says, *"Teachers had not made an effort to get*

Anna to participate in the program as part of the celebration at Special school. We were just spectators at that time. So I was upset". This incident underscores the inadequacy of Special school systems in accommodating people with autism. The incident happened many years ago, but the mother still remembers it because it was one of the most unforgettable incidents for the mother in her life.

Even though some parents acknowledge the care and love the trainers offer the child, some other parents question the professionals' poor commitment and the child's weak relationship with them. One parent felt that the trainers should approach the profession as charity work. If they are not trying to approach like this, it is difficult for them to make a good relationship with the children.

Some parents, although their children are enrolled in Special schools, are not satisfied with the method and quality of the training. But the lack of any alternate choice of education in their native place forces the parents to enrol in Special schools or Buds. The parents who have experienced good training at institutions from other districts hold this critical position. Therefore, they can accurately evaluate and compare the training program. Those good experiences of 'quality training' lead the parents to expect similar outcomes from the institution they decided to send the child to. For example, Amith was enrolled in a Special school by his parents. But he does attend the school regularly due to the low quality of training in the school and also the poor transportation facilities. His parents had the experience of good training outside the district. They had spent eight years in a specialized institution for autism, and they were satisfied with that training. As in the case of Amith, the parents who availed better training for their children at far away institutions decided to withdraw their children from public institutions closer to their native place.

None of the parents wanted to settle in a place far away from home solely for the treatment of the autistic child. In some cases, the trouble taken to live in a faraway place was felt to be not worth it. One parent expressed: *"We wanted to give training for him at home but could not find any proper trainer. Then we took him to a Special school. But the situation regarding the quality of the school was bad; so we decided staying home is better than that"* Some parents pointed out the unfavourable teacher-student ratio as the inadequacy of Special schools. The parents felt that teachers are not able to give proper attention to the children who need special consideration. Another criticism of such institutions is that they treat disability as a 'homogeneous category'. They do not identify the specifics of each disability condition and how to approach them. Parents say that institutions are reluctant to provide a specialized section for imparting training to children with autism. But they classify the children based on age. Some parents have criticized the institutions for keeping parents away from training activities. Such teacher-centred training activities are criticized by parents who recognize the importance of parental involvement in training activities. A parent pointed out: *"Buds trainers do not allow the parents to interact with the child during training. We know what a teacher can do in half an hour... nothing. Teachers always claim they do their part, but in the presence of parents, it is difficult"*. By connecting with the parental engagements with the children, a parent criticizes this system, "*The teacher has experience of eight years, but I have 14 years of experience as a parent. We know everything about the child. They say it is a professional way, but they cannot implement it"*. The lack of a common platform for parents and professionals is due to the fact that professionals do not consider the knowledge and experience that parents have gained as part of their daily interactions with children. It also contains elements of power relation over the parents by professionals. The devaluation of the knowledge acquired by the parents through the engagement with the child (Dale, 1996) and hierarchies of knowledge create barriers in the parent-professional partnership. The status of the habitus of disability (Hodge, 2006; Mackenzie& Leach Scully, 2007) by the parents and the professional knowledge by the professionals which reproduce the power relation creates barriers to the parents' participation in the institutional training system (Hodge & Runswick- Cole, 2008).

There are situations where some children are even expelled from Special schools due to problems that occur as part of their hyperactive behaviour. Therefore, parents are forced to pay extra attention to their children at home. Ankita, for example, is a child who spends time alone at home without being able to go to any institution. This is due to some unfortunate incidents that took place at the Special school as part of her behaviour. Her mother Reena said, *"My daughter had bitten two people at school. It was a big problem. As part of this, one day, the school authorities called me and asked me to take the child home. They said the child's enrolment could not be continued".*

The children's disinterest in attending the Special school/ Buds classes can also be correlated to the atmosphere, which is not compatible for children with autism. For instance, a 26-year-old young boy named Jinan was enrolled in a Buds but has been absent for the last several months. His mother Jinu said about the feeling that Jinan usually expressed after reaching home from school. He does not like to go there; after he returns from school, he looks sad and often cries.

In some cases, the trainers from the Special school themselves understand the child's activities and convey the fact that Special school is not a suitable place for children with autism. For example, Krishi shows extraordinary ability in using computers, mathematics, and solving puzzles. His mother, Shyna, recalls an incident in a training centre. The teacher from the school told the mother in a positive sense, "This is not Krishi's place". The trainer's comments reflect the necessity of encouraging children with autism to the social world than confining them in a Special school atmosphere.

In Special schools and Buds, most of the children are under the label of Mental Retardation and Downs Syndrome. So, parents are concerned that children will imitate the behaviour of other children. Therefore, they are not interested in enrolling their children in Special schools. The parents of younger children are more vigilant in the selection of education and training system. On the premises of the autism centre, I met a mother who had come to inquire about taking admission to the autism centre. The conversation with her revealed that she has some knowledge about the education of autism. She asked other mothers, *"Is here individual wise training right? Husband told, 'if it is like special school do not admit. Because already he has a problem, if he imitates them..."*. In this case, too, parents share the concern that their child will imitate the behaviour of other children.

This thought comes because the parents realize autism is not a condition similar to other psychosocial disabilities. Not only that, they fear the stigmatized identity which holds the 'Mental Retardation' and 'Down's Syndrome' affects their children.

It is clear from the above descriptions that while one group of parents favours the Special school system, another group approaches it critically. Lack of proper care, problems with teacher-student ratio, low-quality training, disagreements with the training system, lack of capacity to accommodate autistic children, and stigma are the major factors behind the disagreement of parents with the special education system.

Inclusive Education

Inclusive education is a formal education system based on regular classroom instruction. The system is based on the idea that children with different physical and mental differences do not need to be separated from other children and that they need to learn with other children of their age. Most of the children who are part of this study are enrolled in regular schools near their homes. Although they are considered a regular student in the concerned schools, they rarely sit in classrooms regularly. Some children, after therapy, spend an hour or two in a regular school affiliated with it. Schools with such children are trying to change the school environment in a way that makes them friendly.

Just as there are two opinions among parents regarding special education, there are many positions among parents regarding inclusive education. Even if parents have no objection towards inclusive education, parents critically view the way it is implemented. During the study, it was observed that in addition to demonstrating the inefficiency of Special schools, some parents emphasize the potential for inclusive education. These parents are taking much effort to ensure social integration and improvement through regular schooling. Most parents realize that regular schools are a good place for children to make a difference. Therefore, parents are willing to make an extra effort for it. Despite many difficulties, parents strive to make their autistic children part of inclusive education.

They realize the importance of it rather than the hardship they experience. In the case of Adwaith (10 years old; V standard), a boy attending a regular school is a good example. Every day, after therapy, his mother accompanies him to the nearest regular school. Then, he sits in that class with the other kids. His mother sits on the back bench in the classroom, watching him. It allows her to view the child's activities and monitor if he needs any intervention. They return home after one or two classes. She strongly believes that her efforts will bring changes in her son's behaviour and cognition. Although this mother shares various difficulties in attending regular school, she emphasizes in attending school despite such difficulties. She believes there will be no change in the child if he does not go to school. Moreover, parents fear that child's behaviour may worsen if he does not go to school. She says, *"At first, I was upset because he could not do many things that the other children could.. Their behaviour is also different. But when we got used to it, it did not matter to us"*.

In this way, many parents try to educate their children by sitting with them. Adwaith's grandmother says autism is not a condition that should be addressed in a Special school. Their position is that autism is a normal mental condition and should not be treated as a special case. They point out that in the past, there were no such institutions for children with such intellectual conditions. Yet they have learned to speak, write, and read. Everything they learned was through regular government school. There is no great improvement in children's condition by attending a Special school; Improvement will come from efforts at home and regular schools.

Some parents show strong determination to enrol in regular schools. They have gone through various experiences to ensure a 'seat' in regular schools. In connection with the enrolment of her daughter in a regular school, a mother met the headmaster and informed him that she wanted to enrol her daughter in that school for the next three years and that she too wanted to be in the classroom with her. She attended the school not all days but two or three days a week. *She* describes an emotional situation while attending school. Amira says, *"I studied here from one to seven. The teachers who taught me are still there. They remember me. During school, I was a favourite child of theirs. But now I am coming, not with an intelligent girl."*

Even though the parents argue for inclusive education, they are vocal about the loopholes in the system. Most parents recognize the idea of inclusive education, but its poor implementation pulls them back from approaching it. The school authorities' exclusionary approach is forcing some parents to refrain from approaching regular schools. The children with 'profound' behavioural issues often avoided the classrooms. The attitude of the teachers plays a significant role here. Some children who show reluctance to cooperate are also there in the schools, and they are always outside the classroom. Parents complain that teachers will not take any action to bring the child inside. Parents are of the opinion that the reason for the lack of attention is because the teachers may hold that such children are of no particular benefit to society. Parents point out that some teachers try to keep autistic children out of classroom activities by not calling the name of the child and not asking questions. They also show discomfort in taking the class when the mother and child are in the classroom. Nevertheless, the parents, with strong determination, try to overcome the barriers. For example, Sneha's mother, Ridhi, shares her effort to engage the daughter in classroom activities when she faces avoidance from the teacher. The mother is a strong supporter of inclusive education and has spent much time on this. She raised her voice against the barriers in that system. When her daughter attends school, she often prepares questions for Sneha and gives them to teachers prior to the class. She did this because her daughter should not be ignored in the question-and-answer section. After noticing that the teacher was refraining from asking questions to her daughter, she forced the teacher to ask the question to her, similar to the other children. The mother's focus is not on whether the daughter will answer the teacher's question, but it is about asking the questions routinely. Sneha could answer the question of what the mother taught her. The mother thinks it will be a very happy moment for her daughter. Through this practice, the daughter stands up when other children stand up for answering. Ridhi believes that if the questions were asked by skipping her, she would become nothing. The mother proudly says, *"In this way, I took her as a normal child up to 10th standard, did not face any big problem. In my experience, I can say it is good."*

Parents who are aware of the potentialities of regular school education also acknowledge the difficulties teachers face in regular schools with children with disabilities. The limitations come both from the children and the institution. While supporting inclusive education, parents argue for the need for a more effective atmosphere to improve the child's behaviour. They admit the limitations and difficulties of managing children with behavioural issues. The difficulties intensify due to the lack of facilities for trained staff and teachers. A mother, Suma, suggested some proposals to overcome the barriers to inclusive education. She said, *"Even though the idea of inclusive education is good, its execution is bad. We do not have the facility for it. She recommends providing the classes for these children separately and giving them* *opportunities to play with other children. By doing this, the children can copy the behaviour of other children. There is no need to send the children to Special school, and there is no need to avoid the children in a normal school".*

The parents who support inclusive education expect maximum inclusiveness and results from regular schools. Therefore, they criticize the approaches of regular school teachers when their expectations are not met. As discussed in the previous section, some parents who rely on special education are happy with the love and affection from the teachers, but some other parents who rely on regular schools expect a professional approach from the teacher than an emotional approach. For example, Ashish, who received training from AIISH[8] in Mysore for two years, is attending a regular school. His mother Reema said her son improved a lot after getting training from AIISH. She also received parental training to manage the child in daily life. She responded to her expectations of regular school and said that the teacher often puts the child in another room of the school, keeping him away from other children, which is not correct. She had to tell the teacher to allow her son to sit with other children. The boy stays with other children until noon, and after that, he goes to another room for his other learning activities. The mother also gave instruction to the teacher that he should not be given special consideration and not to be emotional about his issue.

Some other parents talked about the teacher's lack of understanding of the child's behaviour. Akash, an eight-year-old boy, is attending both regular school and Special school. In regular school, if he does not understand the class, he will leave the classroom.

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[8] AIISH- All India Institute of Speech and Hearing is situated in Mysore. It provides assessment and intervention in speech, language, and hearing issues.

But the teacher always compels him to get into the class, and that makes him angry. Because of this attitude from the teacher, the mother decided to move the child to another school. The incident reveals the teacher's lack of understanding of the child's behaviour and its impact on the child's schooling in regular school. In another case of Shahina, Ushtha decided to enrol her in a regular school on the advice of a Special school teacher. The reason why the teacher had put forward that suggestion is that the child does not show any 'severe' autistic behaviour, and she is intelligent and capable of doing many things. But she could not stay in regular school for long because she was not ready to follow classroom etiquette. She does not like to sit with other children. Her mother reports that the teacher closes the door and keeps her out; she is out of the class whenever the mother visits her at the school. The mother believes that there is no benefit in attending regular school. So Shahina's mother finally discontinued to take the daughter to regular school. The mother believes that there are no benefits in attending regular school. In some regular schools, autistic children get the benefits of special teachers. But the irregularity of special teachers discourages the parents to resume attendance of their children to regular schools.

Narratives of family members, particularly that of mothers, reveal the advantages and the loopholes of the regular school system. Even though a group of parents agree with the idea of regular school and its potential for social interaction, the implementation is viewed to be ineffective. The study thus supports the contention that it gives an opportunity for the inclusion of the students into the education system but not in the mainstream (Singal, 2006). Crucial matters like the teachers' pedagogical skills, curriculum, and attitudes towards those with disabilities have been neglected. The lack of training for the teachers who attend the children with disabilities in regular school is one of the major loopholes of regular school education (Singal, 2006).

Lack of Education System and Feeling of Guilt

Parents confess that they could not provide good training to their children due to a lack of proper and advanced training facilities. It results in children staying at home most of the time without any social interaction. Among the parents, there is a common conception that the child would not improve if he or she is confined at home. Therefore, sending the child to some training institutions and involving them in social engagements give some sort of satisfaction to the parents. Children are spending time at home in some social isolation while their peers are enjoying their life being in school results in guilt feeling among the parents. Whenever the parents meet any person, they enquire first about his/her schooling. These questions give a pang of guilt feeling to the parents. In such cases, parents resort to 'self-blame' because they are unable to provide external intervention and are not able to recognize the child's skills. The advice from other people and the appreciation of the skills of the child intensify the guilt. The parents are worried about the time they have spent without ensuring any exposure to advanced training. For example, a child may receive the label of autism at the age of two, but the parents may enrol her/him in some institutions only at the age of six. The parents whose children are now grown up had to enrol the child in a Special school in the neighbouring district due to the lack of such facility in their native district at that time. Later a Buds school was also started in their locality, and they shifted the child to this. One parent remarked, "*We failed to provide necessary inputs for him; we were unaware of autism in detail.*" The parents believe that if they had the opportunity to gain accurate knowledge about autism, they would have given their children better opportunities. Here, the lack of available resources is the factor of the hurdles and guilt. In another case, the family travelled long distances to provide education for the child. They approached good institutions in Delhi, Bangalore, and Coimbatore. The mother has also received institutional parental training from these places. Because of the skills in operating computers, the professionals from some institutions recognized that the child is 'high functioning'. While people in such institutions certify that the child is 'high functioning', the mother became even more worried. She thought that they had been spoiling his future. Here, the labelling of 'high functioning' makes the parents more worrisome lack of educational facilities and the guilt feeling of parents drive the parents to work for alternatives and for activism.

Demand for a Different System

The above sections show that both special education and regular schools are not foolproof systems for the social inclusion of children with autism. Therefore, some parents and professionals agree with the need for a different approach for children with autism.

Although many Special schools in the district are offering training activities upbringing the children's skills, they have not accommodated autistic children. These institutions are designed for children with other types of psychosocial conditions. They do not have the resources to develop training programs for autistic children. These institutions in the study area suffer from a lack of trained staff and awareness. In those schools, the teacher-student ratio is around 1: 25, though one autistic child needs one teacher according to the accepted norms. The teachers admit that the training given to children with autism is similar to the training given to mentally retarded children. There is no special training for autism. Most of them have Bachelor of Education qualifications in special education. Most of the syllabus in such programs is related to training for Mentally Retarded and Downs children. A special course for giving training for children with autism is, however, available. The trainers provide the training based on the knowledge they acquired from the training institute. A mother of a 10-year-old son worries that available facilities are not apt for children with autism. The mother points out the need for specific institutions for children with autism. In regular school, some people know about autism, and some do not. If the teacher knows about autism, they will show disinterest to give admission.

In parents' opinion, children with autism are comfortable only with teachers qualified in autism training. They advocate that change should come from there. A mother of a 10-year-old son, Vismaya worries that available facilities are not apt for children with autism. The mother says about the need for particular institutions for children with autism. She said all children, which means children other than autism have all, but autistic children do not have anything. In regular school, some people know about autism, and some do not. If the teacher knows about autism, they will show disinterest in giving admission. In Special schools also, sitting with children with autism is difficult.

Parent-Professional Participation

Despite the quality of the education imparted in different types of institutions, most children are involved in institutionalized education and training. Various inadequacies at home lead parents to seek refuge in institutionalized training. Simultaneously, the derisory means of institutionalized training led the children to confine at home. As a solution to this, training activities with parental participation have been put forward. This emphasizes that there should be continuity of training provided in the institutions at home. The collaboration of parents and professionals comes as part of the Individuals with Disabilities Education Act (IDEA), 1975. It aims to work together in the education process of children with disabilities. The present study dealt with this issue of parent-professional participation, too.

While looking at the perceptions of parents regarding the training, they have different opinions. One group argues that parental involvement is essential in training and the other category relies heavily on institutionalized training. The parents who realize the need for parental involvement in the training search for the institutions which provide parental training and try to follow the institutional training methods at home. However, in other cases, the parents who heavily rely on institutional training believe that giving the training is the duty of the specialized trainers, and parents do not have any role.

Previous section have discussed the parents' perceptions of participation in the institutional training. Some parents disagree with the trainers' approach in discouraging the parents from attending training sessions. Here, the parents argue for participating them in the institutional training system. They argue institutions should be the place to practice parental intervention. Parents focus on how well the trainers are trying to get parents involved in the training session at the institution.

The trainers who talked about parental participation expect participation through training at home, not in the institutions. Here is where the difference in opinion comes between parents and professionals. The trainers evaluate parents based on how much effort they take in following the training given at the institution and their approach to the education of the autistic. “Homes become training centres, and parents become trainers” is the expectation of the trainers in this profession. But they are not satisfied with many parents in this regard. A trainer, Sradha, is critiquing a mother's approach and the need for the role of mothers in training. She says, *"Some parents say they cannot (do the training at home). One mother said she has neck pain when teaching the child".*

Trainers are of the opinion that mothers should be prepared to do what teachers do in relation to their children's training. Parents know what the child is doing and not doing. The perception of children with autism is different from that of children with Mental Retardation. Therefore, parental involvement gives significant results. A trainer described how they try to engage the parents in the training process. They often tell parents about the training methods at the training centre, for instance, toileting. At the training centre, they record the time the child goes to the toilet. Then the parents are informed about the same. Trainers suggest taking the child to the toilet at that particular time to become self-sufficient. But this method is not followed at home by the mothers. Also, quiet. Parents and trainers disagree on measuring the success of the training. Some parents measure their child's improvement based on whether or not their child has learned to write.

Although the concept makes training a part of life, the problem remains that homes cannot become training or 'therapeutic' centres but remain 'custodial' places (Sarret, 2015). The trainers also complain about parents' irresponsible attitudes and poor attention given to the children. They say that some parents send the child directly from bed to school. They complain that family members give importance to 'normal' children and tend to discriminate children with challenges. The following excerpts from the interview reflect the attitudes of the staff of the schools:

"*Parents send their children to institutions not to study, but because they can take rest at home during that time. If there was the school on Sundays too, there would be people interested in sending their children".*

"*One day, we had to bathe a baby from here. Because he was sent home without a bath… A fewer number of parents attend the meeting. Nevertheless, everyone comes to buy Onam rice or scholarships. Parents ask why they are taught! To become a collector".*

On the contrary, it is also agreed that some parents show much responsibility in children educational activities. They will inquire about what is being done at school. Even though the parents admit the trainers' suggestions, they shared many difficulties in following these suggestions for home training. The mothers express the difficulties they face in-home training due to gender-related household chores. Moreover, it is said that continuous care is impossible for those who have more than one child.

‘Taking out’: Encouraging Social Interaction

Encouraging and arranging the atmosphere for social interaction is one of the recommendations by the professionals. Other than professional recommendations, some parents decide to take the initiatives to take the child out of the home to the functions, sightseeing, market, park, etc. The 'taking out' is considered a part of parental participation. The idea of 'taking out' comes from the professionals because of their realization that the 'classroom should not be the only world of the child'. Trainers argue that the classroom and the classroom performance should not be the measuring tool for the children's improvement. Some parents have admitted the professional recommendations because they realize that social etiquette is only acquired through social engagements. As pointed out by a parent, *"They (autistic children) do not have the social concept. They do not have table manners. At home, it is okay but in a hotel…? So, we take him to the hotel regularly to learn how to behave in hotel".* Many parents take the initiative to 'taking out' their children at an early age and try to continue as much as possible. The progress in behaviour and capabilities of the child motivates parents to follow this method. For example, in the case of Sneha, her mother Ridhi is very much enthusiastic to take the child out of the home. They often take the daughter to watch the cinema in the theatre. They practised this up to last year. The mother says*, "She sits like she can understand the story; she claps hands when other people are doing the same. When we took her to these places, first time only, it was difficult, but she understands it is theatre, so she should keep silent".*

As many family members expressed, it is not easy for parents to create opportunities for social interaction for their children. Social attitudes play a major role in hindering the child's social participation directly or indirectly. The parents' bad experiences from society lead to the decision to keep the child inside the home. Parents described a number of events that have prompted them to reconsider their proposal to take the child out. For example, Safiya's mother recollected that earlier they used to take the child with them wherever they went out. But now, she would not do the same. The mother does not want to take the daughter to all the events but wants to go to places where the child is accepted, understood and loved. Parents show interest to participate only in the events that their relatives do not attend.

The humiliating words and the unnecessary questions from the relatives lead the parents to refrain from going out and attending family functions. As the mothers pointed out, if the child and mother attend a function, the subject of the talk will be related to the child. The people ask many questions related to the condition of the child's status of improvement and make suggestions for treatments. A mother said, *"Some relatives can understand, and some do not understand. Some look at her like a clown".*

The stereotypes related to gender and age too influence 'taking out' options. The mothers of adolescent autistic children feel stigma regarding the age and gender of the child. When a child is grown up, especially boys, they are expected to go out, spend time with friends, and make relationships on their own. But in the case of children with autism, all their daily needs are taken care of by the mother. So mothers are always with them. When going out, it is necessary to accompany the son to all places. The sons often hold the hands of the mothers in public places. At an age when boys have to travel alone apart from their parents' control, it is embarrassing for mothers when sons are walking through public places by holding their mothers' hands. The gaze of people in public places makes it difficult for the parents to move in the public spaces comfortably. Therefore, parents are forced to curtail the movement in public places.

Professionals Evaluate Parents

Professionals evaluate the parents in relation to their training engagements with the child. Concerning the attitude towards autism and the parents' decision in education and training, the trainers categorize the parents as 'good' and 'bad'. They say the virtues of 'good' parents are that they communicate regularly with trainers, understand the child's problems accurately, provide ongoing training at home, and attend classes without losing continuity. Good parents spend time engaging with the improvement of the child, and they are therapeutic. On the other hand, bad parents are not interested in improving the child's ability, and those who ignore the child rely more on the institution, care, and management. The trainers say such parents send the child to school to avoid trouble at home. They are unaware of the importance of training and the role of parents' intervention in the improvement of the children, but they are only concerned about the government's financial and material support. Trainers do not agree with parents' consideration of Special schools as mere shelters and criticize the approach of Special schools as dumping centres. They do not hold any critical approach to the trainers and the training system. But they expect that the changes should come from the training by the trainers, but not acknowledging the parents' responsibility. The 'bad' parents are often interested in keeping the children sitting peacefully than engaging in any activity. According to a trainer, bad parents allow the child to practice bad habits at home. The bad parents do not follow the instructions that are given by the teachers to perform at home. The bad parents want to sit the child at home silently, especially in the presence of any guest or family occasion. They focus on preventing any disturbances the children can make. Therefore, they give medicines or give food and make them sit in front of the Television.

Trainers also categorize the parents as 'new' and 'old' regarding their attitudes towards the education and understanding of autism. The new young parents are aware of autism and the need for training. But some old parents are still the same as in olden times. They know what autism is, and they are willing to study and spend time with the child. They are active and do things perfectly. The young parents also hold the belief that their interventions can make a change in the child.

Parents Evaluate Professionals

Similar to professional evaluation, parents also evaluate the trainers and categorize them as 'good' and 'bad'. The trainers who treat the children by understanding their strengths and weakness categorize them as good. The good and bad categorization often comes from the child's improvement after training under a particular teacher. The teachers do not always work in the same place for a long time. They get transferred to many places. Most of the time, the transfers are effected based on the parents' complaints. Sometimes the teachers come from outside the district. Parents evaluate the training methods, qualifications, and the improvement of the child and the teacher's attitude to the child. Incidents were there when parents collectively moved to complain against the trainer, which led to the removal of the teacher. The parents of children with autism have many conflicts with the trainers because most of them have not completed the training for autistic children.

Parents Owned School

Inadequacies in the training and education system and the lack of institutions to accommodate children with autism motivate parents to start institutions under their control and supervision. The fact is that many parents often thought of starting such institutions, but none of them could actually ground their plans. The lack of financial resources and very limited support for such matters poses challenges in starting such institutions. However, in the study area, the parents mustered support for a cooperative effort, and a school named *'Chetas'* was started under the supervision of parents, which is a classic example of community engagement in this area.

***'Chetas'*- A Centre for Autism'**

The school was started by the parents of three 18-year-old autistic children. Two of the families got familiar since they had been together for years at an institution related to child training. Their friendship continued for many years later. The third is a family found during the search done by the first two families as part of a plan to start a school. There was no external financial support to start the school. It is these three families who have raised the entire amount for it. They had to find a large sum of money to pay the rent and purchase the school's necessary items. The school is situated on the outskirts of the town. No teachers or other helpers' were hired by them. These mothers took the roles of the teachers in the school. Two of the three mothers have professional training experiences from other institutions. Moreover, they have years-long experience in caring for their child.

The school is open from 10 am. to 3.30 pm. They follow a rigid timetable for many things that children need to do daily. Parents engage their children in solving puzzles, making them learn with building blocks and mechanics that emphasize their mental health and physical activity. In order to improve the cognitive skills of the children, various pictures have been painted on the school walls. In addition, the school has parent-generated action guidelines, school timings, and a dress code. Although many parents wanted to enrol their children in this school, many were reluctant to do so as it required parent participation. This parent-led school aims to overcome the practical difficulties at home by becoming a training centre. These initiatives can be considered institutional reform and the extension of home training. Mothers feel that better results can be obtained in such an institutional environment than through training provided in the home environment. Here, 'location of training' is an essential factor in the training activities. Parents claim that the institutional environment enables them to provide systematic training instead of the home environment.

Parental Activism

Many parent-led groups are working in Kerala to achieve children's rights with various disabilities and mobilize institutional resources. Although such groups for children with autism are not common, there is a group called 'Autism Club' operating in several districts. Parents are the main members of this group. The Club seeks to achieve economic and social rights, ensure their participation in the social sphere, and further call the government's attention to the area of autism. The Club also organizes various programs for autistic children on Autism Awareness Day on April 2 and Autism Pride Day on June 18. Such programs are aimed at creating awareness in the community about autism. As part of this, a magazine called 'Autism Voice' is being published to include the voice of autistic children in the community. The Club is active in some parts of the state. Although the Autism Club has been formed in the area where this study is undertaken, the Club is not active. The lack of parental involvement weakened the Club's activities.

Only a few parents who are part of this study reported working for this Club. Parents in such parental groups seek to change and accept their behaviour by focusing on their children and addressing and adapting to social realities. Desai et al. (2012) explained this using the 'double paradox' concept. He argues, "There was a double paradox of acceptance/ change of both the child and the surrounding environment. Parents embraced this paradoxical attitude towards the social world by accepting but changing the social reality" (p.626).

Parents cannot ensure the social participation of autistic children without acknowledging social realities and looking for ways to socialize. However, parents also cannot easily accept social realities, which is why autistic children are unable to participate easily. That is why parents have to go out and change the social world.

Resource Mobilization and Factors in Decision Making

Several factors play a role in the parental perception and decision-making regarding the choice and selection of education and training facilities. The availability of Special schools and regular schools in their local places forces the parents to select that option for the children's formal education. Even though most parents may not have any prior knowledge of autism initially, some of them acquire the knowledge subsequently with an autistic person. Therefore, parents understand autism in different ways. The parents interested in searching for knowledge can get more understanding of autism. The available new knowledge on autism leads them to acquire new perceptions. Exposure to more resources helps the parents acquire new knowledge regarding the condition. For instance, the parents associated with the 'Autism centre' tend to favour inclusive education and other Special school education. Since only Special school systems are available in other areas, autism training is limited to knowledge of the Special school system. The lack of availability of advanced institutions makes the scarcity of new knowledge about education and training. Therefore most parents rely on the 'traditional' education and training system. Exposure to new educational systems is likely to bring changes in the perceptions of parents. The parents who got training and knowledge from the advanced institutions can contribute more to the education and training of the children. They can provide creative inputs to the education system. Therefore, the availability of educational systems also plays a significant role in the perceptions and the decision-making process among the parents. The social background of the families influences acquiring new knowledge of the condition. In a nutshell, the availability of educational resources acquired, knowledge and understanding, and the families' social background plays a significant role in decision-making regarding the formal education and training of the children.

Conclusion

Parents of autism realize the child's behaviour creates an uncertain situation as a member of society. Therefore the parents search for the available resources and engage in reshaping the social world to admit the abilities and limitations of the child (Desai et al., 2012). The parents aim to enable the capacity to live in a society (Edwardraj et al., 2010 . There are two major types of the formal education system for autistic children: special education and inclusive education. Parents opt for, and children practice, these education systems at different ages of the child. The choice, decision making, and satisfaction with the systems are based on the awareness of the parents, the behaviour of the children, and the methods of education. Along with the purpose of socialization, educational institutions are also changing in the sense of daycare centres. Educational institutions are considered an extension of the home. But in the case of children with autism, neither of these systems can be said to be able to fully integrate children's social interactions or ensure their social participation. Compared to the systems for consultation and labelling, the education system is not very efficient. The lack of knowledge about training for children with autism and the lack of specialized institutions that can provide it are causing concerns and ambiguities among parents. Further, each child's behavioural patterns, capacity, and needs are different; there are many limitations to the education system that is generally designed for the generally categorized as 'disabled'. Therefore, parents take the initiative to develop a child-centred education system to overcome such problems. Instead of formal educational practices, culturally specific systems emerge under parental supervision.

CHAPTER- 5

DIMENSIONS OF FAMILIAL CAREGIVING

The previous chapter explained the different ways in which families can cope with autism through institutions outside the family and the processes associated with it. In parallel with exploring such avenues, caregiving is conducted with a focus on children in the family context. The present chapter examines the meaning of caregiving in the familial context, the different circumstances that lead to it and the ways in which family members adopt to execute care activities. The chapter is organized into two parts. The first part describes a set of common and specific behaviours and activities that can be seen in person with autism. In addition, this part also describes the situations where autistic children are in demand of care and the process of how family members provide care. In this context, the chapter analyses the challenges faced by the family members with regard to care in the prevailing social and cultural context. The second part deals with the involvement of individual family members in caregiving. It presents the interventions of parents and close kin members and the significance of their interventions. In addition, this part also analyses the approaches adopted by families for providing care and how each of the caregivers addresses challenges that may arise.

The popular conception of autism asserts that autistic children are not interested in social interactions and social relationships, but instead, they like to live in a world of their own with their own thoughts and styles. But this is a little simplistic understanding of autistic behaviour. In addition to the reluctance to form social relationships, autistic children exhibit various other behavioural patterns not seen in normal children. There may be many similarities and differences in regard to these behaviours of autistic children. However, it may also be true that the behaviour of one autistic child may be too unique and not seen in any other autistic child. Even if one child shows the same traits as another child, there may be considerable differences in the intensity of such behaviours. Moreover, a variety of 'abnormal' behaviours can be seen within a child. Also, in a single child, different behaviours may appear at different times. Among the different behaviours shown by a child, the family may be able to handle only certain types. Further, the likes and dislikes of children vary in many ways according to their developmental stages. 'Hyperactivity' and 'epilepsy' conditions which are found in many children along with autistic behaviour, play an important role in determining the differences and severity of a child's behavioural pattern. Therefore, these conditions play an important role in initiating autism as a challenging one. A broader picture of autism will be revealed by exposing the thoughts and activities of autistic children, their behaviour and relationships with their everyday life and the experiences of those who live with them.

Social Behaviours

According to the well-known definition of autism, children with autism do not show much interest in personal interactions or initiate social interactions. We can find several types of behaviours that come under this category, like the reluctance shown by children to come out of their house. They prefer to spend all their time inside the house. For this purpose, they find any special place inside the house that is comfortable for them. They often sit idly, listen to music, or lie on the bed. If someone asks them to come out, they refuse and sometimes get upset and angry. They do not like to move away from space. For example, a child named Jinan spends most of his time indoors. If anyone asks, 'Are you coming with me out?' he will reply 'No'. If we repeat the question, he will say 'No' a little louder. Thus, each time we ask, the reply will be even louder, and he will get angry and will express his indifference in different ways. Actually, family members do not pay serious attention to this type of behaviour. However, such reluctance to interact with others raises concerns for parents about the child's socializing behaviours.

In some other cases, although children are not interested in the interaction, they like to move around the house and its surroundings without resting anywhere. If anyone asks them to sit somewhere, sometime they will obey for a few moments depending on their mood but will get up again and start walking. Such children usually are interested in travelling in vehicles. If they wish to go out for a trip in a vehicle, someone in the family has to do it. Otherwise, the children will get angry. For example, a child named Anna shows temper tantrums if any family members try to leave the house without taking her with them. She will not allow anyone in the family to leave without her. If anyone tries to leave, she will cry and bang her head against the wall to express her anger. Therefore, when anyone in the family needs to go out for any purpose, they move without the child noticing them.

Among children with such behaviours, we can identify that some have a habit that can be classified as 'restless'. They often run from one place to another on the premises of their house, in the neighbour's house, or even out in the street. They walk briskly from one place to another. It is difficult for family members to follow them because of the restlessness and speed with which they walk. Members of respondent families reported many instances where children have fallen and suffered major and minor injuries due to such behaviours. The researcher, during his visit to a respondent's residence for data collection, the child Safiya was resting with a broken leg. It was reported that she fractured her leg as she fell down during such a brisk walk in the yard. It was also reported that she had fallen and injured several times before this incident. She has a habit of standing at the edge of the stairs, and she also has a problem maintaining body balance. Because of these frequent incidents, family members are forced to be more vigilant about her movement and activity. In the case of children who like to walk, some parents have arranged facilities for their children to walk indoors to express their interests. For example, a child named Amith, his parents have made a large hall inside their home for him to walk and play as he wishes. Parents believe it would help the child express his joyfulness, anger and other feelings by walking in the hall. Similarly, in another case, a mother renovated her house to make it friendly for her daughter's needs. She designed a sit-out along with the hall inside for her daughter's free movements. The mother shared the context of this decision to arrange a space for her daughter, saying that she was earlier compelled to tie her daughter to windows due to her restless behaviour. But now, she was able to solve the problem to a certain extent. Here, the parents applied 'accommodation strategies' (Gallimore et al., 1996) to manage the child's behaviour.

Wandering is another behaviour that is associated with restlessness. As part of some instinct, such children run away from their parents' eyesight. This behaviour can be challenging for parents as their child may be at risk of missing out. Therefore, this type of behaviour raises many concerns for parents. They need to maintain a constant vigil on the whereabouts of the child and his/her activities. The location of the house closer to busy roads and water bodies double the anxiety of the parents regarding these behaviours. One parent pointed out that when our child is out of sight, the first thing we do is to go to the open well that is located close to our house and confirm that she has not jumped into that open well. It shows that there is so much fear inside the parents regarding the location of the house. The case of a family of a child living with his mother and grandmother near a riverside is another example of this. Along with his wandering behaviour, the child is very much infatuated with water and likes to play in the water. The mother said the child would be restless if he found water anywhere nearby. If the mother manages to arrange a drum full of water, he can enjoy it for a long time. During the rainy season, their surroundings will be flooded. At that time, staying in that place with their son was stressful for the parents. In another case, the yard of the house leads to a large ditch, and it then leads to a main road. Living in such an area with a restless son creates much worry for parents. These kinds of locations with risks badly affect the parents' daily activities and peace. Referring to such circumstances, the father of an autistic child narrated the effort they have to make to ensure their child's safety. He said: "We have to use eight eyes". The father revealed that even when he is in the workplace, he often has tension over the safety of the child, and that affects his concentration on work.

Many parents have gone through the experience of missing their child as part of the wandering behaviour. The missing incidents not only happen in domestic spaces but also in public spaces. A mother narrated that once, during a rainy season, their son went missing. After a long search, he was found near a stream. He was sitting there enjoying the stream. Another mother shared that her son also went missing a couple of times, that too in public places. She remembered the missing incident on a festive day when her son was about eight years old. She said: *"Suddenly he disappeared; I went here and there… the situation became chaotic. We searched the suspected route, but he was not there. Where we have to find!. It is a forest area. I got tired, and while coming back from the search, we saw a woman coming with him. The woman does not know him, nor does he know the woman… that day we had... Ohh God"*.

The parents are quite often disturbed during their sleep also. Disturbing dreams and nightmares are common among parents of autistic children; mostly, they dream of their child going missing and meeting with life-threatening accidents. 'Falling into the well' or 'water-logged areas' and 'missing somewhere' is a common terrifying nightmare for many mothers and other family members. A mother explained that her father had seen a nightmare, a 'child dipping her hand into boiling oil'. In a phone call, he warns her to alert the child. These narrations show the intensity of worries of mothers and other family members regarding the safety of their autistic child.

As a precautionary action and strategy to avoid risks and missing due to wandering, many of them keep the doors and gates locked d even during the daytime, and most of the houses have courtyards and wells covered with iron grills or iron nets. If the houses have enough space inside, the parents will prefer to keep the child inside most of the time. In addition to locking the gate, other precautionary measures are also taken. A mother informed that she always keeps a note in the pocket of her daughter's dress with contact details like phone numbers and addresses of their own and the nearest police station. The mother had chosen this strategy when the child often went to therapy with her father at the age of fourteen. For this, the mother specifically selects a dress for her daughter with pockets, or if it is not there, she stitches one. The mother shared her fearful feelings: “*since she is a girl, does not capable of expressing their needs through speaking if she misses at any place, what will we do”*. Due to the fear of missing, the mother is highly reluctant to hand over the daughter to anyone, even to her husband.

It is common to see autistic children carrying some objects which are available in the house with them. Quite often, they have an obsessive attachment to the items such as belts, bottles, books and scrap items. Attachment can sometimes be related to the colour or shape, or texture of the object. They spend a lot of time with such material. But after spending hours or days with the object, the child loses interest in it and then turns his attention to other objects. If they lose interest in an object, they will try to destroy it. If they are unable to destroy it, they seek the help of others. A variety of items which are useful are also destroyed in this way. This type of special interest in material objects is connected to another behavioural pattern or tendency that can be termed 'grabbing behaviours'.

Some children have a habit of 'grabbing' household items without others knowing it. But, the inappropriate handling of such items creates dangerous outcomes. For example, mouthing or swallowing pain balm, cosmetics, medicines, kerosene, soil, taking hot water from the gas stove, and grabbing and playing with fire are common behaviours in this regard. Such behaviours of children cause concerns among parents. Earlier experiences of accidents caused by unsafe handling of items make parents more vigilant. Because of such behaviour, the family members have to be always alert about the place of the household items, whether the item is small or big. Therefore, parents always think twice before keeping items in specific locations in the house. They always ask themselves, 'Is this place safe from them?' or 'Is it the place to ensure no damage to the item?' A mother says, because of her daughter's grabbing behaviour and unawareness of the dangers these items can cause, she always keeps checking to unplug the electrical items such as an iron box or electric sewing machine. Even though the mother did not confront any dangerous incidents previously related to the electrical items, she has taken this action as a precaution. In another case, a child named Jibri likes to chew on plastic bags. His mother said he exhibits violent behaviours if he does not get plastic covers. Even if the plastic bags are taken away without him noticing, he will pick them up and bring them back. The child is again unaware of the hygiene and plays with soiled items. In order to eliminate the hazards created by these behaviours, household items are often placed in a safe location and out of reach of the children or safely disposed of. In the case of children who like certain foods, parents may be forced to hide bakery items, such as sugar, milk and ghee, in the washing machine to avoid overeating. In fact, family members of children with autism are accustomed to keeping objects in homes in a way that avoids harm without being aesthetically pleasing and usable.

Self-Injurious Behaviours

Self-injurious behaviours such as head-banging, biting, hitting, scratching, kicking, pinching, slapping, and punching are common in autistic children. These behaviours that the children showed as an expression of their emotions. These behaviours are more common in children with hyperactivity. As evidence of self-injurious behaviour, wounds and scars can be seen on the bodies of many children. In one case, a girl often hit her hands or head on a hard surface when she got angry. Once, when she got angry, she hit her hand on the window glass powerfully, and the glass shattered, and her hand was deeply injured. Another matter is that most children do not allow the application of medicines or bandages to treat such wounds. Therefore, due to the inability to carry out proper treatment, the wounds become infected, leading to more complications. As children have a tendency to hurt not only themselves but also others, injuries can be found on the body of the parents also. Disruptive behaviours, making loud sounds, and closing the door loudly are also found along with self-injurious behaviours. They may behave in this way at times when they feel any discomfort. For example, a child got upset when he heard women's voices on Television and hit on it to express his anger. Similarly, when strangers (women) come to the house, he shows such annoyance. Moreover, he picks up anything available nearby to him to throw at when his younger sister starts to cry. Therefore, parents should be vigilant when they hear the voices of women bit loudly and cry of babies. Parents often try to send back women guests to their homes as soon as possible. As a result of disruptive behaviour, furniture, doors, tables, chairs, Television and many other household items are found to be damaged in the houses of respondent families.

Parents use various strategies to manage these behaviours and the difficulties they cause in parents' daily lives. To avoid the danger of head banging, a mother puts a pillow where the daughter often hits her head (But the child is clever enough to throw it off). Thus, she usually ties clothes on her head to prevent injuries. Some parents, who cannot take care of their children while they are doing other daily chores, often tie the child's hands somewhere until such work is completed. Some other mothers always carry a stick in their bag while travelling with their wards in public transportation facilities. If the child suddenly becomes aggressive, they will threaten to beat. When girls are angry, some mothers try to control them by holding their hair. But some parents try to avoid situations that make their children angry and upset by diverting their attention. Some parents find strategies to develop certain habits according to their child's interests. For example, some children with autism are more interested in electronic gadgets such as a tablet, personal computers or smartphones. Using such devices, they spend considerable time watching videos, musical shows, or movie songs. They can sit and listen to it for as long as they want. Therefore, some mothers encourage and use this interest of the child as a strategy to keep their children quiet.

Not everyone applies the same strategy, but it varies according to the logic and circumstances. Another matter with regard to the adoption of strategies is that one particular successful strategy used by the parents of one child may not be as successful in the case of some other child. For example, a mother tried the hand-knitting technique mentioned earlier on her daughter. But the child lost her balance and fell in the yard, and injured her front teeth. Such failures in the adoption of strategies often lead parents to despair and guilt that they are responsible for the accident. The strategies that the parents have applied can be divided into four types, 'surveillance,' 'control', 'avoidance', and 'habit formation'. 'Surveillance' is the most common form of strategy parents adopt. This type of intervention validates the concept of 'custodial home' (Sarret, 2014, 2015), which says that families in Kerala mainly focus on the care and management of the children rather than any therapeutic intervention.

Daily Living Skills

Self-sufficiency in undertaking day-to-day activities is important for a human being to lead a healthy life. When we talk about the development of 'typical- children', they need external help only up to a particular age till they attain self-sufficiency to think and act independently. But for persons with profound disabilities, whether physical or psychosocial, it is necessary to provide help and assistance throughout their life or more than the assistance required in the case of 'non-disabled'. In the case of autism, children face many difficulties in achieving 'adaptive behaviours' in their everyday life. Therefore, most of the children are not able to navigate everyday matters such as personal care, hygiene behaviours such as toileting, bathing, brushing, nail clipping, haircut and combing and even eating. Parents have to help and provide guidance to do these primary things even for older children, just as they do for toddlers.

Personal Hygiene

Although children are able to acquire the knowledge needed to perform toileting as part of training, they do not become self-sufficient in all areas of toileting. Although the bowel movement can be understood, many children are hesitant about what to do next. Many people are unable to communicate that they want to go to the toilet. Parents can understand this only when they see their body language. Some children defecate in bed or public places instead of going to the toilet. Parents say that they have no shame in it. Normally children communicate their needs through gestures, pointing fingers at the toilet, or holding their parents' hand. Some children go to the toilet and defecate during a bowel movement, but they are incapable of cleaning after defecation. Some children try to clean, but they do not show the desired perfection. Some children will make a sound after finishing toileting to inform his/her parents to take care of the wash. In some cases, if the parents do not accompany the child during defecation, the child may smear the faces on their body. Many children fail to cultivate the habit of closing the toilet doors while defecating. A mother said, *"She (daughter) does not seem aware that people will observe. She behaves like this at school also. If guests are here, she will take off her clothes if she wants to go to the toilet. We must be careful. She does not know what shame is."*

In addition to the common behaviours, there are some specific cases related to toileting. In a case, the child does not have control over the urinary bladder. Therefore, when urinary incontinence occurs, the child is unable to communicate with anyone. She does not have control to urinate at a specific place and time. By following the professional recommendation, the mother often takes her daughter to the toilet at regular intervals. Due to this situation, the mother has expressed her worries about how her daughter will manage her first menstruation. At one point, she shared her worry, *"I applied all methods… beating, crying, laughing (to overcome the panic situations). There is only one thing I cannot control. I do not know how to teach the child". These narratives reveal that parents* have to spend a lot of time and energy to deal with the difficulties that children face in toileting.

Child's limitations to manage personal bodily-related care cause embarrassment to parents in public spaces. Therefore, many mothers tell their companions not to speak loudly in public if their child urinates or defecates in open places while attending any family events. Such concerns of the mothers reveal that the mothers feel guilty and that they believe that they are blamed finally for 'not teaching/training the child on such matters'.

In addition to the toileting issues, autistic children fail to take the initiative for their body care and as such, activities such as brushing their teeth, bathing, cutting nails and combing hair are also problematic. Many children do not understand how, where and why to undertake these activities. A mother said that she has the dual burden of taking care of herself and taking care of her child as far as body care is concerned. Such comments of mothers reflect the effort mothers are forced to make to fulfilment of the daily needs of the child.

Eating Patterns

Just like the difficulties encountered in maintaining personal hygiene, autistic children also have difficulty in learning certain eating habits. Due to the issue of touch sensitivity and lack of coordination, autistic children do not show interest to eat foods by hand. Therefore, most children just sit in front of the food and wait for their parents to come and feed them. But some children overcome this condition by using a spoon. If the parents force them to eat without the help of someone, they will try to eat but cannot follow the etiquette. They get up several times during the meal and do not eat the whole of the served dishes. In addition, the surroundings in which they sit are littered with food. At this point, parents need to instruct their children to eat in a proper way. Many children often show tantrums to grab food or drinks from other people. Seeing food on other people's plates can cause discomfort to many children. Children often show this behaviour, both in domestic spaces as well as in public places. Such habits that children display in the presence of guests are a source of embarrassment to family members. Many mothers also say that their children are not able to feel 'hungry' and 'stomach fullness' properly. A mother said that she would only feed a certain quantity of food without bothering about whether it is sufficient ('stomach full') or not. These narratives show that 'self-feeding difficulties', 'inability to keep premises neat', and 'unawareness of table manners' are the main problems associated with eating habits.

However, some parents adopt home training as a strategy to manage the difficulties in daily living skills. A mother said her son learned the skills in daily living through consistent home training. She adds, *"Never think they will learn in a day. He picked up some skills only after a tedious home training; like the training given to animals in a circus".* Some parents realize 'what the exact child needs' through the day-to-day engagements with the child. Therefore, some parents give importance to daily living skills than waiting for any academic skills. A mother says, "*If we realize the child is unable to study, no need to put pressure on them. There is nothing they can get in life by learning the number three or four- no benefits to just identifying a number without understanding a currency and its value. I always think the better is to deliver the knowledge which they can apply in their life. Give the training to eat food, wear the dress, wear chapel, etc.”*

Sleeping Behaviours

Irregular sleep with nocturnal awakenings is a characteristic feature of most children with autism. Most children's sleep does not have depth or breadth. They often fall asleep late at night and wake up early in the morning. In case of noise during their sleep, they will wake up and leave the bed. Children wake up in the early morning and do not allow other family members to sleep. If the parents are asleep, the child may disturb to wake them up. Therefore, the mothers also need to wake up at the time their children wake up. The rest hours of the mothers are thus curtailed. Further, the mothers try to be alert at night as they are worried about the child getting fits at night. So, they cannot sleep peacefully. They put on the light in the room throughout the night. Many mothers have commented that they have not been able to sleep properly since the child was born. Many children who have not acquired sleeping habits do not go to sleep without parental instructions. Children play outside the house even at bedtime. When children are called to sleep, they are reluctant to obey. Therefore, parents may physically lift them to bed. Further, they do not sleep on time and without the presence of their parents. For example, a daughter would need her mother's hand under her head while sleeping. Even the slightest movement of the hand can disturb the daughter's sleep. If the mother wakes up to go to the toilet, the child will wake up and follow the mother. In some cases, even older children have to be cradled in their mother's lap to sleep. Such sleeping habits affect the sleeping habits of other family members too, especially mothers. The lack of sleep increases the stress on the parents. So parents of children who have helped to develop specific sleeping habits for their child believe that it is a great achievement.

As a result of parental training, some children are accustomed to going to bed alone and sleep when they fall asleep. A mother shared, *"I had worked hard when my daughter was very young to help her develop the habit of sleeping alone. She had the habit of hugging me tight prior to getting into sleep. To change that habit, I bought a doll and left* *it in her bed to hold when she gets sleepy. She liked that. Then gradually, I got her used to sleeping in a separate bed".*

Even though most of the children show differences in behaviour, no one is given a label for any sleep disorder. Therefore, children do not take any medicines to overcome sleeping issues. But many mothers said that they often feel like taking sleeping pills for good sleep.

Mothers' Strategies to Cope with Challenges Due to Behavioural Attributes

Mothers evolve or choose different strategies to overcome the different behaviours that pose a risk to their children themselves and others as well. These strategies are in tune with the socio-cultural contexts of their lives.

Ankita's case

Ankita, is an 18-year-old girl, lives with her mother Reena and grandmother Ammini. It was when she was two years old that the label of autism was medically determined. Along with her autistic behaviour, she is also hyperactive and epileptic. Although she has been given speech therapy since she was young, she has not acquired the ability to speak. Because of the hyperactive behaviour, her child often shows aggression through biting, hitting with sharp tools or utensils, beatings etc. The mother showed scratches on her face due to such behaviour of her child. Because of this hyperactive behaviour, the school officials of the special school where she was enrolled did not allow her to attend classes.

After realizing that Ankita was autistic, her father left the family. After that, Reena moved with her parents and started living with her mother and brother's family. Reena later applied for divorce, and the court ordered the husband to pay compensation. But Reena said she is not getting the amount regularly every month. After the divorce, Reena's brother had built a house for her. After that, Ankita, Reena and Ammini moved to a new house.

The house consists of a small bedroom, hall, kitchen and a sit-out. Due to their poor financial condition, they could not afford for doors to any of the rooms. The house is situated on the side of a slope. So, Reena fears to allow Ankita to spend time outside the house. She tries to keep Ankita in a separate room inside the house. Her worry is that she cannot take up any employment as she cannot leave her child to the care of even her mother completely. Ankita living room which has grilled doors is always locked. When she gets angry, she badly hits the grills with her legs, arms, and head. Thus, the gaps in the iron grills have been lined with cloth to avoid injury to her body. Sometimes, her mother would open the grill door when she felt compelled to go outside. The mother said her primary aim is nothing but to teach the daughter to stay calm. The mother said, *"I am tired of this behaviour… it cannot be fixed."*

Her grandmother is unable to look after Ankita's daily affairs due to her old age and related health problems. Reena fears that Ankita may hurt her grandmother when she gets angry. Grandmother spends most of her time sitting somewhere outside the house but keeps a watch on Ankita. Even though Reena brother's family lives near their house, she would not get much help from them. Because of this, Reena is 'all in all' in Ankita's daily life.

Inability to do everyday things, Anjali needs her mother's help to do all her tasks. The mother says she cannot manage to brush, bathe and even eat. Sometimes if she gets angry, she will throw the food items. The mother says that the severity of such behaviours increases with age. She says, *"No one is willing to share my suffering".* In this case, the mother is feeling helpless without any support to deal with the situation. She feels that being a single parent, her life is unimaginable.

Ankita's case is a typical example of the challenges family members face in taking care of their children. This specific case reveals different aspects of caregiving. The support system, in this case, comprises an only mother and her aged mother. The lack of support from other kin or friends makes the caregiving process very challenging. The family members are unable to take up any paid work, which makes the families' economic burden even worse.

Parental Concerns

Concerns about Physical Violence

We have seen the behaviour of children and the difficulties it causes. The following is a list of some of the concerns related to the behaviour and gender of the child that parents may have about their children's behaviour. Many mothers shared that the girl child - whether the child is 'normal' or 'not normal' - needs more security these days when the number of rape cases is growing in the present social conditions. Because of this situation, many mothers shared that they are a bit lucky that they are the mothers of boys. A mother of a girl child said that the parents of autistic boys could send their children to remote residential schools for training, but parents of autistic girls cannot. The mother holds this opinion because she has confronted some news about incidents of physical abuse of girls in training centres. Therefore, the mother does not dare to send the daughter anywhere without her and teaches the daughter not to stay away from her eyesight. The mother says, *"their bodies are not safe".*

Some mothers worry that the child's lack of awareness of gender differences may lead to sexual abuse. Parents are concerned about such matters at home and in public places. Therefore, parents keep instructing their children and putting some restrictions on their interactions. A mother commented, *"Daughter does not know the male-female difference. For her, all people are the same. Earlier, she used to mingle with everyone who used to visit our home. So, I told her she should come out only after the guests were gone. She learned to sit in her room till the guest leave".* She says this act is not to hide the daughter at home from the public, but it is a strategy for protecting the daughter from the strange people who come with diverse characters. According to the mother, this method gives a lot of relief.

Concerns about self-protection and sexual violence are felt to be best handled by the menfolk. For example, a mother who got divorced from her husband said that she is often advised to hand over her daughter to her father and even advised to remarry. The mother, however, has a different opinion. She raised the question, *"How can I trust a person who comes after marriage ?. As the daughter knows nothing, what if he exploits her?"*

Similar to the mothers of girls' children, some mothers of boys have also reflected worries regarding sexual abuse. While a mother described the story of her son starting to sleep alone, she shared some indication of this aspect. She says the son does not like to be touched by anyone while sleeping. If anyone lies close to him, he will push away. The mother considers it good behaviour because it will protect him from any sexual exploitation.

In addition to the sexual abuse, some parents were concerned about 'responsiveness' and safety. Parents are concerned that their children cannot protect themselves from any physical violence by others. Parents say that speech impediments create limitations for their defence. A father says, "If someone comes and beats him, he must be able to say, 'do not beat me'" Parents are concerned not only about their children's own safety but also about the inability to provide security for their companions in times of need. A mother said, *"Suppose he and I are alone in the house; he will not respond if any thief comes at that time".*

Parents are often concerned about whether their children, especially girls with autism, will be sexually abused because of their inability to understand social realities and their inability to take self-defence. Therefore, parents think their children are sexually vulnerable. Further, the above discussion makes it clear that the context of increasing sexual violence against women in society raises concerns about the physical safety of children. In this way, some of the events that take place globally can be seen to have local repercussions. But the parents of boys are mostly concerned with the safety from physical violence rather than sexual abuse.

Concerns about Children’s Physique and Caregivers’ Health

Although children with autism show delayed growth in the early years, most of them achieve good body growth and strength according to their age. In some cases, regular and continuous psychiatric medications can cause the child to gain excess body weight. Not only that, in some cases, the lack of physical activity also does the same. Physical management is not a big task for parents when the children are young and not overweight. But over time, the lack of intellectual development, together with the physical growth of the body and increase in weight, poses challenges. Parents have to take a great deal of physical effort to manage their children. The children do not obey what the parents are saying. Thus, the engagement between them creates a 'physical war'. Parents of older children often fail in such a 'war'. Some mothers said they could not chase their children when they ran away. The situation of a strong child and the debilitated parents makes the care process even more problematic.

In many cases, the physical labour by the parents, especially the mother or other female folk who takes care of the child, affects their health badly. Relatively young mothers who are part of this study reported suffering from various health problems. Body pains, backache, high blood pressure and mental stress are the most common health issues reported by mothers. Mothers say that the constant running after their children to get things done, as well as the lack of adequate rest and food, cause considerable health problems for them. Reflecting on this situation, a father said, *'Wife is taking more medicine than son'*. Mothers say that the constant running after their children to get things done, as well as the lack of adequate rest and food, cause considerable health problems.

The previous section discussed the contexts of familial caregiving by describing various situations that arise related to different behavioural patterns of autistic children. The narratives reveal that the condition of autism pulls the children from learning, recognizing and overcoming the risks lurking in everyday situations and basic living activities. In 'normal' situations, children acquire knowledge of the danger and adopt ways to overcome it in the different stages of their growth and development. One part of the parents' role ends there when the children learn to do the basic activities themselves and become aware of how to overcome dangerous environments through their experiences and knowledge. But in the cases of autistic children, they cannot assess how certain situations or objects can cause harm to them lifelong. The 'missing' and 'risk' concerns among the parents come because of these realizations. The responsibility of the family members toward their autistic child will not end at a certain age of the child, but it will continue throughout their life.

The narratives also revealed that the family members play a significant role in the everyday life of autistic children. As described, by engaging in those caregiving activities, family members go through a lot of challenges and concerns. It also reveals that although autism is a condition of 'behaviour', the 'activities' that children do as part of that behaviour and their 'capacity' would create challenges for parents. Thus, it can be said that the 'autistic identity' that comes as part of their behaviour causes various concerns and worries among parents. Later, such concerns demand care. But the prevailing social environments create new concerns, and it exacerbates their life conditions as they continue their caregiving throughout their life.

Family Members’ Engagement in Caregiving

As the previous descriptions reveal, caregiving is primarily the responsibility of the mother. However, in many cases, fathers, grandparents, siblings, other kin members and also the neighbours become part of the caregiving. In view of such a situation, it is useful to see how these members share the responsibilities in the behavioural contexts of the autistic children described above. It also explores the relationships that emerge between caregivers and the care receivers as part of the caregiving process.

Mother

The presence of mothers can be seen in every moment related to the everyday life of an autistic child. It includes engagement in their child's day-to-day affairs and taking care of their safety, ensuring their participation in training activities, and helping him/her in improving social interactions.

Issues related to child safety and self-sufficiency are explained earlier. From waking up in the morning to going to bed at night, mothers have to constantly take care of their children. It is mothers who need to ensure that their children do not get into risky situations, whether inside or outside the home. While other family members are vigilant in such matters, principally, it is the mothers who assess the issues related to such situations. They are the ones who understand what kind of dangerous objects are there in the house. Every day, many such things go through the minds of mothers, which are in a way unseen to others. For example, a mother spots even the shower leaks in the toilet first and insists on fixing it as soon as possible as she appreciates the risk of it to an autistic child much better.

Mothers are the 'master brains' of the various methods and strategies for avoiding risks. Many times these simple yet effective preventive behaviours are often passed on to other parents, and such practices are turned into the 'common ways'.

It is the duty of the mother who selects the clothes and other items for the child. Mothers make such choices by carefully considering the colours, materials, and textures that their children like.

Another important matter in this regard is medication. All the children who were part of this study were taking medicine for a variety of reasons. The mother supervises giving medicine to the children on time, informs others when the medicine runs out and buys new ones. Similarly, mothers play an important role in the diet of their children. Mothers are required to feed food to those who have difficulty in eating on their own. As they do that, they also keep giving suggestions for developing 'healthy eating habits'. In this way, mothers also take on the job of a trainer. We have already seen that children with autism are not able to present their bodies in front of society according to societal expectations because they do not internalize social perception of the body. That is why mothers are always vigilant about their child's behaviour at home as well as in public places. Mothers try to make sure that they do not behave in such ways that are contrary to social norms. Therefore, it can be said that mothers act as a bridge to their child's social relationships.

Mothers are the ones who participate in the institutional training sessions. Some mothers are also focusing on activities related to their child's social rights. They are active in parental groups, bringing the required pressure for the acceptance of their children into society. In this way, mothers take the role of an activist.

Father

Two couples in the study were divorced, and children do not live with their fathers but live with their mothers and mothers' families of orientation. Twelve fathers are working in the Gulf countries or outside the state. Therefore, the interaction of these fathers with the children is through phone calls and only when they come home. The other fathers who are available at home spare some time only in the evenings and on holidays due to their work demands.

There are two ways in which fathers support their children. One is to ensure financial support to the family and the child. They are the main source of income for the family. The other is engaging with the child to 'entertain'. That is, the fathers focus on playing with the child to keep them happy. For instance, they take them for short drives in a vehicle, or to a beach, or to a local festival. When it comes to the matter of fulfilling a child's personal hygiene needs, fathers do not prefer to engage in those matters. They do such things only when 'necessary'. The gender limitation to manage the girls is the main reason for this difference. The engagement of fathers in such matters is less common in extended families than in nuclear families. The gender limitation to manage the girls is the main reason for this difference.

Mothers opined that many fathers do not have a clear understanding of autism. This lack of understanding on the part of fathers is also reflected in the way they treat their children. Many fathers spend time pampering their children. Therefore, they accept to do everything that the child demands as part of a tantrum. Fathers try to justify their child's behaviour when they do anything wrong. Many fathers do not admit completely that their child has any problems. They think that when they grow up, they will behave normally like everyone else. The difference in approaches and engagements of the father reflects that they accept less than the mother the medical condition of their child. Although mothers are the ones who pay the most attention to their children's day-to-day affairs, they also say that most children are more attached to their fathers. Children show attachment in many ways. For example, a child waits for his father at the door of the house until he arrives. The child only goes to bed when his father goes to bed to sleep.

Some mothers are critical of their father's pampering attitude. A mother complained that her husband is making their sons' condition more problematic.

As the observations and interviews revealed, some fathers do not show any interest to cooperate with their spouse in managing the child's upbringing. For example, one of the respondent's families decided to celebrate the birthday of an autistic child at her school. As part of that, they sponsored lunch for the school children and teachers. Before noon, the mother and the child visited the centre where the child was taking therapies and celebrated the birthday with a cake cutting. Father was not present at that function. After that, the father came and took them in a two-wheeler to school, where the child was enrolled. The lunch has been arranged there. The father dropped his wife and daughter and left on the pretext of some work. The mother herself managed the whole event. Even though the father provided some support for some arrangements like the arrangement of caterers, the mother had to take the responsibility mostly. The incidents reflect the difference in style of engagements, the time allotments, and the priorities of the fathers and mothers with regard to the child's condition. Fathers do not seem to take the initiative and engage in childcare proactively.

Grandparents

The involvement of grandparents in matters related to the care of an autistic child is significant. Most grandmothers spend time at home doing household chores. Some of them go for daily wage work at least on certain days of the week. Some of the grandfathers are retired government employees. Grandmothers often share the works of personal hygiene, feeding and supervision for their autistic grandchild. Such sharing allows the mothers to go out for some work. For example, in a case, the grandmother and great-grandmother are together involved in care activities in addition to the mother. But the grandmother's and great-grandmother's engagements were confined to the surroundings of the house only. If the mother wants to go for any essential activities, the grandmother will take care of the child. Grandmother and great-grandmother do most of the daily chores and give a lot of relief to the mother.

At times grandmothers' engagement is not only confined to the home, but it extends beyond the house. There are cases where the grandmother is taking care of the child's education besides the routine tasks at home. One such grandmother takes the child to BUDS school and spends time there until the classes are over. The care of the grandmother is essential here as the father of the child is working abroad and the mother of the child has to look after another child who is only one and a half years old. In this case, the continued support (for many years, now) of the grandmother is significant. In another case, the grandmother takes the child for therapy as her mother is unable to take care of such a task due to some health problems. Moreover, there are situations where the child's parents have lost hope in matters relating to the child's improvement. But grandmother does not want to leave the child alone at home. Grandmother's hope and confidence in the child motivates her to take on this job. In fact, when evaluating grandmothers' interactions with children, it can be seen said that they are 'mothers' extensions'. In many cases, after the mother, the caregiving of the child is mostly handled by the grandmother.

Though mothers and grandmothers do similar work in caregiving, they often have different opinions. Both of them cannot approve of certain attitudes of them toward the autistic child. It sometimes leads to 'mother blaming'. For example, when a child shows tantrums, the grandmother often says that the child does this because the mother does not give appropriate advice to the child and helps to learn things. In another case, the child's mother does not allow her mother (the child's grandmother) to accompany them when they go to consult the doctor or leave the house for any other purposes. This is because she thinks her mother does not have an accurate understanding of the child's issues.

Like fathers, grandfathers do not do many jobs that female members of the family do. They mainly supervise, accompany the daughter (with the mother of the child) to the hospital and so on. For example, the mother of a child named Adwaith seeks the help of her father (Adwaith's grandfather) on most occasions if they need to go out. In the absence of the child's father (the couple are divorced), his grandfather has assumed the father's responsibilities.

In some exceptional cases, (in the absence of the parents) responsibility of care has been taken completely by the grandparents. In some others, the grandparents have taken the bulk of the responsibility. For example, in the case of a child named Jinan, his father and mother are teachers and do not find time for the child's care during working days. Therefore, the child is cared for mostly by the grandparents. Since Jibin is more or less able to manage his personal body care tasks, supervision of the child is the main duty of the grandparents.

The narratives show the involvement of the maternal grandparents is more than the involvement of the paternal grandparents. Among the maternal grandparents, the intervention of the grandmothers is noteworthy. Although it is customary for couples to stay at their husband's home after marriage, the reasons for the presence of the maternal grandmother are mostly specific and are explained in another section.

Siblings

In the present study, 11 families have a single child, and children in 13 families are firstborn, 11 families have children of second-born, and one twin. In most cases, the brothers and sisters of autistic children are younger. Therefore, the involvement of siblings in the matters of 'assistance' in the care process can be seen only in a few families.

When considering the adult siblings, there are differences in the interaction of sisters and brothers in the needs of autistic children. In the case of children with sisters, they are the ones who involve in the care work that mothers do. For example, in one case, a child named Shikha has an elder sister named Navya. She is an undergraduate student. During her leisure time at home, the child's mother often entrusts Navya tasks of household activities. The mother is very comfortable in handing over Shikha to Navya; she feels proud of her daughter for her responsible behaviour, as the following narrative shows. *"Recently, I went to attend a program of children at Buds . Navya assured me that she would take care of Shikha. After I went, she defecated in her dress. But without any hesitance, she cleaned her and washed the clothes. Because I also took care of her like that. I told her I never expected she would defecate. At that time, she said, if you were here, you would do these things, so what is wrong if it was done by me. For me, I feel it is pride".*

In another similar case, a boy named Farhan has two elder sisters. His father is working in the Middle East. Farhan 's sisters' study at a distant place and commute from home to college every day, spending a lot of time and energy. , The mother is very pleased with the sisters' involvement in childcare. The mother says, *"The sisters show very much attachment to him. If his sisters are in the house, they will give him whatever he wants. On weekend days, they spend time and look after him. The daughters adjust their study after Farhan goes to sleep"*. If the mother needs to attend any family functions, the daughters often ask the mother to attend the event and tell her they will take care of their brother. The mother says that because of such cooperation from the daughters, the neighbours appreciate them. Neighbours say that the mother was lucky to have two daughters who are loving and caring towards their younger brother. In such cases, mothers consider the attachment between the child and the siblings to be an advantage. Mothers consider female siblings to be comfortable companions in caregiving. They would act as a 'second mother', similar to grandparents.

Unlike female siblings, male siblings do not play a significant role in the caregiving process. Most of the time, they are busy with their work or studies. The main role of older male siblings is to look after the child without being directly involved in it. However, parents consider having siblings a great advantage. For example, the father of a child says, "*The child always sleeps with his brother, and they are very much attached to each other, which is a good thing".*

It has already been said that in many cases, the siblings are younger than the autistic child. Therefore, they are not old enough to recognize what autism is so much. Their involvement with the autistic child is often in the form of a playmate. At the same time, they show love and care for each other.

Most parents hope that siblings will take care of the child in the future. A father remarked, *"we will look after the child until our time. Later, his grown-up brothers will take care of him".*

Parents with single child share their limitations in relation to the problems of the present and are also worried about the future. For example, a mother says, "if the children do not have siblings, in future, the child will be handed over to any institutional home or government agency by relatives. But if the child has siblings, they will take care of the child or at least will arrange a home nurse."

However, some parents with single child talk about the possibilities of institutional care in the future. In one case, the mother and father often discussed about the future care of their single child. During such conversations, the father always says, *"We can do something for his future. For example, institutions are there like old age homes. So we can send him to such institutions. We can give whatever the institution wants, the money".* These narratives reveal that the parents who have a single child are more concerned about the future of the child when compared to parents with more than one child. Among the families of a child with more than one child, the age, gender, and their readiness to involve are the factors that influence their support to the parents/guardians.

Other Kin Members

In addition to the parents, grandparents, and siblings, other family members, such as uncles, aunts, cousins, and even neighbours, are involved in the caregiving process. In some cases, these family members live together in a house, but in some other cases, they live separately in the neighbourhood. In the case of families who live close to the residences of their paternal kin, in addition to grandparents and siblings, fathers' brothers, their wives, and children may extend support. If the father's sisters are married and are living faraway places, their visits to home are less. In the case of those who live close to their mother's side, relatives, in addition to grandparents, siblings, uncles or their wives, may be present. If the mother's sisters are married and are living in other localities, they come and stay in their homes occasionally. What has been observed is that those living close to their father's side relatives are not as advantaged as those living close to mother's side relatives as far as support to caregiving to the autistic child is concerned.

Neighbours

The families involved in this study live in the midst of a neighbourhood. In many of the cases, the families had settled in the present locality years ago on the basis of caste-based occupation or religious factors. Therefore, neighbours are often close or distant relatives. In cases where the families have come and settled down from any other place, the neighbours may not be members of their own community and are not their relatives. Although neighbours do not make any significant contribution to the care of the autistic child, it is common to inquire into matters relating to the child. Neighbours often inquire about matters related to hospital visits due to any physical ailments or inquire about the experience of outing with the child or ask about the disturbance the child has made the previous night. In this way, the neighbour makes engagements in the form of an 'inquiry' rather than 'intervention'. In some cases, the women in the neighbourhood are close friends of the mothers. When no one is at home, they spend time talking to their neighbours. They also keep a watch on the safety of the child. Neighbours play a role in informing the family and bringing the child to home when the child with a wandering nature moves away from home. Further, they often give suggestions regarding the treatment to the child and specialist doctors.

Even if the neighbours are relatives, parents have inhibitions about taking the child to their house. They do not want to spend too much time even when they visit their neighbours for any purpose. Most parents have the opinion that it is not fair to put the neighbours into any inconvenience or any hardship, even if they are relatives.

There are some cases of conflicts with neighbours over issues related to a child's behaviour. When a child goes to a neighbour's house and does something bad, or when the children are sick, and the neighbours do not visit them, it leads to quarrels with the neighbours.

Although this type of relationship exists with neighbours, knowledge related to the child's condition is very less to neighbours. Neighbours know that the child has 'some problem'. But they usually do not possess any specific knowledge about the condition of the child. They know that the child has no speech or the child is mentally retarded. The child's family are usually not interested in sharing matters related to the condition of the child with neighbours. In this way, gaps emerge among the neighbours in relation to the child's condition. In many cases, the family wants to hide the real facts about the child. Social stigma is the main reason behind this. They face such stigma everywhere outside of their own family.

In the above section, we have discussed the role of each family member in caregiving. The mother does the major work in caregiving. Along with the mother, other family members and neighbours also participate in care work in various ways. Many similarities and differences can be seen in the interaction of family members related to care. Female members of the family, such as the mother, grandmother, female siblings, and auntie, are directly involved in the care of the children. Female members participate in tasks relating to the daily needs of the child, more or less. They engage with the child to ensure basic sustenance. The grandmother and female siblings also take up a similar role as that of the mother. But the father, grandfather, and male siblings contribute to care, which is different from that of the female members. It can be concluded that they are the primary caregivers, and men just provide the assistance.

Caregiving and Residential Pattern

When we discuss the involvement of family members, it is necessary to talk about the 'residential pattern' of the family. Five types of residential patterns were observed in the families involved in this study. These are, 'paternal residence', 'maternal residence', 'paternal neo-local residence', 'maternal neo-local residence', and neo-local residence. Families living in paternal locality and paternal neo-locality have the presence of the father's siblings, along with the grandparents. For families living in maternal locality and maternal neo-locality, the presence of the mother's siblings in addition to the grandparents is available. In the cases of neo-local residence, parents and siblings become part of the care for the child. The grandparents come and stay with them only when needed.

Another matter that needs to be explained in relation to the residential pattern is that there is a trend of shifting of residential locality for these families. Generally, after marriage, the couple moves into the house where the husband's family lives or a new house close to the husband's family of orientation. The wife's subsequent life will thus be with the husband's family. The couple's children grow up in this locality. Therefore, the wife becomes an occasional guest in her own house where her parents live. But in the case of families with children with autism, there are some changes in this residential pattern. Mothers say that staying with their own family is more helpful than staying with the husband's family in dealing with the child. Therefore, mothers feel more comfortable in their own residences with their autistic children. That is why mothers prefer to live in their own home or near to that with their husbands by building a new house. That is, mothers choose neo-local residences but are careful not to get alienated from their mother's family. For example, the Jabri family lives in a rented house away from their natal residence. They have been allotted land by the government for housing. But they do not want to go there because they want to live close to their mother's family. Jabri's mother says, *"If we get the land at this place, it's good. Mother's house is here. No relative in that place. What do we do when something goes wrong or when we have to go to the hospital to hand over him; we should have a safe place"*. Another mother said that whenever they plan to build a house, she would demand that it be built at a place that is easily accessible to her mother's house. One factor that motivates the mother to make such a demand is that if she becomes fed up or unable to take care of the child, someone should be there to take care of the daughter.

In many cases where the husband is working in the Gulf or outside the state, the mothers prefer to stay with the mother's family with the child. For example, in the case of Amith, his father bought a plot of land from his mother's in-law's family and settled there after constructing a new house. The new house and the wife's paternal house are situated in the same compound. The grandmother also lives with them. In this case, the grandmother provides a significant contribution to the child's caregiving. Therefore, settling near the maternal residence has provided relief to the parents.

The above cases reflect the involvement of family members in caregiving with regard to the 'residential patterns'. Residential patterns often determine the number of family members and their presence. The decision-making regarding residence happens based on the convenience of providing care. Parents realize that it is best to share the care activity with the mothers' family members. In this way, we can say that shifting to a new locality for residence is a long-term strategic move to overcome the hurdles of care work.

Combinations in Caregiving

So far in this chapter, various behaviours of children with autism and the daily caregiving activities of families related to those behaviours have been explained. Essentially, family members work for two things: well-being and safety. As such, this section intends to analyse the set of activities they perform based on the concept of 'caregiving'. Kleinmann (2010) approaches caregiving as a very fundamental component of the human experience; embodying the essence of moral meaning is significant in this context. He says that care is a collection of "acknowledgement, concern, affirmation, assistance, responsibility, solidarity, and all the emotional and practical acts that enable life" (p.97). At the same time, he adds that caregiving is a self-strengthening exercise rather than a medical phenomenon or financial exchange (Kleinman, 2008). It connotates, as a social being, the importance of mutual caregiving for the progress of human society generally and for the betterment of human lives particularly.

Although human beings care for each other in many different ways in their daily lives, the caregiving provided in the context of vulnerable conditions such as disability, very young and old age is something different. It is often very challenging and lasts for a lifetime. This type of caregiving requires much time and energy as caregiving in a 'normal' condition, which means it is persisting. Here, we can say that caregiving in these situations is not simple but a mixture of different emotions such as love, affection, reciprocity, trust, commitment, obligation, and responsibility, burden, overwork, hardship, psychological stress, and physical wearing away (Hoyert& Seltzer, 1992; Livingston 2005).

Family can be considered the prominent site of caregiving because a major amount of caregiving occurs in a family context. Each family member does his/her role for the well-being of the child. As Dalley (1996: 99) noted: 'In societies, which do not have formal segregated care systems, the principal structure of kinship has to provide the basis for caring'. Although not exactly distinguished, the journey of families into caregiving activities can be seen to go through several stages. it can be explained in the following manner. Once the child's autistic condition is understood, family members begin to construct their daily lives around the child in order to manage and 'normalize' it. They construct their lives by aiming at the betterment of the child. In this way, the daily life of the family members is determined based on the condition of the child. The child's condition constantly influences the thoughts and actions of family members. Gradually, family members spend considerable time and energy on care. Later, caregiving becomes a part of their life and a 'life-altering task' (Barg et al., 2014: 182). In the current cultural context, the activities that are performed by the parents are presented under many names other than caregiving. They describe their involvement in the way that they are 'helping', 'doing', and 'giving instructions' for children. Family members do not consider the activities they perform for the children as caregiving and themselves as the caregivers to the children. They understand their involvement in such a way that things were done for them as they were children. They make such interventions believing it to be a familial role and their responsibility. They do not consider it a 'special duty' to take extra effort in doing things for the children. They never differentiate their identity from 'casual parent' to 'caregiver'.

Depending on the individual's position in the family system and the duty that determines it, the involvement of family members in the caregiver activity varies. In such a situation, child care, gender roles, kinship and reproduction are inextricably linked, and it can be said that mothers are at the helm of care. They are the person who has a direct connection with the child in caregiving activities. Mothers perform their roles as nurturers, therapists, advocates, and case managers (Nicholas et al., 2016). For mothers, caring for a person with autism becomes 'unending hard work' and 'constant mothering' (Vaidya, 2016). The value of mothers is calculated based on their performance in the care of children. Ruddik (1989) argues, "Preservation, growth and social acceptance constitute maternal work; to be a mother is to be committed to meeting these demands by works preservative love, nurturance and training (1989: 17). In any issue related to the child, the onus is on the mother to answer. The culture defines it as a 'bad mother' if she does not look after the children's needs efficiently.

However, along with the mothers, many other family members are also involved in the caregiving. As the gender division of caregiving persists, similarities can be found in the actions of female members of the family. At the same time, there are similarities in the interactions among the male members of the family. While there may be some gender shifts in care, the fact remains that the division of labour within the family also stands firm in the context of care. Caregiving is provided on the ground of the family system that has existed over time. The presence of care-related ideas such as 'caring for' and 'caring about' can be seen more or less in every family member. 'Caring for' is to do with the tasks of tending to another person; and 'caring about' is to do with the feelings for another person (Graham, 1983; Dalley 1996). Although both meanings can be found in the activities of all families, caring for is mostly reflected in the female members and the caring about in male members. The existing gender division in care can also be seen here. Based on the interaction with the child, the responsibility and the effort taken, caregiving activities happen on several levels. Primary and secondary are the two major levels of caregiving. The mother, maternal grandparents, paternal grandmother, female siblings, and father are the caregivers who hold the position at the primary level. At the secondary level, it would be the paternal relatives and the male siblings.

Although the depth and breadth of each family member's involvement in care activities vary, care in the family is a collective activity. It can be explained by the relationships and the directions that are formed in relation to caregiving. Two types of care relationships are formed in caregiving: the unidirectional relationship between the caregivers and the care receivers and the multidirectional relationship among different caregivers. The relationship between caregivers and care receivers is said to be unidirectional because autism creates limitations in the return of any kind of work or financial assistance to those who give care by those who receive care. In fact, they are only the receivers of care. It has already been said that care is a collective activity. Family members interact and work with each other to bring care to a practical level. Therefore, it can be said that it is multidirectional. Such collective action reflects the ideology of 'familism' and 'collectivism' (Dalley, 1996: 1). In such collaborative work, combinations of family members are formed to carry out the whole care process. Such combinations are formed consciously or naturally. The common person in any such combination is the mother. Other members, such as fathers, grandmothers and siblings, come to make combinations with mothers. In the caregiving of autistic children, four main types of combinations have been identified mother and father, mother and maternal grandmother, mother and maternal grandfather, and finally, mother and female siblings. The strength and weaknesses of these combinations are related to the way they interact with children. For example, the nature and intensity of the relationship between husband and wife are determined by the way they interact with their children. If the husband does not collaborate with the mother in the affairs of the child, that relationship will remain weak, and if the couple continues to share the caregiving, their relationship becomes stronger. It makes clear that care is not just a transaction between caregivers and receivers but also between caregivers.

There are many reasons for the formation of such combinations. Firstly, familial gender roles ascribe that women are the caregivers and men are the breadwinners.

Therefore, in doing many things related to children, the joint work between the mother and the maternal grandmother and the mother and the siblings can be seen. Secondly, the age of the family members. Young children with siblings and grandparents with geriatric health problems do not have an active role in care. Only healthy family members can take part in the caregiving work with the mother. Thirdly, perceptions about autism. People with an accurate understanding of autism can easily understand the behavioural patterns of children with autism, deal with them, and make decisions related to children. Therefore, mothers are comfortable working together with such members of the family. Fourthly, the genealogical and numerical composition of the family to which the child belongs. In extended families, grandparents are available to help their mother. But in a nuclear family, only the husband and the siblings are available to the mother for caregiving. Therefore, the combination of grandmothers is more commonly found in the extended family, and the mother and father or mother and siblings combinations are more commonly found in the nuclear family. Moreover, the participation of kin in care depends on the availability of other close kin in the neighbourhood of the family of an autistic child.

Conclusion

The present chapter discussed the different dimensions of familial caregiving. As part of this, the various contexts of caregiving and the involvement of caregivers were analysed. This chapter suggests that the family system serves as the main site of care and family members as the main caregiver. There is no doubt that caregiving is an essential element of human life, as the literature has conceptualized it (Kleinman, 2010). Especially in the cases of the human condition that need external help.

Even though society has a formal segregated care system, due to the inefficiency in accommodating autistic children, the full responsibility of caregiving is confined to families. It reflects the lack of outside support systems increases the responsibility of families in the caregiving process. As mentioned in the previous chapter, the limited investment of the government in this area and the lack of better-sophisticated facilities for the education and training of autistic children make the protection and care of children who need extra effort limited to the family system. In addition, the non-friendly social environment for autistic children and the existing patriarchal social background make the care process even more challenging, particularly for the mothers.

CHAPTER- 6

CONCLUSION

I

This chapter aims to highlight the important findings stated in the previous chapters and to conclude the study. In the context of the questions raised in this study, and the objectives formulated to achieve it, this chapter summarizes the findings of the research, as well as discusses the theoretical and practical significance of this research. Thus, it attempts to showcase the contribution of this research as a whole. Moreover, this chapter deliberates some of the limitations and future research possibilities in the broad area of medical anthropology and caregiving and also in the area of disability studies.

The framework of the present study is arranged by using concepts of interdisciplinary literature in the fields of anthropology and disability studies. The study accommodated the critiques of the medical and social model of disability and took the vantage point of the critical disability study perspective, which deals with the role of both agency and structure in the conceptualization of disability.

Although there were several studies on 'disability' from an anthropological perspective, the majority of them focused on physical disability. The psychosocial disability in general and the challenges of care in different socio-cultural contexts for the family and society in general, as well as the consequences of such disability for the family of the child, have been discussed in a limited way. The inadequate studies on the processes and dynamics of caregiving open up many research opportunities more particularly for studies based on qualitative research strategies.

The present study thus primarily asked the question of how families and society in general defined, understood, managed, and experienced the condition autism? In this way, the research sought to analyse the social world and social realities of autism from the perspective of the caregivers and the family. At the same time, it explored the nature of the involvement and influence of various institutions outside the family in creating the experiences.

The study was conducted in a district located in the northern part of Kerala. The primary informants of this study are the family members of autistic children and the persons who worked with autistic children in various institutions.

II

The chapters are arranged roughly based on the chronology of events associated with autism and with a focus on perceptions of the caregivers and the engagements of the family members in the caregiving process. The first chapter, 'Introduction', tried to locate the present study in the discipline of medical anthropology and disability studies. The chapter presented major theoretical discussions in the area of disability. The second chapter, 'Methodology and Fieldwork', discussed the epistemological, ontological, and methodological background of the present research. The chapter also presented the fieldwork process. The third chapter discussed the labelling process of the condition of autism. The chapter described different realization events of the condition, which led to help-seeking, labelling, and medical treatment. The realization of the condition mainly takes place within the family by the family members. The events do not happen in a similar manner in all families. Therefore, realization is classified based on the differences in events of realization. The major realization events include unusual incidents at birth, aberrations during the initial growth phase later to birth, delayed developmental milestones, and strange behaviours and activities. Realization of a child's behavioural differences depends on family members' knowledge of the growth and development of children and the inter-familial relationships. Generally, every stage of a child's development is carefully evaluated by any parent. Soon after the birth of a child, many expectations are placed on that child's growth and development. Children are also viewed as assets of the family. As family systems have become more nuclear, parental attention to children has become more efficient. Parents are more cautious about their children's health and education in the changed social situation. They raise their children with more care and attention. They want their children to grow up to be better individuals. Moreover, parents have specific goals for their children's future. Therefore, opportunities for careful assessment of children's development are available in such a system. In such a situation, differences in children's behaviour are easily and quickly recognized.

Autism comes unexpectedly without giving any time for particular preparation for families. Therefore it changes the family's existing affairs and members' perception of survival. Moreover, Families begin to think about ways to cope with and overcome such a situation that happens to a family member.

The realization events lead the family members to an effort to understand what the condition is. It also marks the beginning of the trajectory for medical care and other therapeutic centres. The initial hospital visits culminate in the labelling of the condition. The number of hospital visits at this stage varies from family to family, depending on various factors. The journey then continued to clarify the details of the condition, reconfirm, evolve the best ways of caring, and search for strategies for coping with the medical condition. Along with reliance on biomedical systems, religious faith-based systems are also relied upon for help-seeking. In many cases, the dilemmas relating to the rejection of earlier labelling and for new definitions are faced and resolved. Thus, the labelling of the condition itself is a long journey consisting of several stages and moving back and forth.

This process of labelling cannot be so easily compartmentalized into definitive stages too in many cases due to simultaneous experiments with different medical institutions and therapeutic centres. In some cases, the journey starts from the realization phase to the consultation phase and then again and again to the consultation phase with the experiences of further realization of differential behaviours and inadequacies of intellectual development. The application of the 'trial and error' method can be seen in these situations. Some families have been able to make follow-up decisions with fewer hospital visits. But others needed multiple visits to make those decisions. Such differences result in delays in acquiring and incorporating accurate information about the child's condition. In some cases, after the realization events, parents go to school to make a decision and fix it before they even know what it is. Multilevel interactions and relationships occur between the family and other institutions in relation to realization, consultation and labelling. It may not always come within the criteria of the Diagnostic and Statistical Manual. But such subtle distinctions and personal and social knowledge cannot be ruled out.

As realization, consultation, and labelling take place, family members begin to think of strategies for overcoming it and make efforts to put it into practice. Similar to the trend in consultation, bio-medicine is the prominent medical system used for treatment modalities. Ayurveda and Homeopathy are relied upon as second or third options. Along with these three medical systems, religious-based medicines also have been utilized. In this way, proceeding with the use of various treatment methods reflects the situation of 'medical pluralism'. This situation proves that even though biomedical systems are deeply entrenched, people are always willing to explore the possibilities of alternative healing systems.

Parents pay attention to the causes of autism in the early stages of labelling but then do not pursue it as an important goal. Due to the absence of definite explanations for the causes, it opens possibilities for several assumptions. Biological, social and supernatural causes are mainly constructed. In this way, both scientific and non-scientific constructions of causes exist within the same social context.

The fourth chapter- 'Education and Training'- deals with the differential strategies to overcome several challenges posed by the medical condition of the child. Families' go through more or less similar phases in regard to understanding the child's 'deviant' behaviours. But the methods they seek to adapt to overcome the condition are different.

In addition to the primary mechanism of medical treatment, parents adopt different supplementary therapies and educational and training facilities to cope with the condition. Based on the recommendation of professional opinion, parents have decided to seek the help of different therapies like speech therapy, physiotherapy, occupational therapy, and behavioural therapy. But the therapy and training institutions in local areas are functioning in a very limited way in terms of human resources as well as instrumental resources. Hence, in the absence of better therapy institutions in local places, some families approach better institutions working in faraway places. Providing better therapies and training to autistic children is closely related to the family's financial resources as well as human resources.

Children's educational activities are primarily carried out by two types of systems, namely 'special education' and 'inclusive education'. These education systems are executed through the institutions like Special schools, Buds institutions, and regular schools. Special school institutions are conceptualized to accommodate children with different psychosocial conditions other than autism. Trainers are the major human resource in that institutions. But in regular schools, along with the teachers, autistic children are given a variety of inputs by observing and participating in the activities with their classmates and the school environment.

Some parents are exploring the possibilities of 'special education' and others of 'inclusive education'. The parents who rely on special schools consider the institutions as 'shelters' to take care of the children. They are comforted in having a place for children to spend a day, rather than focusing on the inputs the children are getting from the school by inquiring about the syllabus, learning methods and the child's improvement. But parents who recognize that interaction with 'regularly developing children' is essential to overcoming autistic features explore the possibilities of inclusive education. These educational methods have been adopted by the parents based on their understanding and experience with autism. Parents who perceive autism as any other psychosocial disability try to find changes through special education systems. They rely more on 'institutional' systems without raising much criticism of its working. But the second group of parents do not think autism is like other types of psychosocial disabilities; they see it as a separate category. Moreover, they tried to point out the shortcomings of the institutional system and advocate for a new educational system for autistic persons.

The reality is that these two educational systems are not able to contribute significantly to the development of autistic children. Here, the different opinions among parents regarding children's education clearly indicate that education systems have not yet been developed for autistic children. The special schools are conceptualized for children with disabilities other than autism, and regular schools are designed to accommodate children with 'normal' behaviour. These institutions have shown difficulties in accommodating children with autistic characteristics. In fact, no educational systems are prevailing in front of the parents to rely on with complete faith. This situation indicates that in the present scenario, pedagogy for other psychosocial disabilities has been developed, but not for autism. Although the condition of autism has been well defined, the mechanisms for its management have not been developed. The need for curriculum and pedagogy to include children with diverse characteristics and to ensure the social participation of such children is evident here. To overcome these pedagogic issues, acknowledgement of the practical knowledge of the parents and theoretical knowledge of professionals is necessary.

A school to solve the educational problems of autistic children, and a club to ensure the participation of the government, have been started and run under the supervision of parents. In this way, parents try to make social interactions based on their identity as 'caregivers'. Such situations are explained through the concept of 'biosociality' (Rabinow, 1996).

The problems of education and rehabilitation of autistic children are not unique to the particular area. Although there are differences in the severity of the difficulties, it is significant issues that exist globally. A lot of research is going on in this area of education and rehabilitation all over the world. As part of that, many efforts are being made to address their educational activities. But its benefits have not reached everywhere.

The knowledge about autism comes from the biomedical system through the wings of globalization of communication. However, the fact is that there is no equal distribution of proper knowledge and services about autism. Even now, a major portion of society understands autism as a so-called 'mental problem'. But people try to understand the condition of autism by combining globalized knowledge with local knowledge. This trend is seen in the ways in which autism is explained, approached, and adopted to overcome it. We can see variations in experience in the same location. Due to the different socio-cultural backgrounds in terms of religion, economy, education, and resource availability, people experience and comprehend the condition differently. Moreover, globalization tries to create homogeneity in the definition of autism, its treatment, and education on this topic. Nonetheless, in a local context, we can find heterogeneity in each of these matters.

While the mobilization of external resources in relation to coping mechanisms takes place, on the one hand, the mobilization of family-based resources takes place on the other. The fifth chapter- 'dimensions of familial caregiving' discuss this peculiar theme. The various contexts of familial caregiving and the involvement of family members in caregiving activities were analysed in this chapter.

Although family members face many difficulties in caregiving, they approach it as a responsibility rather than a burden. Basically, 'well-being' and 'safety assurance' of the autistic person are the two major components of caregiving in the family context. It includes ensuring the development of the child's daily living skills and supervising the various activities of the child that may lead to the harmful situation at home and the public spaces. At this stage, parents are also concerned about the sexual abuse of their children, especially among mothers with girls. The situation regarding sexual exploitation against women in society leads the parents to such concerns. It can be considered as an example of how some conditions that exist globally are reflected locally.

Although autism is a condition of 'behaviour', the 'activities' children do as part of that behaviour, and their 'capacity' would create challenges for parents. Thus, it can be argued that the 'autistic identity' that comes as part of behaviour causes various concerns and worries among parents. Later, such concerns demand care. But the prevailing social environments create new concerns, and it exacerbates their life conditions as they continue their caregiving throughout their life.

Each family member, kin members, and neighbours are more or less involved in caregiving activities based on their gender roles. Female members such as mother, grandmother, and girl siblings are mainly taken responsibility for the day-to-day care of the child. Mothers spend more time on child care than other female members. Mothers' efficiency has been judged based on their engagement in care activities. The positive changes that children have to undergo become the responsibility of mothers. In fact, the prevailing social system, where childcare is entrusted to mothers, does not change much in this particular situation too.

Based on the nature of care work done by the family members, it can be divided into two categories, namely 'primary' and 'secondary' caregiving. The mother, maternal grandparents, paternal grandmother, female siblings, and father are the caregivers who hold the position at the primary level. At the secondary level, it would be the paternal kin members and the male siblings.

It has been mentioned that all family members are involved in the caregiving process; therefore, it is argued that caregiving cannot be a completely individual activity. A method of collective activity beyond individual activity is seen here. Human resources which are available in the family are mobilized to implement care. As part of this, certain 'combinations' of family members are formed to perform care work. Mother and father, mother and maternal grandmother, mother and maternal grandfather, and female siblings are some of the major combinations.

In the context of interventions that are part of caregiving, relationships between family members and their relatives are strengthened or weakened. Establishing the relationship between many families experiencing similar problems also can be seen at this stage. In this way, changes in the priorities that families hold regarding relationships are evident.

Along with changes in the nature of relationships, it is common among families to change places of residence to make caregiving much easier. We can see temporary residential changes to support treatment systems and permanent residential changes to emphasize care. The permanent residential changes are either mother's place of birth or the mother's parents' place of residence. Through these types of residential changes, a paradigm shift can be seen in the traditional residential patterns of couples living with the paternal residence. A new way of life is established out of the formation of new thoughts, new ways, and new relationships related to the condition. Families adopting these changes can be described as the 'new kinship imaginary' (Rapp and Ginsburg, 2011).

Exploring the different dimensions of caregiving reveals that it is a complex system where emotional, physical, practical and sociopolitical spheres come together to perform. The social phenomena have been defined by the 'care ethics model' (Rogers, 2016). The relationship between autistic children and their family members based on love and affection, the practical engagements of the family members for the well-being of the child and the socio-political context in which it all takes place are significant factors that determine the dimensions of caregiving.

III

Autism occurs in an individual, but the autistic person's behaviour and activities, which are not in line with social norms, and social life, lead the caregivers to a condition of 'disability'. The ripples it creates have repercussions on the persons who come in contact with the individual and then on various social systems. Opportunities for caregivers' personal development are disrupted by the inability to participate in social production, work, creative activities, leisure, and travel. Their lives always revolve around the child; this situation leads them to a state of disability. Even if parents involved in the caregiving process do not have physical or mental disabilities, the difficulties they experience in caregiving make them disabled. Although some people engage in social interactions, it is for child-related matters. Parents who are professionally engaged may have to quit their jobs or find it very difficult to carry on. Although love and intimacy are at the core aspects of caregiving, it is also difficult in such circumstances. Caregiving is a process in which the two aspects are inextricably intertwined. Addlakha (2020) states, "On the one hand, care work is tiresome and oppressive, with massive opportunity costs for the caregivers, and yet it is essential. On the other hand, caring and being cared for are a source of reciprocity, intimacy, and emotional fulfilment" (p.53). It can be argued that certain existing social conditions make autism become a 'disability'. In the absence of effective institutional support systems for the care of children with autism, much of the responsibility for children lies in the hands of families. The inefficiency of the society and the state machinery to provide consistent support for the autistic person and their families to overcome the difficulties they face renders the whole family 'disabled'. Lack of proper medical knowledge and limitations in access to health and other services hamper the quality of life of autistic people and their families. Due to the lack of appropriate supportive systems in the context of autism, a section of people are unable to ensure social participation and participate in the social production process. Because women are its main victims, a social condition that creates obstacles to women's empowerment is reproduced here. Such conditions create obstacles to the efforts to mould a society without inequalities. This problem can only be solved by problematizing existing social systems and developing proper support systems.

IV

Anthropology is a branch of knowledge that seeks to understand human conditions and behaviour in a nuanced and holistic way. The present study, which has attempted to conceptualize the human condition of autism in this way, is expected to add new knowledge to the field and accelerate subsequent research. First, by studying the condition of disability in terms of family, society, and state, the discipline is directed toward finding new questions and answers about the human condition. Second, this study has been able to be part of efforts to assess disability from a socio-cultural perspective by questioning the way in which disability is assessed from a medical point of view. Third, this study has discussed the need for government policies to engage in the areas of the well-being of autistic persons and to address the challenges facing their families. Undoubtedly, such issues are areas where action research in anthropology can effectively intervene. Fourth, by bringing the knowledge generated as part of this study into academic communities and the public, the emphasis on the social responsibility of anthropology is increasingly recognized. It leads the discipline to deal more effectively with social issues. Fifth, there is no doubt that practical approaches to dealing with different human conditions can enrich the methodology of a discipline. This study has identified some practical limitations and possibilities of dealing with such sensitive human conditions. Through such experiences, this study has provided some inputs to the methodology of the discipline. Sixth, most studies on disability have until recently been from a Western perspective. Actually, non-Western perspectives and experiences of caregiving for autism differ from the perspectives based on the Western context. While Western society emphasizes the rights and social inclusion of children with autism, families in non-Western societies face challenges in meeting children's daily needs. But recently, there are also studies focusing on Global South countries on this particular issue. As a continuation, the study is also an initiative to disentangle anthropology from its colonial legacy and construct anthropology in the context of the Global South. As an anthropologist from the Global South, this study posits the imperative of alternative anthropology based in Third World countries. Unravelling the voices of people from such geography will undoubtedly reinforce the importance of the discipline.

I would like to describe some of the limitations of this study. One, this study is based on a particular district in Kerala. The study did not attempt to document and analyse people's experiences outside this particular geographical area. Such an approach has been adopted due to time constraints and belief in depth rather than breadth of study. Second, the selection of children and their families was based on information from educational institutions. The fact that many children with behavioural differences may not be accurately reported to schools cannot be ruled out. Third, as the study focuses on families of autistic children, the analyses are mainly based on data collected from family members rather than educational institutions and hospitals. Among the family members, the majority of the data were collected from mothers. Therefore, the mothers' perspectives are mostly included in this study rather than other family members. Four, although class criteria were applied in selecting families, caste factors were not considered as a criterion in this study. Therefore, families belonging to the lower strata of the caste hierarchy were not significantly included in this study. It is because children from such communities cannot be found in educational institutions and therapy centres.

Further studies in this area are needed to address such limitations. Analysis of the disability experiences from an anthropological perspective needs to be extended to include people living in different socio-cultural contexts. Along with family, there need to be more studies focusing on educational institutions, hospitals, and public spaces. Studies should focus on educational institutions to develop new learning methods for person with autism.

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Appendix

1. Interview schedule for family members of autistic children

How is the child's developmental issues recognized?

Who is the first person in the family identified the developmental issues and deviant behaviour?

How was the other family members initial responses to the recognition of the issues?

What are the further steps taken after identifying the developmental problems of the child?

What were the discussions between the family members behind the decision- making for further steps?

What were the other family members' responses to the decision regarding further steps?

What are the various medical systems you have approached?

Have you been consulted at any medical institutions outside of your local area?

Where was the child diagnosed with autism?

Has your child been diagnosed with autism?

Which professional diagnosed the child with autism?

At what age is the child diagnosed with autism?

What was the other family members' initial response to the diagnosis?

Does your child have any other co-morbid conditions?

Have you heard autism before?

What is your understanding of autism?

Have you attempted to know about autism?

What are the sources of knowledge you depended on to understand autism?

Do you consider autism the same as any other intellectual disability?

Do you have any assumption of the causes of autism?

Is anyone told the child's autistic behaviour is because of your fault?

What was the further steps have been taken after the autism diagnosis?

Is your child taking any medicine for autism related issues?

The reliance on medicine for what type of problems?

What is your experiences with the available treatment systems?

Do you believe that medications are the proper mechanism for managing autistic behaviour?

Other than the medical system, what other institutional systems have you approached?

How do you evaluate the working of therapies, training, and educational institutions in your area?

Have you traveled a long distances to ensure training?

Where does the child currently receive treatment and training?

Who will accompany the child to training centres and schools?

Have you noticed any improvement in your child as part of the training sessions?

Is the child enrolled in regular school?

What type of educational systems do you prefer for autistic children?

To your knowledge, which is the best way of rehabilitation of an autistic child?

Do you train your child at home? If yes, what kind of training is provided?

Did you get any training from anywhere?

What type of training and education you wish to provide your child?

What is the training and teaching method you would like to demand in autism, as distinct from other intellectual disabilities?

What are the behavioural and developmental peculiarities of your child?

What are the autistic features in your child?

What is the child's daily routine?

How is your engagement with the child?

What is the most challenging behaviour you have identified in you child?

Does the child need your help to meet daily living activities?

In which area does the child need more help?

What are the major concerns during the caregiving activities?

What is the most challenging issue you face in caregiving?

What is the social attitude when you carrying the child in public places?

What are the strategies you have taken to manage the child at home and public spaces?

Do you believe those strategies are effective to manage the child?

What method do you adopt to encourage the child to interact with society?

What changes did the endosulfan movement bring about in this field?

Do you believe that your life events are limited to the child, that your mobility is restricted and that your desires are limited?

Do you have any questions to me?

2. Interview schedule for parents owning school

When you started the school?

What was the motivation behind the establishment of the school?

What do you intend to accomplish by setting up the school?

How many students and teachers are in this school?

What are the major activities in the school?

How did you frame the teaching approaches?

3. Interview schedule for activists

When was the 'Autism Club' started??

What was the purpose of starting the Club?

What are the main activities?

Is the club running effectively?

How do you evaluate the parental involvement in club activities?

4. Interview schedule for trainers and therapists

What is your designation in the school?

What is your educational qualification?

How many years have you been in this field?

Have you received any special training to train children with autism?

How many students and teachers are here?

What activities are offered here for children with autism?

Are you dealing same syllabus for all children?

Do you think autistic children need a different pedagogy?

How do parents approach training?

Do they regularly attend the training session?

What is their primary aim?

How do they understand autism?

Do parents follow your instructions?

Do you have any questions to me?

5. Interview schedule for school teachers

How many autistic children are studying here?

What are the arrangements you have made to accommodate the autistic children?

What is the other children approach to the autistic children?

What is your opinion regarding the regular schooling of autistic children?

What are the main problems you face in teaching children with autism?

What is your opinion regarding education for children with autism?

Do you have any questions to me?

6. Interview schedule for doctors

What is your method of treatment of autism?

Is there any medicine for autism?

Which medical system is most preferred by parents?

Do you have any questions to me?

CARE, CONTENTION AND FAMILY: AN ANTHROPOLOGICAL INQUIRY ON AUTISM

by Sandeep K

Submission date: 03-Oct-2022 11:25AM (UTC+0530)
Submission ID: 1915166598
File name: Sandeep_K__Thesis_Full_Draft__Care,_Contention_and_Family.pdf (1.4M)
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